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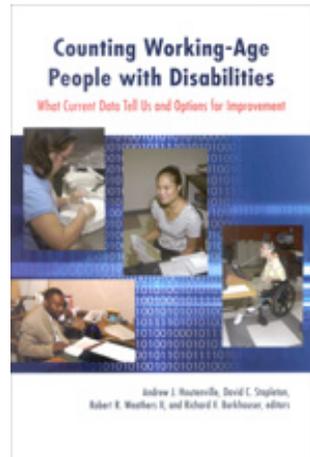
Purpose, Overview and Key Conclusions

David C. Stapleton
Mathematica Policy Research

Andrew J. Houtenville
New Editions Consulting

Robert R. Weathers
Social Security Administration

Richard V. Burkhauser
Cornell University



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Counting Working-Age People with Disabilities: What Current Data Tell Us and Options for Improvement

Andrew J. Houtenville, David C. Stapleton, Robert R. Weathers II, Richard V. Burkhauser, eds.

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“When you cannot measure, your knowledge is meager and unsatisfactory.”

—Lord Kelvin¹

“If you are not counted, you don’t count.”

—Cyndi Jones, Center for an Accessible Society

Efforts to provide statistics on the number and status of working-age people with disabilities have a history of being fragmented and sporadic. As a group, they are often overlooked in mainstream discussions of the latest statistics on employment, income, poverty, and other measures of the status of the population. In contrast, government agencies routinely compile and report such statistics for groups defined by sex, age, race, ethnicity, and marital status. Indeed, one of the most frequently cited statistical reports on the socioeconomic status of the U.S. population—the U.S. Census Bureau’s *Annual Report on Income*,

Poverty, and Health Insurance Coverage in the United States—does not mention this group.

The overarching objective of this book is to support and facilitate efforts to improve statistics and data on working-age people with disabilities. Many of the limitations with statistics and data on this population are well-known. There have been significant efforts to address the limitations, and some progress has been made. That progress, however, has often been at the whim of external forces, such as the extent of support for improvements to federal data collection, advances in information technologies, concerns about privacy protection, and government expenditure priorities, rather than for the purpose of systematically capturing the size and socioeconomic characteristics of this population. As a result, statistics and data for working-age people with disabilities are not on par with those for other “at-risk” working-age populations—groups that are more likely than others to experience adverse socioeconomic outcomes, such as some racial and ethnic minorities, children, unmarried parents, and the elderly. This book provides a systematic review of what current statistics and data on working-age people with disabilities can and cannot tell us, and how they can be improved to better inform policymakers, advocates, administrators, analysts, service providers, and others.

This book will inform two broad audiences. The first consists of those interested in what current data can tell us about the prevalence of disabilities among working-age people and their socioeconomic status, but who are dissatisfied with the limited, and often confusing, statistics cited in the mainstream press. For this audience, the book also offers the best available statistics on levels and trends in their employment, income, poverty, and health and functional status.

The second audience is a more specialized group of professionals (academics, advocates, government policymakers, service providers, etc.) who require reliable information to support evidence-based public policy and administrative decisions. For them, we go beyond “facts” to 1) examine how robust these facts are across data sets, 2) consider the strengths and limitations of current data as a whole, 3) describe current efforts to improve the data, and 4) offer options to advance this process.

In the next two sections of this chapter, we discuss the importance of having reliable data on working-age people with disabilities and the substantial limitations with the currently available data. We then summarize the major components of federal efforts to collect data for this population, both through surveys and administrative data systems. Each of these substantially independent efforts costs millions annually. Although they have not been well-coordinated, they still constitute an informal and substantial “national disability data system” (NDDS). A major conclusion of this book is that better coordination of these independent components could result in an NDDS that would be significantly greater than the current sum of its independent parts. We argue that this can be achieved by the use of a subset of common disability questions on existing survey data sets; expansion and improvements to the matching of agency administrative records to survey data sets, as well as matching of administrative records across agencies; and provision of easier access of the matched data to the broader research community, without compromising individual privacy. We further argue that efforts to improve the quality and usefulness of existing data collection are a more cost-effective method of advancing our knowledge about the working-age population with disabilities than adding yet another new and expensive survey.

We conclude the chapter with a summary of the content of the remaining chapters. These chapters provide the best current statistics on the size and socioeconomic characteristics of the working-age household population with disabilities, discuss the strengths and limitations of the current statistics, and offer alternatives to improving these statistics through greater coordination.

THE VALUE OF RELIABLE STATISTICS AND DATA FOR THE WORKING-AGE POPULATION WITH DISABILITIES

Government statistics and data on population characteristics are used by public policymakers, advocates, the private sector, and individuals for a wide variety of reasons. The primary rationale for government efforts to collect data and publish statistics is that they are the

foundation of evidence-based public policy, providing critical information to support the management and improvement of public programs, as well as the formulation, analysis, and evaluation of new programs and policies.

Numerous federal agencies serve the needs of working-age people with disabilities, and they all need information about their program participants, as well as those potentially eligible for their services, to effectively administer and improve their programs. The Social Security Administration (SSA), the Department of Health and Human Services (HHS), the Department of Education (ED), and the Department of Veterans Affairs (DVA) are the most prominent in terms of the number of working-age people with disabilities served and program expenditures. These agencies, as well as the congressional committees that oversee them, need to know the size, geographic distribution, demographic characteristics, and status of the populations their programs are designed to serve. They need to know if their “target populations” are obtaining the benefits and services for which they are eligible and the extent to which their needs with respect to health care, family economic status, and participation in major life activities are being met.

Although the primary purpose of data collection and production of statistics is often to meet agency needs, there is an extremely important “public good” aspect of data and statistics. Once created, statistics can be used by others at little or no additional cost. Hence, similar to other such investments in basic science, at their optimal level of investment, their marginal value to society as a whole is greater than the marginal value to those who produce them. Without government support of the initial collection of these data, too little investment in the data collection necessary for both basic and program research would be made. Further, from a social perspective, optimal investment in data collection and the production of statistics on this population ought to exceed the level that can be justified by the narrow interests of the agencies themselves.

Beyond this, the additional value of data and statistics comes from the identification of significant social problems, the formulation and analysis of new policies to address them, and ultimately, the evaluation of the extent to which major policy changes adequately address the identified problems. Such analyses are conducted by researchers and

analysts at government agencies, think tanks, universities, and advocacy organizations.

The first step in solving a social problem is to identify its nature. For example, a leading problem for people with disabilities is the increased risk of economic insecurity—loss of household income, increased risk of poverty, reduced employment, and increased need for medical services. The second step is to determine the dimensions of the problem both in terms of the number of people affected (e.g., the incidence and prevalence of disability among working-age people) and the size of the increased risk on each individual (e.g., the average magnitude and distribution of increased economic risks related both to the onset and duration of a disability). To achieve these two steps, it is critical to have reliable data both on the general population and the target population. From a cross-sectional data perspective, how different are the risks of economic insecurity of those with and without disabilities at a moment of time? From a longitudinal data perspective, how much do these risks change at the onset of a disability, and thereafter, as the individual ages and other events occur?

Such investments in data are even more important in considering public policy responses once a social problem is well-defined. Data are necessary to answer the following questions with respect to any proposed policy. Who will the policy benefit and by how much? Who will the policy harm and by how much? What behavior will the policy change and by how much? For example, an increase in Social Security Disability Insurance (SSDI) benefits or a relaxation of its eligibility rules is likely to reduce the loss in income associated with the onset of a disability. It is also likely, however, to cause an increase in the costs of the program. Further, it could discourage some workers who experience the onset of a disability from returning to work, even further increasing the costs of the program and reducing their employment. Each of these questions can be partially answered using currently available data and statistics, but improvements in disability data and statistics could substantially improve our ability to reliably answer such questions.

Although it is important to have data that support projections of the potential consequences of policy changes, it is more important to have data that support assessments of whether changes have or do not have specific outcomes. Even if the implemented policy is functioning well,

program administrators need information about changes in the size and characteristics of a target population, including changes in population outcomes, to develop program management plans and budgets.

It is primarily for these reasons that the government routinely produces statistics for population groups such as racial and ethnic minorities, children, unmarried parents, and the elderly. For each of these at-risk groups, there is a clear population concept, a broadly accepted means for identification of members of the population, and well-established outcomes of policy interest. These groups are at risk of adverse socioeconomic outcomes, and it is critical to keep track of their outcomes in substantial detail. Researchers, program administrators, and policymakers collect data on these populations to improve and manage the programs and policies that are designed to reduce risk and provide support to those who experience adverse outcomes.

THE LIMITATIONS TO CURRENTLY AVAILABLE DISABILITY DATA AND STATISTICS

In contrast to the copious statistics produced for the at-risk populations discussed above, the government produces very few statistics on the working-age population with disabilities.² This is astonishing, given the size of the working-age population with disabilities and the magnitude of public resources devoted to its support. Based on the 2006 American Community Survey (ACS), almost 13 out of 100 persons aged 25–61³ in the noninstitutional population have a disability of some sort—an estimated 22.4 million people (Rehabilitation Research and Training Center on Disability Demographics and Statistics 2007). The limited production of disability data may stem from the lack of an agreed-upon operational definition, or set of operational definitions, of disability, as well as the limited amount of longitudinal and state-level data on the population, among other reasons. More than 2 million working-age people with disabilities are not included in this figure because they live in institutions; these individuals constitute more than half of the working-age institutional population.⁴

Operational Disability Definitions

People with disabilities clearly constitute a large, at-risk population, and one that is of considerable interest to policymakers and the general public. Why, then, does the government not publish statistics on this population in many of its major statistical publications? The most immediate reason is that no statistical agency has developed an “official” operational definition of working-age people with disabilities, and considerable controversy still exists in the research community over the appropriate questions to ask to determine this. The absence of an official operational definition for this population is in sharp contrast to the existence of such definitions for other at-risk groups—even groups whose definitions are controversial, such as racial and ethnic minorities.

As a result, the statistics used by researchers to capture this population and its socioeconomic outcomes have been subject to considerable controversy. For example, doubts were initially raised about the accuracy of reports of a long-term decline in the employment rate of people with disabilities (Hale 2001; National Council on Disability 2002). The reports ran counter to expectations about improvements in employment opportunities after the passage of the Americans with Disabilities Act (ADA); indeed, articles published in top economics journals attributed the employment decline to the passage and implementation of the ADA (Acemoglu and Angrist 2001; DeLeire 2000). The reports also seemed to contradict the experiences of well-educated people with disabilities, whose professional opportunities were expanding because of the growing importance of information technology in the workplace.

These statistics were questioned largely on the grounds of how “disability” was identified in surveys. Questions currently used vary across surveys, and they are conceptually unclear and inconsistent. Many people with significant physical or mental impairments might fail to respond positively to some questions, but the same questions might elicit positive responses from people with minor or short-term impairments. Further, answers to some questions, such as those about “work limitations,” might be sensitive to the economic environment. How can we be sure, then, that the trends observed in the statistics are not an artifact of how we identify people with disabilities?

These issues and others made it relatively easy to be skeptical of the evidence on the decline in employment. Yet trends in the employment rate from multiple surveys, using multiple definitions of disability and looking across comparable points in the business cycle, were all in the same direction, and they were also consistent with the growth in the percentage of the working-age population that receives federal disability benefits, even after adjusting for changes in the age distribution of the working-age population (Burkhauser et al. 2001; Stapleton and Burkhauser 2003). With time, the existence of a decline in the employment rate among people with disabilities became more widely accepted, but the limitations of federal disability data clearly slowed the process of recognition.

Longitudinal Data

Because the experiences of people with disabilities, and disability itself, are dynamic, longitudinal data on people with disabilities is very valuable but also very limited. This data limitation is an important reason why it has been difficult to determine the causes of the decline in the employment rate. For instance, evidence that the ADA was the cause of the decline relied heavily on trends in cross-sectional (i.e., one period) data from the Current Population Survey (CPS). Acemoglu and Angrist (2001) looked at the number of weeks worked by people who self-reported a work limitation relative to those who did not and observed that this ratio started to fall at the national level as the ADA was implemented. But the CPS measure of the disability population from a single interview does not differentiate between short- and long-term limitations. More recent analysis, using a subset of households interviewed twice for the CPS (12 months apart), compared the weeks worked of those who report a work limitation in both surveys relative to those who do not, and it showed that the employment decline for people with longer term work limitations started well before the passage of the ADA (Houtenville and Burkhauser 2004). These findings do not invalidate the use of existing data to evaluate public policy outcomes, but they do suggest that researchers must be more sensitive to data limitations when making causal inferences. Better use of limited existing longitudinal data would have shown the sensitivity of the research findings

to alternative ways of capturing working-age people with disabilities. Longer term longitudinal data would also have been very useful.

Limited State-Level Data and Statistics

In the past, very few disability statistics have been produced at the state level. Yet state-level statistics are critical because the population of working-age people with disabilities is not distributed across states in proportion to the entire working-age population and because important environmental factors vary considerably from state to state as well as influence the status of people with disabilities. These factors include the economic and policy environments, as well as the physical and cultural environments.

The importance of state policy deserves emphasis. All of the major public disability programs are federally financed, in whole or in large part, so there is a strong tendency to think of disability policy as a national, rather than state, issue. In fact, however, state and local governments play important roles in the implementation of these programs. State-administered vocational rehabilitation programs help people with disabilities enter and stay in the workforce. States also run Disability Determination Services that make the initial decision of whether applicants for SSDI or Supplemental Security Income (SSI) are eligible. A number of states also provide state supplements to federal benefits. State welfare agencies have a strong financial interest in helping low-income parents with disabilities transfer from Temporary Assistance to Needy Families to federal disability benefits. State governments also control Medicaid programs within limits set by the federal government, including eligibility determination, fee schedules, coverage for optional services, and eligibility for optional populations of workers with disabilities (under the Medicaid Buy-in). Many other services are delivered by, or under the supervision of, state agencies, even when the federal government provides support. Further, one of the most important disability programs for working-age people, workers compensation, is state run and receives no federal support or oversight.

State leaders and the electorate need to be informed about how working-age people with disabilities in their state are faring, both absolutely and relative to comparable people in neighboring states and the

rest of the country. National data cannot identify the specific needs of a state's population with disabilities, how federal funding to meet those needs is commensurate with that of other states, or the extent to which efforts to address the needs of the working-age population with disabilities within a state are successful.

Decennial Census data have long been the primary source for state-level disability statistics, and until 2000, even the long form of the Census had just three disability questions. Since then, the implementation of the ACS has supported the production of annual disability statistics at the state level, although the continuous improvements made to the survey in its first six years have limited cross-year comparability.

The consequences of inadequate state data can also be illustrated by the difficulties encountered in understanding the decline in employment of people with disabilities. The possible causes of the decline likely varied across states. As a specific example, any negative effect of the ADA would be greatest in states that did not have their own disability rights laws before the ADA, and least in the states with the strongest such laws—including reasonable accommodation provisions for employers as well as anti-discrimination provisions. In the 1990s, however, it was not possible to reliably track employment of people with disabilities at the state level except in a few very large states (with large samples in national surveys) or over very long periods (e.g., by examination of moving averages that dampen the effects of annual sampling errors), so differences in trends across states were not readily apparent. In light of a later study (Jolls and Prescott 2005), it seems likely that reliable state statistics would have also challenged Acemoglu and Angrist's (2001) finding that the ADA was the principal cause of the decline in the relative employment of working-age people with disabilities in the early 1990s. Jolls and Prescott demonstrated that the ADA had short-term negative impacts on employment in states that had no disability rights laws before the ADA or had laws with anti-discrimination provisions only, and that longer term declines in employment for people with disabilities were unrelated to pre-ADA laws. This research took longer to complete than the research of Acemoglu and Angrist (2001), which relied on national data, because the researchers had to painstakingly collect data on state disability rights legislation and use it to group states

into meaningful categories. Only then could they produce employment statistics for the groups.

Over the last two decades, considerable effort has been invested in improving policies for working-age people with disabilities. Many of these have been instigated by federal legislation, especially the ADA, the Rehabilitation Act, the Individuals with Disabilities Education Act, the Workforce Investment Act, and the Ticket to Work and Work Incentives Improvement Act. The impact of these efforts is very dependent on the actions of state and local governments, as well as other aspects of the state and local environments. These initiatives make it all the more important to produce statistics at the state level.

Other Limitations

The above discussion illustrates just three of the current limitations of disability data for working-age people with disabilities. The growing interest in disability policy and research has exposed many other limitations of disability data as well. As discussed extensively in later chapters, these include the following:

- Some data collection methodologies lead to the exclusion of people with disabilities from surveys, either intentionally (e.g., because they do not live in the household population) or unintentionally (e.g., because interviewers are not adequately trained to interview them). Some federal surveys fail to identify respondents with disabilities in any fashion. People with intellectual or psychiatric disorders are perhaps the most likely to be overlooked.
- Sample sizes in many national surveys are too small to produce statistics for subgroups of people with disabilities. Limitations on state-level statistics are just one example. The availability of statistics on people with specific impairments or conditions is also limited. Yet one of the tenets of disability policy is that people with disabilities are an extremely heterogeneous group. Without information on the heterogeneity of people with disabilities, it is difficult to identify people who are least well served by current policies, those who would benefit the most by a new policy, and those who might be harmed by the same new policy.

- Information on certain topics that are very salient to disability is collected very infrequently or is nonexistent. Examples include the accessibility of the environment, employer accommodations, use of employment and personal services, time use, allocation of expenditures, community participation, living arrangements, and the characteristics of disability onset and progression.
- Program data collected from survey respondents is highly unreliable. Many respondents either fail to report they participate in a program or confuse the program they participate in with a similar program. Information about the services and benefits they receive is also very limited and of low reliability.
- Administrative data for public programs that serve people with disabilities contain a wealth of longitudinal information about the many people with disabilities who participate in such programs, but the quality of the data is limited by its administrative uses. Substantial effort is required to build and document useful research files, and the privacy of the data must be carefully protected. These obstacles can often be overcome, but it is costly and can delay analysis by years.
- There are currently no national or state efforts to collect information on the physical and social barriers that restrict the participation of people with disabilities in work and other major activities.

THE NATIONAL DISABILITY DATA SYSTEM (NDDS)

Given the number of working-age people with disabilities and the magnitude of federal and state assistance provided, investments in the collection of data and production of statistics on this population should be a national priority. Extensive data are collected by numerous federal surveys, and data are captured in the administrative records of the agencies responsible for programs that target people with disabilities. To a large extent, the limitations of these statistics are not the result of low

investment in data collection; instead, they are the result of not taking full advantage of the existing efforts.

We use the term “national disability data system” to encompass all federal efforts to collect information about people with disabilities. There is, of course, no formal system. Nonetheless, we find it helpful to think about this large effort as a system because it leads to recognition of significant, and often lower cost, options for substantially improving the system.

The key components of the informal NDDS are the major national household surveys, smaller national household surveys that focus on specific issues, a multitude of surveys of specific subpopulations, surveys of nonhousehold populations, and program administrative data. Livermore and She (2007) provide a more detailed description of these components, and individual components are featured in various ways later in this book.

Major National Household Surveys

Major national household surveys include the ACS, the CPS, the National Health Interview Survey (NHIS), and the Survey of Income and Program Participation (SIPP). These surveys are all integral parts of the federal statistical system. Data from each are deemed critical to monitoring some aspect of the U.S. population and provide basic information needed to administer federal programs. All provide some information about people with disabilities, including information about their demographic characteristics, health and functioning, employment, and economic well-being. All except the ACS (from 2006 forward) exclude people living in institutions, and inclusion of those living in noninstitutional group quarters varies (see She and Stapleton 2009).

Other National Household Surveys

There are a number of other federally sponsored national surveys designed to regularly provide more detailed information on specific aspects of population health, well-being, activities, and expenditures than what is available in the larger surveys identified above. These topical surveys generally have smaller sample sizes than the major surveys, and in some cases, the samples are derived from one of the major sur-

veys. With the exception of those that are focused specifically on health issues, these surveys tend to include few measures of disability. The following are important examples: American Housing Survey, American Time Use Survey, Behavioral Risk Factor Surveillance System, Consumer Expenditure Survey, Medical Expenditure Panel Survey, National Health and Nutrition Examination Survey, Panel Study of Income Dynamics, and Survey of Consumer Finances.

Surveys of Subpopulations

A number of surveys have focused specifically on youth and young adults in the general population, including the National Longitudinal Survey of Adolescent Health and the National Longitudinal Survey of Youth. The Health and Retirement Study provides extensive longitudinal data on the working-age population as it reaches the normal age of retirement, and the National Beneficiary Survey, the Medicare Current Beneficiary Survey (MCBS), and the Longitudinal Study of the Vocational Rehabilitation Services Program collect information on people with disabilities who are participants in major government programs. One federal survey, the 1994–1995 Disability Supplement to the NHIS, collected unusually extensive information about working-age people with disabilities. Many of these surveys contain extensive disability-related information and/or focus specifically on subpopulations with disabilities. With the exception of the annual MCBS, these surveys are conducted very infrequently or have been conducted only once.

Surveys of Nonhousehold Populations

Most national surveys include only the household population and intentionally exclude those living in institutions and other types of group quarters. A few federal surveys of nonhousehold populations have collected information on residents of institutions (including nursing homes, jails, and prisons) and on homeless individuals. The Nursing Home Minimum Data Set (MDS) and the National Nursing Home Survey collect information on nursing home residents. Three periodic surveys by the Department of Justice collect information on the incarcerated population: Survey of Inmates of Local Jails, Survey of Inmates of State Correctional Facilities, and Survey of Inmates of Federal Correctional

Facilities. The only nationwide survey data available for the homeless population is the National Survey of Homeless Assistance Providers and Clients, which collected health and disability-related data on the users of homeless assistance programs. The Decennial Census collects limited data on people in all residential settings, and the annual ACS began to include people living in almost all residential settings in 2006.

Program Administrative Data

Program administrative data are an important source of information about people with disabilities and, especially, statistics on their participation in those programs. There are more than 20 federal agencies and nearly 200 programs that provide assistance to people with disabilities, sometimes in the context of programs that serve a broader target population. 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. Although limited by the fact that they only include people with disabilities who are enrolled in or have applied to a program, the number of working-age people actually participating in programs is about half as large as the ACS estimate of the number of people with disabilities in the household population (see Stapleton, Wittenburg, and Thornton 2009).

SUMMARY OF WHAT IS CURRENTLY KNOWN

The first step in any empirical study of people with disabilities is to define the term “disability.” In Chapter 2, “The Disability Data Landscape,” Robert Weathers identifies the definitions of disability used in this book, describes the major national surveys, reviews the questions available in these surveys, and places them within a conceptual model of disability. He also compares the prevalence estimates derived from these various definitions and data sources, to highlight both their similarities and differences. The conceptual framework and prevalence estimates in this chapter provide a foundation for the rest of the book.

Chapters 3 through 7 present recent statistics from the major surveys for working-age people with and without disabilities in the household population. The focus on the household population reflects the fact that the vast majority of the information we have on the prevalence and socioeconomic characteristics of working-age people with disabilities comes from social-science-based data sets that track the health, employment, and the economic well-being of the general U.S. population living in households. Some of these statistics are for households, rather than individuals, as the economic well-being of people, including those with disabilities, must be considered in the context of their households, since ultimately income and the risk of poverty is shared among all household members. Each chapter presents the most recent available statistics, assesses their strengths and limitations, compares statistics from multiple sources, and provides some historical statistics. As will be discussed later, however, none of these surveys captured the working-age population that lives in institutions and other group quarters until 2006, when the Census Bureau expanded the ACS sample.

In Chapter 3, “Disability Prevalence and Demographics,” Andrew Houtenville, Elizabeth Potamites, William Erickson, and Antonio Ruiz-Quintanilla examine trends in disability prevalence and also consider variation in prevalence across states and demographic subpopulations. A great deal is known about trends in the prevalence of disability among those aged 65 and older, but much less is known for working-age people. The authors examine variation in prevalence across demographic groups, present trends in prevalence estimates, and also provide state prevalence statistics.

In Chapter 4, “Employment,” Robert Weathers and David Wittenburg use data from the major nationally representative surveys to examine the employment of people with disabilities, including long-term trends and state-level estimates. As discussed earlier, prior work has shown a long-term decline in employment among persons with disabilities, especially when measured relative to the employment of those without disabilities. This chapter provides clear definitions of the employment rate, labor-force participation, and the unemployment rate. It describes why some numbers often cited in the popular press, notably the 70 percent unemployment rate for persons with a disability, are not comparable to the unemployment rate for the population that is produced regu-

larly by the Bureau of Labor Statistics. The authors update previously published estimates of employment rates (Burkhauser, Houtenville, and Wittenburg 2003; Maag and Wittenburg 2003) through 2006 and expand this literature with statistics from the ACS. They also identify and discuss both consistencies and inconsistencies in the estimates from various sources of data.

In Chapter 5, “Household Income,” Richard Burkhauser, Ludmila Rovba, and Robert Weathers examine the household incomes of working-age people with disabilities. The analysis includes examination of trends in income and its composition, the effects of adjustments for household size on income trends, and the sensitivity of income trends to the business cycle. Sources of income include an individual’s labor earnings, self-employment income, interest income, Social Security income, SSI benefits, and other miscellaneous personal income sources, plus income from other household members. The authors examine the decline in labor earnings across comparable years in the business cycle over a 16-year span (1989, 2000, and 2004) and the extent to which this decline is replaced by growth in income from public programs and other sources.

In Chapter 6, “Poverty,” Richard Burkhauser, Andrew Houtenville, and Ludmila Rovba present and discuss statistics on the poverty rate for people with disabilities, using the official federal definition of household poverty. The Census Bureau provides official poverty rates for most economically disadvantaged populations in the United States, but it does not do so for working-age people with disabilities. The authors also provide background on the measurement of poverty and present statistics from the ACS, CPS, and SIPP. They also analyze trends in the poverty rate from 1981 to 2005, based on the CPS. In contrast to other disadvantaged populations whose economic well-being improved substantially during the 1990s, the poverty rate of working-age people with disabilities increased both absolutely and relative to the rate for working-age people without disabilities over the business cycles of both the 1980s and 1990s.

In Chapter 7, “Health and Functional Status,” Gerry Hendershot, Benjamin Harris, and David Stapleton discuss the challenges of collecting data on the health and functional status of the population and the history of federal efforts to do so. They present health and functional

status statistics for people with and without disabilities from the 2006 NHIS and compare them to those from four years earlier.

SUMMARY OF LIMITATIONS AND OPTIONS FOR IMPROVEMENT

The remaining chapters of the book focus on the limitations of current data and options for improvement.

In Chapter 8, “Survey Data Collection Methods,” Janice Ballou and Jason Markesich examine alternative methods for collecting survey data, how these methods affect the inclusion of people with disabilities in survey samples, and whether and how sampled subjects respond. The authors identify the many ways in which survey methodology can lead to the exclusion of individuals with disabilities and inconsistencies in disability statistics derived from different surveys—even if the questions used to identify subjects with disabilities are identical. They point to the need for methodological changes and standards to improve the inclusion of people with disabilities as well as the quality of disability statistics in the areas of sample frame definitions, sampling methods, questionnaire design (structure, question design), and data collection (interview training and interview methods/technology).

In Chapter 9, “Program Participants,” David Stapleton, David Wittenburg, and Craig Thornton describe the available data and statistics on working-age people with disabilities who participate in major federal programs. Survey data generally capture program participation poorly because subjects sometimes fail to report participation, or they are confused about which programs they participate in. Further, some program participants are excluded from participation in major surveys, partly because a relatively large share lives outside the household population, but also because of data-collection methodologies. The authors summarize the availability of participation information in major federal surveys and also describe the availability of administrative data and statistics from the federal agencies that are responsible for program administration and oversight. They present state-level program participation statistics for major federal and federal/state income sup-

port, health insurance, and employment service programs in 2005, and they compare them to ACS estimates of the size of the state household population with disabilities. The authors conclude with a description and discussion of important efforts to improve data on program participants, including the matching of administrative data with survey data and administrative data across agencies.

In Chapter 10, “The Group Quarters Population,” Peiyun She and David Stapleton review the availability of data on people with disabilities who live in institutions and other group quarters. Household surveys exclude most such individuals. Disproportionately large numbers of people with disabilities live in group quarters. This includes disproportionately large numbers in the largest institutional group, the incarcerated population, as well as people in nursing homes, psychiatric hospitals, institutions for adults with cognitive disabilities, and others. There has been a large increase in the share of the working-age population living in jails and prisons and a more modest decline in the shares living in nursing homes and other group quarters. These trends potentially have a substantial effect on the prevalence of disability in the household population, as well as on statistics for people with disabilities in the household population. Available data on this population are inadequate for fully understanding the implications of these trends.

In Chapter 11, “Options for Improving Disability Data Collection,” David Stapleton, Gina Livermore, and Peiyun She provide a synthesis of the major limitations of the NDDS based on earlier chapters in the book as well as interviews conducted with producers and consumers of disability statistics. They then present and discuss high-priority options for improving disability data and statistics for the working-age population. Because most of these improvements stem from recognition of the existence of the informal NDDS, they would be relatively inexpensive because they involve relatively small changes to existing data collection efforts and/or improved data usage. The authors also recognize, however, that periodic supplements of existing surveys or additional surveys of specific groups of people with disabilities are needed to address some of the system’s most significant limitations.

CONCLUSIONS

This book provides a systematic review of what current statistics and data on working-age people with disabilities can tell us, what they cannot tell us, and how they can be improved to better tell us what we need and want to know.

What We Know

An extensive and valuable disability data collection effort exists in the United States, but to our knowledge, it has never been previously recognized as a “system,” as we do in this book. Researchers, analysts, administrators, and others can glean extensive information about working-age people with disabilities from the data sources that comprise the NDDS. This point is illustrated in Chapters 2 through 7, which tell us what we currently know about the prevalence, employment, income, poverty status, health, and functional status of working-age people with disabilities who live in the household population. Chapter 9 provides a sketch of what we currently know about the program participation of working-age people with disabilities, and Chapter 10 provides a very limited set of information on what we currently know about the population that is not captured in most national household surveys and the substantial numbers of working-age people with disabilities who live in institutions or other group quarters.

What We Don’t Know

Historically, several important limitations of the NDDS have undermined its ability to inform public policy. The delayed recognition of the decline in employment of this population, the premature attribution of the decline to the ADA, and the widespread failure of scholars and policymakers to recognize the growing gap between the average income and risk of poverty of working-age people with and without disabilities over the last three decades are examples of the consequences of these limitations.

We also do not know the extent to which increases in incarceration represent increases in incarceration for people with disabilities. Nor do

we know the extent to which these increases and more modest declines in the proportion of working-age people with disabilities living in nursing homes and other types of group quarters have affected the trends for people with disabilities living in the household population, and we have almost no information on trends for all people with disabilities (i.e., including all those living in group quarters).

Finally, while we know that the ratio of working-age participants in federal disability programs to estimates of the number of people with disabilities in the household population exhibits enormous variation across states, we do not have detailed state statistics that would help us understand the causes of this variation.

What Needs to Be Improved to Better Tell Us What We Want to Know

Significant progress is being made toward addressing some of these limitations, and it is important to sustain the efforts that are responsible for that progress. In Chapter 2, Weathers points out that the inclusion of several disability questions in the 2000 Census long form, and the subsequent implementation of the annual ACS using the same questions, have for the first time made it feasible to produce a wide variety of state-level statistics on the prevalence and status of working-age people with disabilities in the household population on an annual basis. Although changes in the methodology of the ACS during its start-up years have limited the usefulness of ACS disability statistics for trend analysis, these changes are also gradually improving the quality of the statistics themselves. Included among these improvements is the expansion of the ACS sample frame to include most of the nonhousehold population in 2006.

The expansion of, and recent improvements to, efforts that match data from major surveys to administrative records, described by Stapleton, Wittenburg, and Thornton in Chapter 9, are also a very welcome development. These efforts are improving our knowledge about the program participation status of people with disabilities, as well as about their characteristics and health, functional, and economic status.

Records from the SIPP have been matched to SSA records for a number of years and have been a source of important information about

program participants. The longitudinal nature of the SIPP and the extensive information about income and program participation in this survey make these matches especially valuable for understanding the dynamics of disability and program participation (e.g., exits from employment and entry into the SSA programs) and for studying participation in multiple programs. The Census Bureau has been developing plans to replace the SIPP with a different system for collection of income and program participation data. A new system would be most welcome by disability researchers, analysts, and users of disability statistics if it addressed some of the limitations of the SIPP, but only if it preserved the scope of information that SIPP offers for people with disabilities. We also applaud the efforts of the National Center for Health Statistics, in collaboration with the SSA and Centers for Medicare & Medicaid, to match data from the NHIS and several other surveys to SSA and Medicare records. Among other things, these data offer the opportunity to learn much about health conditions, health care, functional limitations, and insurance status of people with disabilities who apply for benefits from SSA. This includes those denied as well as those awarded benefits, before, during, and after SSA's lengthy disability determination process. The exploratory efforts by the Census Bureau and SSA to match records from the ACS to the SSA records are tantalizing. The latter match would make it feasible to produce many new state-level statistics about participants in the SSA disability programs.

The efforts of several agencies to develop analytical files from administrative records and to match administrative records across agencies are also contributing to an expansion in our knowledge about program participants (especially those who participate in multiple programs) and to our ability to rigorously evaluate policy initiatives. Because administrative records are longitudinal, these efforts have also expanded our capacity to produce statistics on the dynamics of disability and program participation. Additional efforts in this area could be extremely valuable, including efforts to make existing data more available to responsible researchers under safeguards that protect individual rights to privacy.

In Chapter 11, Stapleton, Livermore, and She describe a number of relatively low-cost options for further improving the NDDS—options that primarily would improve existing data collection efforts and/or

our ability to make use of data that are already being collected. Chief among these is establishment of a common set of disability questions to be used in all federal surveys. Significant progress is already being made on this option. The 2008 ACS includes an improved set of disability questions, and the 2008 CPS adopted this same set of questions. These questions are also slated for inclusion in the NHIS. Inclusion of this same set of questions in the SIPP would mean that statistics about people with disabilities from these major surveys would be for the same disability population, at least conceptually; the population represented would vary from survey to survey only because of differences in other aspects of data collection methods and the survey context.

This conceptual population will not be exactly the *right* population for most specific research and policy purposes because the number of disability questions is necessarily limited. However, the production of statistics from all four surveys about the same conceptual population would greatly advance the dialogue about people with disabilities and disability policy. A next step would be to add the same question set to additional federal surveys—ideally all of them. Also, as we proceed to adopt these questions, it is critical to maintain some of the questions used in the past (e.g., the CPS work limitation question) in at least some surveys for purposes of historical continuity; otherwise we will have no basis to compare disability statistics for those identified by the new questions to historical statistics for those identified by existing questions.

Other relatively low-cost options for improvement include development and standardization of survey methods that will increase the inclusion of people with disabilities in federal surveys, as well as minor changes in questions, probes, or response options that will yield relevant disability information (e.g., reasons for not working, accessibility of transportation, etc.). It would be worthwhile to carefully review the data collection methodology and questionnaires of all major federal surveys to identify easy ways to increase the inclusion of respondents with disabilities and increase disability-relevant content.

As elaborated in Chapter 11, some limitations in the NDDS can only be addressed through initiatives that are relatively expensive because they require additional data collection. Nonetheless, several such initiatives might be well worth the expense. Such initiatives include

disability topic supplements of existing surveys, and implementation or expansion of periodic surveys on special populations, such as program participants, residents of noninstitutional group quarters, and homeless people.

Although we think periodic national surveys focused solely on the population of people with disabilities, like the 1994–1995 supplement to the NHIS, have considerable value, they are very difficult to design and expensive to conduct. It seems to us that many of the benefits of periodic national disability surveys could be obtained through less expensive improvements to the NDDS. Such improvements would not likely eliminate the need for periodic national surveys, but they might substantially reduce the need, make such surveys easier to design, and be less expensive to conduct.

Notes

1. As etched on the facade of the University of Chicago's Social Science Building when it was built in 1927.
2. For example, the Census Bureau ignores the population with disabilities in its annual report on "Income, Poverty, and Health Insurance Coverage in the United States," and the Bureau of Labor Statistics has yet to produce an official employment rate for this population. The Census Bureau first added disability statistics, based on the ACS, to the annual American FactFinder in 2004. See <http://www.factfinder.census.gov>.
3. Throughout the book, we define the working-age population as persons aged 25–61 unless otherwise indicated. The working-age population is often defined as persons aged 18–64 in published statistics. We use a narrower definition because of the large number of persons aged 18–24 whose primary activity is education and the large number of persons aged 62–64 who are retired.
4. Based on the 2000 Census, there were 2.2 million persons with disabilities aged 18–64 living in institutional group quarters in 2000, representing 54 percent of all persons in that age group who were living in institutions (She and Stapleton 2009). The 2006 ACS statistics cited above include the substantial number of working-age people with disabilities who are residents of noninstitutional group quarters; ACS statistics for earlier years that are cited in this book exclude those living in noninstitutional group quarters, however, because they were not included in the ACS sample frame in those years.

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Andrew J. Houtenville
David C. Stapleton
Robert R. Weathers II
Richard V. Burkhauser
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W.E. Upjohn Institute for Employment Research
300 S. Westnedge Avenue
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