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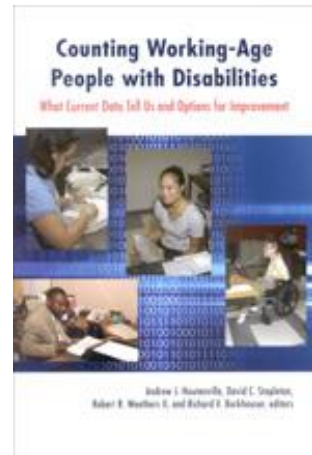
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# Options for Improving Disability Data Collection

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

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# 11

## Options for Improving Disability Data Collection

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This book has demonstrated the great value of the extensive federal data on working-age people with disabilities, but it also provides insights on how the value of these data might be enhanced through efforts to coordinate the numerous diverse, and largely independent, federal data collection efforts (Table 11.1).<sup>1</sup> We have used the term national disability data system (NDDS) to informally encapsulate these efforts, but they are not recognized or managed as a system (Livermore and She 2007). The good news is that there are efforts in place to improve coordination, and they are already paying dividends. In this chapter, we summarize the limitations of the NDDS, briefly review how they are being addressed, and present options for further improvement.

The limitations of the NDDS and efforts to address them are described in the next section. We then lay out options that would improve the comparability of disability data across surveys, use linkages across administrative and survey databases to improve statistics on program participants, improve the disability-relevant content in major surveys, and add periodic disability supplements to existing surveys and implement periodic special surveys. We conclude by discussing the priorities of the options presented.

**Table 11.1 Federal Sources of Data on the Working-Age Population with Disabilities**

Major national household surveys	
American Community Survey	National Health Interview Survey
Current Population Survey	Survey of Income and Program Participation
National household surveys on specific topics	
American Housing Survey	Medical Expenditure Panel Survey
American Time Use Survey	National Health and Nutrition Examination Survey
Behavioral Risk Factor Surveillance System	Panel Study of Income Dynamics
Consumer Expenditure Survey	Survey of Consumer Finances
Surveys of subpopulations	
National Longitudinal Survey of Adolescent Health	National Beneficiary Survey
National Longitudinal Survey of Youth	Medicare Current Beneficiary Survey
Health and Retirement Study	National Health Interview Survey—Disability Supplement
Longitudinal Study of the Vocational Rehabilitation Services Program	
Surveys of nonhousehold populations	
Nursing Home Minimum Data Set	Survey of Inmates of State Correctional Facilities
National Nursing Home Survey	Survey of Inmates of Federal Correctional Facilities
Survey of Inmates of Local Jails	National Survey of Homeless Assistance Providers and Clients
American Community Survey (includes the nonhousehold population from 2006 forward)	
Administrative data from federal and federal-state programs	
Social Security Administration: Social Security Disability Insurance and Supplemental Security Income	
Centers for Medicare and Medicaid Services: Medicare and Medicaid Enrollment and Claims	
Rehabilitation Services Administration: State Vocational Rehabilitation Service Agency Closure Data	

NOTE: The age range for the sampling frame varies from survey to survey; each includes some, if not all, of those age 18 to 65.

SOURCE: Based on Livermore and She (2007).

## **LIMITATIONS OF THE NATIONAL DISABILITY DATA SYSTEM**

Although extensive information about people with disabilities is collected through national surveys and program administrative data, the information is limited by a variety of factors: the manner in which disability is defined and measured, sample size limitations, exclusion of certain subpopulations or inability to identify them, limitations to disability-relevant survey content, infrequency of data collection, limited availability of longitudinal data, and limitations of data on program participation. In addition, many important topics for people with disabilities are not adequately covered in national surveys. Below, we briefly highlight some key limitations of the existing data on people with disabilities. Livermore and She (2007) offer a more in-depth discussion of these issues as do earlier chapters of this book. We also describe current initiatives to address some of the limitations identified.

### **Identification of People with Disabilities**

The health, functional status, activity limitation, and participation restriction variables that are used to identify people with disabilities vary greatly across survey and administrative data sources. The inconsistencies across the major national surveys—in particular the Decennial Census, the Current Population Survey (CPS), the American Community Survey (ACS), and the National Health Interview Survey (NHIS)—create two important problems when studying persons with disabilities. First, because disability is measured very differently across surveys, these instruments yield very different estimates of the size of the population with disabilities (see Weathers 2009) as well as different characteristics of that population (e.g., demographic characteristics, employment, income, and poverty rates; see Houtenville et al. 2009; Weathers and Wittenburg 2009; Burkhauser, Rovba, and Weathers 2009; and Burkhauser, Houtenville, and Rovba 2009). Although the sometimes widely different estimates can be explained by technical differences in questionnaires, survey methods, and instruments, inconsistencies of the estimates can undermine their perceived credibility among nontechnical audiences. This can negatively affect their usefulness in supporting

arguments for change. Second, the lack of consistent indicators across data sources prohibits researchers and policymakers from identifying a common target population for which information from multiple data sources can be generated and thereby providing much richer information about people with disabilities than can be obtained from a single data source.

In addition, some national surveys, in essence or in fact, do not have questions to identify people with disabilities; hence, statistics on the topics of these surveys cannot be generated for any population with disabilities. The indicators available in most surveys perform particularly poorly in identifying people with psychiatric, cognitive, and intellectual disabilities.

Since we began work on this book, the government has undertaken an extremely important step toward addressing this issue. As of 2008, the ACS and the CPS will adopt a common set of questions for the identification of respondents with disabilities (Table 11.2), and the NHIS will soon adopt the same questions.<sup>2</sup> The Bureau of Labor Statistics (BLS) announced their decision to adopt the new ACS questions for the CPS after parallel efforts by the BLS and the Census Bureau to develop better disability questions for these surveys led to two sets of questions that were conceptually quite similar (McMenamin et al. 2005).<sup>3</sup> As a consequence of the adoption of the ACS questions by the CPS, another important survey—the American Time Use Survey (ATUS)—that uses the CPS as its sampling frame will implicitly use the same questions to identify respondents with disabilities.

The questions that will be adopted by the ACS, CPS, and NHIS were developed by the Disability Subcommittee of the ACS Interagency Committee, under the auspices of the Office of Management and Budget (OMB), and chaired by the National Center for Health Statistics (NCHS). The committee took the data needs of its many member agencies into consideration, using the Classification of Functioning, Disability and Health (ICF) model of disability (see Weathers 2009) as a conceptual framework. The questions were designed to identify people who are “at risk” for disability, specifically people who, without accommodation, are likely to experience restrictions in participation because of a functional limitation, as well as the population needing assistance to maintain independence. The questions cover three con-

**Table 11.2 New Disability Questions for the ACS and the CPS, 2008**

- 
1. a. Is this person deaf or does he/she have serious difficulty hearing?  
 b. Is this person blind or does he/she have serious difficulty seeing even when wearing glasses?  
 For persons aged 5 years or over:
  2. a. Because of a physical, mental, or emotional condition, does this person have serious difficulty concentrating, remembering, or making decisions?  
 b. Does this person have serious difficulty walking or climbing stairs?  
 c. Does this person have difficulty dressing or bathing?  
 For persons aged 15 years or over:
  3. Because of a physical, mental, or emotional condition, does this person have difficulty doing errands alone such as visiting a doctor's office or shopping?
- 

SOURCE: U.S. Census Bureau (2006b).

ceptual domains: functional limitations (vision, hearing, mobility, and cognitive), activities necessary to support independent living (self-care and mobility in the community), and one major participation restriction (work limitations).

The new questions for the ACS, CPS, and NHIS are also quite similar to the set of questions developed and recommended by the United Nations affiliated Washington City Group (WCG) on Disability Statistics.<sup>4</sup> The WCG questions were designed to identify people (in any country) at risk of not being able to perform activities of daily living (ADL) or participate in major life activities because of significant functional limitations. The four core WCG questions cover the same types of functional limitations as the Census questions, although the wording differs. Two additional questions ask about specific activity limitations: difficulty with self-care and difficulty with communication. Hence, statistics from the ACS and the CPS will not be comparable to those from countries that adopt the WCG questions. Nonetheless, it seems likely that the ACS and, especially, the CPS disability statistics will be more comparable to those from other countries than they have been in the past.

### **Small Sample Sizes**

Although people with disabilities represent a sizeable share of the working-age population, they are in a minority. Hence, the samples of most surveys limit the ability to analyze specific subgroups of people with disabilities. Subgroups of interest often include people of certain age ranges (e.g., transition-age youth or working-age individuals), people with specific health conditions or types of disabilities, residents of particular states and smaller geographic regions, users of specific programs or services, and people categorized by length of disability duration. The national surveys with the largest sample sizes (Decennial Census, the ACS, and the CPS) generally have the most limited amount of information about disability. These surveys can allow some analyses of people with disabilities as a group at the state and substate level, but they cannot provide much information about specific health conditions causing disability. The Behavioral Risk Factor Surveillance System (BRFSS) and NHIS can provide more detail about some specific health conditions, but they are narrower in terms of addressing the breadth of disability-related issues.

The major national surveys generally do not have sample sizes large enough to permit in-depth analyses of people with disabilities who use particular programs or services. In some instances, pooling data across survey years and linking survey data to administrative data can provide large enough samples to study program participants, but these approaches are challenging.

### **Exclusion of People with Disabilities from Survey Samples**

The major surveys that provide disability data exclude most individuals residing in most group quarters (GQ), many of whom have disabilities. Data on people residing in GQ other than correctional facilities and nursing homes are especially limited (e.g., long-term psychiatric facilities and noninstitutional group homes). Until very recently the Decennial Census long-form survey was the only one to collect disability data on the entire population, regardless of residence type. Starting in 2006, the ACS has been expanded to do so every year. This represents a major improvement in the NDDS and one that is already starting to

yield important new disability information. Nonetheless, the extensive information that is available about people living in the household population from other surveys will remain unavailable or limited for those living in institutions and other GQ.

Disability prevalence is also high among homeless people (see She and Stapleton 2009), and they too are unlikely to be captured in any survey sample. In addition, individuals with disabilities captured in the sample frames for household surveys can be excluded from the survey sample because of access issues related to location and interview methodologies.

### **Subject Areas Poorly Addressed**

A number of important topic areas are inadequately addressed for people with disabilities in national surveys, for at least one of three reasons: 1) surveys that address the topic area do not include adequate disability measures; 2) surveys that address the topic area are conducted very infrequently or cover only very specific subpopulations of people with disabilities; or 3) the topic area, as relevant to people with disabilities, is simply not addressed in any survey. Examples of subject areas that are poorly addressed for people with disabilities include time use and allocation of expenditures, transportation issues, program participation and benefits, employment services and supports, community participation, living arrangements, and the characteristics of disability onset and progression.

The inclusion of new disability questions in the CPS, discussed previously, will expand knowledge about the household population with disabilities in the subject areas covered by the CPS because this information was previously only available for the “work-limited” disability population captured by the pre-2008 CPS question. It will also allow researchers to produce statistics on time use for people with disabilities from the ATUS, which uses the CPS as its sampling frame.<sup>5</sup>

### **Untimely or Outdated Data**

The surveys that provide the most in-depth information about people with disabilities are those that are conducted very infrequently or have only been conducted once. The NHIS Disability Supplement



(NHIS-D) represents the most ambitious effort to date to collect a wide range of disability-relevant information from a large, nationally representative sample of people with disabilities of all ages. The survey was conducted in two phases in 1994 and 1995. The data are now more than a decade old, and the survey has not been repeated. Similarly, the major programs serving people with disabilities only survey their populations very infrequently. The Social Security Administration (SSA) has conducted five large-scale survey efforts over the last three decades, covering various subgroups of its disability beneficiary population. All were special-purpose surveys, spaced many years apart, and not part of a systematic survey program that generates comparable information over a long period. Only one survey of state/federal vocational rehabilitation (VR) service users has ever been conducted, and that was in the mid 1990s. Although data from the large national surveys (e.g., the ACS and the CPS) are generally released fairly quickly, the public-use files for surveys that provide the most in-depth information about people with disabilities (e.g., the Survey of Income and Program Participation [SIPP] and the NHIS) are generally not released for two or more years after they are fielded.

### **Limited Longitudinal Information**

Longitudinal survey data are more difficult and costly to collect than cross-sectional data. As most survey data are cross-sectional in nature, they do not permit analyses of the progression of disability and disability-related consequences over long periods. The most significant longitudinal national survey of the general household population, the Panel Study of Income Dynamics (PSID), included only very limited measures of disability until recently. The SIPP provides a limited longitudinal perspective (two and a half or four years, depending on the panel), but the sample sizes of people with disabilities are too small to conduct anything more than very high-level descriptive analyses of disability onset and progression unless data are pooled from multiple years. The data sources that provide the most in-depth longitudinal information focus on very specific subpopulations, such as older adults (e.g., the Health and Retirement Study) and youth (e.g., the National Longitudinal Survey of Youth).

Efforts to match data from the SIPP, CPS, NHIS, and several other surveys to administrative data from the SSA and, for some, the Centers for Medicare and Medicaid Services (CMS) have added important longitudinal information to major surveys (see Stapleton, Wittenburg, and Thornton 2009). The matches do not, however, add longitudinal information in content domains covered only by the surveys, and access to the data is restricted because of privacy issues. Incomplete matches are also a significant problem for some years.

### **Inadequate Program Participation Data**

As discussed in Stapleton, Wittenburg, and Thornton (2009), there are numerous limitations associated with data on the program participation of people with disabilities. Administrative data from each major program are rich in many respects, but quality information is largely limited to items that are important for administrative purposes, and privacy issues create significant barriers to researcher access. Although many agencies produce public-use files that contain administrative data from the programs they oversee, the data in such files are necessarily limited to protect privacy. Further, each agency's data contain little or no information about participation in programs administered by other agencies. This limitation is important because many people with disabilities participate in multiple programs. Matches across multiple program administrative databases can help address this issue, but privacy issues and the challenges of interagency cooperation have limited the number and utility of such efforts to date.

In general, it is extremely difficult, if not impossible, for individual researchers or state governments to obtain access to federal program administrative data with identifiers that would support matches to data from other sources. It can also be very difficult for federal agencies to obtain data from other federal agencies unless specifically needed for purposes of administering their programs. Interagency agreements to match data can take years to develop, and once in place, the actual matching process, development of analytic files and documentation, and establishment of protocols to allow secure access to the matched data can be very time consuming and costly. Fairly recent bilateral agreements between SSA and CMS and the Rehabilitation Services Admin-

istration (RSA) are supporting the production of statistics on participation in multiple programs that have previously been unavailable.

In addition, survey data on program participation is generally poor. Participants living in institutions and some group homes are excluded from the sampling frame. Questions about participation in some programs are not included, or they are lumped in with other programs. Respondents often fail to report participation when they are asked, or confuse similar programs (most notably Social Security Disability Insurance [SSDI] with Supplemental Security Income [SSI], and Medicare with Medicaid).

The limitations of administrative and survey data are being partially addressed by the previously mentioned efforts to match administrative records to survey records. Despite the limitations of these efforts, they have added considerably to our knowledge about program participants, as well as to our understanding of the quality of survey data.

## **IDENTIFICATION AND INCLUSION OF PEOPLE WITH DISABILITIES IN FEDERAL SURVEYS**

In this section we describe six options to improve the identification and inclusion of people with disabilities in federal surveys. The first three options pertain to the identification of people with disabilities in survey questionnaires; the next two apply to the definition of the sampling frames from which federal survey samples are drawn; and the last concerns the methods used to locate and interview survey respondents.

### **Defining Disability in Federally Funded Surveys**

The government's decision to adopt a common set of questions for the ACS, CPS, and NHIS is a major step toward the establishment in all federal surveys of a definition of the population "at risk" for disability. Our recommendation goes further—deploy, and eventually require, the inclusion of the new ACS disability questions in all federally funded surveys. In a similar vein, the National Council on Disability recently included promotion of a standard set of disability questions in national

surveys among its recommendations for the Government Accountability Office's Key National Indicator Initiative.<sup>6</sup>

It would be enormously helpful to researchers, policymakers, advocates, administrators, and others to have a common understanding of how the population at risk for disability is defined in federal surveys. There would no longer be competing statistics about people with disabilities that vary solely because of differences in the questions used to identify this population. Statistics on prevalence, demographic characteristics, income, employment, and participation in other activities would continue to vary across surveys, but the variation would presumably be much narrower, and the plausible causes of variability would be narrowed in a very important way. With a standard definition in place, researchers and others could draw on disparate surveys to describe this population, with less concern about whether the disability statistics from different surveys are representative of the same populations. A standard definition would also help in developing a more comprehensive and coherent indicator system for the status of people with disabilities than is currently available—comparable statistics on various aspects of the status of this population could be drawn from multiple survey sources.

It must be acknowledged that these disability questions will not meet the needs of all researchers, administrators, policymakers, and advocates. Some people who are truly at high risk of disability will not be captured by these questions, and others at little or no risk will be. These questions will also fail to identify important subgroups of people at risk for disability. No short set of questions can adequately define this population for specific purposes, but specific surveys can add additional disability questions consistent with the survey's objectives. Such questions will also be instructive about those who are at risk but who are not captured by the common questions and those at low risk who are. Such research would likely lead to modifications of these questions in the future. One particular concern is that the ACS might fail to identify many people with significant psychiatric conditions.

It seems especially important to include the common questions in the SIPP, which provides a great deal of information about health conditions, functional limitations, disability, employment, income, and program participation not found in other surveys. The longitudinal nature of SIPP would also provide the opportunity to better understand the

dynamics of self-identification of disability under the common questions.<sup>7</sup>

More broadly, it would be extremely valuable to include the ACS questions in all federal surveys, including those that currently have very poor or no disability questions (e.g., the Consumer Expenditure Survey, American Housing Survey, and Survey of Consumer Finances). The inclusion of these questions in all federal surveys would greatly expand the extent of information that we have about the population at risk for disability.

In 1977, the OMB mandated the use of a standardized set of questions on race and ethnicity in all federal data collection.<sup>8</sup> A similar mandate for those at risk for disability now seems justified and would be welcomed by many users of disability data and statistics.

### **Maintain Old Disability Questions for a Transition Period**

In order to monitor the status of people with disabilities and identify trends, it is necessary to have data for comparable groups over long periods. Statistics for people with disabilities are very sensitive to seemingly small changes in the definition of disability. Hence, as survey measures are improved, the risk of losing historical continuity becomes a factor. Every change can create a “seam” in the data; trends can be observed before and after the seam but not across the seam. This gap can be bridged by continuing to ask the old questions for some period of time, perhaps to just a random sample of survey respondents. This would allow researchers to examine how statistics for the newly defined population relate to those of the previous one. Continuation for a single survey period would permit simple adjustments to the level of historical statistics. A longer continuation period would permit examination of differences in the trends of statistics under the new and old populations.

There is also great concern about the possible loss of continuity in statistics for people with work limitations. Currently, work-limitation questions are the only disability questions in the CPS, but they also appear in the ACS, NHIS, SIPP, and others. Conceptually at least, these questions are the standard across these important surveys, although the questions themselves are not identical. Work-limitation questions have

been heavily criticized (Hale 2001). The National Council on Disability (NCD) has even recommended that the federal government cease funding and reporting research on people with disabilities that uses “unreliable databases” such as the CPS (National Council on Disability 2001). Although we think many of the criticisms of the work-limitation question are justified, this question also has the significant merit of being used in multiple surveys over a long period of time. Further, research based on the NHIS and SIPP, both of which include other disability questions, has shown that long-term trends in employment and income for people with work limitations, after controlling for the business cycle, are similar to those for disability populations defined by broader functional and activity limitation measures less sensitive to the economic environment (Burkhauser et al. 2002; Weathers and Wittenburg 2009; Burkhauser, Rovba, and Weathers 2009). As experience is gained with a standard set of functional limitation questions in all these surveys, the value of work-limitation questions will likely decline, and perhaps they could eventually be dropped from some, or even all, surveys without loss of significant information.

### **Comprehensive Sampling Frame for the ACS**

Disability statistics can be affected in substantial ways because people with disabilities are not uniformly distributed throughout the population. How the Census Bureau determines who is in a population, how it classifies residence status, and how it and other agencies draw samples for various surveys supported by the Census sampling frame can all impact these statistics. Disproportionately large numbers of people with disabilities live in nonconventional housing, including institutional GQ such as nursing homes, prisons, and long-term psychiatric facilities, and noninstitutional GQ such as various group homes for people with disabilities (She and Stapleton 2009). Changes in policies and the economic environment can affect where people with disabilities live. With the exception of the ACS and surveys of specific institutional populations, all federal surveys exclude people living in some or all types of GQ. Hence, changes in the policy and economic environment can affect disability statistics by changing the number and characteristics of the disability population in a survey’s sampling frame.

Over the past two decades, increased levels of incarceration and efforts to move people with disabilities out of nursing homes and other institutions have likely had substantial effects on statistics for some groups of people with disabilities in the household population, but these effects are hard to identify because of inadequate data on the nonhousehold population. This illustrates the importance of including all living quarters, especially GQ, in the ACS sampling frame. The ACS is by far the survey with the most extensive coverage of the entire population, and it should continue to adopt and maintain a comprehensive sampling frame.

The Census Bureau maintains the national Master Address File (MAF), which is the official inventory of known living quarters (housing units and GQ) and selected nonresidential units (public, private, and commercial; U.S. Census Bureau 2006c). The MAF is used as the source of addresses for the ACS, the decennial census, and other demographic surveys supported by the Census Bureau, including the SIPP, CPS, and NHIS.

Only people living in housing units were included in the ACS before 2006. After that, the ACS started to include GQ. The new ACS sampling frame covers most institutional and noninstitutional GQ populations, but it does not provide 100 percent coverage of the entire population.<sup>9</sup> Locations that were classified in the 2000 Census as specific GQ types but excluded from the ACS sample frame include domestic violence shelters, soup kitchens, regularly scheduled mobile food vans, targeted nonsheltered outdoor locations, crews of commercial maritime vessels, natural disaster shelters, and dangerous encampments (U.S. Census Bureau 2006a, 2006c). The reasons for their exclusion include concerns about privacy and the operational feasibility of repeated interviewing for a continuing survey.

As the ACS has now replaced the Decennial Census long-form survey, it has become the only survey that has nearly complete coverage of the entire U.S. population. Thus, it is very important for the ACS to continuously and consistently provide annual data for the population living in housing units and most GQ.<sup>10</sup> This information will be particularly valuable for disability research and statistics, especially for the working-age and child populations, given the large gaps in currently available information.<sup>11</sup> Additionally, the Census Bureau should con-

tinue to explore ways to include the GQ types that are currently out of the scope of the ACS. Although the GQ excluded represent a very tiny share of the entire population, we suspect that a disproportionately large number of residents have disabilities. The ultimate goal is to gather data that are representative of the entire population, and the ACS is the only survey that comes close.

### **Consistency in Other Federal Surveys**

Other federal surveys need to clearly define the residence types in their sampling frames, use well-developed frames, and sample in a clear and consistent manner. Sampling frames for other surveys will not be as comprehensive as the ACS sampling frame, in part because of cost, and in part because the surveys focus on collection of information that is only germane for the household population. Because many people with disabilities live in residential settings that are at the margins of the sampling frames used in household surveys (i.e., noninstitutional GQ), some disability statistics may be very sensitive to how the sampling frame is defined and the sample drawn. The Census Bureau coordinates sampling for many federal surveys (U.S. Census Bureau 2006d), but survey rules and procedures might result in coverage differences that are important for people with disabilities, even if they are immaterial for those without disabilities.

We are particularly concerned that the household populations captured in the ACS, CPS, SIPP, and NHIS are not identical. It is possible that the differences in the disability prevalence estimates from these surveys (see Weathers 2009) reflect differences in sampling, although there are many other possible causes. The sample frame for the NHIS, unlike those for the ACS, CPS, and SIPP, cannot use the address file that the Census Bureau develops from the most recent Decennial Census; instead, it must rely on other sources of address information. One result is that the collection of data for the NHIS must rely on field interviewers to identify GQ and make a decision about whether each unit identified meets the survey's inclusion criteria (Botman et al. 2000).<sup>12</sup> It is unknown at this time how important this difference between surveys is for disability statistics.



Federal surveys that use a sampling frame not maintained by the Census Bureau are of greater concern. The triennial Survey of Consumer Finances provides an example. Sponsored by the Federal Reserve System, the survey uses a dual sample frame (Kennickell and McManus 1993). One frame is described as an area probability design and the other is a list sample, drawn from tax records and weighted in a manner to ensure adequate representation of households with relatively high income and wealth, reflecting the survey's purpose. We have found no information on the extent to which the sampling methodology includes those living in GQ of any kind.

As a first step in pursuit of this option, it would be worthwhile to conduct a review of sampling methodologies for all federal household surveys and assess what is known about the inclusion of subjects residing in GQ.

### **Survey Methodology**

Ballou and Markesich (2009) describe how people with disabilities can be excluded at every stage in the survey data collection process. Every federal survey would likely benefit from a review by experts, including experts with disabilities, in the collection of data from and about people with disabilities. Such a review could lead to modest changes in locating methods, respondent selection, interview mode and accommodations, use of proxy respondents, interviewer training, item and response wording, and possibly other aspects of a survey's methodology that would increase the inclusion of people with disabilities and improve the quality of disability data. Although we do not know enough about how various aspects of survey methodologies affect disability data quality, a body of knowledge is emerging. The long-term goal would be to establish standards for all federal surveys.

## **LONGITUDINAL AND ADMINISTRATIVE DATA ENHANCEMENTS**

Longitudinal survey data on people with disabilities are important because of the dynamics of disability and related events, but they are also very limited. Administrative data, however, can help address these limitations because they can often be used to create longitudinal administrative files. In addition, administrative data are the best source of information on the participation of people with disabilities in public programs. As discussed by Stapleton, Wittenburg, and Thornton (2009), there have been numerous efforts to make use of administrative data, often matched to survey data. These efforts have resulted in substantial, fruitful research, especially that which requires both longitudinal and program data. A great advantage of such efforts to use administrative data is that they do not impose additional burden on respondents and program participants; instead, they make better use of the data already being collected. We offer five options for strengthening longitudinal and administrative data in ways that would improve disability statistics.

### **Maintain and Strengthen the Federal Government's Longitudinal Survey Efforts**

Recently, budgetary pressures and an array of data collection problems have threatened the continuation of the SIPP. This would be a great loss for disability statistics because it is the primary source of longitudinal survey data on disability, employment, income, and program participation. At this writing, it appears that SIPP will continue for at least the near future, but with a diminished sample size. The Census Bureau has been developing a replacement longitudinal data collection system, called the Dynamics of Economic Well-being System (DEWS). In principle, DEWS would address some of the limitations of SIPP, at least in part by relying more heavily on administrative records and reducing the burden of data collection on both respondents and the federal government. True improvements to the collection of longitudinal data focused on SIPP topic areas, especially those with significant disability content, would be of great value to disability researchers, policymakers, and the disability community, but replacement of SIPP with a system

of lesser quality for the sole purpose of reducing data collection costs would undermine this very valuable component of the NDDS.

### **Maintain and Strengthen Efforts to Match Survey Data to Administrative Records**

Past efforts to match survey data to administrative records have proven very effective as a means to learn more about characteristics of program participants and how they compare to nonparticipants, factors that affect participation, and the experiences of participants before, during, and after program entry. SSA and Internal Revenue Service (IRS) administrative records have been matched to survey data from many of the SIPP panels, and continuation of that effort through SIPP or its successor is critical. Recent matches between the NHIS and both SSA and Medicare records are likely to be the source of many statistics on people with disabilities in the near future.

One other survey-administrative data matching effort deserves attention. As described by Stapleton, Wittenburg, and Thornton (2009), the SSA and the Census Bureau have pursued a pilot effort to match records from the ACS to SSA administrative data. The success of this effort has not been reported, and it appears that the effort is languishing because of other agency priorities. However, this data matching effort would have enormous value for policy research and development. It would, for the first time, provide substantial socioeconomic information about participants in major programs at the state level on an annual basis. It would also introduce a longitudinal dimension to the ACS that, among other things, would allow production of state-level statistics on individuals who participate in a program (e.g., SSDI) before, during, and after entry. Matches of the SIPP, NHIS, and CPS to SSA data have been used to produce such statistics at the national level, but these surveys are not large enough to support state-level participation statistics on an annual basis. At the state level, such statistics would be a valuable tool for monitoring the status of people with disabilities as the economy and disability policies change.

Finally, we encourage the continuation of recent efforts by the Census Bureau to improve match rates for federal surveys, as described in Stapleton, Wittenburg, and Thornton (2009). The considerable increase

in the match rate reported for the 2006 SIPP data, reversing a long decline, is a welcome development.

### **Maintain and Strengthen Efforts to Match Administrative Data Across Agencies**

As described in more detail in Stapleton, Wittenburg, and Thornton (2009), fairly recent bilateral agreements between the SSA, CMS, and RSA have allowed these agencies to match their records for research and administrative purposes. Such matches help address the very limited nature of other data on participation in multiple programs and support analysis of how various programs interact. For example, Medicare and Medicaid records from CMS provide extensive information about the insurance coverage, medical diagnoses, and service utilization of SSDI and SSI beneficiaries, and SSA records provide longitudinal information on the SSDI and SSI participation of state VR agency clients. Although use of these recent agreements has been limited to date, they have great potential to enhance the value of the NDDS. Efforts to build matched analytic files under these agreements, especially longitudinal files, could be quite valuable.

### **Allow the Matching of Unemployment Insurance Records to Administrative Records**

State unemployment insurance (UI) programs must submit their records to SSA for two administrative purposes, as specified by law: to support the efforts by the Office of Child Support Enforcement to enforce child support orders and to support the administration of SSI (see Stapleton, Wittenburg, and Thornton 2009). These records contain quarterly wage data for most people who are not self-employed, as well as information about new hires and UI benefits. SSA and other federal agencies are not allowed to use these data for purposes other than those indicated above, including research.

Many states have successfully used matches between UI data and other state administrative data to support welfare and, to some extent, disability research. The UI wage data are complementary to the IRS earnings data. Most importantly, the wage data are quarterly, not just annual, which can be critical for observing the timing of changes in em-

ployment and earnings when a policy or program is changed. Although the UI data for individual states can sometimes be accessed for research purposes, it can be very cumbersome to do so, and single-state data have the distinct disadvantage of not including records for residents who are employed in other states.

### **Improve Researcher Access to Administrative and Matched Records**

Agencies must necessarily protect the privacy of their administrative data, and this means imposing substantial restrictions on access. In general, these data are accessible to qualified employees of the agency and qualified staff of contractors conducting work on an agency's behalf; in the latter case, usage is limited to the scope of work of the contract. The IRS earnings data are an important exception; only qualified federal employees are allowed to access these data.

Researchers conducting independent projects have much more limited access to data derived from administrative records, and it seems very likely that numerous disability-related research efforts have been thwarted or never pursued because of these barriers. There are important exceptions, however (see Stapleton, Wittenburg, and Thornton 2009). CMS has a long-standing and extensive system for providing independent researchers with access to Medicare and Medicaid administrative data, including Medicare Current Beneficiary Survey records that are matched to Medicare enrollment and claims data. The National Institute on Aging and SSA have established an application process through which independent researchers can obtain access, under restrictive conditions, to the Health and Retirement Survey data that have been matched to SSA data. The Census Bureau, under an agreement with the SSA and IRS, also has a process to provide restricted access to SIPP data matched to SSA and IRS data, but the research project must support the legislated goals of the Census. Very recently, the Census Bureau developed synthetic matched SIPP files. These files will provide researchers with access to data that are designed to have all the characteristics of the real matched files, but they are not data for real respondents.

None of these efforts are designed for the specific purpose of supporting disability research and statistics. Yet their value for disability

research and statistics is considerable, in part because such a large share of the population with disabilities receives a benefit from at least one federal or federal-state program (see Stapleton, Wittenburg, and Thornton 2009). Improvements in researcher access to matched data, in ways that protect privacy, will substantially increase the value of data that are already being collected.

## **ENHANCING THE DISABILITY CONTENT OF EXISTING SURVEYS**

Adding disability measures to surveys with poor or nonexistent measures is the most important way that disability-relevant content in existing national surveys can be improved. The addition of questions to the PSID in 2003 and the planned addition of disability questions to future rounds of the CPS (and, by extension, ATUS) will make the data from these surveys much more valuable for studying and understanding disability issues.

Aside from improving the identification of people with disabilities in surveys, there are at least two low-cost ways of improving disability-relevant content.

### **Modify Existing Questions, Probes, or Response Options**

A careful review of the instruments for each major federal survey from the perspective of individuals with a wide range of disabilities would likely identify numerous small changes to the questions, probes, and response options that would improve disability content. For example, take disability services, resources, and concepts out of the “other” response option category. When soliciting information about service programs, response options and probes should explicitly include programs like state VR and independent living centers. Questions about employment services should include probes for services such as job coaching and assistance with accommodations. Another change would be to add disability-relevant education categories as response options. For example, some individuals in special education complete high

school but receive a special certificate that is not equivalent to a high school diploma. Finally, survey developers should refrain from using responses to work- or activity-limitation questions as the only means for skip patterns into questions about disability-related topics. Many individuals with sensory, intellectual, and other types of disabilities do not view their activities as limited by their conditions.

Of course, it only pays to make the survey questions more disability sensitive if the surveys include an adequate set of questions to identify respondents with disabilities and the sample sizes are large enough to conduct analyses of their responses. For large surveys with disability identifiers, however, very small changes can be enough to significantly improve disability content.

### **Add a Few Disability-Related Questions in Selected Surveys**

In some cases, a few additional questions might substantially improve the usefulness of the survey data for purposes of studying issues related to disability. For example, questions about specific barriers to employment, reasons for not working, employer accommodations, and job demands could be included in the CPS. Questions related to transportation and community accessibility could be added to the ACS.

It is not easy to add even a small number of new questions to an existing survey. Aside from potential cost and logistical issues, changes and added questions can affect other items in the survey and comparisons with statistics derived from past surveys. Convincing the responsible agency that such changes are good investments is likely to require substantial effort. We think, however, that there is a compelling argument to review major federal surveys with respect to the potential of adding significant content through just a few additional questions in each survey.

## **PERIODIC DISABILITY SUPPLEMENTS AND SPECIAL SURVEYS**

As noted previously and described in more detail in Livermore and She (2007), there are many disability-related topics for which little or no information is routinely collected. We discuss three approaches to addressing limitations of this sort: supplements to existing surveys, periodic surveys of specific subpopulations of people with disabilities, and a stand-alone national disability survey.

### **Develop Periodic Disability Supplements to Existing Surveys**

Adding a topical supplement to an existing national survey would seem to be a useful approach when a large amount of new information is required (e.g., extensive information about environmental factors that might contribute to, or reduce, disability),<sup>13</sup> or when there is a need to study a specific subpopulation that cannot be easily identified with existing information. In either case, an existing, large national survey would act as the screener, as well as provide additional information that enhances the supplement in ways that make this addition to an existing survey more efficient than conducting a stand-alone survey. If this is done, the national survey would have to include disability identifiers; the use of a standard set of identifiers in all federal surveys would increase the utility of this approach.

We have identified three models for supplements to existing surveys. “Topical modules” are supplementary questionnaires administered during one of many interviews. SIPP exemplifies this model because it is built around a core of labor force, program participation, and income questions designed to measure the economic situation of people in the United States. Because SIPP is a longitudinal survey, these core questions are repeated at each wave of interviewing, to capture the dynamics of income and program participation. In addition, the survey was designed to provide a broader context for the analysis of income and program participation dynamics by adding questions on a variety of topics not covered in the core survey. These questions are part of what is termed topical modules and are only administered at particular interviewing waves of the survey. Topics covered by the modules span



a variety of subjects, including personal history, child care, wealth, program eligibility, child support, health care, school enrollment, taxes, income sources, and disability. SIPP sample sizes substantially limit the value of SIPP supplements for studying subpopulations of people with disabilities. Uncertainty about the future of the survey and the planned replacement (DEWS) means that we do not know whether the disability information collected via the SIPP disability module will be available at any time in the future, let alone whether the disability supplements could be improved.

SIPP's longitudinal design makes it possible to spread the burden of asking questions in topical modules over multiple interviews. Supplementary questions to those with disabilities identified during an interview for a cross-sectional survey would presumably be asked during the same interview. This would add to the length of the interview and potentially impose an unacceptably large burden on the respondents. The CPS is fielded monthly and has a rotating panel design, under which each subject is interviewed eight times. Similar to SIPP, the CPS already takes advantage of this design by routinely including supplementary questionnaires.

The second supplementary survey model is a "topical survey." This is a survey that appears to be a stand-alone survey but derives its sample from a parent survey, and in essence, it is an extensive topical module of the parent survey. For example, the ATUS derives its sample from the CPS sample, and the Medical Expenditure Panel Survey sample is derived from the NHIS sample. In each case, supplemental interviews are conducted separately from the original interviews, but the data from the original survey can be combined and used with the topical survey data. The NHIS-D also falls in this category, although unlike the other examples of topical surveys, the NHIS-D was designed to be a one-time survey. We return to the NHIS-D in our later discussion of a national disability survey.

The third supplementary survey model is a "topical question battery" that can be added to a core survey questionnaire, perhaps only to respondents identified by a short screen. This model is exemplified by the BRFSS, the Centers for Disease Control (CDC) survey under which topical supplements can be used in concert with a core national survey and administered in a single interview. Under cooperative agreements

with the CDC, each state administers the core BRFSS questionnaire every year. The survey's platform provides flexibility to meet the information needs of states, and at the same time, support national and state-level estimates of a core set of items. In addition, each year the CDC offers a variety of approved topical modules that can be used by the state at its discretion and cost. States can also add their own sets of questions, subject to certain procedures and requirements, at their own expense.

Given the inadequacies of disability content in existing surveys, it seems highly desirable to add disability supplements to existing surveys, following one or more of the above models. A single topical module added to a single survey, fielded periodically, could add considerable information to existing data. A program of multiple supplements to multiple surveys, strategically designed to address gaps in current disability data, would be very powerful—especially if all surveys had a standard set of disability questions.

Adding a periodic disability supplement to the ACS is an extremely attractive idea because of the survey's size and ability to produce state and even smaller area estimates. The ACS is already a critical tool for measuring the status of people with disabilities at the state and local level. Adding questions would provide the opportunity to find out about aspects of status that are specific to people with disabilities, such as access to public places, transportation options, and use and availability of assistive devices. From a technical perspective, it seems feasible to develop an infrastructure and process for prioritizing the implementation of relatively brief topical modules attached to the ACS.

As noted previously, the means to add supplemental questionnaires already exists in the CPS. With the adoption of the new ACS disability questions, the CPS has the potential to become a very useful avenue for topical supplements on disability issues, particularly those related to employment.

We do not wish to minimize the challenges of adding disability modules to existing surveys. Resources and support for any supplement must be obtained and, in many cases, might require the cooperation of two or more agencies, including the agency that sponsors the parent survey. There are likely to be numerous technical issues to resolve regarding how the module will be administered. Ideally, administra-

tion will maximize efficiency and quality but not alter the nature of the other data that are collected by the parent survey; there can, however, be significant trade-offs between these two objectives. The value of the data collected through some new supplements, however, might greatly exceed the cost of meeting such challenges.

### **Periodic Surveys of Specific Subpopulations**

Periodic surveys of specific subpopulations of people with disabilities would add significant value to the NDDS. We discuss two types of populations of particular interest: 1) the nonhousehold population (including those without disabilities) and 2) participants in major disability programs.

The household population has been surveyed on a regular basis, but the nonhousehold population has been surveyed irregularly, component by component. The two examples of fairly systematic data collection for the nonhousehold population are surveys of nursing home residents and the incarcerated population. We do not have periodic surveys of groups that live in other types of GQ, many of which are intended to house people with disabilities. These include group homes, long-term psychiatric facilities, and residential care facilities. The ACS added these populations in 2006, and they are also included in the Decennial Census, but these data are limited. Periodic surveys that provide more detail about the residents of all GQ seem critical if we are to adequately track the status of people with disabilities.

We also need periodic surveys of homeless people. This population is either not covered at all or covered to an unknown extent in all national surveys, including the Decennial Census and the ACS. One past survey—the 1996 National Survey of Homeless Assistance Providers and Clients—collected information on homeless persons who used homeless assistance programs. There are no more recent data about the homeless population and no data about those who are homeless but do not use homeless services. A national effort led by the Department of Housing and Urban Development (HUD) is implementing the Homeless Management Information Systems (HMIS) in communities across the country, partly to support the collection of national data without having to mount a national survey of this population. Objectives in-

clude production of unduplicated counts of homeless individuals and the identification of disabling conditions.<sup>14</sup> In 2007, HUD reported to Congress that local communities have made great progress toward HMIS implementation, and HUD will continue to build local and national capacity to collect, report, and analyze data on the homeless population (U.S. Department of Housing and Urban Development 2007). Successful national implementation of HMIS will add substantially to the NDDS and might also pave the way for special surveys that target the homeless population.

It would also be very useful to periodically survey participants in major programs designed to serve people with disabilities, such as SSDI, SSI, Medicare, Medicaid, and state VR programs. As detailed by Stapleton, Wittenburg, and Thornton (2009), the agencies that run these programs do conduct surveys of the participants, but only the Medicare program has a continuous, systematic survey program, the Medicare Current Beneficiary Survey, which is in its 15th year. RSA has conducted one major survey of VR clients. There is no systematic, ongoing survey program for Medicaid enrollees, SSDI beneficiaries, or SSI recipients. SSA's recent National Beneficiary Survey, conducted to support the Ticket to Work evaluation, was designed as a one-time effort. The last previous SSA survey of adult beneficiaries, the New Beneficiary Survey, was initially fielded in 1982, with a 10-year follow-up in 1991. The population for this survey was limited to new SSDI enrollees and new recipients of Social Security retirement benefits; existing beneficiaries and SSI-only entrants were not included. SSA conducted a survey of SSI children in 2001. States occasionally survey their Medicaid enrollees, but there is no national survey of this population.

### **Periodic National Disability Surveys**

A final approach to improving the NDDS is to conduct periodic national surveys. We think this is the least preferred option for feasibility reasons. It seems to us that the options described above, which improve existing data collection efforts with respect to their disability content, are more feasible, less expensive, and more likely to provide higher quality data for almost all purposes. It seems that the only reason to implement a periodic national survey is the inability to take sufficient

advantage of the other options. In principle, a periodic, national disability survey could address many of the limitations of existing disability data: inadequate sample sizes, limited disability measures, limited longitudinal information, limited disability-relevant content, and others. But these and other limitations could, in principle, be addressed by the other options discussed in this chapter, and the return on investment, measured in terms of the extent to which they would address existing data limitations relative to their cost, is higher than that in a periodic national disability survey. The other options generally allow direct comparisons of respondents with disabilities to those without disabilities on the many items that are relevant to both groups (e.g., household structure, living conditions, education, employment, participation in other social activities, consumer expenditure, time use, etc.).

The NHIS-D represents the only large-scale national disability survey ever undertaken in the general population. As mentioned earlier, it is an extensive topical module of a major survey, not a stand-alone survey. For that reason, comparable data on many items were available for respondents without disabilities. The NHIS-D was implemented in two phases. The first phase was conducted along with the NHIS core, and the second was administered approximately one year later to a subset of respondents selected, in part, on the basis of first phase questions.

The NHIS-D differs from the other examples of disability topical modules noted above in two important respects. First, the supplement was designed to be a one-time survey, although many of its developers probably hoped it would be repeated periodically in the future.

Second, a significant number of questions were added to the parent survey interview for the purpose of screening respondents for inclusion in the later topical module, as well as to support the design of the module's response categories and skip patterns. The addition of screening questions to a parent survey can greatly increase the cost and complexity of the design relative to a design that relies solely on responses to existing parent-survey questions. Adding questions to the parent survey can also create some risk that answers to other questions in the survey will systematically differ from those in earlier or later rounds because of changes in the context of those questions.

The NHIS-D was very large, costly, and complex. It involved funding from and coordination across 10 or more federal agencies. Some ex-

perts believe that the many compromises necessary to obtain agreement from multiple stakeholders may have created unnecessary complexity, reduced its usefulness, and lowered its chances of ever being replicated in the future. Questions regarding who is responsible for funding and development, what topics to include, how large the samples should be, how they should be derived, and how the survey will be administered all had to be addressed.

At the same time, however, the NHIS-D produced valuable disability information that had not previously been collected (e.g., on accommodations, assistive devices, and personal assistance services), and it has been used extensively to study a wide variety of disability issues (Hendershot 2005). Further, the valuable lessons and experiences from the development and use of the NHIS-D could inform the development of periodic national disability surveys and help make them more useful and efficient. It appears to us, however, that the bulk of needs to be met by a national survey could be met by a less expensive, and less logistically challenging, effort to improve the disability content of other surveys. The fact that the NHIS-D is really an extremely large topical module of the NHIS reinforces this point; much less ambitious topical modules attached to a variety of surveys could address the same needs as a national disability survey.

There are two important, but implicit, features of the NHIS-D that could not be replicated through a series of supplements to existing surveys unless there are other important changes to those surveys. All of the NHIS-D disability statistics are based on a single set of disability identifiers, and they are obtained from data that were collected via a single set of methodologies (i.e., the sampling methodology, the methods for finding and interviewing respondents, and the methods for addressing nonresponse and missing data). These implicit features of the NHIS-D serve to emphasize the importance of including a standard set of disability questions in all major surveys, and using consistent, well-defined data collection methods. Without improvements in these areas, researchers cannot expect to collect information on comparable disability populations from a system of disability topical modules attached to diverse surveys. In the absence of such improvements, a periodic national survey might be the only feasible way to obtain this important information.

## PRIORITIES

In this chapter we have described options that would greatly enhance the quality and value of the data collected by the NDDS. Most of these are of relatively low cost because they require collection of little or no new data. Instead, they focus on better use of already collected data, or on relatively small, but important improvements to collection efforts that are already in place. Institutional constraints are likely to be the greatest obstacle to implementation, not costs. The limitations of the NDDS can be attributed in part to the fact that the government has not viewed, developed, and managed its components as a system, formal or informal, reflecting the diverse interests and constraints of the various agencies involved.

A list of the options, organized by section, appears in Table 11.3.<sup>15</sup> The columns identify specific limitations of the NDDS (see Section 2), double check marks indicate the limitations that would be addressed by each of the options, and single check marks indicate limitations that might be addressed by the option, depending on how it is implemented.

In general, we think the greatest gains can be achieved by deploying the new ACS questions in all federal surveys (first section of Table 11.3), building on the significant gains that will already be achieved by using common, carefully designed questions in the ACS, CPS, and NHIS. As noted earlier, these questions will apply to ATUS, too, because those surveys use the CPS as their sampling frame. The second option, continuation of old disability questions during a transition period, is important to maintain the historical continuity of disability statistics as the new ACS questions are deployed.

We also think that options to strengthen longitudinal and administrative data should receive high priority (second section of Table 11.3), in part because they do not call for extensive collection of new data. The first of the five options in this area calls for the continuation and strengthening of existing longitudinal data collection efforts, most importantly the SIPP, and the rest call for making better use of data that are already collected. Attending to the first option is particularly urgent and needs to be given very high priority; we do not have strong views about priorities of the remaining four.

We give lower priority to options for collecting additional disability content (last section of Table 11.3) than to those that would improve the identification and inclusion of people with disabilities, and options to improve longitudinal and administrative data. Pursuit of the options in these first two areas will greatly increase disability content without requiring additional data collection.

We place a periodic national disability survey at the end of the options list. As discussed previously, a very large share of the informational gain that could be obtained from a national survey would be gained by implementation of other, more practical improvements. A national disability survey is a very expensive undertaking and requires the extensive cooperation of many interested agencies. In contrast, many of the other options require no new data collection and less interagency cooperation, if any.

Perhaps we are too optimistic about the implementation of what we think are much more practical options for improving the implicit NDDS. Recent developments feed our optimism, however, most notably the adoption of common disability questions in the ACS and CPS, progress toward increasing the completeness of matches between SIPP and SSA administrative data, and establishment and productive use of interagency matching agreements. Furthermore, the Department of Labor has now announced that it will start to routinely produce and publish CPS-based statistics on the population with disabilities.<sup>16</sup> People with disabilities will finally be counted.



**Table 11.3 Summary of Options to Address Limitations of the National Disability Data System**

Limitations of the national disability data system														
Options	Limitations on identification of people with disabilities			Small samples of people with disabilities	Limitations of data on subpopulations of people with disabilities			Subject areas poorly addressed <sup>a</sup> Untimely and outdated information	Limited longitudinal data	Limitations of disability program data				
	Compara-	Poor/no	Mental		GQ	Homeless	Collection			Research	Survey	Admin.	Multiple	Match
	bility	measures	disabili-		residents	people	methods			access	data	data	programs	limitations
Identification and inclusion of people with disabilities in federal surveys														
Deploy new ACS disability questions in all federal surveys	√√	√√						√√						
Continue old disability questions for a transitional period	√√							√√						
Maintain a comprehensive sampling frame for the ACS				√√	√√	√√								
Improve sampling methodologies					√√	√								
Address methods that exclude people with disabilities							√√							
Longitudinal and administrative data														
Strengthen the collection of longitudinal survey data				√√				√√	√√	√√		√√		
Strengthen efforts to match survey and administrative records									√√	√√	√√	√√		

Strengthen efforts to match data across agencies										√√	√√	√√	√√	√√
Allow the matching of unemployment insurance records										√√	√√	√√	√√	
Improve research access to administrative and matched data											√√			
<hr/>														
Disability content														
Modify existing questions, probes, and response options												√		√√ √√
Add a few disability-related questions in selected surveys												√√		√√ √√
Add periodic disability supplements to existing surveys												√√		√√ √√
Conduct periodic surveys of specific subpopulations													√√	√√ √ √√ √√ √√
Conduct periodic national disability surveys	√√	√√	√√	√√	√	√	√√	√√	√√	√	√	√	√√	

NOTE: √ = Some variants of option would address the limitation; √√ = option would be designed to address limitation.

<sup>a</sup>These include time use, consumer expenditures, transportation, employment supports, community participation, living arrangements, and disability onset and progression.

## Notes

1. See Stapleton et al. (2009) for additional details.
2. The planned use of these questions in the NHIS is documented in a letter from Jim Nussle, Director of the Office of Management and Budget, to Congressman William Lacy, Chairman of the Information, Policy, Census, and National Archives Subcommittee of the Committee on Oversight and Government Reform, U.S. House of Representatives, July 24, 2008.
3. See Washington Group on Disability Statistics (2008).
4. Terence McMenamin announced the decision at a public meeting of the Interagency Subcommittee on Disability Statistics in January 2007. The introduction to the BLS questions will differ somewhat from that in the ACS because of contextual differences in the two surveys, and the questions will be converted to a household format, rather than the individual format used by the ACS.
5. The ATUS sample is much smaller than the CPS sample, so production of time-use statistics for persons with disabilities from ATUS will probably require pooling of ATUS data over several years.
6. See U.S. Government Accountability Office (n.d.).
7. This assumes continuation of SIPP. As discussed later, this is doubtful, and it is not clear that any successor to SIPP will collect extensive disability information.
8. See OMB's Statistical Policy Directive 15 adopted in 1977 and most recently revised in 1997 at Office of Management and Budget (1997).
9. Nevertheless, ACS estimates of the total population are controlled to be consistent with the intercensal population estimates (U.S. Census Bureau 2006c). The exclusion of certain GQ types may result in a small bias in some ACS estimates.
10. Due to differences in the sampling method or the sampling frame, statistics based on the 2005 ACS would not be comparable with those of the 2004 ACS.
11. Medicare statistics for those aged 65 and over can be considered very close to statistics for the entire population aged 65 and over.
12. The NHIS excludes only institutional and military GQ.
13. The Craig Hospital Inventory of Environmental Factors includes 25 such factors (Harrison-Felix 2001).
14. See U.S. Department of Housing and Urban Development (2004).
15. These options and their ordering benefited substantially from input received during and as follow-up to the October 2006 conference organized by the Rehabilitation Research and Training Center on Disability Statistics and Demographics, "The Future of Disability Statistics: What We Know and Need to Know," held in Washington, DC, and sponsored by the National Institute for Disability and Rehabilitation Research.
16. This policy was announced by Neil Romano, Assistant Secretary for the Office of Disability Employment Policy, at "A Summit on Disability Employment Policy," Gallaudet University, June 3, 2008.

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