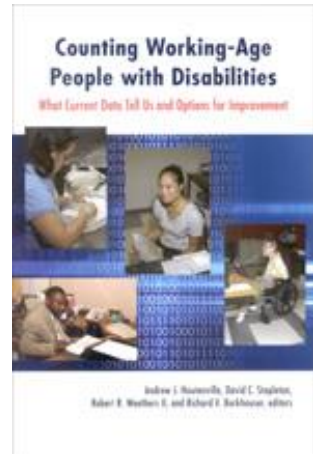

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The Disability Data Landscape

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Social Security Administration



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According to the Survey of Income and Program Participation (SIPP), there were 26.6 million working-age Americans (aged 25–61) with disabilities in 2002. In contrast, there are only 17.1 million working-age Americans with disabilities according to the 2003 American Community Survey (ACS).¹ Why these and other major federal-government-funded data sources yield such vastly different values for even the most fundamental of statistics on the working-age population with disabilities is the focus of this chapter. More importantly, it will delineate the strengths and limitations of currently available data sets in capturing levels and trends for this population.

This chapter will concentrate on the five major, nationally representative data sets used in the United States (and in this book) to capture the size of the working-age population with disabilities as well as their socioeconomic characteristics (e.g., demographics, employment, income, poverty, and health and functioning status). Four of the data sets are run by the U.S. Census Bureau: the ACS, Current Population Survey Annual Social and Economic Supplement (CPS-ASEC), 2000 Decennial Census, and SIPP. The fifth, run by the National Center for Health Statistics (NCHS), is the National Health Interview Survey (NHIS).

A taxonomy is developed that classifies disability questions found in these five data sets into concepts based on the International Classification of Functioning, Disability and Health (ICF) (World Health Organization 2001). This disability taxonomy places each survey question into one of six classifications—sensory impairment, physical impairment, mental impairment, activity of daily living (ADL) limitation, instrumental activity of daily living (IADL) limitation, and work limitation. Each classification flows from one of the three basic ICF concepts—*impairment*, *activity limitation*, and *participation restriction*.

The taxonomy is used to document the differences in the disability questions included in these surveys to capture each classification, as well as the ability for each survey to capture all of the classifications and thus the total population with a disability. This chapter also describes how the data sources differ in other important ways, including the degree to which they capture the population living in group quarters (GQ), defined as persons living in nursing homes, prisons, college dormitories, juvenile institutions, and emergency and transitional shelters. These differences can lead to dramatic disparities across the data sets in the prevalence of disability they find among working-age people and in the socioeconomic characteristics—employment rates, income levels, poverty rates, etc.—of the working-age population with disabilities discussed in later chapters of this book.

This chapter concludes with considerations of which data sets are best for answering various public policy questions and the value of the next generation of data sets that have just been or are in the process of being developed to better answer these questions.

DEFINITION OF DISABILITY

Unlike age and sex, which are readily identifiable individual attributes, disability is a complex interaction between a person's health condition and the social and physical environment. Hence, it has been defined in a variety of ways. The Interagency Committee on Disability Research (ICDR) documents 67 acts or programs that define disability. Of these, 35 have self-contained definitions of disability, 26 use definitions from other statutes, and 6 are in more than one statute (CESSI 2007). To compare estimates from the five national data sets used in this volume, we first developed consistent conceptual definitions and factors of disability.

The two most common conceptual models of disability used in the United States are the ICF developed by the World Health Organization (2006) and the disability model developed by Saad Nagi (1965, 1976). Both definitions explicitly recognize disability as a dynamic process involving the interaction of a person's health condition and personal

characteristics, as well as the physical and social environment. Changes in any of these factors can impact a person's ability to function and participate in everyday activities. Jette and Badley (2000) provide a detailed description and comparison of these models. In this volume, we adopt ICF concepts to create operational definitions of disability. The concepts used are *impairment*, *activity limitation*, and *participation restriction* (World Health Organization 2001). A prerequisite for each of these concepts is the presence of a health condition encompassing diseases, injuries, health disorders, and other health-related conditions. Examples of health conditions are listed in the *International Statistical Classification of Diseases and Related Health Problems, 10th Revision* (World Health Organization 2006).

An *impairment* is defined as a significant deviation or loss in body function or structure. For example, loss of a limb or vision may be classified as an impairment. We identify three types of impairments: 1) sensory, which includes difficulty hearing or seeing; 2) physical, which includes difficulty moving, climbing, reaching, and performing other physical functions; and 3) mental, which includes difficulty learning, remembering, concentrating, or performing other mental functions.

An *activity limitation* is defined as a difficulty that an individual may have in executing activities. For example, a person who experiences difficulty dressing, bathing, or performing other ADLs related to a health condition may be classified as having an activity limitation. We identify activity limitations based upon ADL questions.

A *participation restriction* is defined as an inability to engage in societal activities. For example, a working-age person with a severe health condition may have difficulty participating in employment as a result of the physical (e.g., lack of reasonable employer accommodations) or social (e.g., discrimination) environment. In some surveys, participation restrictions are identified by questions that ask whether the person has a long-lasting health condition that limits his or her ability to work or whether a health condition affects his or her ability to go outside the home to go shopping, to church, or to a doctor's office. We identify participation restrictions using IADL and work limitation questions.

A *disability*, then, is the presence of a health-based impairment, an activity limitation, and/or a participation restriction. This concept is similar to the definition used in the Americans with Disabilities Act

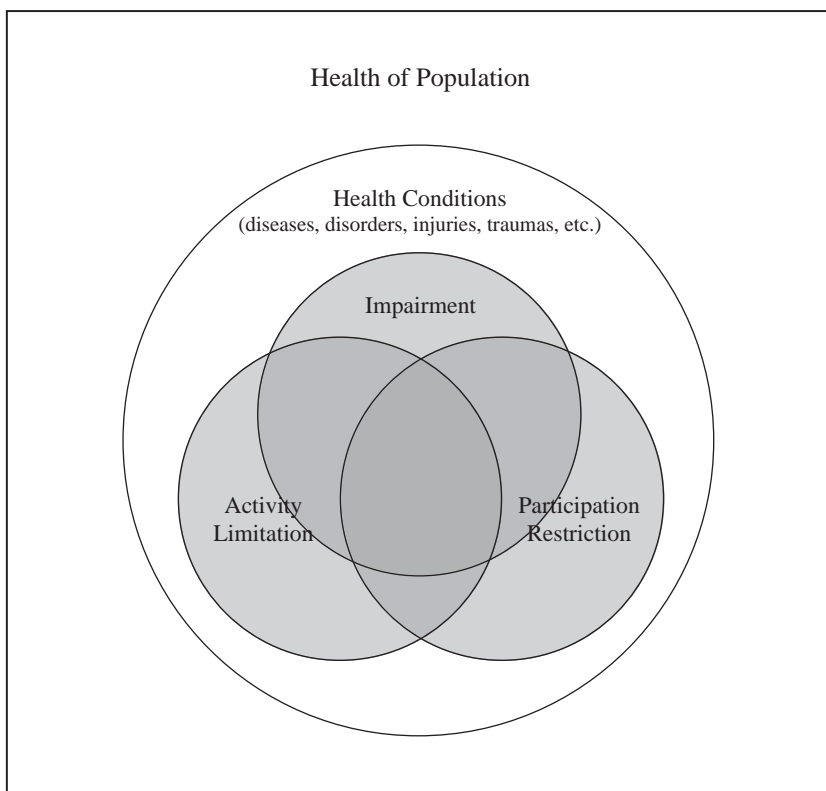
of 1990 (ADA). The ADA defines a disability as “a physical or mental impairment that substantially limits one or more of the major life activities, a record of such an impairment, or being regarded as having such an impairment.”

Although these concepts may seem to follow a progression—that is, an impairment leading to an activity limitation leading to a participation restriction—this need not be so. A person may have a participation restriction that is the direct result of the social environment without having an activity limitation or impairment.² For example, someone diagnosed as HIV positive with no impairment or activity limitation may be unlawfully refused employment on the basis of their health condition. Similarly, a person with a history of mental illness, but no current loss in capacity or activity limitation, may also be unlawfully refused employment based on past history. Figure 2.1 summarizes these ICF concepts, showing how they can overlap or occur singularly. The ICF universe is the health of the population, and the shaded area represents the population with disabilities.

Translating questions in currently available surveys into these ICF concepts of disability is not always a straightforward task, and there are no well-defined rules for doing so. For example, some survey questions may be interpreted as both an activity limitation and a participation restriction. The approach I used in these cases is to make consistent judgments. In doing so, I attempt to provide an ICF-based framework for comparing disability populations across surveys.

OVERVIEW OF NATIONALLY REPRESENTATIVE DATA SOURCES

Each of the five nationally representative surveys used in this volume to describe characteristics of the population of persons with a disability was designed for a different purpose, and each uses various methods, survey instruments, and sample designs to identify this population. As described below, these differences can have an important influence on the information that is collected on the population with disabilities. Ballou and Markesich (2009) and Mathiowetz (2000) both

Figure 2.1 Simplified Conceptual Model of Disability Using ICF Concepts

provide a good review of the general methodological issues as well as those specific to the population with disabilities.

American Community Survey (ACS)

The ACS is a relatively new continuous data collection effort by the U.S. Census Bureau designed to produce annual estimates at the national, state, and local levels on the characteristics of the U.S. population. Its purpose is to replace the Decennial Census long form, and it represents an improvement by providing data users with annual information on demographic, housing, social, and economic statistics that

can be compared across states, communities, and population groups. One of the main objectives of the ACS is to provide federal, state, and local governments with an information base for the administration and evaluation of government programs.

The population sampled for the ACS has changed substantially during the transition from the testing phase to full implementation. The testing phase began in 2000 and continued through 2004, and it is based on a national sample of addresses with an overall sampling rate of 0.7 percent annually (i.e., approximately 800,000 addresses per year).³ From 2000 to 2004, the ACS is representative of the U.S. population living in households, but it excluded persons living in GQ such as nursing homes, prisons, college dormitories, juvenile institutions, and emergency and transitional shelters. Full implementation of the ACS national household sample began in 2005 and included the collection of data on an annual basis from a nationally representative sample of approximately three million addresses. In 2006, the ACS added a sample of 2.5 percent of the population living in GQ and a sample of 36,000 addresses in Puerto Rico (U.S. Census Bureau 2003).

The ACS includes three sections: 1) resident characteristics, 2) housing characteristics, and 3) person-level characteristics. The resident section provides basic information on people living in the household, including name, sex, age, and relationship to the person who either owns or rents the house, apartment unit, or mobile home. The housing component contains information on the residence, including the type of building, costs of residing in the building, home equity, and other housing characteristics. The person-level section contains information on each person living in the household, including demographic characteristics, educational attainment, disability status, fertility status, living situation, employment status and conditions, and income.

There are six disability questions in the person-level section of the ACS. The questions were designed by a federal interagency workgroup for the 2000 Decennial Census (Adler et al. 1999). The first three questions identify household members aged 5 and older who have a long-lasting health condition associated with disability, including severe sensory impairment (hearing or vision), physical impairment (substantial limits on activities such as walking, climbing stairs, reaching, lifting, or carrying), or mental impairment (difficulty learning, remembering,

or concentrating). The fourth question identifies household members aged 5 and older who have a health condition for at least six months that affects the performance of ADLs (dressing, bathing, or getting around inside the home). The final two questions identify household members aged 15 and older who have a health condition lasting at least six months that affects participation in usual life activities (e.g., going outside the home alone to visit a doctor's office or go shopping and working at a job or business). The Census Bureau identifies a person with a disability based upon a "yes" response to at least one of the six disability questions.

Many features of the ACS will be useful to disability policymakers, service providers, and the disability advocacy community. First, the ACS contains a unique combination of data on disability, demographic characteristics, economic well-being, and employment. Second, the sample size and design of the ACS allow users to examine a variety of annual disability statistics at the national, state, Metropolitan Statistical Area (MSA), and county level. Third, because after 2006 the data will be collected in a consistent manner over time, users will be able to estimate trends in various disability statistics at a level of geographic detail (e.g., the county level) that is not possible in any other national survey. Users will be able to track changes to the disability population so that localized issues can be identified, services can be more effectively targeted to the population, publicly and privately funded disability programs can be more effectively administered, and new programs can be evaluated.

Although the ACS can provide information on a wide variety of topics, there are some limitations. First, the ACS does not detail the prevalence of specific health conditions (e.g., cancer, paralysis, HIV/AIDS, etc.) or distinguish between levels of severity. Second, the ACS definition of disability does not explicitly include important societal and environmental factors such as discrimination and lack of reasonable accommodations. Finally, prior to 2006, the ACS data did not include the population living in GQ.

Current Population Survey Annual Social and Economic Supplement (CPS-ASEC)

The CPS-ASEC is typically collected in March of each year as part of the monthly CPS data collection effort used to describe labor force characteristics of the U.S. population. In addition to providing the usual monthly labor force and demographic data, the CPS-ASEC collects data on work experience, including weeks worked and hours per week worked, as well as reasons for not working full time; total income and income components; noncash benefits, including food stamps, school lunch programs, employer-provided group health insurance and pension plans, private health insurance, Medicaid, Medicare, TriCare (formerly CHAMPUS) or military health care, and energy assistance; and migration. Data on employment and income are for the preceding calendar year, and demographic data are for the time of the survey. The CPS-ASEC is conducted by the U.S. Census Bureau for the U.S. Bureau of Labor Statistics.

The CPS-ASEC sample is drawn from the civilian, noninstitutional U.S. population living in housing units as well as members of the armed forces living in civilian housing units on a military base or in a household not on a military base. Beginning in 2002, the CPS expanded its sample to study the State Children's Health Insurance Program. In March 2007, the CPS completed interviews from members of about 57,000 households containing approximately 112,000 persons aged 15 or older.⁴ Prior to 2001, the CPS collected data from a smaller sample of households from the same population.⁵

The CPS-ASEC survey instrument contains one work-limitation question, which has been included since March 1980, and provides a consistently defined annual measure of the population with a work limitation: "(Do you/Does anyone in this household) have a health problem or disability which prevents (you/them) from working or which limits the kind or amount of work (you/they) can do?" The data from this question has been used by researchers and policymakers to measure demographic, employment, income, and poverty trends among the population of persons with a disability.

The question is located in the income section of the CPS survey instrument and was designed to be a prompt for the receipt of disability

income from sources other than Social Security Disability Insurance (SSDI) or Supplemental Security Income (SSI). The CPS-ASEC reinterviews part of the sample one year later, and this feature allows users to construct a two-period measure based upon reports of a work limitation in two consecutive March CPS interviews.

Some researchers and policymakers have criticized the use of this question to identify the population with disabilities because it was not designed or tested to measure such a population, and they have also argued that it is too narrow in scope. For instance, those who are limited in the amount of paid work that they can perform, or are prevented from performing, may not capture a population of people with disabilities that is relevant for broader disability policies such as the ADA (see Hale 2001). Although the question may not be useful for estimating the number of persons with a disability using a broader definition, Burkhauser et al. (2002) demonstrated that the trends in both the disability prevalence and employment rate using this measure are not statistically different from data sources that do use a broader definition. Burkhauser et al. (2002) have therefore concluded that the question is useful for studying longer term trends for the population.

The major strength of the CPS-ASEC is that it is the only nationally representative data source that can be used to construct a consistent set of annual estimates of those with a work limitation. It is also the primary source of data on employment, income, and poverty of the U.S. population. Therefore, it provides users with reliable information on important socioeconomic indicators for persons with a disability.

The CPS-ASEC, however, is limited in that its sole means of capturing the population with a disability is the one work-limitation question. And, as will be seen in subsequent chapters, this work-limited population is quite different in size and characteristics from the broader population with a disability that is captured in the ACS and other data sets that include additional disability classifications. However, the trends of the work-limited population closely track shorter term disability trends using the broader disability definitions found in the NHIS and provide plausible evidence that it is a valid measure of trends (Burkhauser et al. 2002). It also excludes those living in institutions, and the sample size in years prior to 2001 is not large enough to adequately measure the annual characteristics of persons with a disability in many states. The

CPS may be used to construct state-level estimates of the work-limited population from 2001 onward.⁶

2000 Decennial Census Long Form

Every 10 years the Census Bureau conducts a census to count the number of people in the United States, including those living in GQ. The data are used for a variety of official purposes, including the allocation of seats in the House of Representatives among the states. But Decennial Census data also provide a snapshot of the social and economic characteristics of the nation.

The Decennial Census includes a short form that collects basic demographic data from five of six households and a long form that adds social and economic data from every sixth household. Data are also collected from GQ, a population that is rarely included in surveys (see She and Stapleton 2009).

The 2000 Decennial Census long form is similar to the ACS. It includes the exact same six questions used in the ACS to identify the population with a disability.⁷ The disability questions were newly designed for the 2000 Decennial Census, so it is not possible to compare those results with those from earlier Decennial Census years.

The main advantage of the 2000 Decennial Census long form survey is that it has the largest and most comprehensive sample among the national data sources for studying the population with a disability. Sample sizes are sufficient to produce small area estimates, including those at the state, MSA, congressional district, and even tribal territory levels. It also provides the most complete set of data on the population living in GQ. The addition of the GQ population in the 2006 ACS will provide a new and updated source for this population.

The 2000 Decennial Census long form has many of the same limitations as the ACS. The survey does not allow one to identify the prevalence of specific health conditions (e.g., cancer, paralysis, HIV/AIDS, etc.) and does not directly address external factors that may contribute to a disability, such as discrimination and lack of reasonable accommodations. The Census Bureau discovered problems with two of the questions in the Decennial Census long form. The Decennial Census IADL and work-limitation questions may have been administered in a

way that creates an overestimate of the population with these two disabilities as well as the overall population with disabilities.⁸

National Health Interview Survey (NHIS)

The NHIS is the primary data source on the health of the civilian, noninstitutionalized population of the United States. The survey was initiated as part of the National Health Survey Act of 1956 (Public Law 652–84th Congress), “to produce statistics on disease, injury, impairment, disability, and related topics on a uniform basis for the Nation.” In general, the NHIS exists to monitor the health of the U.S. noninstitutional population and to display these characteristics by socioeconomic and demographic characteristics. NHIS data are used within government agencies and the academic research community to monitor developments in the prevalence of illness, disability, and other health-related conditions. Researchers rely on the NHIS to measure trends in the U.S. health care environment, including changes in access and utilization. The NHIS is also used to measure the efficacy of federal health programs, and the NCHS cooperates with other federal agencies to meet their needs for health data.

The target universe of the NHIS is all dwelling units that contain members of the civilian noninstitutionalized U.S. population. The NHIS sample does not include those residing in institutions (including those in prisons and long-term care facilities), members of the active duty armed forces, or U.S. nationals living abroad. In 2002, the NHIS sample consisted of more than 36,000 households that yielded a total of approximately 93,000 persons interviewed. For the sample adult component (explained below), 31,044 adults from the 93,000 persons were interviewed.

The NHIS consists of two basic components: a core section that remains unchanged across years and sets of supplemental questions that change annually. The core consists of three general sections: the family core section, which collects demographic and health information on every member of the household; the sample adult section, which randomly selects an adult and collects additional health-related information for that person; and a sample child section, which collects additional health-related information for the randomly selected child. In

2002, there were nine supplemental topics included: 1) alternative and complementary medicine; 2) vision; 3) hearing; 4) asthma; 5) arthritis; 6) child mental health; 7) disability and secondary conditions—assistive technologies and environmental barriers; 8) environmental health—lead paint; and 9) child and adult immunizations.

Data on disability within the NHIS are derived from questions in both the person-level file of the family core and the sample adult file. Within the family core file, the questions used to identify disability are from the “health status and limitation of activity section,” which contains survey questions on work, ADL and IADL limitations, difficulty walking without special equipment, and trouble with cognition. Within the sample adult survey, the NHIS asks respondents questions about sensory, physical, and mental health impairments. The specific questions used to identify each of these, and the definition of disability, are described in the next section of this chapter.

There are several strengths of the NHIS relative to other national surveys. The NHIS contains the largest amount of health-related data of all the major surveys, including particularly unique and extensive data on health insurance, health care access and utilization, health status, and health-related conditions and behaviors. The NHIS also contains a broad set of data on disability-related topics, including activity limitations, measures of psychological distress, and limitations in sensory and work ability. Moreover, the NHIS questionnaire asks those who indicated a limitation to a functional activity the source or condition of their limitation. Additional strengths of the NHIS include its continuous administration during the past five decades, which allows for the comparison of some health trends, and the specialized information contained in the supplemental survey section.

However, there are several limitations to the data contained in the NHIS. One significant drawback is the omission of several segments of the population, including the institutionalized and homeless populations, nationals living abroad, and members of the armed forces (although families of active duty military members are included). Second, the NHIS has much less comprehensive socioeconomic information than some of the other major surveys, such as the CPS and SIPP. Although the survey contains a section on income and assets, the NHIS has experienced a high rate of nonresponse for these types of questions.

Moreover, income data are only reported at the family level, making analysis of personal income impossible. Third, due to confidentiality concerns, the NHIS sample does not allow for state-level estimates. This is a significant drawback when analyzing the impact of area-specific public programs or analyzing state-level changes in the health status of the population with disabilities.

Finally, the NHIS core questionnaire items are redesigned every 10 to 15 years, the latest in 1982 and 1997. The redesign has an important impact on the use of the NHIS to track long-term trends. It can be used to track annual trends between 1982 and 1996, for instance, and between 1997 and 2006 but, because of the substantial differences in the questionnaires across these two periods, as well as other changes in the design and administration of the NHIS, it may not be used to track trends across the two periods. Thus, the survey is unable to track the long-term trends from 1980 to the present, whereas the CPS is able to measure such trends using the work-limitation definition. Because many of the important social indicators are sensitive to the business cycle, as shown in Houtenville et al. (2009); Weathers and Wittenburg (2009); and Burkhauser, Rovba, and Weathers (2009), and because the peak and trough years of the business cycle span the two different NHIS time periods, the survey is limited in its ability to describe important changes in social indicators over time. See National Center for Health Statistics (2003) for further details on the NHIS redesign and Hendershot, Harris, and Stapleton (2009) for a more detailed discussion of the strengths and weaknesses of the most recent NHIS data and the relationship between disability and health that it captured.

Survey of Income and Program Participation (SIPP)

The primary purpose of the SIPP, which is administered by the U.S. Census Bureau, is to collect information on the income and program participation of a nationally representative sample of households and individuals living in the United States. The SIPP has been conducted 13 times since it was first implemented in 1984, and each survey is referred to as a “panel” because it includes multiple interviews of sample members conducted every four months over a period of at least 32 months. The 2001 SIPP panel is used in this volume, and it includes nine waves of interviews occurring at four-month intervals.⁹

The SIPP sample is designed to be representative of the civilian noninstitutionalized population living in the United States. This includes the population 1) living in households; 2) living in some types of GQ, such as dormitories, rooming houses, and religious group dwellings; and 3) foreign visitors and their families who work or attend school in this country.¹⁰ Persons who were at least 15 years of age at the time of the interview were eligible to be in the survey. The population excludes 1) institutionalized persons, such as correctional facility inmates and nursing home residents, 2) crew members of merchant vessels, 3) armed forces personnel living in military barracks, and 4) U.S. citizens residing abroad. Members from approximately 35,000 households completed 2001 SIPP wave 1 interviews. The sample sizes for subsequent waves are lower.¹¹

Each SIPP interview includes core and topical module questionnaires. The core questions, which address demographic, program participation, and employment information over the previous four-month period, are repeated in each wave of interviews. Topical modules cover a broad range of subjects that vary by interview wave within each panel. The modules also vary by panel and include questions on personal history, child care, assets, program eligibility, child support, disability, school enrollment, taxes, and annual income. In some cases, the topical modules within a panel are repeated in subsequent interviews.

The SIPP includes one question about the presence of a work limitation during the core interview and more detailed questions about health, functional limitation status, and medical history in two topical modules. The question about the presence of a work limitation in the core interview is as follows: “Does [insert name] have a physical, mental, or other health condition which limits the kind or amount of work [insert name] can do?” There is an extensive set of more detailed disability questions in the two topical modules that have been used to identify broader concepts of disability (Steinmetz 2004). The next section describes how these questions are used in this volume to establish different conceptual definitions of disability.

The SIPP has several advantages for disability research. First, it contains a large set of questions on health and disability status that researchers can use to construct a variety of disability measures. Second, it contains a longitudinal component because sample members are rein-

interviewed every four months for between two to four years, depending on the SIPP panel. Thus, users can examine changes at the individual level among persons with a disability in terms of their health, employment, income, and program participation (e.g., how health is related to employment and economic well-being over time). A third advantage is that data users can obtain special permission to link individual-level Social Security Administration (SSA) administrative data on program participation and earnings to SIPP sample members. As described in more detail in Stapleton, Wittenburg, and Thornton (2009), the ability to link the SIPP to SSA administrative records is important for researchers interested in examining longer term trends in earnings and program dynamics among people with disabilities.

Despite these advantages, the SIPP is also limited in the extent to which it can support other types of disability analyses. The most notable drawback has to do with cross-panel and within-panel comparisons based on the work-limitation question. Because the SIPP is essentially a longitudinal panel, its usefulness in producing trend estimates is limited, particularly relative to cross-sectional surveys such as the CPS and the NHIS. In addition, prevalence rates of work limitations across interview waves change because of the placement of the question (Maag and Wittenburg 2003). Finally, attrition bias is significant, especially from wave 1 to wave 2, and must therefore be accounted for in any SIPP-based analysis.

TRANSLATING SURVEY DISABILITY QUESTIONS INTO CONCEPTS

The heterogeneity among these five data sets in the questions they use to capture the working-age population with disabilities suggests that there will be substantial differences among them in the data they capture. To demonstrate these differences, this section classifies these disability questions into the disability taxonomy flowing from the ICF. This disability taxonomy places each survey question into one of six operational concepts—sensory, physical, or mental impairments and ADL, IADL, and work limitations—each of which flows from the three

previously discussed basic ICF concepts, impairment, activity limitation, and participation restriction.

Because the questions used in these data sets were developed before the ICF came into being, many are not directly related to the specific ICF-defined impairments, activity limitations, or participation restrictions concepts. For example, the ACS asks whether a person is blind or deaf without relating it to the ability to perform specific activities or participation restrictions, which may allow the concept to be interpreted as impairment, activity limitation, or participation restriction.

Even within each of these specific disability classifications, there are substantial differences in the questions used to identify a disability. These differences include the length of time of the limitation or impairment—some survey questions include qualifiers such as a “long lasting condition” or a condition “lasting six months or longer,” whereas others do not; how a survey question captures the level of difficulty carrying out a task or activity—some surveys ask whether a person has difficulty performing an activity, whereas others ask whether the person needs assistance from another person to do an activity; and the relationship between a health impairment and the performance of an activity—some questions define hearing impairment as a health condition that results in long-lasting deafness, whereas others define hearing impairment as difficulty in hearing what is said in normal conversation even with a hearing aid. Each of these differences changes the definition of disability and may result in variation in estimates of the population across surveys.

In this section, we present the specific questions used to identify each disability classification in the five survey instruments and show the differences in both the population and prevalence rates for each concept across the data sources.¹² Table 2.1 reports the population size and prevalence rate for each disability concept based on data from the five data sets.

Sensory Impairments

Sensory impairments include difficulty hearing or seeing. The specific questions used to identify these concepts in each survey are shown in Table 2.2. The ACS and 2000 Decennial Census include one survey

Table 2.1 Population Size and Prevalence Rate by Survey and Disability Type (Adults Aged 25–61)

Survey year and source	Any disability	Sensory impairment	Physical impairment	Mental impairment	ADL	IADL	Work limitation
Population (in thousands)							
2003 ACS	17,146	3,944	10,819	5,746	2,925	4,227	9,854
2003 CPS-ASEC	11,155	—	—	—	—	—	11,155
2000 Decennial Census	14,005	3,346	9,447	5,218	2,627	—	—
2002 NHIS	23,192	2,730	14,546	4,628	1,351	3,169	13,726
2002 SIPP	26,620	6,490	18,790	4,394	3,363	4,931	14,420
Prevalence rate (%)							
2003 ACS	11.9	2.7	7.5	4.0	2.0	2.9	6.9
2003 CPS-ASEC	7.8	—	—	—	—	—	7.8
2000 Decennial Census	5.5	2.6	6.8	3.8	1.9	—	—
2002 NHIS	16.7	2.0	10.5	3.3	1.0	2.3	9.9
2002 SIPP	18.7	4.6	13.2	3.1	2.4	3.5	10.1

SOURCE: Weathers (2005, ACS), Burkhauser and Houtenville (2006, CPS), Erickson and Houtenville (2005, Decennial Census), Harris, Hendershot, and Stapleton (2005, NHIS), and Wittenburg and Nelson (2006, SIPP).

Table 2.2 Survey Questions Used by National Surveys to Identify Sensory Limitations

Data source	Question
ACS	Does this person have any of the following long lasting conditions: blindness, deafness, or a severe vision or hearing impairment?
CPS-ASEC	None
Decennial Census 2000	Does this person have any of the following long lasting conditions: blindness, deafness, or a severe vision or hearing impairment?
NHIS	Which statement best describes your hearing without a hearing aid: good, a little trouble, a lot of trouble, deaf Do you have any trouble seeing, even when wearing glasses or contact lenses? (If yes) Are you blind or unable to see at all?
SIPP	Do you have any difficulties seeing the words and letters in ordinary newspaper print even when wearing glasses or contact lenses if you usually wear them? (Note: “person is blind” response is included in addition to yes/no response.) Are you able to see the words and letters in ordinary newspaper print at all? Do you have difficulty hearing what is said in a normal conversation with another person even when wearing your hearing aid? (Note: “person is deaf” response is included in addition to yes/no response.) Are you able to hear what is said in normal conversation at all? Do you have difficulty having your speech understood (Note to interviewer: do not enter yes if they simply can’t speak English)? In general, are people able to understand your speech at all?

SOURCE: Actual survey questionnaires as reported in Weathers (2005, ACS), Burkhauser and Houtenville (2006, CPS), Erickson and Houtenville (2005, Decennial Census), Harris, Hendershot, and Stapleton (2005, NHIS), and Wittenburg and Nelson (2006, SIPP).

question that captures long-lasting conditions resulting in hearing or visual impairments, including deafness and blindness. The NHIS includes two questions, one that asks about the level of difficulty hearing without a hearing aid and prompts the respondent to provide one of four answers ranging from “good” hearing to being deaf. The other asks whether the respondent has difficulty seeing even when wearing glasses and/or contact lenses and allows the respondent to provide a “yes” or “no” answer. Finally, the SIPP includes several questions that ask whether the hearing or vision problem results in difficulty with the performance of specific activities and a follow-up question that asks whether the problem prevents the respondent from performing the activity.

Estimates of the size of the working-age population with a sensory impairment and the corresponding prevalence rate differ substantially across the surveys (Table 2.1). The differences may reflect differences in the survey design or differences in the question wording. The NHIS data has the lowest population estimate (2.7 million people) and prevalence rate (2.0 percent), whereas the SIPP has the largest population estimate (6.5 million) and prevalence rate (4.6 percent). Estimates from the ACS data (population, 3.9 million; prevalence rate, 2.7 percent) are similar to those from the 2000 Decennial Census.

Physical Impairments

Physical impairments include difficulty carrying out physical functions or activities, and they may cut across ICF impairment and activity concepts. For example, the NHIS survey instrument asks whether the person can, without the use of special equipment, perform a series of different physical activities. Because some respondents may be able to perform these activities with the use of special equipment, it is unclear as to whether the person has an impairment that, with the use of special equipment, does not result in an activity limitation. Table 2.3 shows the questions used to identify physical impairments in each of the national surveys.

The surveys also differ in both the number and content of the questions used to identify physical impairments. For example, the ACS and Decennial Census both include one question that identifies whether the person has a long-lasting health condition that limits one or more basic

Table 2.3 Survey Questions Used by National Surveys to Identify Physical Limitations

Data source	Question
ACS	<p>Does this person have any of the following long lasting conditions:</p> <p>b. A condition that substantially limits one or more basic physical activities such as walking, climbing stairs, reaching, lifting, or carrying?</p>
CPS-ASEC	None
Decennial Census 2000	<p>Does this person have any of the following long lasting conditions:</p> <p>b. A condition that substantially limits one or more basic physical activities such as walking, climbing stairs, reaching, lifting, or carrying?</p>
NHIS	<p>By yourself, and without the use of special equipment, how difficult is it for you to...</p> <p>a. Walk a quarter of a mile—about 3 city blocks?</p> <p>b. Walk up 10 steps without resting?</p> <p>c. Stand or be on your feet for about 2 hours?</p> <p>d. Sit for about 2 hours?</p> <p>e. Stoop, bend, or kneel?</p> <p>f. Reach over your head?</p> <p>By yourself, and without the use of special equipment, how difficult is it for you to....</p> <p>a. Use your fingers to grasp or handle small objects?</p> <p>b. Lift or carry something as heavy as 10 pounds such as a bag full of groceries?</p> <p>c. Push or pull large objects like a living room chair?</p> <p>Respondent is classified as having a physical disability if respondent answers “can’t do at all” or “very difficult” to any question.</p>

Table 2.3 (continued)

Data source	Question
SIPP	<p>Do you have any difficulty lifting and carrying something as heavy as 10 pounds—such as a bag of groceries?</p> <p>Are you able to lift and carry a 10 pound bag of groceries at all?</p> <p>Do you have any difficulty pushing or pulling large objects such as a living room chair?</p> <p>Are you able to push or pull such large objects at all?</p> <p>Do you have any difficulty...?</p> <ol style="list-style-type: none"> a. Standing or being on your feet for one hour? b. Sitting for one hour? c. Stooping, crouching, or kneeling? d. Reaching over your head? <p>Do you have difficulty using your hands and fingers to do things such as picking up a glass or grasping a pencil?</p> <p>Are you able to use your hands and fingers to grasp and handle at all?</p> <p>Do you have any difficulty walking up a flight of 10 stairs?</p> <p>Are you able to walk up a flight of 10 stairs at all?</p> <p>Do you have any difficulty walking a quarter of a mile—about 3 city blocks?</p> <p>Are you able to walk a quarter of a mile at all?</p> <p>Do you have any difficulty using an ordinary telephone?</p> <p>Are you able to use an ordinary telephone at all?</p>

SOURCE: Actual survey questionnaires as reported in Weathers (2005, ACS), Burkhauser and Houtenville (2006, CPS), Erickson and Houtenville (2005, Decennial Census), Harris, Hendershot, and Stapleton (2005, NHIS), and Wittenburg and Nelson (2006, SIPP).

physical activities such as walking, climbing stairs, reaching, lifting, or carrying. The NHIS includes nine separate questions that identify the amount of difficulty with these activities, as well as with other physical activities such as sitting or standing for about two hours, using fingers to grasp or handle small objects, lifting or carrying up to 10 pounds (e.g., a bag full of groceries), and pushing or pulling large objects (e.g., a living room chair). A key difference with the NHIS is that it allows the respondent to use a response scale ranging from “not at all difficult” to “can’t do at all,” whereas the ACS and Decennial Census use a “yes/no” response. Finally, the SIPP questions are similar to those in the NHIS, but the SIPP uses a different method to identify the degree of difficulty. The SIPP questionnaire first asks whether the person has difficulty performing a specific physical activity and then asks whether he or she is able to perform that activity at all.

The estimates of the working-age population with a physical impairment are higher among data sources that use a larger number of questions to capture a broader range of physical impairments. The SIPP data contain the most questions, and the estimates show 18.8 million working-age Americans with a physical impairment and a prevalence rate of 13.2 percent. The NHIS contains fewer physical impairment questions than the SIPP but more than the ACS and Decennial Census. NHIS estimates show 14.5 million working-age Americans with a physical impairment and a prevalence rate of 10.5 percent. Estimates based on the ACS data show 10.8 million working-age persons with physical impairment and a prevalence rate of 7.5 percent. Estimates from the 2000 Decennial Census are somewhat lower than those from the ACS.

Mental Impairments

Mental impairments include health conditions that affect a person’s ability to perform basic mental activities. The questions used to identify these impairments are shown in Table 2.4. As with the sensory and physical impairment questions, these may capture both impairments and activity limitations, and they do so to varying degrees across the different survey instruments.

Table 2.4 Survey Questions Used by National Surveys to Identify Mental Limitations

Data source	Question
ACS	Because of a physical, mental, or emotional condition lasting 6 months or more, does this person have any difficulty in doing any of the following activities: a. Learning, remembering, or concentrating?
CPS ASEC	None
Decennial Census 2000	Because of a physical, mental, or emotional condition lasting 6 months or more, does this person have any difficulty in doing any of the following activities: a. Learning, remembering, or concentrating?
NHIS	During the PAST 30 DAYS how often did you feel... a. So sad nothing could cheer you up? b. Nervous? c. Restless or fidgety? d. Hopeless? e. That everything was an effort? f. Worthless? Responses were assigned the following point value: (0) None of the time/Don't know/refused (1) A little of the time (2) Some of the time (3) Most of the time (4) All of the time. Individuals with a combined score of 13 or greater were classified, under the Kessler Index, as having a mental disability.
SIPP	Do you have... a. A learning disability such as dyslexia? b. Mental retardation? c. A developmental disability such as autism or cerebral palsy? d. Alzheimer's disease or any other serious problem with confusion or forgetfulness? e. Any other mental or emotional condition?

SOURCE: Actual survey questionnaires as reported in Weathers (2005, ACS), Burkhauser and Houtenville (2006, CPS), Erickson and Houtenville (2005, Decennial Census), Harris, Hendershot, and Stapleton (2005, NHIS), and Wittenburg and Nelson (2006, SIPP).

The differences in the methods used to measure mental impairments are substantial across the national data sources, perhaps reflecting the challenges related to identifying what constitutes a mental disability and how to measure it in survey data. For example, in some cases, the SIPP uses a health-condition-based definition that asks whether the person has conditions such as autism or cerebral palsy, Alzheimer's disease, or other health conditions that are usually related to a person's capability to perform mental activities. The ACS and Decennial Census question focuses on how a person's health condition affects his or her ability to perform activities such as learning, remembering, and concentrating.

The measure used for the NHIS is the Kessler Index (Kessler et al. 2002, 2003), which is based on the person's assessment of how often, over the course of the past 30 days, he or she felt: a) so sad nothing could cheer him up, b) nervous, c) restless or fidgety, d) hopeless, e) that everything was an effort, or f) worthless. The response to each item was assigned a point value ranging from 0 to 4.¹³ The Kessler Index identifies those with an aggregated score of 13 or greater as having a mental disability.

The SIPP mental impairment measure is based almost solely on a health condition measure. A person is considered to have a mental impairment if they have a learning disability (e.g., dyslexia), mental retardation, a developmental disability (e.g., autism or cerebral palsy), Alzheimer's disease or any other serious problem with confusion or forgetfulness, or any other mental or emotional condition.

The estimates of the working-age population with a mental impairment and the corresponding prevalence rate are largest in the ACS, with 5.7 million working-age people and a prevalence rate of 4.0 percent. Estimates from the Decennial Census are slightly lower than those in the ACS. The NHIS and SIPP estimates are very similar to each other—data from the NHIS show 4.6 million people with a mental impairment and a prevalence rate of 3.3 percent, and the SIPP estimates are 4.4 million people and a 3.1 percent prevalence rate.

Activities of Daily Living Limitations

ADL questions are used to identify whether survey respondents have a health condition that makes it difficult to perform normal ev-

eryday activities such as dressing, eating, bathing, using the toilet, getting in and out of a bed or chair, or getting around inside the home. These questions were originally used to construct an index measuring the physical functioning of the elderly and chronically ill patients, but they are now being used for the broader population in national surveys (Mathiowetz 2000).

The differences across the questions in each of the data sets reflect 1) the number of questions used to identify the presence of an ADL limitation, 2) the number of ADL limitations mentioned in the question or set of questions, 3) the type and duration of the health condition, and 4) the severity of the limitation (any difficulty, need help from others). Table 2.5 shows the questions used in each of the data sets. The ACS and Decennial Census use one question that focuses on only three activities, specifies a physical, mental, or emotional condition lasting at least six months, and asks whether the person has any difficulty with the activity. The NHIS also includes one question, but it includes four activities, specifies a physical, mental, or emotional condition without a duration qualifier, and asks whether the person needs the help of other persons with personal care needs. Finally, the SIPP uses six questions, includes six activities, specifies a physical or mental health condition without a duration qualifier, and asks whether the person has difficulty with any of the activities.

The implied severity of the activity limitation within the questions appears to be related to the population and prevalence estimates. The NHIS, which may be limited to relatively severe limitations because the question defines an ADL limitation as needing the help of other persons, produces the lowest working-age population estimate (1.3 million) and prevalence rate (1.0 percent). The SIPP, which defines an ADL limitation as difficulty with any one of the six activities, has the largest population estimate (3.3 million) and prevalence rate (2.4 percent).

Instrumental Activities of Daily Living Limitations

IADL questions ask about the level of difficulty performing tasks such as preparing meals, doing housework, managing finances, using a telephone, and shopping. Jette and Badley (2000) describe some of the conceptual issues about using IADL questions to measure disability.

Table 2.5 Survey Questions Used by National Surveys to Identify Limitations in Activities of Daily Living (ADLs)

Data source	Question
ACS	Because of a physical, mental, or emotional condition lasting 6 months or more, does this person have any difficulty in doing any of the following activities: b. Dressing, bathing, or getting around inside the home?
CPS-ASEC	None
Decennial Census 2000	Because of a physical, mental, or emotional condition lasting 6 months or more, does this person have any difficulty in doing any of the following activities: b. Dressing, bathing, or getting around inside the home?
NHIS	Because of a physical, mental, or emotional problem do you need the help of other persons with personal care needs, such as eating, bathing, dressing, or getting around inside the home?
SIPP	Because of a physical or mental health condition, do you have difficulty doing any of the following by yourself? (Note to interviewer: this excludes the effects of temporary conditions—if an aid is used, ask whether the person has difficulty when using the aid) a. Getting around INSIDE the home? c. Getting in and out of bed or a chair? d. Taking a bath or shower? e. Dressing? g. Eating? h. Using or getting to the toilet?

SOURCE: Actual survey questionnaires as reported in Weathers (2005, ACS), Burkhauser and Houtenville (2006, CPS), Erickson and Houtenville (2005, Decennial Census), Harris, Hendershot, and Stapleton (2005, NHIS), and Wittenburg and Nelson (2006, SIPP).

As with the ADLs, the differences across the questions in each of the data sets are the 1) number of questions used to identify the presence of an IADL limitation, 2) number of IADL limitations mentioned in the question or set of questions, 3) type and duration of the health condition, and 4) severity of the limitation (any difficulty, need help from others, etc.). Table 2.6 shows the questions used in each of the data sets. The ACS and Decennial Census use one question, focus on only one activity (going outside the home for shopping or a visit to the doctor's office), specify a physical, mental, or emotional condition lasting at least six months, and ask whether the person has any difficulty with the activity. The NHIS also includes one question, but it includes four activities, specifies a physical, mental, or emotional condition without a duration qualifier, and asks whether the person needs the help of other persons with his/her everyday routine. Finally, the SIPP uses six questions, includes four activities, specifies a physical or mental health condition without a duration qualifier, and asks whether the person has difficulty with any of the activities.

Similar to the differences for the ADL estimates, the differences across the national surveys in the working-age population with an IADL limitation and prevalence estimates appear to be linked to differences in the question content. The NHIS uses the most severe definition (needs the help of other persons) and has the lowest population estimate (3.1 million) and prevalence rate (2.3 percent) among the national data sources. The SIPP uses the least severe definition and has the highest population estimate (4.9 million) and prevalence rate (3.5 percent). The ACS estimate falls between the two, with a population estimate of 3.1 million and a prevalence rate of 2.9 percent.

Work Limitations

Work-limitation questions focus on the presence of a health condition that either limits or prevents a person from performing paid work. Although most researchers agree that there are substantial limitations to using this question to measure the size and characteristics of the population of persons with a disability, it is useful for examining trends (Burkhauser et al. 2002), studying the population eligible for Social Security disability benefits (Dwyer et al. 2003), or examining the

Table 2.6 Survey Questions Used by National Surveys to Identify Limitations in Instrumental Activities of Daily Living (IADLs)

Data source	Question
ACS	Because of a physical, mental, or emotional condition lasting 6 months or more, does this person have any difficulty in doing any of the following activities: a. Going outside the home alone to shop or visit a doctor's office?
CPS-ASEC	None
Decennial Census 2000	Because of a physical, mental, or emotional condition lasting 6 months or more, does this person have any difficulty in doing any of the following activities: a. Going outside the home alone to shop or visit a doctor's office?
NHIS	Because of a physical, mental, or emotional problem do you need the help of other persons in handling routine needs, such as everyday household chores, doing unnecessary business, shopping, or getting around for other purposes?
SIPP	Because of a physical or mental health condition, do you have difficulty doing any of the following by yourself? (Note to interviewer: this excludes the effects of temporary conditions—if an aid is used, ask whether the person has difficulty when using the aid) b. Going OUTSIDE the home, for example, to shop or visit a doctor's office? i. Keeping track of money or bills? k. Doing light housework such as washing dishes or sweeping a floor? l. Taking the right amount of prescribed medicine at the right time?

SOURCE: Actual survey questionnaires as reported in Weathers (2005, ACS), Burkhauser and Houtenville (2006, CPS), Erickson and Houtenville (2005, Decennial Census), Harris, Hendershot, and Stapleton (2005, NHIS), and Wittenburg and Nelson (2006, SIPP).

population targeted for vocational rehabilitation services (Adler et al. 1999). The limitations associated with these questions are thoroughly covered in Wunderlich, Rice, and Amado (2002), and the influence of the different ways that the work-limitation question is asked in surveys is described in Banks et al. (2005). Table 2.7 shows the wording of the question for each of the national surveys.

The differences in the work-limitation question in each of the national surveys are related to the definition of the health condition and severity of the work limitation. The ACS defines a health condition as a physical, mental, or emotional condition lasting six months or more and the severity as any difficulty working at a job or business.¹⁴ The CPS-ASEC defines a health condition as a health problem or disability and severity as prevention of or limits on the kind or amount of work the person can do. The NHIS defines a health condition as a physical, mental, or emotional problem and severity as “keeping” a person from working at a job or business. Finally, the SIPP also defines a health condition as a physical, mental, or health condition and severity as limiting the kind and amount of work the person can do.¹⁵

The estimates of the size and prevalence of the working-age population with a work-limiting health condition range from a low of 9.8 million people and a 6.9 percent prevalence rate in the ACS to a high of 14.4 million people and a 10.1 percent prevalence rate in the SIPP (Table 2.1). The CPS-ASEC estimates are closer to those of the ACS, whereas the NHIS estimates are similar to those of the SIPP.

Disability

Disability is defined as the presence of at least one of the six disability classifications identified above. This definition is similar to the one that the U.S. Census Bureau uses within the ACS and posts on its American FactFinder Web site. It is important to note that the definition was not created to measure the population covered by the ADA nor has it been shown to be a valid measure of the ADA definition.

The national surveys differ in measuring this concept in three important ways. 1) The surveys measure each of the six disability classifications differently. 2) The CPS-ASEC and the 2000 Decennial Census do not capture all the disability concepts. The CPS-ASEC captures only

Table 2.7 Survey Questions Used by National Surveys to Identify Work Limitations

Data source	Question
ACS	Because of a physical, mental, or emotional condition lasting 6 months or more, does this person have any difficulty in doing any of the following activities: <p style="margin-left: 40px;">b. Working at a job or business?</p>
CPS-ASEC	Do you have a health problem or disability which prevents you from working or which limits the kind or amount of work you can do? Does anyone in this household have a health problem or disability which prevents them from working or which limits the kind or amount of work they can do? If yes to . . . , who is that? Anyone else?
Decennial Census 2000	Because of a physical, mental, or emotional condition lasting 6 months or more, does this person have any difficulty in doing any of the following activities: <p style="margin-left: 40px;">b. Working at a job or business?</p>
NHIS	Does a physical, mental, or emotional problem NOW keep you from working at a job or business? Does a physical, mental, or emotional problem NOW keep any of these family members from working at a job or business? (interviewer is instructed to read each adult family member's name) Are you limited in the kind OR amount of work you can do because of a physical, mental, or emotional problem? Are any of these family members limited in the kind OR amount of work they can do because of a physical, mental, or emotional problem? (interviewer is instructed to read each adult family member's name)
SIPP	Do you have a physical, mental or health condition that limits the kind and amount of work you can do?

SOURCE: Actual survey questionnaires as reported in Weathers (2005, ACS), Burkhauser and Houtenville (2006, CPS), Erickson and Houtenville (2005, Decennial Census), Harris, Hendershot, and Stapleton (2005, NHIS), and Wittenburg and Nelson (2006, SIPP).

the work-limitation concept, and the 2000 Decennial Census work-limitation measure is not used here because of potential problems that have been identified with that question. 3) The five surveys capture different overall populations (e.g., some include noninstitutional GQs and others do not) that are likely to disproportionately include working-age people with disabilities (see She and Stapleton 2009).

These differences contribute to substantial variation in the estimates of the size of the population of persons with a disability and the prevalence rate, as shown in the first column of Table 2.1. The surveys that use a larger number of questions tend to find a larger population with disabilities. The population estimate based upon the CPS data, which uses only one work-limitation question, is the lowest among the data sources, with a population estimate of a little more than 11 million working-age people with disabilities and a prevalence rate of 7.8 percent. Estimates using the ACS data are somewhat larger, with 17.1 million working-age people with a disability and a prevalence rate of 11.9 percent. The NHIS and the SIPP, which use a larger number of questions and both cover some portion of the population living in GQs, have the largest estimates of the working-age population with a disability and the prevalence rate. Estimates based upon the NHIS find 23.1 million working-age people with a disability and a prevalence rate of 16.7 percent, and estimates using the SIPP data show 26.6 million working-age people with a disability and a prevalence rate of 18.7 percent.

STRENGTHS AND LIMITATIONS OF THE DATA SOURCES

Each of the data sets discussed above has its strengths and limitations. The data set that is most appropriate to use to answer a research or policy question ultimately depends on the question itself. In many cases, no perfect data source exists to answer the question, so the researcher must weigh the strengths and limitations of each existing data set. This chapter considers the relative strengths of the five data sets discussed above in answering four generic questions. Later chapters will do likewise with respect to measuring employment (Weathers and Wittenburg 2009), income (Burkhauser, Rovba, and Weathers 2009),

poverty (Burkhauser, Houtenville, and Rovba 2009), and health (Hendershot, Harris, and Stapleton 2009) of the working-age population with disabilities.

Capturing Alternative Populations with Disabilities

The number of questions used to identify individuals with a disability, along with the wording of these questions, varies substantially across the national surveys. The NHIS and SIPP provide data users with the largest set of questions to capture alternatively defined populations with disabilities. One advantage of these data sources is that they can be used to capture clearly defined disability subgroups. Houtenville (2003) provides a good example of the strength of the NHIS in his examination of the employment and economic well-being of those with severe vision impairments.¹⁶

The ACS and the 2000 Decennial Census long form provide users with six questions that may be used to identify a broad population of persons with disabilities, but both of these sources also provide limited opportunities to capture specific subgroups with disabilities. It is not possible to use these data to identify a subpopulation that has vision impairments because the question does not allow users to separate those with vision impairments from those with severe hearing impairments. Similar problems exist for examining specific types of ADL limitations, IADL limitations, physical impairments, and mental impairments.

The CPS questionnaire contains only a work-limitation measure of disability. Although this definition is suitable for some purposes, it is not suitable for others. For instance, whereas the CPS can provide information on trends in the employment of working-age people with disabilities, it will clearly understate the level of employment in the broader population with disabilities, as will be seen in Weathers and Wittenburg (2009). Thus, data users must exercise caution when using the CPS to examine the broader population of persons with a disability.

Capturing State- and Local-Level Disability Populations

The 2000 Decennial Census and the ACS allow data users to construct estimates at a variety of different geographic levels, including counties, cities and towns, ZIP codes, census tracts, and tribal territo-

ries. The Census Bureau recommends using the ACS rather than the CPS to construct state-level estimates. However, in some circumstances, the CPS-ASEC may be the only source that contains state-level data on a particular topic, such as health insurance coverage.

The 2000 Decennial Census and the ACS allow data users to construct small-area estimates. They may also be used to construct estimates at a variety of different geographic levels, including counties, cities and towns, ZIP codes, census tracts, tribal territories, and other levels. The 2006 ACS data are available for geographic areas with a population of 65,000 or more, including 783 counties, 436 congressional districts, 621 metropolitan and micropolitan statistical areas, and all 50 states and the District of Columbia. Beginning in 2008, the ACS data will be available for all areas with a population of 20,000 or more, and beginning in 2010, it will cover even smaller geographic areas. Small-area estimates provide policymakers and service providers with the data necessary to identify how local services can be more effectively targeted to persons with a disability and how publicly and privately funded disability programs can be more effectively administered.

Capturing Long-Term Time Trends

The CPS and NHIS may be used to estimate various types of time trends. The NHIS is limited to some extent by the major redesign of the survey that occurred in 1997. Despite its limitations, it has proved extremely useful to verify that the trends in the employment rate of persons with disabilities found in the CPS-ASEC are not an artifact of the definition of disability used (Burkhauser et al. 2002).

The CPS allows data users to examine annual time trends for the population both with and without a work limitation since 1980. These data have been used to examine long-term trends in the population with a work limitation, including their employment rate, poverty rate, and other measures of economic well-being. The data have also been used to examine how the characteristics of those with a work limitation have changed over time and how these changes may be related to the declining employment rate among persons with a disability (Houtenville and Daly 2003). In doing so, the CPS provides information that policymakers can use to understand the underlying structure of long-term trends in

employment and economic well-being and the ways that public policy may be used to improve the lives of people with disabilities.

Capturing Movements of Individuals over Time

The SIPP, and to a limited extent the CPS, reinterview sample members, which allows data users to examine how a person's circumstances change over time. The CPS-ASEC reinterviews some participants about one year later. Researchers have used reinterview data to identify those who have longer term disabilities, which are referred to as two-period work limitations and defined as a report of a work limitation in both the first interview and the reinterview. For example, Houtenville and Burkhauser (2004) used the CPS-ASEC to show that the decline in employment appeared to occur soon after SSA rule changes were implemented that made it somewhat easier to qualify for disability benefits.

The SIPP reinterviews sample members up to nine times during the course of a SIPP panel. This allows data users to examine changes over an almost three-year period. Researchers have used the longitudinal component to study those with longer term disabilities, which are defined as a report of a disabling condition in consecutive interviews (Wittenburg and Nelson 2006). The data have also been used to examine changes in employment (Stapleton, Wittenburg, and Maag 2005), income (Bound, Burkhauser, and Nichols 2003), and program participation (Stapleton, Wittenburg, and Maag 2005).

SUMMARY AND EMERGING DEVELOPMENTS TO THE DISABILITY DATA LANDSCAPE

The concept of disability remains contentious, as does the appropriate method of operationally capturing the size and socioeconomic characteristics of those with disabilities in random samples of the population. As a result, dramatic differences can be found in even the most basic statistics on the working-age population with disabilities coming from current data sets sponsored by the federal government. Using a taxonomy that places disability questions found in the five major

nationally representative data sets used in the United States into one of six classifications based on ICF concepts of disability, substantial differences were documented. There are differences in the questions used across the data sets to capture each classification, as well as differences in the ability of these data sets to capture all of the classifications. Hence, there are also dramatic differences in the estimates of the total population with a disability. These differences in survey design are responsible for the variations across the data sets discussed in later chapters in both the prevalence of disability found among working-age people and the socioeconomic characteristics of the working-age population with disabilities.

This taxonomy was also used to examine the various strengths and limitations of the current national data sources to answer key disability questions. Although it was shown that at least one of the existing data sources could be used to measure each of these questions, no single existing data set is ideal for answering them all. Indeed, there are substantial gaps in the five surveys that limit the types of analyses that can be performed.

Fortunately, the disability data landscape is rapidly evolving and new data sources provide opportunities to fill these gaps. The Centers for Disease Control (CDC), for example, has recently included two new questions in the Behavioral Risk Factor Surveillance System (BRFSS) to identify the population with disabilities. The BRFSS, which is the world's largest ongoing telephone health survey system, provides an extremely useful new source of data for tracking the health and health behaviors of the population with a disability at the state level (Centers for Disease Control 2006).

The Bureau of Labor Statistics plans to include a new set of questions in the CPS to measure the employment of persons with a disability (McMenamin et al. 2005). This expanded set of disability questions will allow the Census Bureau to provide better statistics on the employment rate, poverty rate, and economic well-being of individuals with a disability.

Finally, the Census Bureau is considering changes to the disability questions within the ACS (Stern 2006). The downside of using new questions in the ACS is that it will delay the date when the ACS may be used to measure trends in both the employment rate and economic

well-being for persons with disabilities. However, if these questions are scientifically shown to be an improvement over the ones currently used, then the ACS will provide a more accurate picture of persons with disabilities.

Notes

1. These and other statistics on the working-age population with disabilities can be found in Table 2.1. The differences reported here are similar to ones reported for the entire adult population with disabilities by the Census Bureau using the SIPP (Steinmetz 2004) and the ACS (U.S. Census Bureau n.d.).
2. As will be seen in later chapters, this distinction is one reason that some people may report a work limitation without reporting an impairment.
3. The purpose of the national sample was to compare the national population estimates from the ACS to those from the Decennial Census long form.
4. It also contained demographic data on 31,000 children aged 0–14 years old and 450 Armed Forces members living with civilians either on or off base within these households.
5. For details on the history of the CPS-ASEC sample design, see U.S. Census Bureau (2002).
6. It may also be used to create state-level estimates for many states before 2001.
7. See Adler et al. (1999) for a description of the process used to determine the disability questions that were included in the 2000 Decennial Census.
8. Analysis of the Decennial Census 2000 data by Stern (2003) suggests that the work-limitation measure may be subject to substantial nonsampling error due to respondent and/or enumerator error relating to the enumeration process. In a recent Census Bureau report using Decennial Census 2000 data to examine the population with disabilities, the work limitation question was excluded from the definition of disability due to the potential nonsampling error (Wang 2005).
9. The 2004 SIPP is in the process of being released by the U.S. Census Bureau.
10. People staying in homes, schools, hospitals, or wards for the physically handicapped, mentally retarded, or mentally ill or in drug/alcohol recovery facilities are classified as living in “institutions” and not GQ. For more information on the Census Bureau classification rules, see U.S. Census Bureau (2000).
11. For more information on the sample design of the 2001 SIPP, see U.S. Census Bureau (2005).
12. The Census 2000 questions and estimates are similar to the ACS. The only exception is with the work-limitation question, where the Census 2000 may be subject to substantial measurement error.
13. Specifically, for each item (a) through (f), the survey respondent has an option of five responses. The responses and point values are as follows: “None of the time/Don’t know/Refused” was assigned 0 points, “a little of the time” 1 point, “some of the time” 2 points, “most of the time” 3 points, and “all of the time” 4 points.

14. The 2000 Decennial Census included a work-limitation question, but we do not use it in this volume because of potential problems with the administration of the question identified by the U. S. Census Bureau (Stern 2003).
15. See Wittenburg and Nelson (2006) for a good description of the issues with the work-limitation question in the SIPP.
16. Houtenville (2003) used the 1982–1996 NHIS for his analysis. The 1997–2007 NHIS only asks about specific health conditions for those who report a limitation, and therefore it is not possible to use his methodology to update his analysis. Chapter 7 describes the potential limitations of the NHIS for this purpose in greater detail.

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