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LIMITATIONS OF THE NATIONAL DISABILITY DATA SYSTEM

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ABSTRACT

The federal government collects extensive survey and administrative data pertaining to disability. In a real sense, this extensive effort comprises a national disability data system, although it is not recognized or managed as such. From a variety of perspectives, however, the national disability data collected are limited in their ability to meet the needs of federal programs, policymakers, and disability researchers. In this paper, we document the key components of the national disability data system and identify major gaps in the data that are currently collected. The findings are based on information collected via interviews conducted with a wide range of disability data users, and on information collected from a review of over 40 national surveys.

Our findings indicate that, although a large amount of information about people with disabilities is collected through national survey and program administrative data, the information is limited by a variety of factors: the manner in which disability is measured; small sample sizes; the inability to identify certain subpopulations; infrequent data collection; predominantly cross-sectional, as opposed to longitudinal perspectives; and restricted access to administrative data. In addition, many important topics are not adequately covered for people with disabilities in national surveys, such as time use and expenditures, transportation issues, employment services and supports, community participation, living arrangements, and the characteristics of disability onset and progression.

Disability is both an important determinant and consequence of the health, productivity, and well-being of the population. Our findings suggest that the national surveys designed to monitor the U.S. population could be improved in many ways to better identify people with disabilities and provide information about their needs and well-being. Finding ways to more effectively collect data on people with disabilities seems especially important as people with disabilities represent a large and growing share of the U.S. population, and an even larger share of individuals who rely on public programs. High-quality and timely information on disability-related issues is essential to understanding the needs of the population, to assessing how existing programs and policies are performing, and to planning for the future needs of our aging population.

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I. INTRODUCTION

Currently, the federal government collects extensive survey data pertaining to disability, through a number of national survey programs, as well as through the administration of major disability programs. In a real sense, this extensive effort comprises a national disability data system, although it is not recognized or managed as such. In fact, the disability data collected are of much lower quality and value to the government and general public than they would be if the system were formally recognized, developed, and managed.

The purpose of this paper is to describe the existing national disability data system, to discuss ways in which the data are used by various stakeholders, and to identify important gaps and shortcomings of the system. Our findings are based on interviews conducted with disability data users and a review of documentation associated with over 40 national surveys sponsored by the federal government.

The stakeholder interviews were conducted with 36 individual disability data users, representing nine federal agencies, two state agencies, five disability consumer organizations, and ten university and contract research organizations. The interviews solicited information about how and why interviewees needed and used disability data, and their views on disability data gaps and limitations. The interviewee perspectives represent a broad range of data users, but are not necessarily representative of all disability data users.

The review of the national surveys entailed an assessment of the following survey features: the populations covered by the survey; the geographic level of estimates generated by the survey data; the frequency and timing of survey administration; the types of health and disability indicators available from the survey; and the subject areas addressed for respondents with disabilities.¹

The remaining sections of this paper are organized as follows: In Section II, we describe the components of the existing national disability data system. These components include: the major national household surveys; smaller national household surveys that focus on specific issues; surveys of non-household populations; a multitude of surveys of specific subpopulations; and program administrative data. In Section III, we briefly discuss ways in which disability data are used. In Section IV, we discuss the major limitations of the existing survey data that we have identified. We provide concluding remarks in Section V. The Appendix to this paper contains a summary of selected information collected from the review of the national surveys.

II. THE EXISTING NATIONAL DISABILITY DATA SYSTEM

Our national disability data system is comprised of literally hundreds of individual sources of data about people with disabilities and disability-related issues. For purposes of describing this system, we have organized the data sources into five major components. These components include: the major national household surveys; smaller national household surveys that focus on specific issues; a multitude of surveys of specific subpopulations; surveys of non-household populations; and program administrative data.

¹ One important area was not addressed in our review: the methods used to define a survey's sample population, locate those sampled, and conduct the interviews. These methodological issues are described in Ballou and Markesich (forthcoming).

A. Major National Household Surveys

The U.S. government conducts a number of large, national household surveys. These surveys are conducted on a regular basis and form an integral part of the federal statistical system. Data from these surveys are deemed critical to monitoring the U.S. population, and they also provide basic information needed to administer federal programs. All of the major national household surveys provide some information about people with disabilities, including information about their: demographic characteristics; health and functioning; employment; and economic well-being. Here, we briefly describe the major national surveys of the U.S. population. For each, we note important characteristics of their samples, topical foci, and disability indicators.

The **decennial census** and the **American Community Survey (ACS)** are two very important data sources, as they provide basic information for almost the entire population. Responding to either survey is required by law. The ACS is a new Bureau of the Census survey developed as part of the decennial census program to replace the long form in the 2010 census.² Though intended to replace the long form, there are some important differences between the two data sources.³

The Census 2000 Long Form Survey made significant improvements in the disability questions that were included relative to those included in the 1990 census (Census 2001). For the first time in history, census data provided information on six disability types, including sensory disability, physical disability, mental disability, self-care disability, go-outside-home disability, and employment disability.⁴ Although the Census 2000 includes information on the group quarters (GQ) population,⁵ the Public Use Microdata Samples (PUMS) data only identify institutional and non-institutional GQ with no finer distinction possible. This limits the utility of the PUMS for providing disability information for this population (Erickson and Houtenville 2005).

The ACS is a nationwide monthly survey designed to provide communities with reliable and timely demographic, housing, social, and economic data every year. Instead of surveying approximately one sixth of the population every ten years using the census long form, as was done in the past, the ACS collects data on approximately three million (1 in 40, or 2.5 percent) American households every year. The questions used in the ACS between 2000 and 2002 are essentially the same as those in the 2000 Census long form; beginning in 2003, the ACS made changes to the structure of the two disability questions regarding go-outside-home disability and

² The ACS was in the development phase from 1996 to 2004. Full implementation began in January 2005.

³ Important methodological differences between the census and the ACS are related to the mode of survey and follow-up procedures, and the reference periods used to determine the residency, employment, income, and school enrollment status of respondents (Mather et. al. 2005).

⁴ The Bureau of the Census found evidence of misinterpretation of the go-outside-home disability and the work disability questions by those who mailed in the long-form, which resulted in an overestimation of the population with these two types of disabilities, as well as the overall population with disabilities (e.g., Stern 2003).

⁵ Several special questionnaires were created for the GQ population as the household questions in the household unit forms were not appropriate for places housing large groups of unrelated people. The four main forms used were (1) Individual Census Report (ICR) used for the vast majority of group quarters, (2) Individual Census Questionnaire (ICQ) used only for soup kitchens and regularly scheduled mobile food vans, (3) Military Census Report (MCR) used to enumerate military personnel, and (4) Shipboard Census Report (SCR) used to enumerate military and civilian shipboard residents. The census long-form disability questions for the GQ population are the same as for the household population (Census 2005).

employment disability in light of the errors associated with those two questions in the Census 2000 (Weathers 2005). Prior to 2006, the scope of the ACS had been limited to housing units; beginning in 2006, most group quarters have been included in the sample. Disability questions for the household population and the GQ population are the same in the 2006 ACS (Census 2006a; 2006b).

Sponsored by the Centers for Disease Control and Prevention (CDC), the **Behavioral Risk Factor Surveillance System (BRFSS)** collects uniform, state-specific data on preventive health practices and risk behaviors that are linked to chronic diseases, injuries, and preventable infectious diseases in the adult population in order to plan, implement, and monitor public health programs (National Center for Chronic Disease Prevention and Health Promotion 2006). It is an annual population-based survey of households conducted separately by each state and targeted to the civilian non-institutional adult population (ages 18 or over) residing in households with telephones.⁶ CDC developed a standard core questionnaire for states to use to provide data that could be compared across states.⁷ Each state has at least 4,000 interviews (National Center for Chronic Disease Prevention and Health Promotion 2006). Questions cover behavioral risk factors (for example, alcohol and tobacco use), preventive health measures, HIV/AIDS, health status, limitation of activity, health care access and utilization, and demographic and socioeconomic characteristics.

Conducted by the National Center for Health Statistics (NCHS), the **National Health Interview Survey (NHIS)** provides data on the health of the civilian, non-institutional U.S. population, primarily to monitor the country's health and health care utilization (National Center for Health Statistics 2007b; Harris et al. 2005). The NHIS is a repeated cross-sectional survey conducted annually since 1957. Following a multistage area probability design that permits the representative sampling of households, it has a nationally representative sample of roughly 100,000 persons in recent years.⁸ The survey includes a core set of questions that is modified every 10 to 15 years, with the last major modification occurring in 1997, and various sets of supplemental questions that change annually. The NHIS contains a broad range of health and disability-related data including health insurance and access to and utilization of health care. It also provides information on household composition, socio-economic status, and family income and assets, but is not as comprehensive as the Current Population Survey and the Survey of Income and Program Participation. Disability-related questions in the 2006 NHIS cover a lengthy list of conditions, sensory, functional, and activity limitations, and mental and cognitive disabilities

The **Current Population Survey (CPS)** is a monthly survey of households conducted by the Bureau of Census for the Bureau of Labor Statistics (BLS) (BLS 2002). The survey has been conducted for more than 60 years, and is the primary source of information on the labor force characteristics of the population. The CPS sample is selected to represent the civilian non-institutional population ages 16 and over. The target sample size for the CPS is 50,000 housing units each month, and eight panels are used to rotate the sample. The basic CPS provides a

⁶ The BRFSS was initiated in 1984, with 15 States participating; since 2001, it extends to all 50 States, three territories (Puerto Rico, Guam, and the Virgin Islands), and the District of Columbia.

⁷ The surveys also include optional modules and state-added questions.

⁸ The sampling design of the NHIS is modified every 10 years; the recent change is for the 2006 survey (National Center for Health Statistics 2007b).

comprehensive body of data on the labor force, employment, unemployment, and persons not in the labor force. The Annual Social and Economic Supplement (ASEC), known as the Annual Demographic File before 2003, provides information on income and work disability status in addition to the usual monthly labor force data (BLS 2007a).⁹ The ASEC Supplement also surveys some of the military population: Armed Forces members residing with their families in civilian housing units or on a military base. Information about disability in the CPS is restricted to work limitation; nonetheless, it provides an opportunity to study employment trends for people with and without a work disability over a very long period (Burkhauser and Houtenville 2006). Under an Executive Order, BLS is in the process of designing a small set of disability questions that would be added to future rounds of the CPS (McMenamin et al. 2005).

B. Other National Household Surveys on Specific Topics

There are a number of federally-sponsored national surveys designed to provide, on a regular basis, more detailed information on specific aspects of population health, well-being, activities, and expenditures than what is available in the large national surveys described above. These topical surveys generally have much smaller sample sizes, and in some cases, the samples are derived from one of the major national surveys. With the exception of those that are focused specifically on health issues, these surveys tend to include few measures of disability. Examples of regular, national surveys that collect detailed information on very specific issues include the following:¹⁰

The **American Time Use Survey (ATUS)** collects information on how people spend their time in their normal daily activities, such as working, sleeping, caring for children, volunteering, or relaxing, and with whom they spend their time. The ATUS sample includes about 26,000 households drawn from households that have completed the final month of interviews for the CPS. This survey yields approximately 13,000 completed interviews. ATUS has been administered annually since 2003 (BLS 2007b). ATUS contains only very limited information about work disability (Do you have a disability that prevents you from accepting any kind of work during the next six months?) (BLS 2007c). As noted previously, there is a plan to add several disability indicators to the CPS at some time in the future. These additional indicators should also be available for use with ATUS, as the ATUS sample is drawn from the CPS and the CPS data are available for the ATUS sample.

Cosponsored by the Agency for Healthcare Research and Quality and NCHS, the **Medical Expenditure Panel Survey (MEPS)** provides comprehensive information about health care use and costs in the U.S. (Agency for Healthcare Research and Quality 2007). It is the most complete source of data on the cost and use of health care and health insurance coverage. The MEPS began in 1996, and collects nationally representative data on the civilian non-institutional population annually.¹¹ Design features of the MEPS include linkage with the NHIS, from which

⁹ Currently, the CPS is the official source of estimates of income and poverty in the United States.

¹⁰ Additional examples include the American Housing Survey (AHS), Consumer Expenditure Survey (CEX), Survey of Consumer Finances (SCF), National Crime Victimization Survey (NCVS), and the National Survey on Drug Use and Health/National Household Survey of Drug Abuse (NSDUH/ NHSDA). Features of these surveys are briefly described in the Appendix.

¹¹ The MEPS also included a Nursing Home Component in 1996 that gathered information from a sample nursing home residents, but it was a one-time event with no plan of conducting another one.

the sample for the MEPS core interviews is drawn, and enhanced longitudinal data collection for core survey components. The MEPS core survey collects detailed data on demographic characteristics, health conditions, health status, use of medical care services, charges and payments, access to care, satisfaction with care, health insurance coverage, income, and employment. In 2004, about 13,000 families were interviewed and information on about 33,000 individuals was collected. These data are then linked with additional information collected from the respondents' medical providers, employers, and insurers. This series of data collection activities is repeated each year on a new sample of households, resulting in overlapping panels of survey data.

Conducted by NCHS and CDC, the **National Health and Nutrition Examination Survey (NHANES)** was designed to assess the health and nutritional status of adults and children in the United States (National Center for Health Statistics 2007a).¹² The NHANES 1999–2006 surveys used a stratified multistage probability sample of about 5,000 persons each year, designed to be nationally representative of the U.S. civilian non-institutional population. The survey is unique in that it combines interviews and direct physical examinations.¹³ The examination component consists of medical and dental examinations, physiological measurements, and laboratory tests administered by highly trained medical personnel. The detailed interview component includes demographic, socioeconomic, dietary, and health-related questions. Substantial data on chronic disease and conditions (including undiagnosed conditions), risk factors, diet and nutritional status, immunization status, infectious disease, health insurance, and measures of environmental exposures are collected. Disability-related information includes hearing, vision, mental health, and physical functioning.

The **Panel Study of Income Dynamics (PSID)** is a longitudinal study of a representative sample of U.S. individuals and the family units in which they reside, conducted by the Survey Research Center at the University of Michigan (Hill 1991). It began in 1968 with a sample of 4,800 families and re-interviewed these families on an annual basis until 1997. Since then, it has re-interviewed them biennially. As a consequence of low attrition rates and the success in following young adults as they form their own families, the sample size has grown from 4,800 families in 1968 to more than 7,000 families in 2001. In 1997, the PSID sample also introduced a refresher sample of post-1968 immigrant families and their adult children. The PSID emphasizes the dynamic aspects of economic and demographic behavior, but its content is broad, including sociological and psychological measures. A series of health supplements funded by the National Institute on Aging in the early 1990s contain a rich set of questions regarding the health of family members ages 55 and over, to support analysis of aging issues. In recent years, the PSID has collected more data on health, including specific health conditions and limitations in activities of daily living (ADL) and instrumental activities of daily living (IADL) (Burkhauser et al. 2006). Prior to 2003, the PSID contained only very limited information about disability.

¹² The NHANES began in the early 1960's and has been conducted as a series of surveys focusing on different population groups or health topics. In 1999, the survey became a continuous program that will have a changing focus on a variety of health and nutrition measurements to meet emerging needs (National Center for Health Statistics 2007a).

¹³ Health interviews are conducted in respondents' homes. Examinations are performed in specially-designed and equipped mobile examination centers, which travel to locations throughout the country (National Center for Health Statistics 2007a).

Conducted by the Bureau of the Census, the **Survey of Income and Program Participation (SIPP)** provides comprehensive information about the income and program participation of individuals and households, and about the principal determinants of income and program participation (Westat and Mathematica Policy Research 2001). The SIPP is designed as a continuous series of panels, with sample sizes ranging from about 14,000 to 40,000 interviewed households. The duration of each panel is from two-and-half years to four years. Each SIPP panel is representative of the civilian non-institutional population ages 15 and over.¹⁴ Each SIPP panel includes a core set of questions which were asked during each interview, supplemented by questions on selected subjects in topical modules that vary across interviews. Since a major redesign undertaken in 1996, the core contains information about work limitations at every interview, and substantial additional disability information is found in selected topical modules, including data on mental disabilities and sensory, functional, and activity limitations (Wittenburg and Nelson 2006). The Bureau of the Census has fielded 13 SIPP panels since 1984. The most recent panel began in 2004. Due to federal funding constraints and methodological issues, the SIPP is scheduled to be replaced by a re-engineered system called the Dynamics of Economic Well-Being System (DEWS), after the completion of the 2004 panel.¹⁵

Two federally-sponsored national surveys focus on the opinions and attitudes of adults on specific issues, and are conducted on a regular basis. These are the **American National Election Studies (ANES)** survey and the **General Social Survey (GSS)**. Both surveys are sponsored by the National Science Foundation. The ANES seeks to collect information about public sentiment on the political process, the role of government, and social and economic issues. The GSS solicits information about individuals' attitudes toward social and public policy issues, economic status, political events, work, and family life. Both surveys collect only very limited and inconsistent information about disability.

In addition to the special topic surveys described above, which are conducted on a fairly regular basis, there are several national surveys that have been conducted only once or very infrequently. These include the **National Comorbidity Survey (NCS and NCS-R)**, the **National Household Travel Survey (NHTS)**, the **National Survey of Family Growth (NSFG)**, and the **National Survey of Families and Households (NSFH)**. With the exception of the NHTS, these surveys all include a variety, although not a comprehensive set, of health status and disability indicators.

C. Surveys of Subpopulations

The federal government has sponsored a multitude of surveys that focus on a wide variety of population subgroups, and focus on special topics of particular relevance to those subgroups. The large number and variety reflect the widely different purposes of the surveys and specific needs for the data. Many of these surveys contain extensive disability-related information and/or focus specifically on subpopulations with disabilities. With a few exceptions, these data collection efforts are conducted very infrequently, or have been conducted only once. We describe several of these surveys below. Additional information about the features of these and other subpopulation/special topic surveys is contained in the Appendix.

¹⁴ During each panel, interviewers attempt to follow original SIPP sample members who move, provided they do not move abroad or into institutions or military barracks. In other words, the adults who become institutionalized during the panel years are excluded from the samples.

¹⁵ For information about the DEWS, visit <http://www.sipp.census.gov/sipp/dews.html>.

1. Youth and Young Adults

A number of surveys have focused specifically on youth and young adults in the general population. Examples include the: **Early Childhood Longitudinal Survey (ECLS)**; **National Longitudinal Survey of Adolescent Health (AddHealth)**; **National Education Longitudinal Surveys (NELS)**; **National Longitudinal Survey of Youth (NLSY)**; and the **National Survey of Child Health (NSCH)**. All of these contain a number of health and disability indicators, with those contained in the AddHealth and NSCH being the most extensive, and those in the NELN being the least extensive. Several additional surveys focus specifically on youth who are program participants and youth with disabilities or chronic health conditions. We note these in the relevant sections below.

2. Older Adults

The **Health and Retirement Study (HRS)** started with a sample of over 20,000 individuals ages 50 and over. This biennial, longitudinal study has been ongoing since 1992 and represents one of the exceptions to the infrequent nature of the other national special topic/special population surveys discussed in this section. The **Longitudinal Studies of Aging (LSOA)** represents another set of longitudinal studies of the older population (those ages 70 and over) that has been conducted twice since 1984. The **National Long Term Care Survey (NLTC)** consists of a series of nationally representative surveys of Medicare beneficiaries aged 65 or over, with a particular emphasis on the elderly who are functionally impaired. The NLTC began in 1982, and follow-up surveys were conducted in 1984, 1989, 1994, 1999, and 2004. Survey data from the HRS, LSOA, and NLTC all contain extensive information about health and disability.

3. Program Participants

Several surveys derive their samples from participants in government programs. The **Longitudinal Study of the Vocational Rehabilitation Services Program (LSVRS)** focused on people with disabilities who applied for and used state vocational rehabilitation services. The **National Survey of SSI Children and Families** focused on children with disabilities who participated in the Supplemental Security Income (SSI) program. The **National Beneficiary Survey (NBS)** focused on people with disabilities ages 18 to 64 who were participating in the SSI and Social Security Disability Insurance (SSDI) programs. Each of these represent one-time efforts intended to study or evaluate particular aspects of specific programs. The **National Longitudinal Transition Survey (NLTS/NLTS-2)** focused on the educational and other outcomes of children in the special education system and has been conducted twice. The **Medicare Current Beneficiary Survey** and the **National Long-Term Care Survey** both focus on Medicare program participants and represent ongoing, as opposed to one-time, efforts. All of these surveys contain extensive information about the health and disability status of the specific subpopulations surveyed.

4. People with Disabilities and Chronic Health Conditions

Two federal surveys have focused specifically on people with disabilities or special health care needs in the general population. The **National Health Interview Survey on Disability (NHIS-D)** represents the most ambitious effort to date to collect a wide range of disability-relevant information from a large, nationally-representative sample of people with disabilities of all ages. The survey was developed in response to a lack of data on people with disabilities covering a

wide range of topics of interest to the multiple federal agencies that govern programs and policies affecting people with disabilities. The survey, conducted in two phases in 1994 and 1995, was administered to samples drawn from the NHIS. Although the data from the NHIS-D have been used extensively (Hendershot 2005), the NHIS-D has not been repeated.

The **National Survey of Children with Special Health Care Needs (CSHCN)** identifies children in the non-institutionalized population who have special health care needs, defined as those who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally (Blumberg et al. 2003). This definition would include many, but not all, children that might be considered to have disabilities, and the survey contains some information that could be used to further identify children with disabilities. The purpose of the CSHCN is to document the prevalence of special health care needs among children, and provide information about access to insurance and health care-related experiences of those identified as having special health care needs.

D. Surveys of Non-Household Populations

While most national surveys include only the non-institutionalized, household population, a handful of federal surveys of non-household populations have collected information on residents of institutions (nursing homes, jails, and prisons) and on homeless individuals.¹⁶

The **Nursing Home Minimum Data Set (MDS)**, sponsored by the Centers for Medicare and Medicaid Services (CMS), is a standardized, primary screening and assessment tool designed to measure the health status of all residents in Medicare or Medicaid certified nursing and long-term care facilities (CMS 2005). Facilities are required to electronically transmit MDS data to their State agencies, and the State agencies have the overall responsibility for collecting MDS data in accordance with CMS specifications. Since 1990, the MDS measures physical, medical, cognitive, psychological, and social functioning of nursing home residents. Assessments are administered on admission, quarterly, annually, whenever the resident experiences a significant change in status, and whenever the facility identifies a significant error in a prior assessment.

The **National Nursing Home Survey (NNHS)** is another source of information on nursing home residents. NNHS is a continuing series of national surveys of nursing homes, their residents, and their staff that has been conducted by NCHS seven times between 1973 and 2004 (NCHS 2007c). The sampling is a stratified two-stage probability design: first the selection of facilities and then the selection of residents and discharges. The NNHS sample includes about 1,500 nursing home facilities. Data for the survey were obtained through personal interviews with administrators and staff and occasionally with self-administered questionnaires. Detailed information on health and functional status is collected, including diagnoses and sensory, mobility, ADL and IADL limitations.

Disability and health information on the incarcerated population is collected through three surveys: the **Survey of Inmates of Local Jails (SILJ)**, the **Survey of Inmates of State Correctional Facilities (SISC)**, and the **Survey of Inmates of Federal Correctional Facilities (SIFCF)**. Conducted by the Bureau of the Census on behalf of the Bureau of Justice Statistics, these surveys provide nationally representative data on persons held in local jails and state and

¹⁶ A more extensive discussion of these data sources appears in She and Stapleton (forthcoming).

federal prisons. They serve as the major source of data for studying the characteristics of the incarcerated population (Harrison and Beck 2004; James 2004). Stratified two-stage sample selection designs were used for the surveys: jails or prisons were selected in the first stage, and samples of inmates in these jails or prisons were selected in the second stage. Jail inmates have been surveyed about every six years between 1972 and 2002. State inmates have been surveyed about every five or six years between 1974 and 2004. Federal inmates have been surveyed only three times, about every six years between 1991 and 2004. Recent surveys interviewed about 20,000 inmates. These surveys collect information on: the individual characteristics of prison inmates and their family backgrounds; current offenses, sentences and time served; criminal histories; jail or prison activities, conditions and programs; prior drug and alcohol use and treatment; and health care services provided while in jail or prison. Beginning in the 1996-97 surveys, a series of disability questions were added, including work, sensory, physical, learning, and mental disabilities (Maruschak and Beck 2001; Maruschak 2006).

The only nationwide survey data available for the homeless population is the **National Survey of Homeless Assistance Providers and Clients (NSHAPC)**. The survey was conducted in 1996 by the Bureau of the Census on behalf of the 12 federal agencies responsible for administering homeless assistance programs and other interested parties (Burt et al. 1999). The study was designed to represent homeless assistance programs nationwide and the users of these programs, including urban, suburban, and rural areas. This survey, however, does not include homeless people who do not use services, and omits entirely those in communities that have few or no homeless assistance services. The study identified and gathered information about 16 types of homeless assistance programs, interviewed representatives of about 12,000 programs (representing an estimated 40,000 such programs nationwide), and interviewed a nationally representative sample of over 4,000 program clients. Clients were asked about a list of 17 medical conditions, indicators of alcohol, drug, and mental health problems, and treatment experiences related to these problems.

E. Program Administrative Data

Disability is a criterion used in determining eligibility and benefits in many public programs, such as SSI, SSDI, Medicare, Medicaid, state vocational rehabilitation, special education, food stamps, and state and local mental health service programs. The GAO (2005) estimates that there are over 20 federal agencies and nearly 200 programs that provide assistance to people with disabilities. Administrative data from these programs can provide extensive information about the income, public benefits, and health care and other service utilization of people with disabilities. They are limited, however, in that they only include people with disabilities who meet the particular program's definition of disability and who have applied for the program. In other programs, such as Temporary Assistance to Needy Families (TANF) and the state workforce development systems, people with disabilities can represent a large share of participants, but because disability criteria are not used in eligibility or benefit determinations it may not be possible to identify people with disabilities based on the administrative data from these programs alone.

We do not provide a review of the many sources of administrative data on people with disabilities. A detailed discussion of these data sources appears in Stapleton, Wittenburg, and Thornton (forthcoming). Program administrative data are an important source of information about people with disabilities and a critical component of the national disability data system, and

as such, warrant mention here. In general, however, unless the administrative data can be linked to some external source of information about disability in the broader population, such as survey data, their use in studying people with disabilities is limited by the restricted population coverage of the data, inadequate information to identify people with disabilities, and lack of broader information important for studying people with disabilities. When linked to survey data, however, program administrative data offer a powerful means to minimize the cost of data collection, reduce respondent burden, provide a longitudinal dimension, and provide validated data on program participation and benefits.

III. HOW THE DATA ARE USED

The disability data users we interviewed described a variety of purposes for which they needed and used data relevant to people with disabilities. We briefly describe these uses to provide a context for the discussion of gaps and limitations of disability data presented in the next section.

Describe the population of people with disabilities. A very fundamental need for and use of disability data is simply to document the prevalence of disability in the population and to describe the characteristics of people with disabilities. Information from the major national surveys (Census, ACS, NHIS, BRFSS, CPS) and selected smaller national surveys (SIPP, NSDUH) is frequently used for this purpose. Data from these surveys are also used to identify disparities between people with and without disabilities with respect to educational attainment, employment, service use, and economic well-being. As several of these surveys have been conducted consistently over long periods of time and will continue in the future, they are also used to monitor trends in the characteristics and experiences of people with disabilities and disparities between those with and without disabilities for purposes of assessing progress, and identifying and understanding important changes.

Administer programs and assess program performance and needs. Information on disability is used by a number of federal agencies to distribute funds and develop programs for people with disabilities. For example, federal grants are awarded based on the number of elderly people with physical and mental disabilities (under the Older Americans Act), disability data are used to allocate funds for mass transit systems to provide handicap access, and the Housing and Urban Development Act requires data about disability to distribute housing funds for people with disabilities (Census undated). Data are also needed to describe the characteristics of the people being served by particular programs and to evaluate service outcomes. For example, the legislation that created the Ticket to Work program requires the Social Security Administration to conduct an evaluation of the program's impact on services to disability beneficiaries and employment outcomes, and the Individuals with Disabilities Education Act requires the Department of Education to collect data on children with disabilities in the special education system.

Educate the public and support arguments for change. Many individuals we interviewed, particularly representatives of the advocacy community, emphasized how critical it was to have disability data for purposes of educating the public and demonstrating the magnitude and importance of specific issues relevant to people with disabilities. Several interviewees noted that anecdotes and intuition are not sufficient to support arguments for change. Hard data is necessary to provide a rationale and build support for new policies, initiatives, or resources.

Develop models to estimate future demand and the impacts of new programs/policies.

Disability data are frequently needed to estimate future demand for existing programs. For example, states use data on people with disabilities to estimate the demand for Medicaid long-term care and other disability-related services for planning and budgeting purposes. Social Security Administration (SSA) actuaries need data about the disability and health of the population in order to estimate future Old Age, Survivors, and Disability Insurance benefit expenditures and to project Social Security Trust Fund balances. Because some manner of cost and impact estimates are necessary for the planning and justification process of any new government program, information about people with disabilities is used to estimate the demand for new or proposed programs and their costs. Every bill reported out of committee in Congress must be ‘scored’, that is, have the impact on government revenues and expenditures estimated, therefore, the Congressional Budget Office requires data on people with disabilities in order to score any disability-related legislation.

Conduct research on specific issues. Disability data are used to conduct research on a wide variety of specific issues that may be medical, service-related, social, or economic in nature. Such research is frequently funded by the government or foundations, and conducted by contract research organizations and university researchers.

IV. GAPS AND LIMITATIONS OF DISABILITY DATA

As evident from the previous discussion, a very large amount of disability-related information is collected through national survey and program administrative data, and is used for a variety of purposes. The existing sources of data on disability do, however, have a number of shortcomings that limit their usefulness. Here, we discuss the primary limitations of the national disability data system, as identified through our interviews and review of federal surveys. These limitations are related to: the manner in which disability is measured; small sample sizes; the inability to adequately capture certain subpopulations; poor coverage of certain disability-related topic areas; infrequent data collection; predominantly cross-sectional, as opposed to longitudinal perspectives; and restricted access to administrative data.

A. How Disability is Measured

Disability is a complex and multi-dimensional concept. Several theoretical frameworks have been developed to characterize the various dimensions of disability and to model the process of disablement (Nagi 1965; WHO 1980; IOM 1991; Verbrugge and Jette 1994; WHO 2001). In reality, however, it is very difficult to take a concept as complex and multi-faceted as disability and boil it down to a manageable set of survey questions that can be used to identify people with disabilities in a manner that meets the needs of all who may want to use the data. As Wunderlich et al. (2002) aptly note, “Once the definitions are applied under real-world conditions, they necessarily operate under constraints of one sort or another, leading to numerous definitions used in public laws and private contracts offering different kinds of benefits or services or in a survey context to measure inability to undertake major activities of daily living. No single definition is feasible or desirable that will fit all purposes of assessment.” The myriad of needs for disability data and a general lack of consensus regarding an operational definition of disability leads to data collections that use different questions and combine information in different ways to define the population of people with disabilities (GAO 2006).

The nature of health and functional status indicators that can be used to identify people with disabilities vary greatly across survey and administrative data sources. In Exhibit 1, we present the health and disability measures contained in several national surveys to illustrate the differences across surveys. Although some surveys collect more detailed disability information than others, even when the general concepts of disability covered are in agreement, there are substantial operational differences in the collection of information for each conceptual definition. Surveys vary greatly in the wording and placement of questions, and the specific items used to identify broad categories of disability. For example, the decennial Census, ACS, and a variety of other household surveys (e.g., the NHIS and SIPP) contain six common subcategories of disability: sensory limitation, functional limitation, mental, ADL, IADL, and work disability, but the wording and manner in which these disability categories are identified in each survey are very different. Except for surveys that focus on health issues, the major national surveys generally offer only very limited ways in which people with disabilities can be identified.

Disability information for the elderly population is more extensive than for working-age adults. Surveys such as the NLTCs and the HRS offer far more detailed disability data than most other surveys, ranging from a lengthy list of chronic conditions to a full range of daily activities. The NHIS-D is an exception. While it provides comprehensive health and disability-related data for the household population of all ages, it was a one-time survey and the information is now somewhat outdated. In addition, disability information is limited for some group quarters populations.

The inconsistencies across the major national surveys in particular (Census, CPS, ACS, and NHIS) create two important problems when studying people with disabilities. First, because disability is measured very differently across surveys, the surveys yield very different estimates of the size of the population with disabilities, and of important characteristics of that population (e.g., employment and poverty rates). Although the sometimes widely different estimates can be explained in technical terms based on the differences in the survey methods and instruments, the lack of consistency in the estimates can undermine their perceived credibility among non-technical audiences, and thereby affect their usefulness in supporting arguments for change. Second, the lack of consistent indicators across data sources prohibits researchers and policymakers from identifying a common target population for which information from multiple data sources could be linked to provide much richer information about people with disabilities than can be obtained from a single data source.

In addition to the issue of inconsistent definitions of disability, some national surveys have only poor or no indicators that can be used to identify people with disabilities, and therefore, are of little or no use in studying people with disabilities. Surveys such as the American Housing Survey (AHS) and the Consumer Expenditure Survey (CEX) cover important subject areas but they lack the means to identify people with disabilities. The indicators available in many surveys perform particularly poorly in identifying people with psychiatric, cognitive, and intellectual disabilities. In many surveys, differences between people with cognitive, intellectual, and psychiatric disabilities cannot be distinguished; rather, these types of disabilities are lumped into a general question or questions related to mental health.

Exhibit 1. Health and Disability Measures in Selected National Surveys

Health/Disability Indicators	Census	ACS	CPS	SIPP	NHIS-D	NLTCS	HRS	NNHS	SISCF
General Health Status				X	X	X	X		
Body Mass (weight, height, obesity)					X	X	X		X
Sensory/Communication Limitations	X	X		X	X	X	X	X	X
Physical Limitations/Functional Limitations	X	X		X	X	X	X	X	X
ADL Limitations	X	X		X	X	X	X	X	
IADL Limitations	X	X		X	X	X	X	X	
Limitations in Work/Usual Activities	X	X	X	X	X		X		X
Learning Disability				X	X				X
Mental/Emotional Disorders or Symptoms	X	X		X	X	X	X		X
Cognitive or Developmental Disorders				X	X	X	X		
Limitations in Social/Interpersonal Interactions				X	X				
Substance Abuse/Dependence				X	X		X		X
Specific Chronic Conditions/Medical Conditions				X	X	X	X	X	
Use of or Need for Assistive Equipment/Home Modifications				X	X	X	X	X	
Use of or Need for Personal Assistance				X	X	X	X	X	
Bed Days/Lost Productivity Days					X				
Disability Benefit Receipt/Program Participation		X	X	X	X	X	X	X	
Self/Others Identify as Disabled					X				

B. Small Sample Sizes

According to one source and disability definition, about 18 percent of all persons in the U.S. have a disability, and the prevalence of disability increases markedly with age (from about 8 percent among children under age 15, to over 70 percent among those age 80 and older) (Census 2002). While disability is not uncommon, the samples of most surveys limit the ability to analyze specific subgroups of people with disabilities. Subgroups of interest can include: people with specific health conditions or types of disabilities; residents of specific states or sub-state geographic areas; users of specific programs or services; and people categorized by different lengths of disability duration.

The surveys with the largest sample sizes (Census, ACS, and CPS) generally have the most limited information about disability. These surveys can allow some analyses of people with disabilities as a group at the state and sub-state level, but cannot provide much information about, for instance, specific health conditions causing disability. The NHIS was specifically designed to collect information about the prevalence of specific conditions, and therefore, has large enough sample sizes to support analyses of the more common health conditions that might result in disability, but only at the national or regional level. The BRFSS also collects information on a core set of health conditions, many related to disability, that might be used to produce state-level estimates of prevalence and could potentially be used to study subgroups defined by specific health conditions. The data contained in the BRFSS, however, are focused on disease prevalence and risk behaviors, so are quite limited with respect to their ability to address broader disability issues. The MEPS and SIPP are examples of smaller national surveys where researchers have been able to pool multiple panel years of data in order to achieve larger sample sizes of particular subgroups (such as people with disabilities) to support analyses of specific issues. Pooling across survey years is only possible when the survey methodology and data collection instruments remain consistent over the time. But even when possible, it introduces more complexity to the analysis (e.g., ensuring that the appropriate weights are used) and some risk that, due to changes over time, the analysis will produce an inaccurate portrayal of the issue being studied. Also, it does not support analyses of trends except in the very long-term.

The major national surveys generally do not have sample sizes large enough to permit in-depth analyses of people with disabilities who use specific programs or services. In addition, the data often do not permit identification of specific program users or provide information adequate to assess the experiences of service users, or to evaluate program outcomes. Adding further to the difficulty of identifying program participants are issues related to respondent recall. If a single household member is providing information about all members, the individual may not have complete or accurate information about the program participation status of other household members. In addition, respondents who participate in many assistance programs may not recall or may confuse the names of specific programs. For example, respondents often confuse Medicare and Medicaid (and the many different names for specific Medicaid programs in different states). Similarly, they might confuse SSI and SSDI. They might not or know from which specific agency a service or program was rendered if accessed by means of a One-stop service center or other coordinated service delivery venue.

The inability of national survey data to provide high quality and detailed information about program participants is a primary reason why there are numerous surveys focused on program participants (e.g., NBS, MCBS, LSVRS, NLTS-2). While these specialized surveys provide very

rich information about program participants, they are typically undertaken very infrequently, and the information collected usually cannot be analyzed within the context of the general population.¹⁷ Linking survey data to administrative data sources is another way that survey data can be significantly enhanced and used to study program participants. The Social Security Administration has linked its program data with the SIPP and CPS and used these data for a variety of analyses that could not be conducted with either the survey data or the administrative data alone. Because of small sample sizes of program participants in the surveys, however, particularly in the SIPP, multiple years or panels of the surveys sometimes must be pooled to generate adequate samples sizes.¹⁸

C. Subpopulations Not Captured Well

There are at least three reasons why specific subpopulations of people with disabilities will not be represented well in a survey: the survey does not include disability indicators or other information sufficient to identify the subpopulation; the survey's sample size is too small to yield a large enough sample of the subpopulation for analysis; and/or the survey sampling methodology simply does not include the subpopulation of interest. As we have already discussed issues related to the first two reasons (disability measures and small sample sizes), here we focus on the issue of sampling and sample coverage.

For purposes of sampling and data collection, the U.S. Census Bureau divides the entire population into two major components: the household population and the group quarters (GQ) population. The GQ population includes both institutional and non-institutional GQ populations. Institutional GQ populations include residents of nursing homes, correctional facilities, mental and other specialized hospitals, and juvenile institutions. Non-institutional GQ populations include various types of group homes, college quarters, military quarters, religious quarters, and shelters (Census 2005).

Among the surveys providing disability data, coverage for the household population is far more extensive than coverage for those not in the household population. Data on people residing in institutions other than correctional facilities and nursing homes and in some non-institutional GQ are especially limited. Only the decennial long-form survey and the recent ACS cover nearly the entire population. The ACS, which is to replace the census long form in 2010, includes most of the GQ population beginning in 2006.¹⁹ It becomes the most comprehensive survey for disability information in terms of coverage. Nonetheless, it is possible that researchers may not be permitted to generate statistics by certain types of institutions because of privacy issues.²⁰

¹⁷ An exception is the NLTS-2. The NLTS-2 data collection instruments were designed to include items that have been collected in national databases for the general youth population to facilitate comparisons between NLTS2 youth (youth enrolled in special education) and those of the same ages in the general population.

¹⁸ See Stapleton, Wittenburg, and Thornton (forthcoming) for more information about surveys that have been linked to program data.

¹⁹ As of 2006, ACS data collection excludes the following GQ: domestic violence shelters, soup kitchens, regularly scheduled mobile food vans, targeted non-sheltered locations, natural disaster shelters, transient locations (such as RV campgrounds, marinas, and military hotels), dangerous encampments, and maritime vessels (Census 2006c).

²⁰ For the Census 2000 PUMS files, while it is possible to get institutional and non-institutional GQ by disability type, they do not provide institution type; in the summary files, there is institution listed, but not disability type. This

For the institutional population, the nursing home and incarcerated populations are fairly well covered by a number of surveys described previously. No surveys other than the decennial census long-form survey and the 2006 ACS, however, collect information on the population living in other institutions. That portion of the institutional population includes people living in a variety of institutions such as mental hospitals and juvenile institutions, some of which are disability-related.²¹

Other components of the population for which information is very limited are the homeless and the military populations. The homeless population is either not covered at all or covered to an unknown extent in most national surveys, even in the decennial census. As mentioned earlier, the 1996 National Survey of Homeless Assistance Providers and Clients is the only national survey available to study homeless assistance programs nationwide and the users of these programs. Moreover, most national surveys focus on the civilian population; that is, they exclude those in the military, or at least those living in military barracks. The few surveys that do include the military population (e.g., the CPS and the NLSY) are not designed to be representative of the military population, and the number of military persons surveyed is often very small.

Although the vast majority of the national surveys purport to be representative of the civilian non-institutional population, most do not survey all civilian non-institutional GQ. It is not always evident from the survey documentation which specific types of GQ are included or excluded in the sampling methodology, and data users may not be able to identify the types of GQ through the public use data files. For example, information is often not available in most national surveys to identify residents of group homes, some of which house people with psychiatric, cognitive, and intellectual disabilities and substance abuse disorders. There has also been recent growth in the use of residential alternatives to nursing homes among elderly and disabled individuals requiring long-term care. The Census Bureau definitions do not fully capture these types of institutions, which can fall somewhere on the spectrum between private homes and residential care, and institutional and non-institutional settings. Recent analyses suggest that an unknown proportion of the population in community residential care settings may not be captured by national surveys because of sampling methods, small samples, and other data limitations (Spillman and Black 2005, 2006).

D. Subject Areas Inadequately Addressed

A number of subject areas were identified by interviewees and through our survey review as being inadequately addressed for people with disabilities, for at least one of three reasons: surveys that address the topic area do not include adequate disability measures; surveys that address the topic areas well are either outdated or cover only very specific subpopulations of people with disabilities; or the topic area, as relevant to people with disabilities, is simply not addressed in any survey.

Characteristics of disability onset, severity, and duration. Information about the causes, nature, and consequences of disability over time is important to developing the means to prevent disability onset and minimize the negative impacts of disability on quality of life. However, little

prohibits researchers to tabulate disability type by institution type. The ACS GQ data may be more restrictive because the ACS sample size is smaller than that of the Census 2000 PUMS.

²¹ This component of the institutional population represents about nine percent of the institutional population as a whole in 2000 (She and Stapleton, forthcoming).

information exists in national data sources concerning the onset and progression of disability. This is primarily because very few surveys are longitudinal, and those that are do not focus on health and disability. One exception is the HRS. Although limited to adults ages 50 and over, the survey contains information about disability onset, and somewhat detailed information about the health and economic status of individuals over a long period of time. No similar source of information exists for the general population. While the PSID is a national longitudinal survey that follows household over very long periods, the health and disability data available in the PSID is rather limited as the survey is focused on income, rather than health.

Use of Time and Money. How people with disabilities spend their time and money can have important implications for the public programs and policies designed to improve their well-being. Data on how people with disabilities spend their time and money are, however, extremely limited. The primary national data source of information about time allocation to various activities is the American Time Use Survey (ATUS). ATUS is administered to a subsample of the CPS and contains extensive information about time use activities, but only contains indicators for work disability, and thus, has limited applicability to the population with disabilities. The NLSY97 and NLTS-2 also contain a limited set of questions about activities and time use among youth. The Consumer Expenditure Survey (CEX) is the primary source of national data on a full range of consumer expenditures, but, like the ATUS, is extremely limited in terms of disability indicators, and therefore, of limited or no utility for providing information about people with disabilities. As subsamples of the CPS, both the ATUS and CEX have the potential to become much more useful for studying the time use and expenditures of people with disabilities in the future as the CPS adopts additional questions about disability status. Other sources provide selected information about the expenditures of people with disabilities: the MEPS collects extensive information about health care expenditures, and the SIPP collects limited information about expenditures associated with health, work, dependent care, taxes, schooling, housing, and vehicles. Both surveys contain data adequate to determine disability status, however, due to the limited samples sizes of people with disabilities in the MEPS, researchers have often needed to pool data across multiple years.

Transportation. Reliable transportation is necessary for most people to be employed and to live independently. Lack of accessible and reliable transportation frequently comes up as an important issue in surveys and focus groups with people with disabilities, but national data on the transportation-related experiences of people with disabilities is very limited. Except for the National Household Travel Survey (NHTS), most national surveys do not collect data on transportation-related issues. The NHTS is conducted infrequently and the only disability-related information collected is whether individuals had a medical condition that made it difficult to travel outside the home. Those with such conditions were asked how long the condition had lasted and whether or not they used special transportation services. Other national surveys provide only very limited transportation-related information. For example, the ACS asks respondents about means of transportation and travel time to work. The NHIS-D represents the only national survey that has collected somewhat detailed information about transportation-related issues for people with disabilities, but the survey has not been repeated and the information is now quite dated.

Workplace environment and job characteristics. The CPS and the SIPP are designed to collect extensive information about the employment and earnings of the household population. The value of the CPS information for studying the employment of people with disabilities is

limited by the CPS use of a work-limitation question to identify people with disabilities. These data will likely become more useful in future years when additional disability indicators are added to the CPS, as is currently planned. The SIPP offers equally detailed information about employment, along with more options for defining disability, and as SIPP is longitudinal, it also offers the opportunity to observe employment over several years. However, the SIPP is currently scheduled to be phased out. While both the CPS and SIPP include extensive information on employment status, labor force attachment, wages, hours, earnings, occupation, industry, self employment, health benefits, and reasons for not working, neither contain much information about job satisfaction, accommodations, job tenure, employment goals/expectations, or the job environment and barriers to work. The NHIS-D, MEPS, NBS, LSVRS and HRS have addressed some of these issues to varying degrees, but, with the exception of the NHIS-D and MEPS, have done so for only specific subpopulations. The NHIS and the ACS also contain important, but limited, information about the employment of people with disabilities. The PSID provides substantial information about employment dynamics over a very long period, but is limited in terms of disability measures.

Employment services. With respect to employment services and job training, the SIPP includes a few questions about participation in employment and training during the past year, but these are of limited utility for studying people with disabilities because the types of service programs specifically probed do not include programs frequently used by people with disabilities. They also do not address costs, barriers, or needs. The NHIS-D included an extensive module on vocational rehabilitation services, but the information is now very dated. In addition, the use of the specific term ‘vocational rehabilitation’ instead of more generic ‘employment and training’ services may have resulted in an under-reporting of service receipt from non-disability programs. Other NHIS-D questions about employment and training assistance focus on supported employment, sheltered employment, and services from independent living centers. The LSVRS and NBS collect extensive information about service use, satisfaction, barriers, and need, but are limited to the very specific subpopulations of people with disabilities surveyed.

Living arrangements, long-term care, and care giving. Most national surveys collect some information about household size and composition. Information specifically about individuals in small group homes is, however, limited by sample sizes or the ability to identify such living arrangements in the survey data.

ACS and Census collect information about home ownership, including some basic questions about the age of the housing and the type of facilities it includes. Both surveys also contain disability measures, but information about building accessibility and housing affordability are not available. The AHS provides more detailed information about the condition of the housing and amenities (e.g., kitchen sink, dishwasher, clothes dryer), but contains no information about disability. Only a few surveys of specific subpopulations of people with disabilities address accessibility features or the use and availability of accessible housing. For example, the National Survey of SSI Children and Families asks about accessible features of the house and, if the home does not have needed features, it probes into the barriers to acquiring the feature. The SIPP also contains a module that queries about material hardship experiences, which addresses to some degree issues of affordability and the quality of housing.

Although several surveys ask how long household members have lived in their current home, the exclusion of the institutional and homeless population and the predominantly cross-sectional nature of most surveys make it difficult to ascertain the stability of housing for people with

disabilities. With respect to care giving, among the surveys that include most age groups, the MEPS, SIPP, and NHIS-D do contain limited sets of questions about family support and care giving. The Quality of Life and Care Giving module of the BRFSS probes the issue, but has been administered in only a handful of states. Other surveys that address the issue of care giving in more detail do so only for specific subpopulations, such as the LSOA for the elderly, the NLTCs for Medicare beneficiaries age 65 and over, and the CSHCN for children.

Community participation. Data on aspects of community participation (other than employment) are scarce. The NHIS-D included a module on social activities. The GSS contains a set of questions about participation in specific social and political organizations, but has a small sample and limited information about disability. A number of surveys focused on youth that also contain a variety of disability indicators (e.g., NLTS2, NLSY97) generally include information about school, social, and other extracurricular activities.

Community and environmental aspects of disability/accessibility. Individual and household surveys do not generally collect information about neighborhood and community characteristics. It is possible, however, to link some surveys to other databases of community characteristics. There are several sources that characterize counties, for example, the Area Resource File, County Business Patterns, Economic Census, Census of Governments, Consolidated Federal Funds Report, Census of Employment and Wages, FBI uniform crime reports, school district data from the National Center for Education Statistics, or health-related measures from Vital Statistics. These sources have two major shortcomings, however. First, none addresses community characteristics specifically relevant to people with disabilities, such as the availability of affordable and accessible housing, public transportation, quality education and social services, and general community accessibility. Second, for many purposes, the county is too large a geographic area to measure characteristics that might be relevant to people with disabilities in the more immediate neighborhood. The only source of data that can be aggregated to a neighborhood level (defined by census tracts or zip codes) is the decennial census which provides good measures of household characteristics and income, but limited or no data on other characteristics that might be of interest for disability research and policy purposes.

Environmental factors that might facilitate or bar activities and social participation are especially important within the International Classification of Functioning, Disability, and Health (ICF) framework.²² Although the ICF model is quickly being adopted by many countries as the conceptual framework for measuring and studying disability, the operationalization of the ICF domains and concepts remains challenging, and surveys have yet to collect needed information on several domains, particularly environmental factors.

Individual perspectives (experiences, perceptions, needs, and expectations). Attitudes and perceptions are not covered well in most surveys. One reason for this is that many of the large national surveys are administered to one member of the household, but collect data on all members. This method works well for collecting factual information about households and their members, but is not as conducive to collecting information about individuals' experiences, attitudes, perceptions, needs, and opinions on specific issues. A few surveys collect information

²² ICF is a classification of health and health related domains that describe body functions and structures, activities, and participation, and are classified from body, individual, and societal perspectives. ICF also includes a wide range of environmental factors, including: products and technology; natural environment and human-made changes to environment; support and relationships; attitudes; services, systems, and policies (WHO 2001).

about general attitudes, for example, the NSFH and the GSS ask about political, social, and religious attitudes. While the NSFH includes several measures of disability, the GSS does not include any broad measures. The NBS and LSVRS address attitudes about work and self sufficiency, the NHIS-D asks about discrimination. The LSVRS addresses personal attitudes about one's disability (self-esteem, empowerment, attitudinal barriers, and expectations), but the survey is dated and limited to state vocational rehabilitation service applicants. The national surveys of youth (NLTS2, NLSY97) include questions that assess various expectations about the future.

Other issues. A variety of other topic areas were noted by interviewees as lacking adequate information about people with disabilities. These include: the use of and need for assistive technology; the nature of medical, vocational, and occupational rehabilitation services used by people with disabilities; the need for and use of informal supports and important factors that contribute to independence, or act as barriers to independence; unmet needs and out-of-pocket costs associated with disability-related needs; and non-economic aspects of quality of life.

E. Timing Issues

Two timing issues were raised by several interviewees as limitations to existing disability data: the fact that much of the data is old; and the fact that most disability data only provide a cross-sectional, as opposed to longitudinal, perspective.

Untimely or Outdated Data. The surveys that provide the most in-depth information about people with disabilities are also those that are conducted very infrequently, or only once. The NHIS-D represents the most ambitious effort to collect a wide range of disability-relevant information from a large, nationally-representative sample of people with disabilities of all ages. The survey was conducted in two phases, in 1994 and 1995. As it has not been repeated, the data are now over a decade old. The major programs serving people with disabilities only survey their populations very infrequently. The Social Security Administration has conducted large-scale survey efforts with its disability beneficiary population only a few times over the last three decades, and we only identify one survey of state/federal vocational rehabilitation service users, which was conducted in the mid-1990s. The institutional population surveys are generally conducted less frequently. For example, the data from surveys of the incarcerated population are available about every five to seven years. National surveys focused on psychiatric disability have only been conducted twice, and the only large scale survey on the homeless population (NSHAPC) was conducted over ten years ago.

Regardless of how frequently the surveys are administered, there is often a significant time lag between data collection and release. The lag in data release varies, depending on many factors, including the complexity of the survey design and data processing efforts, operational and administrative issues, and other factors. At one extreme, the monthly CPS data are released the following month, while at the other extreme, the SIPP data are released more than two years after data collection. For SIPP, the complexity of the instrument, the need for data imputations, and the need to use longitudinal estimation techniques have led to long delays before the data can be cleaned, documented, and finally, disseminated. Accordingly, one of the reengineering goals of the replacement of the SIPP (i.e., the DEWS) is to deliver data in a more timely manner through improvements in processing efficiency. For some complex surveys, early release datasets which undergo minimal processing are made available a short time after the end of the field period, while it takes much longer for final release datasets, which have been cleaned, processed for ease

of use, and supplemented by imputation, codebook, and user information files, to become available. Final datasets for surveys such as the MEPS, the MCBS, the NLTCs, and the HRS are released within about two years of the survey.

In addition to the aging of the data created by infrequent administration of surveys and long time lags until the data are released, it can take several years after release before extensive analyses based on the data sources become available to the general public in the form of government reports or academic publications.

Lack of Longitudinal Perspectives. Longitudinal survey data are more difficult and costly to collect than cross-sectional survey data. As most survey data are cross-sectional in nature, they do not permit analyses of the progression of disability and disability-related consequences over long periods. The most significant longitudinal national survey of the general household population, the PSID, included only very limited measures of disability until very recently. The SIPP provides a limited longitudinal perspective (three or four years, depending on the panel), but the sample sizes of people with disabilities are too small to conduct anything more than very high-level descriptive analyses of disability onset, progression, and consequences. Small samples of people with disabilities is also an issue in the MEPS, which provides a two-and-a-half year perspective on issues related to health care utilization and costs. The data sources that provide the most in-depth longitudinal information about people with disabilities tend to focus on very specific subpopulations such as older adults (HRS, LSOA) and youth (NLTS-2, NLSY, NELs). Linking survey data to administrative data from programs used by people with disabilities could add a longitudinal dimension to some surveys, but such links are the exception rather than the rule.

F. Limited Access to Administrative Data

As noted previously, administrative data from programs in which people with disabilities participate, when linked to survey data, can provide very rich information that is higher-quality and obtained at a lower cost and reduced burden on respondents than if such information were collected via survey. Links across multiple program administrative data sources can also be very useful for program planning and evaluation purposes. Links between multiple data sources are not routinely undertaken, primarily because of privacy issues.

A number of laws and regulations govern the collection and use of data by the U.S. government with the goals of protecting the privacy of individuals and ensuring the confidentiality of the information collected and maintained by the government.²³ The federal agencies that collect and maintain survey and administrative data are placed in the position of striking a balance between the need for the information for research and planning purposes, and protecting the privacy of individuals. While many federal agencies produce public-use files that contain administrative data from the programs they oversee, these data do not contain any individual identifiers that would permit the data to be linked to other data sources.²⁴ In general, it is extremely difficult, if not impossible, for individual researchers or state governments to obtain access to federal program administrative data that would permit linking to other sources of information. It can also

²³ See GAO (2001) for a discussion of the laws governing the use of data and issues surrounding the linking of multiple government data sources.

²⁴ Examples include the public use Medicare enrollment and claims files compiled by CMS, and SSA's public use data files on SSI and Old Age, Survivors, and Disability Insurance beneficiaries.

be very difficult for federal government agencies to obtain data from other federal agencies unless specifically needed for purposes of administering their programs. Inter-agency agreements to share or link data can take years to develop, and once in place, the actual process of linking the data, developing the documentation, and establishing the security protocols to allow access to them can be time-consuming and costly.

Although access to program administrative can be limited, and links across multiple data sources are not done frequently, there are examples where such links have been undertaken for purposes of facilitating research. Both the SIPP and CPS have been linked to SSA administrative records, and in some years, to CMS Medicare records. Data from the HRS have also been linked to SSA and CMS Medicare data. The National Center for Health Statistics (NCHS) has recently made available for public use SSA administrative data and CMS data on Medicare enrollment and claims that have been linked to the NHIS, LSOA, and the NHANES. In all of these cases, researchers must go through some established channels to obtain access to these data, which often involves an approval process for the research proposal, and restricted use of the data at a secure data access facility operated by the federal government.²⁵

We are aware of only one effort to link program administrative data across agencies for purposes of studying disability issues. Three federal agencies, SSA, CMS, and RSA, have recently established two-way agreements for matching data on participants in their respective programs. These data, however, are only made available to researchers conducting analyses that are sponsored by one of the agencies, and that have been approved by the other agency to which the administrative data will be matched. In general, administrative data matches between state and federal programs are not undertaken, except in specific circumstances and typically only when the federal agency (rather than the state agency) is the sponsor of the project.

V. SUMMARY AND CONCLUSIONS

Physical, cognitive, and emotional functioning are important, fundamental human characteristics. Disability and functional status are both significant determinants and consequences of health, economic well-being, productivity, and needs. As such, disability measures and disability-related information is critical to include in any national efforts to collect and maintain data on the welfare of the population.

Although a very large amount of disability-related information is collected and maintained through national survey efforts and program administrative data, the existing sources have numerous limitations. These limitations are related to: the manner in which disability is measured; small sample sizes; the inability to adequately capture certain subpopulations; poor coverage of certain disability-related topic areas; infrequent data collection; predominantly cross-sectional, as opposed to longitudinal perspectives; and restricted access to administrative data.

Of the limitations described, those related to how disability is measured and the lack of measures in some data sources were frequently noted in our interviews with disability data users. The most popular suggestion for improving existing disability data among those we interviewed was to establish a core set of disability measures and make that set of questions a requirement for all federal surveys. This would be a small set of screening questions designed to identify a broad population of people with disabilities in a consistent manner, that would be efficient to

²⁵ See Stapleton, Wittenburg, and Thornton (forthcoming) for further discussion.

administer and flexible enough to meet a wide range of purposes. This, and other suggestions for improving national disability data are described in a companion paper (Stapleton, Livermore, and She, forthcoming).

Information from existing national survey and administrative data sources is used for a variety of purposes, including monitoring the health and well-being of the population, justifying new programs and policies, and assessing the effectiveness of existing ones. In light of current and projected population characteristics, it would seem especially important to address the limitations of disability data now, as the need for good data is great and growing. A large and increasing share of the population is affected by disability, and disability is very costly to society. It can have wide ranging effects on productivity, economic well-being, program participation, and government expenditures. At the same time, the means for addressing disability, in terms of medical and technological advancements and environmental and social adaptations that can minimize disability-related consequences, have never been more available. Adequate data on disability causes and consequences is needed to better understand the current trends, develop informed policies, monitor progress, and facilitate change that is positive to society. Identifying the gaps and limitations in existing disability data, and finding practical and effective ways to address them is the first step to developing the information needed to make better informed decisions.

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Appendix. Features of Selected National Surveys

Surveys Reviewed

Large National Household Surveys

American Community Survey (ACS)
 Behavioral Risk Factor Surveillance System (BRFSS)
 Census
 Current Population Survey (CPS)
 National Health Interview Survey (NHIS)

Small National Household Surveys

American Housing Survey (AHS)
 American Time Use Survey (ATUS)
 Consumer Expenditure Survey (CEX)
 Medical Expenditure Panel Survey (MEPS)
 National Crime Victimization Survey (NCVS)
 National Health and Nutrition Examination Survey (NHANES)
 National Survey of Drug Use and Health (NSDUH)/National Household Survey of Drug Abuse (NHSDA)
 Panel Study of Income Dynamics (PSID)
 Survey of Consumer Finances (SCF)
 Survey of Income and Program Participation (SIPP)

National Opinion Surveys

American National Election Studies (ANES)
 General Social Survey (GSS)

Infrequent National Surveys

National Comorbidity Survey (NCS and NCS-R)
 National Household Travel Survey (NHTS)

Surveys Reviewed

National Survey of Family Growth (NSFG)
 National Survey of Families and Households (NSFH)

Surveys of Subpopulations

National Longitudinal Study of Adolescent Health (Add Health)
 National Survey of Children with Special Health Care Needs (CSHCN)
 Early Childhood Longitudinal Survey (ECLS)
 Health and Retirement Study (HRS)
 Longitudinal Studies of Aging (LSOA)
 Longitudinal Study of Vocational Rehabilitation Services (LSVRS)
 Medicare Current Beneficiary Survey (MCBS)
 National Beneficiary Survey (NBS)
 National Education Longitudinal Surveys (NELS)
 National Health Interview Survey on Disability (NHIS-D)
 National Mortality Followback Survey (NMFS)
 National Survey of Children's Health (NSCH)
 National Survey of Veterans (NSV)

National Survey of SSI Children and Families (SSI-Kids)
National Longitudinal Survey of Youth (NLSY79) and (NLSY97)
National Long Term Care Survey (NLTCs)
National Longitudinal Transition Study (NLTS-2)

Surveys of Non-Household Populations

Nursing Home Minimum Data Set (MDS)
National Nursing Home Survey (NNHS)
National Survey of Homeless Assistance Providers and Clients (NSHAPC)
Survey of Inmates of Local Jails (SILJ)
Survey of Inmates of State and Federal Correctional Facilities (SISCF and SIFCF)

Survey Features	Major National Household Surveys				
	ACS	BRFSS	Census	CPS (ASEC)	NHIS
Household Population	Y	P	Y	Y	Y
Non-institutional Group Quarters Population*	Y	N	Y	Y	Y
Military Quarters Population	Y	N	Y	P	N
Homeless Population	P	N	P	N	N
Institutional Population	Y	N	Y	N	N
Special Population Subgroup	NA	NA	NA	NA	NA
Age Group: Children (under 18)	Y	N	Y	P	Y
Age Group: Working-Age Adults (18-64)	Y	Y	Y	Y	Y
Age Group: Seniors (65+)	Y	Y	Y	Y	Y
Geography: National	Y	Y	Y	Y	Y
Geography: Regional	Y	N	Y	Y	Y
Geography: State	Y	Y	Y	Y	P
Frequency	annual	annual	decennial	annual	annual
Starting Year	1996	1984	1960	1940	1957
Longitudinal	N	N	N	N	N
Health/Disability Indicators					
General Health Status		X			X
Body Mass (weight, height, obesity)		X			X
Sensory/Communication Limitations	X		X		X
Physical Limitations/Functional Limitations	X		X		X
ADL Limitations	X		X		X
IADL Limitations	X		X		X
Limitations in Work/Usual Activities	X	X	X	X	X
Learning Disability					X
Mental/Emotional Disorders or Symptoms	X**		X**		X
Cognitive Impairment or Developmental Disorders					X
Limitations in Social/Interpersonal Interactions					X
Substance Abuse/Dependence		X**			X**
Specific Chronic Conditions/Medical Conditions		X			X
Use of or Need for Assistive Equipment/Home Modifications		X			X
Use of or Need for Personal Assistance					X
Bed Days/Lost Productivity Days		X			X
Disability Benefit Receipt/Program Participation	X			X	X

Self/Others Identify as Disabled					
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NOTES:

Y=Yes; N=No; P=Partial; ?= Unclear from documentation reviewed.

* Excludes military and homeless populations.

** Very limited or indirect information only.

Survey Features	Small and Frequent National Household Surveys									
	AHS	ATUS	CEX	MEPS	NCVS	NHANES	NSDUH/NHSDA	PSID	SCF	SIPP
Household Population	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Non-institutional Group Quarters Population*	Y	N	P	Y	Y	Y	Y	Y	N	Y
Military Quarters Population	Y	N	N	N	N	N	Y	N	N	N
Homeless Population	N	N	N	N	N	N	N	N	N	N
Institutional Population	Y	N	N	P	N	N	N	N	N	N
Special Population Subgroup	NA	NA	NA	NA	NA	NA	NA	NA	NA	NA
Age Group: Children (under 18)	Y	P	Y	Y	P	Y	P	Y	Y	P
Age Group: Working- Age Adults (18-64)	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Age Group: Seniors (65+)	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Geography: National	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Geography: Regional	Y	N	Y	Y	N	Y	Y	N	N	N
Geography: State	N	Y	P	N	N	N	Y	N	N	N
Frequency	Annual 1973-1980, biennial	annual	annual	annual	annual	frequent	annual	annual 1968-96, biennial thereafter	triennial	frequ

	thereafter									
Starting Year	1973	2003	1980	1996	1972	1960	1971	1968	1983	1984
Longitudinal	N	N	N	Y	N	N	N	Y	Y before 1989; N after 1989	Y
Health/Disability Indicators										
General Health Status				X		X		X		X
Body Mass (weight, height, obesity)						X		X		
Sensory/Communication Limitations				X	X**	X				X
Physical Limitations/Functional Limitations				X	X	X				X
ADL Limitations				X	X	X		X		X
IADL Limitations				X	X	X		X		X
Limitations in Work/Usual Activities		X	X**	X	X	X	X	X		X
Learning Disability								X		X
Mental/Emotional Disorders or Symptoms				X		X	X	X		X
Cognitive Impairment or Developmental Disorders				X	X	X				X
Limitations in Social/Interpersonal Interactions				X						X
Substance Abuse/Dependence						X	X			X
Specific Chronic Conditions/Medical Conditions				X	X	X	X	X		X
Use of or Need for Assistive Equipment/Home Modifications			X**	X						X
Use of or Need for Personal Assistance			X**	X						X
Bed Days/Lost Productivity Days				X			X			
Disability Benefit Receipt/Program Participation			X**	X**			X	X	X**	X
Self/Others Identify as Disabled					X					

NOTES:

Y=Yes; N=No; P=Partial; ?= Unclear from documentation reviewed.

* Excludes military and homeless populations.

** Very limited or indirect information only.

Survey Features	National Opinion Surveys		Infrequent National Surveys		
	ANES	GSS	NHTS	NSFG	NSFH
Household Population	Y	Y	P	Y	Y
Non-institutional Group Quarters Population*	N	Y	N	?	P
Military Quarters Population	Y	N	N	N	P
Homeless Population	N	N	N	N	N
Institutional Population	N	N	N	N	N
Special Population Subgroup	NA	NA	NA	Ages 15-44	Householders ages 19 and older and their children ages 5-18 in 1987-88
Age Group: Children (under 18)	N	N	Y	P	Y
Age Group: Working-Age Adults (18-64)	Y	Y	Y	P	Y
Age Group: Seniors (65+)	Y	Y	Y	N	Y
Geography: National	Y	Y	Y	Y	Y
Geography: Regional	Y	N	N	N	N
Geography: State	N	N	N	N	N
Frequency	before & after presidential elections	frequent	infrequent	infrequent	infrequent
Starting Year	1948	1972	1969	1973	1987-88
Longitudinal	N	N	N	N	Y
Health/Disability Indicators					
General Health Status		X		X	
Body Mass (weight, height, obesity)				X	X
Sensory/Communication Limitations					
Physical Limitations/Functional Limitations					X
ADL Limitations					X
IADL Limitations					X
Limitations in Work/Usual Activities				X	X
Learning Disability					
Mental/Emotional Disorders or Symptoms		X			
Cognitive Impairment or Developmental Disorders					
Limitations in Social/Interpersonal					

Interactions					
Substance Abuse/Dependence		X		X	X
Specific Chronic Conditions/Medical Conditions			X		
Use of or Need for Assistive Equipment/Home Modifications				X	
Use of or Need for Personal Assistance					X
Bed Days/Lost Productivity Days					
Disability Benefit Receipt/Program Participation	X**	X**		X	
Self/Others Identify as Disabled	X	X			

NOTES:

Y=Yes; N=No; P=Partial; ?= Unclear from documentation reviewed.

* Excludes military and homeless populations.

** Very limited or indirect information only.

Survey Features	Surveys of Subpopulations					
	AddHealth	CSHCN	ECLS	HRS	LSOA	LSVRS
Household Population	Y	Y	P	Y	Y	Y
Non-institutional Group Quarters Population*	N	N	N	Y	N	Y
Military Quarters Population	N	N	N	?	N	?
Homeless Population	N	N	N	N	N	?
Institutional Population	N	N	N	P	N	N
Special Population Subgroup	Children in grades 7-12; followup at ages 18-26	Children with Special Hlth Care Needs	Children in kindergarten in 1998; follow through 5th grade	Ages 51 and older	Ages 70 and older	State VR Service Applicants
Age Group: Children (under 18)	P	Y	P	N	N	P
Age Group: Working-Age Adults (18-64)	P	N	N	P	N	Y
Age Group: Seniors (65+)	N	N	N	Y	P	P
Geography: National	Y	Y	Y	Y	Y	Y
Geography: Regional	Y	Y	N	N	N	N
Geography: State	N	Y	N	N	N	N
Frequency	once with followup	once	2-3 years apart	biennial	infrequent	once with followup
Starting Year	1994	2000	1998-99	1992	1984	1995
Longitudinal	Y	N	Y	Y	Y	Y
Health/Disability Indicators						
General Health Status	X	X		X	X	
Body Mass (weight, height, obesity)	X		X	X	X	
Sensory/Communication Limitations		X	X	X	X	X
Physical Limitations/Functional Limitations	X		X	X	X	X
ADL Limitations	X			X	X	X
IADL Limitations	X			X	X	X
Limitations in Work/Usual Activities		X		X		
Learning Disability	X		X			X
Mental/Emotional Disorders or Symptoms	X	X	X	X		X
Cognitive Impairment or Developmental Disorders	X		X	X	X	X

Survey Features	Surveys of Subpopulations (continued)					
Limitations in Social/Interpersonal Interactions	X		X			X
Substance Abuse/Dependence	X	X		X		X
Specific Chronic Conditions/Medical Conditions	X			X	X	X
Use of or Need for Assistive Equipment/Home Modifications	X	X	X	X	X	X
Use of or Need for Personal Assistance	X			X	X	X
Bed Days/Lost Productivity Days	X	X				
Disability Benefit Receipt/Program Participation	X	X	X	X	X	X
Self/Others Identify as Disabled	X					

Survey Features	Surveys of Subpopulations (continued)						
	MCBS	NBS	NCS	NELS	NHIS-D	NLSY97	NLSY79
Household Population	Y	Y	Y	P	Y	Y	Y
Non-institutional Group Quarters Population*	Y	Y	P	N	Y	P	Y
Military Quarters Population	?	N	N	N	N	P	Y
Homeless Population	P	N	N	N	N	N	N
Institutional Population	Y	N	N	N	N	N	N
Special Population Subgroup	Medicare Beneficiaries	SSI/SSDI Beneficiaries	Ages 15-54 in 1990-92, followup in 2001-02	Children in 8th grade in 1988; last followup in 2000	Sample of People with Disabilities from NHIS	Ages 13-17 in 1997	Ages 14-22 in 1979
Age Groups: Children (under 18)	Y	N	N	P	Y	P	P
Age Groups: Working-Age Adults (18-64)	Y	Y	Y	P	Y	P	P
Age Groups: Seniors (65+)	Y	N	N	N	Y	N	N
Geography: National	Y	Y	Y	Y	Y	Y	Y
Geography: Regional	Y	N	N	N	Y	N	N
Geography: State	N	N	N	N	P	N	N
Frequency	annual	four rounds	once with follow-up	infrequent	once	infrequent	infrequent
Starting Year	1991	2004	1990	1988	1994	1997	1979
Longitudinal	Y	P	Y	Y	N	Y	Y
Health/Disability Indicators							
General Health Status	X	X	X		X	X	X
Body Mass (weight, height, obesity)	X	X			X	X	X
Sensory/Communication Limitations	X	X		X	X	X	X
Physical Limitations/Functional Limitations	X	X	X	X	X		
ADL Limitations	X	X	X		X		X
IADL Limitations	X	X	X		X		X
Limitations in Work/Usual Activities		X	X		X	X**	X

Survey Features	Surveys of Subpopulations (continued)						
Learning Disability		X**		X	X	X	
Mental/Emotional Disorders or Symptoms	X	X**	X	X	X	X	X
Cognitive Impairment or Developmental Disorders	X	X**		X	X	X	
Limitations in Social/Interpersonal Interactions		X	X		X		
Substance Abuse/Dependence		X	X		X	X	X
Specific Chronic Conditions/Medical Conditions	X	X	X		X	X	X
Use of or Need for Assistive Equipment/Home Modifications	X	X			X		X
Use of or Need for Personal Assistance	X	X			X		
Bed Days/Lost Productivity Days					X		X
Disability Benefit Receipt/Program Participation		X	X		X	X	X
Self/Others Identify as Disabled					X		

NOTES:

Y=Yes; N=No; P=Partial; ?= Unclear from documentation reviewed.

* Excludes military and homeless populations.

** Very limited or indirect information only.

Survey Features	Surveys of Subpopulations (continued)					
	NLTCs	NLTS-2	NMFS	NSCH	NSV	SSI Kids
Household Population	Y	Y	Y	P	Y	Y
Non-institutional Group Quarters Population*	Y	Y	Y	N	Y	Y
Military Quarters Population	?	P	Y	N	N	N
Homeless Population	N	P	Y	N	N	N
Institutional Population	Y	P	Y	N	N	P
Special Population Subgroup	Medicare Beneficiaries Age 65 and Older	Special Ed Students	Deceased Individuals Age 15 and Older	Children Ages 0-17	Veterans	SSI Childhood Beneficiaries
Age Groups: Children (under 18)	N	Y	P	Y	Y	Y
Age Groups: Working-Age Adults (18-64)	N	P	Y	N	Y	P
Age Groups: Seniors (65+)	Y	N	Y	N	Y	N
Geography: National	Y	Y	Y	Y	Y	Y
Geography: Regional	N	Y	N	Y	N	Y
Geography: State	N	N	N	Y	N	N
Frequency	every five years since 1984	once with followup	infrequent	once	infrequent	once
Starting Year	1982	2000	1961	2003-04	1978	2001
Longitudinal	Y	Y	N	N	N	N
Health/Disability Indicators						
General Health Status	X	X	X	X	X	X
Body Mass (weight, height, obesity)	X		X	X		
Sensory/Communication Limitations	X	X**		X	X	X
Physical Limitations/Functional Limitations	X	X	X	X	X	
ADL Limitations	X		X		X	X
IADL Limitations	X		X		X	X
Limitations in Work/Usual Activities			X	X	X	X
Learning Disability		X		X		X
Mental/Emotional Disorders or Symptoms	X	X	X	X	X	X
Cognitive Impairment or Developmental Disorders	X	X	X	X		X

Survey Features	Surveys of Subpopulations (continued)					
Limitations in Social/Interpersonal Interactions			X	X		X
Substance Abuse/Dependence		X	X		X	X
Specific Chronic Conditions/Medical Conditions	X	X	X	X	X	X
Use of or Need for Assistive Equipment/Home Modifications	X	X	X	X**		X
Use of or Need for Personal Assistance	X	X	X			X
Bed Days/Lost Productivity Days		X	X			X
Disability Benefit Receipt/Program Participation	X	X	X	X	X	X
Self/Others Identify as Disabled		X				

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Survey Features	Surveys of Non-Household Populations					
	MDS	NNHS	NSHAPC	SIFCF	SILJ	SISCF
Household Population	N	N	N	N	N	N
Non-institutional Group Quarters Population*	N	N	N	N	N	N
Military Quarters Population	N	N	N	N	N	N
Homeless Population	N	N	P	N	N	N
Institutional Population	P	P	N	P	P	P
Special Population Subgroup	Nursing Home Residents	Nursing Home Residents	Homeless Assistance Service Users	Federal Prison Inmates	Jail Inmates	State Prison Inmates
Age Groups: Children (under 18)	Y	Y	Y	Y	Y	Y
Age Groups: Working-Age Adults (18-64)	Y	Y	Y	Y	Y	Y
Age Groups: Seniors (65+)	Y	Y	Y	Y	Y	Y
Geography: National	Y	Y	Y	Y	Y	Y
Geography: Regional	N	Y	N	N	N	N
Geography: State	Y	N	N	N	N	N
Frequency	annual or more frequent	infrequent	once	infrequent	infrequent	infrequent
Starting Year	1990	1973	1996	1991	1972	1974
Longitudinal	N	N	N	N	N	N
Health/Disability Indicators						
General Health Status						
Body Mass (weight, height, obesity)	X			X	X	X
Sensory/Communication Limitations	X	X		X	X	X
Physical Limitations/Functional Limitations	X	X		X	X	X
ADL Limitations	X	X				
IADL Limitations	X	X				
Limitations in Work/Usual Activities				X	X	X
Learning Disability				X	X	X
Mental/Emotional Disorders or Symptoms	X		X	X	X	X

Survey Features	Surveys of Non-Household Populations (continued)					
Cognitive Impairment or Developmental Disorders	X					
Limitations in Social/Interpersonal Interactions	X					
Substance Abuse/Dependence			X	X	X	X
Specific Chronic Conditions/Medical Conditions	X	X	X			
Use of or Need for Assistive Equipment/Home Modifications	X	X				
Use of or Need for Personal Assistance	X	X				
Bed Days/Lost Productivity Days						
Disability Benefit Receipt/Program Participation	X	X				
Self/Others Identify as Disabled						

NOTES:

Y=Yes; N=No; P=Partial; ?= Unclear from documentation reviewed.

* Excludes military and homeless populations.

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