



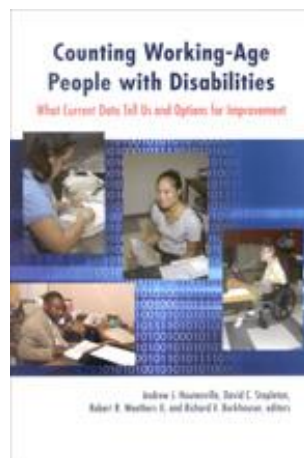
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Program Participants

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In this chapter we review the data available for studying working-age (aged 18–64)¹ participants in the largest federal and federal-state programs that serve people with disabilities, including Social Security Disability Insurance (SSDI), Supplemental Security Income (SSI), Medicare, Medicaid, state vocational rehabilitation (VR) services, and disabled veterans benefits programs. These data are increasingly important as the number of people covered by these programs and the corresponding expenditures continue to grow. Federal expenditures to support working-age people with disabilities in these programs represented more than 11 percent of all federal outlays in 2002, and that share is growing as the population ages.² In an era of substantial federal budget deficits, policymakers, administrators, advocates, and others have an obligation to monitor and improve these programs, and that can only be done with accurate and detailed information.

Currently, the most widely available data about participants comes from the statistics published by the four federal agencies with responsibility for these programs—the Social Security Administration (SSA), the Centers for Medicare and Medicaid Services (CMS), the Rehabilitation Services Administration (RSA), and the Department of Veterans Affairs (DVA). These statistics include basic information about the numbers of program participants, their state of residence, their basic demographic characteristics, and expenditures for their support.

There are also substantial data contained in agency administrative records and in surveys that can inform effective program monitoring and improvement. The key feature of these data is that they are available for individual program participants and can therefore be used to

study how people with different types of characteristics react to alternative program incentives and options. The administrative records contain a fairly limited set of variables because the agencies tend to collect only data required to administer the programs, but records are generally available for thousands, if not millions, of people. In contrast, the survey data are generally available for smaller sets of individuals, but they can contain a very rich set of information about such important concepts as participation, attitudes, expectations, family circumstances, and day-to-day activities, as illustrated in the earlier chapters of this book.

The challenge facing the agencies, researchers, and others interested in disability policy is to use the available data effectively and to identify the best ways to augment the available data. Federal agencies have made very important advances, including developing longitudinal analytical files from administrative data, collecting more accurate information on program participation in major population surveys, conducting more detailed surveys of program participants themselves, matching survey records to administrative records, and matching administrative records across federal agencies.

To help researchers make use of the advances that have been made and to help guide the agencies in their continuing efforts, this chapter reviews the published statistics, administrative data, and surveys that contain information for participants in each of the major programs. The chapter also reviews the important limitations of the available data. Of particular importance is the lack of good information about people who are not participating but who are potentially eligible for services. For example, we know very little about participation rates because we do not have adequate information to identify people who are eligible but who do not apply for benefits. Another important area for improvement is expansion of state-level statistics to support assessments of how well these programs are meeting the needs of each state's working-age population with disabilities and to facilitate analysis of how changes in a state's policies or a state's economy affect participants, participation rates, and program expenditures. Finally, there is only limited information on the dynamics of participation—how people enter, leave, and re-enter these programs—and on the duration of program participation.

To illustrate the current status of and potential for state-level data, we provide new statistics on the extent to which working-age people with self-reported disabilities in each state participate in the major disability programs. Even though such comparisons fall short of being “participation rates” because many people with self-reported disabilities do not meet all eligibility criteria for any given program, the statistics nevertheless demonstrate that participation in the major disability programs relative to the size of the working-age population with disabilities varies enormously across states, and they are suggestive of numerous additional state-level statistics that could potentially be produced with existing data. These comparisons are the starting points for other analyses using individual-level survey and administrative data that could be used to address the gaps in knowledge noted above about participation rates, state differences, and the dynamics of program participation.

As the development of these data sources continues, continuation of lawmaker and agency executive support for efforts to generate accurate detailed information about program participants is essential. The emergence of new data sources and the extensive efforts of several program administrators offer hope that future data sources can provide a better guide for improving disability policy. We conclude our paper with a brief review of some of the most important new developments and some suggestions for the next steps.

EXISTING DATA ON PROGRAM PARTICIPANTS

In this section we describe current data on working-age participants in the major federal and federal-state programs that serve people with disabilities, under the oversight of SSA, CMS, RSA, and DVA.

In each section, we briefly describe the relevant agency programs, summarize the statistics that are published by the agency, discuss the agency’s efforts to make individual-level data available to outside researchers, identify major federal surveys that collect program participation data for the agency’s programs, and describe the agency’s own efforts to survey its program’s participants. We conclude the section with

a brief discussion of data from other programs that provide assistance to people with disabilities. Discussion of efforts to improve the quality of program participation data is deferred to the “Data Initiatives” section of this chapter.

Each agency holds extensive administrative data on participants in its programs. These data have great value for management, policy analysis, and research. When maintained over long periods, administrative files can contain historical program information about every participant. The content of that information is often extremely rich and often includes extensive longitudinal information that is critical for understanding the dynamics of program participation. Each agency publishes substantial statistics on its program participants, including many state-level statistics. All of them also provide restricted access to administrative data.

Administrative data have important limitations for studying program participation, however. If there is no important programmatic reason for collecting a specific piece of information, the information will not be collected at all, or if collected, is likely to be of poor quality because it is not a priority for the agency. Comparable data are not available for nonparticipants, including eligible nonparticipants and those who are potentially eligible. Administrative data from any single agency contain little information about participation in multiple programs, even though multiple program participation is relatively common for this population.

The limitations of administrative data on program participants are partially addressed through surveys. Several large national surveys capture some information on participants in programs that serve working-age people with disabilities (Table 9.1). Survey data on program participants have their own significant limitations, however. Some program participants are excluded from participation in major surveys because of data collection methodologies or sample definitions (see Ballou and Markesich 2009). Respondents are often confused about which programs they participate in, and some report inaccurate information for other reasons. Increased use of direct deposit options for income support programs has meant that survey respondents can no longer verify their participation in a program by reference to their most recent check. Because most surveys are cross-sectional, they capture information about

Table 9.1 Summary of Program Participation Information in Federal Household Surveys

Survey	SSDI	SSI	Medicare	Medicaid	Veterans' Comp.	Veterans' Pension	Veterans' Comp. or Pension.	Veterans' Health	Vocat. Rehab.	Workers' Comp.	Unempl. Insurance	TANF	Food Stamps	Other
American Community Survey (ACS)	√	√	c	c			√-	c			√	√-	√	
Current Population Survey (CPS)	√	√	√	√	√	√	√	√-		√	√	√		
Health and Retirement Survey (HRS)	√	√	√	√			√	√-		√	√	√-	√	
National Health Interview Survey (NHIS)	√	√	√	√			√-	√		√-	√-	√	√-	
1994-95 Disability Supplement (NHIS-D)	√	√	√	√			√-	√	√	√-	√-	√	√-	
Survey of Income and Program Participation (SIPP)	√	√	√	√	√	√	√	√		√	√	√	√	Energy, housing, general assistance
National Beneficiary Survey (NBS) ^a	√	√	√	√			√	√-	√	√	√	√-	√	Energy
Medicare Current Beneficiary Survey (MCBS) ^b	√		√	√			√	√						

NOTE: A minus sign (–) next to a check mark indicates that the specific benefit identified by the column header is included in a single response category with one or more other benefits.

^aThe NBS sampling frame includes SSDI and SSI beneficiaries only.

^bThe MCBS sampling frame includes Medicare enrollees only.

^cThe ACS will add a health insurance question in 2008.

current program participation but little or nothing about the history of program participation. The broad objectives of these surveys limit inclusion of questions relevant to research on program participation, such as questions about the nature and severity of medical conditions and functional limitations that might be critical to program eligibility or other barriers to work. Agencies partially address these limitations by conducting surveys of program participants, in varying degrees.

Social Security Administration

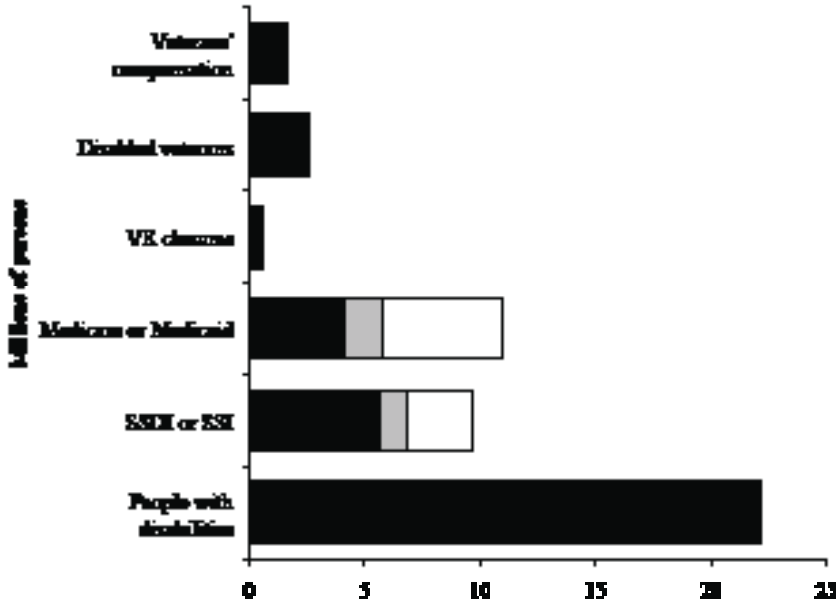
The SSA administers the two most significant income support programs for working-age people with disabilities. SSDI is the disability component of the larger Old Age, Survivor, and Disability Insurance (OASDI) program, commonly known as Social Security, and pays benefits to workers with substantial work histories whose monthly earnings have fallen below a threshold (the “substantial gainful activity” level) because of an impairment that will last for at least one year or result in death. The SSI program is means tested and provides income support to individuals with low or zero earnings because of a significant impairment, regardless of work history.³

In 2005, 9.7 million working-age people (aged 18–64) received benefits from SSDI, SSI, or both (Figure 9.1). That is equivalent to 44 percent of the ACS estimate of 22.2 million working-age people with disabilities in the household population for that year (Appendix 9A).

SSA produces extensive statistics on working-age beneficiaries of these two programs in numerous publications that are available on its Web site, and many of these are available at the state level (Table 9.2, top panel). Statistics for the two programs are typically published separately. Some publications do, however, include statistics on “concurrent beneficiaries” (i.e., people who participate in both programs).

SSA also publishes state-level statistics on the employment and earnings of working-age SSI recipients.⁴ Because SSI is a means-tested program, participants are required to report their earnings, and SSA validates their reports. SSA does not collect comparable data on SSDI beneficiaries because it is not a means-tested program. SSA does, however, have historical data on the annual earnings of virtually every person who has ever held a job covered by OASDI or Medicare. These data are

Figure 9.1 Estimates of the Number of Working-Age Household Population (Aged 18–64) with Disabilities and Number of Program Participants, 2005



NOTE: For SSDI or SSI, SSDI only is black, both SSDI and SSI is gray, and SSI only is white. For Medicare or Medicaid, Medicare only is black, both Medicare and Medicaid is gray, and Medicaid only is white. “VR closures” is the number of cases closed by state VR service agencies. “Disabled veterans” is the estimated number of disabled working-age veterans in the household population. “Veterans compensation” is the estimated number of working-age recipients of veterans’ compensation. VR closure statistics are conceptually not comparable to participant statistics for other programs because they represent a flow of participants through a relatively short-term program rather than the stock of participants in a long-term program.

SOURCE: Source information is provided in Appendix 9A.

Table 9.2 Summary of Sources for Program Statistics and Data on Working-Age Participants in SSA Disability Programs

Published statistics	
Social Security Disability Insurance (SSDI)	Summary of statistics available by state
Annual Statistical Report on Social Security Disability Insurance (2005)	Participation rate (SSDI beneficiaries as a percentage of the population aged 18–64), age and sex, entitlement category (disabled workers, widow[er]s and adult children), major diagnostic group, SSDI payment amount, concurrent beneficiaries, beneficiary filings for workers compensation or other public disability benefits, awards, terminations, and suspension or termination because of work. http://www.socialsecurity.gov/policy/docs/statcomps/di_asr/
Supplemental Security Income (SSI)	
SSI Annual Statistical Report (2005)	Participation by age and category (aged, blind, disabled), percent of resident population, monthly payments by age and category (aged, blind, disabled), concurrent participation by type of beneficiary (workers, widow[ers], adult children), and average monthly SSDI payment; SSI payment; noncitizen participants by category (aged, blind, disabled) and age; diagnostic group; participation in work incentives programs; applications (by age); awards (by age); statistics on state-administered SSI supplements (2002–2004). http://www.socialsecurity.gov/policy/docs/statcomps/ssi_asr/
Administrative records data available to non-agency researchers	
Social Security Disability Insurance (SSDI)	Access
OASDI Public-Use Microdata (2001) State, sex, age, and type of benefit	Available to all users in Statistical Analysis Software: http://www.socialsecurity.gov/policy/docs/microdata/mbr/index.html

Benefits and Earnings Public-use File (2004). Two linkable files—one with benefit information, the other with longitudinal earnings information	http://www.socialsecurity.gov/policy/docs/microdata/earn/index.html
Supplemental Security Income (SSI)	
SSI Public-Use Microdata File (2001) Information used to decide who receives SSI benefits	Available to all users at www.socialsecurity.gov/policy/docs/microdata/ssr/index.html
<hr/>	
Federal surveys identifying SSDI and SSI recipients in the household population	
American Community Survey (ACS)	1994–95 NHIS Disability Supplement (NHIS-D)
Current Population Survey (CPS)	Survey of Income and Program Participation (SIPP)
Health and Retirement Survey (HRS)	Medicare Current Beneficiary Survey (MCBS)—identifies SSDI recipients only
National Health Interview Survey (NHIS)	
<hr/>	
Recent agency survey of SSDI and SSI participants	
National Beneficiary Survey (NBS)	Survey conducted to support the Ticket to Work evaluation. Information on demographics, health, activity limitations, service receipt, work activity, income, and non-SSA benefits.

NOTE: All URLs accessed September 15, 2007.

provided to SSA by the Internal Revenue Service, are often referred to as the “IRS earnings data,” and are housed in SSA’s Master Earnings File. SSA holds the data under confidentiality restrictions that are even more stringent than those for other SSA data because of their source.⁵ SSA also holds quarterly earnings New Hires data that employers must report to state labor agencies under the federal-state unemployment insurance (UI) program. States were initially required to submit these data to support efforts of the Office of Child Support Enforcement. SSA has also started to use the data to identify SSI beneficiaries who have failed to report earnings and might therefore be receiving benefit overpayments. Currently they cannot be used for other purposes, including research. Well-designed state-level statistics on beneficiary employment and earnings based on either of these sources would be of considerable interest to consumers of disability statistics.

SSA produces national statistics on the disability determination process, and six of its nine service performance targets in 2006 were disability determination process measures.⁶ These statistics refer to applicants for SSDI and SSI benefits, rather than the beneficiary population. In 2005, about 2.5 million people filed claims for SSDI and 2.3 million for SSI, including many who filed claims for both.⁷ SSA does not publish state statistics on determinations. SSA has, however, made state-level data on applications and awards available to researchers, and those data are now in the public domain, although they are not readily available.⁸

State data are of considerable interest to researchers and others for numerous reasons. One important reason is that SSA-funded state agencies—Disability Determination Services—play a critical role in the process. A second reason is that extraordinarily long processing times for many applicants have focused attention on the determination process. This reason also explains the presence of so many statistics from this process in the Agency’s service performance measures. State leaders have an interest in how the applicants are faring, and the success of SSA efforts in their states to improve the timeliness and accuracy of disability determinations. A third reason is interest in studying the extent to which variation in application rates, allowance rates, and processing times can be attributed to economic, policy, and other environmental factors that vary across states. Finally, prior research using state-level

data has demonstrated that the number of applications responds negatively to exogenous changes in allowance rates.⁹ Similar analyses might also demonstrate that exogenous increases in processing times reduce application rates.

SSA researchers have recently produced the first national estimates of the number of working-age people who would be eligible for SSDI, SSI, or both were they to experience disablement (Rupp, Davies, and Strand 2008). SSA does not routinely publish state-level statistics on the population that is potentially eligible for SSDI benefits—that is, workers with sufficient work histories in jobs covered by OASDI to gain “disability insured” status. National disability insured statistics and state-level statistics on the number of workers with earnings subject to the OASDI payroll tax, and the amount of taxable earnings, are available in the *Annual Statistical Supplement to the Social Security Bulletin* (SSA 2007a),¹⁰ and county-level data appear in the annual publication *Earnings and Employment Data for Workers Covered Under Social Security and Medicare, by State and County* (SSA 2008).

SSA improved state-level SSDI statistics in several small but important ways from 2000 to 2005. These improvements include the addition of information on beneficiary filings for workers compensation and other public disability benefits, and on benefit suspensions and terminations due to work. At the same time, however, changes in age categories during this period limit the utility of published state-level data for assessing trends.

SSA does not generally make its administrative data files available to outside researchers except to conduct SSA-sponsored research. There are two exceptions, however. First, SSA has released a public-use file containing the earnings history and a limited number of characteristics for a 1 percent sample of OASDI beneficiaries who were on the rolls in December 2004 (Table 9.2, second panel, Benefits and Earnings Public Use File, 2004). Second, SSA has created and made available a public-use file on SSI recipients in December 2001. SSA has made special efforts to protect the confidentiality of its beneficiaries in these files, and these efforts might introduce random error in the data.

All major federal surveys that collect extensive socioeconomic data on the working-age population have questions on SSDI and SSI participation (Table 9.2, third panel), which means they can be used to produce

statistics about participants in these two programs. However, analyses of the collected data have identified numerous problems. For instance, Huynh, Rupp, and Sears (2002) analyzed data from the 1993 and 1996 SIPP panels that had been matched to SSA administrative records. Among other things, they found underreporting of participation in both programs (especially SSI), confusion between the two programs, and frequent discrepancies in monthly benefit amounts of \$100 or more.¹¹ Coder and Scoon-Rogers (1996) found that the 1990 CPS and SIPP survey estimates of Social Security benefit payments were both lower than National Income and Product Account (NIPA) estimates derived from administrative data, by 8 and 4 percent, respectively, due in part to the fact that these surveys do not cover some segments of the population living in group quarters (She and Stapleton 2009). Similarly, the survey estimates of aggregate SSI income, over all age groups, were 11 percent and 5 percent lower than the NIPA estimates. Several of the surveys, including the ACS, do not distinguish between Social Security disability and retirement benefits. This is primarily problematic for respondents between the age of 62 and the full retirement age (now 66), who can potentially receive either SSDI or early retirement benefits.

SSA conducts sporadic beneficiary surveys, driven by the need for specific information. Currently, Mathematica Policy Research, Inc. is completing SSA's National Beneficiary Survey (NBS) in support of the agency's effort to evaluate Ticket to Work and to obtain better information about the employment efforts of beneficiaries (Table 9.2, bottom panel). The NBS is cross-sectional, but matches to administrative data add longitudinal benefit information to the research file.¹² SSA's last major survey effort, started in 1982, sampled new disabled and aged Social Security beneficiaries (New Beneficiary Survey) and included a 10-year follow-up in 1991 (the New Beneficiary Follow-up).¹³

In summary, extensive information about working-age participants in SSA programs is available in published statistics, including state-level statistics, administrative records, major national surveys, and the agency's own recent survey, the NBS. These statistics and data do have significant limitations, however, which are described later in the chapter.

Center for Medicare and Medicaid Services

CMS is responsible for the Medicare and Medicaid programs. Medicare is a health insurance program for both those who are 65 or over, and those who are under 65 who have been entitled to SSDI benefits for at least 24 months, or who have end-stage renal disease.¹⁴ Like SSDI, Medicare is financed by a payroll tax.¹⁵ The Medicaid program is a federal-state, means-tested health insurance program that provides health coverage to low-income families with children, people with disabilities, and the elderly. Within federal guidelines, Medicaid eligibility and benefits vary substantially across states. A very large majority of SSI recipients are automatically eligible for Medicaid, but in some states the means test for Medicaid is more stringent than that for SSI. The Medicaid Buy-in (MBI) program, now available in most states, offers Medicaid coverage for workers with qualifying physical and mental conditions.¹⁶

In 2005, an estimated 11.0 million working-age people with disabilities were enrolled in Medicare or Medicaid, including a substantial number enrolled in both (Figure 9.1). The total enrollment in these two programs is equivalent to about 48 percent of the ACS estimate of the total number of people with disabilities in 2005. This number includes the vast majority of the 9.7 million participants in SSDI or SSI, but it also includes a substantial number in neither program—at least 1.3 million, based on the difference between the Medicare and/or Medicaid total and the SSDI and/or SSI total.

Some state-level Medicare statistics by entitlement status (disability or age) are available on the CMS Web site (Table 9.3, top panel), but there is no other state-level information on demographics. Given the federal-state status of Medicaid, many more state-level statistics are available for that program. A CMS chart book has some state-level information on Medicaid enrollment, including dual eligibility for Medicare and Medicaid (CMS 2007b). A second chart book presents 2002 state Medicaid statistics based on data that have been adjusted to address numerous cross-state comparability issues (Wenzlow et al. 2007).

CMS makes Medicare claims and enrollment data available to researchers and others through a system that allows for varying levels of security, administered by a contractor (Table 9.3, second panel).¹⁷ The

Table 9.3 Summary of Sources for Program Statistics and Data on Working-Age Disability Participants in CMS Programs

Published statistics	
Medicare	Summary of statistics available by state
Medicare Enrollment Reports	Number of enrollees by age and entitlement group. http://www.cms.hhs.gov/MedicareEnrpts/
National Health Expenditures Data	Enrolled health expenditures by service type. http://www.cms.hhs.gov/NationalHealthExpendData/05_NationalHealthAccountsStateHealthAccounts.asp
Medicare and Medicaid	
Medicare and Medicaid Statistical Supplement	Benefit payment information, enrollees by type of coverage, entitlement, payments, and service use. http://www.cms.hhs.gov/MedicareMedicaidStatSupp/
Administrative records data available to non-agency researchers	
Medicare	Access
Medicare Research Identifiable Files (RIF)	Available only to those who successfully obtain a Data Use Agreement (DUA) from CMS. Administered by the Research Data Assistance Center (ResDAC). http://www.resdac.umn.edu/Medicare/data_file_descriptions.asp
Medicare's eight Standard Analytic Files (for inpatient care, skilled nursing facility care, outpatient care, home health agency care, hospice care, carrier ^a care, and durable medical equipment); Medicare Provider and Analysis Review Files, which have more detailed information on inpatient hospital and skilled nursing facility stays; and several enrollment files, including the Denominator File, which contains substantial demographic and enrollment information on every individual enrolled in Medicare. Longitudinal records can be created.	

Medicare Limited Data Set (LDS) Version of the RIF without individual identifiers; cannot be used to construct longitudinal records.	Can be accessed under less stringent conditions than RIF. Public-use file also available. http://www.resdac.umn.edu/Medicare/data_file_descriptions.asp
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Medicaid

Medicaid Analytic eXtract (MAX) Information about Medicaid enrollment, demographics, hospital stays, outpatient visits, other provider visits, and prescription drugs. Longitudinal records can be constructed.	Only available to researchers who successfully apply to CMS for a DUA. Information can be found at http://www.cms.hhs.gov/MedicaidDataSourcesGenInfo/07_MAXGeneralInformation.asp
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Federal surveys that identify Medicare and Medicaid Enrollees in the household population

Current Population Survey (CPS)	1994–95 NHIS Disability Supplement (NHIS-D)
Health and Retirement Survey (HRS)	Survey of Income and Program Participation (SIPP)
National Health Interview Survey (NHIS)	National Beneficiary Survey (NBS)—SSDI and SSI recipients only

Annual CMS survey of Medicare beneficiaries

Medicare Current Beneficiary Survey (MCBS)	Ongoing beneficiary survey with a rolling panel design. Contains demographic, socioeconomic, health, and health care utilization information from respondents. Enrollment and expenditure data are added from Medicare administrative data. A public-use file is available to qualified researchers.
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NOTE: All URLs accessed September 15, 2007.

^aPhysician and other professional care provided in noninstitutional settings.

Medicare Research Identifiable Files (RIF) are available only to those who successfully obtain a Data Use Agreement (DUA) from CMS. The RIF files are especially important because they include information that allows researchers to build person-specific longitudinal records. The less restricted version of the Medicare data cannot be used in this fashion. CMS has developed a nationwide analytical Medicaid research file, called the Medicaid Analytical eXtract (MAX), which is discussed later in the “Data Initiatives” section.

Most major federal surveys include health insurance questions, and Medicare and Medicaid appear as separate categories in the response options (Table 9.3, third panel). The one major exception is the ACS, but a health insurance question was added to the ACS in 2008. This is an important addition because the ACS is the only major survey large enough to produce annual state-level statistics on working-age Medicare and Medicaid enrollees for all states. The quality of Medicare and Medicaid information in other surveys is limited by the fact that significant numbers of respondents fail to report coverage, or confuse Medicare and Medicaid.¹⁸

CMS sponsors a continuous, longitudinal survey of Medicare beneficiaries, the Medicare Current Beneficiary Survey (Table 9.3, fourth panel). The survey data are matched to Medicare claims and administrative data, and a public-use file is available to qualified researchers.¹⁹ The sample size is large enough to produce many national statistics for SSDI beneficiaries enrolled in Medicare, but it is not large enough to produce state-level statistics except for the largest states. CMS does not have a survey program for Medicaid enrollees. Many states conduct occasional surveys, but these are irregular and do not follow a common design.

In summary, extensive information about working-age participants in Medicare and Medicaid is available in published statistics (including some state-level statistics), administrative records, major national surveys, and the agency’s ongoing, longitudinal survey. The long history of CMS investments in survey data collection, systematic development of analytical files from administrative data, facilitating data access for non-agency researchers in a manner that protects privacy, and improvements in the quality and cross-state comparability of Medicaid data are especially noteworthy. Significant limitations with Medicare

and Medicaid statistics for the working-age population with disabilities remain, however, including some that are being addressed by initiatives described later in this chapter.

Rehabilitation Services Administration

The RSA is responsible for federal oversight of state VR agencies. State agencies are responsible for providing employment services to people with disabilities, and they are required to give priority to those with significant disabilities. RSA funds the state services under provisions of the Rehabilitation Act. SSA provides additional funding to pay for services provided to SSDI and SSI clients, provided those clients attain specified earnings levels over a sufficient period. States themselves provide additional funding in varying degrees.

RSA statistics on VR participants differ conceptually from those for the other programs discussed in this chapter, in part because most VR clients participate in the program for two years or less, whereas the typical participant in the other programs is on the rolls for many years. The annual RSA statistics are for “closures,” that is, the number of clients exiting the VR program during the year. In 2005, the number of closed VR cases (the standard measure of case activity, see Figure 9.1) was less than 3 per 100 working-age people with disabilities; the number who actually received services during the year was no doubt substantially larger, but data on that number are not routinely published. In 2002, VR expenditures accounted for just 1 percent of federal expenditures for working-age people with disabilities (Goodman and Stapleton 2007). The VR program is the largest federally supported program designed to help people with disabilities work and live independently.

RSA publishes substantial state-level closure statistics for VR clients based on data submitted by state agencies (Table 9.4, first panel). It also produces a public-use version of closure data submitted by the state agencies. These are known as RSA 911 data, and state agencies are required to submit it when a client’s case is closed (Table 9.4, second panel). These data include demographic, disability, and program participation information about each client at the time of application and closure; information about service eligibility and receipt; closure status; and employment at closure. These data do not include any information on employment and earnings after closure, however.

Table 9.4 Summary of Sources for Program Statistics and Data on State VR Agency Clients

Published statistics	
Summary of statistics available by state	
RSA Program Data and Statistics (2005)	Outcomes of cases at the state level, such as employment outcomes, hourly wage at closure, mean age, hours worked per week, services provided, and expenditure. http://www.ed.gov/rschstat/eval/rehab/statistics.html
RSA Management Information System (MIS)	The MIS system includes extensive state-level statistics on applications, eligibility determinations, employment, wages, and SSDI and SSI status, based on state reports. http://rsamis.ed.gov/info_for_new_users.cfm
Administrative records data available to non-agency researchers	
Access	
RSA 911 Data Records on the closed cases of state VR agency clients	RSA makes a public-use version of the data available to researchers. http://www.ed.gov/rschstat/eval/rehab/911-data.html
Federal surveys that identify Medicare and Medicaid enrollees in the household population	
1994–95 NHIS Disability Supplement (NHIS-D)	National Beneficiary Survey (NBS)—SSDI and SSI recipients only.
National survey of VR Clients	
Longitudinal Study of the Vocational Rehabilitation Services Program	Content: Characteristics, service receipt, and employment outcomes on VR participants over a three-year period. http://www.ilr.cornell.edu/edi/lsvrsp/application/index.cfm?cfid=24033099&cftoken=83765168

NOTE: All links accessed September 15, 2007.

Major federal surveys do not include information on receipt of VR services (Table 9.4, third panel). No doubt this reflects the formidable challenges of collecting data for the very small share of the household population that is receiving services at any given time. The one time Disability Supplement to the National Health Interview Survey (NHIS) did collect such information, but those data are now more than 10 years old. The NBS also includes extensive information about beneficiary receipt of many services and identifies those who have received services from a VR agency, but its services cannot be distinguished from those delivered by others.

RSA conducted a longitudinal study of state VR applicants, clients, and recent clients from 1995 through 2000 (Table 9.4, fourth panel). Additional data were extracted from state agency administrative files.²⁰ A new longitudinal survey of recent VR clients, the Post Vocational Rehabilitation Experiences Study, is in progress.

In summary, RSA makes available extensive statistics and data on participants in state VR programs, including many state-level statistics, based on administrative records. In contrast to those for other programs, VR statistics are based on program exits or closures, rather than current enrollment, reflecting the short-term nature of the program. VR participants and service use are not identified in major ongoing national surveys, but this deficiency has recently been substantially addressed through RSA's own longitudinal participant survey.

Department of Veterans Affairs

The DVA administers a number of programs for veterans. The Veterans' Compensation (VC) program pays income benefits to veterans with service-connected disabilities; the Veterans' Pension (VP) program pays income benefits to low-income veterans with nonservice disabilities; and Veterans' Health Care (VHC) provides health care benefits to all eligible veterans who enroll. VHC eligibility and copays depend on the veteran's priority group assignment. If funding is inadequate, those in the lowest priority groups are ineligible; VC participants are in the highest priority groups (1 to 3), and VP participants are in an intermediate group (5). Several smaller programs offer educational assistance, life insurance, loan guarantees, and vocational rehabilitation.²¹

In 2005, 1.6 million working-age veterans received VC payments (Figure 9.1), or about 65 percent of the estimated 2.7 million working-age veterans with disabilities in the household population (ACS; Appendix 9A). Far fewer working-age veterans received VP payments, only 138,000. We were not able to find a count of the number who received payments from both programs in 2005, nor could we find published statistics for the number of working-age VHC enrollees.

The Veterans Benefit Administration publishes a limited number of VC and VP participation and cost statistics every year (Table 9.5, top panel). More detailed participant characteristics are published at the national level only. County-level statistics are available online for the number of veterans and annual expenditures for each of the three programs (USDVA 2007). DVA does not have a systematic program for making its administrative records available to outside researchers, although DVA has provided restricted access to researchers on some occasions in the past.

All major federal surveys have veteran status questions, often including period of service, and statistics on veterans are often produced from these surveys. Most also include information on VC and VP receipt, although not all surveys distinguish between the two programs (Table 9.5, third panel). Analyses of the CPS and the SIPP for 1990 found that the survey-based estimates of the number of veterans receiving benefits from these two programs combined were 32 percent and 11 percent, respectively, below the number reported by DVA (Coder and Scoon-Rogers 1996). There also appears to be confusion among survey respondents between military retirement benefits and income from veterans' disability programs.

VHC is often included as a health insurance category, although sometimes as part of a larger one that includes TRICARE (formerly CHAMPUS), the health care system for dependents of military employees as well as for civilian employees and their dependents. The DVA conducted the last major survey of veterans in 2001 (Table 9.5, fourth panel).

In summary, published statistics based on DVA administrative data are very limited by comparison to those produced for the other programs we have considered in this chapter, and DVA does not systematically make these research files available to outside researchers. Receipt

Table 9.5 Summary of Sources for Program Statistics and Data on Veterans' Disability Programs

Published statistics	
	Summary of statistics available by state
Veterans' Compensation (VC)	Participation statistics for broad age groups as well as monthly expenditures.
Annual Benefits Report (2005)	http://www.vba.va.gov/reports/2005_abr.pdf
Veterans' Pensions (VP)	Participation statistics for broad age groups as well as monthly expenditures.
Annual Benefits Report (2005)	http://www.vba.va.gov/reports/2005_abr.pdf
Veterans' Health Care (VHC)	None.
Administrative records data available to non-agency researchers	
No formal program to provide researchers with access to administrative records on individual participants.	
Federal surveys that identify veterans and participants in DVA programs	
American Community Survey (ACS)—VC and VP, combined; not VHA	1994–95 NHIS Disability Supplement (NHIS-D)—VC and VP combined, VHA
Current Population Survey (CPS)—VC, VP, and VHA	Survey of Income and Program Participation (SIPP)—VC, VP, and VHA
Health and Retirement Survey (HRS)—VC and VP combined, VHA	National Beneficiary Survey (NBS)—VC and VP combined, VHA—SSDI and SSI recipients only
National Health Interview Survey (NHIS)—VC and VP combined, VHA	Medicare Current Beneficiary Survey (MCBS)—VC and VP combined, VHA—Medicare beneficiaries only
Annual CMS survey of Medicare beneficiaries	
National Survey of Veterans (NSV) 2001	Contains demographics, financial characteristics, military background, health, and benefit use. http://www1.va.gov/vetdata/page.cfm?pg=5

NOTE: All links accessed June 8, 2008.

of benefits in the major DVA programs is captured in several national surveys, however, and the DVA does periodically collect information about participants through its surveys of all veterans.

Other Programs

Several other government programs that provide benefits for working-age people with disabilities are not covered in the discussion above, primarily because of the lack of federal data on the participants with disabilities. The most notable of these is workers' compensation (WC), a system of programs that provide medical and cash benefits to covered workers for work-related injuries or illnesses. Benefits can be temporary or permanent, and cash payments can be partial or full, depending on the extent and permanence of the injury or illness. A vast majority of workers are covered under WC programs that are designed and administered by state boards. Program administrative and coverage provisions vary widely across states and state laws require employers to obtain insurance or demonstrate the financial ability to self-insure. Employers who are not self-insured pay experience-rated premiums. In addition, federal employees are covered under special federal programs administered by the Department of Labor (DOL), except for active duty military personnel, as the VC program is their WC program.

States and the WC industry collect limited data on coverage and claimants, but the federal government does not make an effort to collect and produce data that are comparable across states. The National Academy of Social Insurance compiles the limited data that are publicly available for all states and produces an annual report on WC,²² with support from SSA, CMS, DOL, and the WC insurance industry. The most recent National Academy of Social Insurance report (Sengupta, Reno, and Burton 2007) provides state statistics on covered workers and wages, and benefits paid per \$100 of covered wages by type of insurer (private, state, self-insured, or medical), type of benefit (medical or cash), per \$100 of covered wages.

The CPS, SIPP, and HRS include questions about WC benefit receipt (Table 9.1). Analyses of the CPS and the SIPP for 1990 found that estimates of total WC income based on each of these surveys were 11 percent lower than the total derived from administrative data (Coder

and Scoon-Rogers 1996).²³ The ACS has no WC information; hence, there is no reliable information on the characteristics of recipients at the state level other than the limited information from administrative records. The NHIS includes WC benefits among several items in an “other income” category and is included as a separate income item in the NBS.

Numerous other federal and federal-state programs provide services to working-age people with disabilities but serve broader populations. Also, they do not routinely identify this population group in their published state-level statistics. These include Temporary Assistance to Needy Families (TANF), food stamps and other Department of Agriculture programs, unemployment insurance, state workforce development programs under the purview of DOL, the state-administered Section 8 housing programs under the purview of the Department of Housing and Urban Development (HUD), and Department of Transportation programs that provide transportation support for people with disabilities. Five states have short-term disability programs, and many others provide temporary support under variously named general assistance programs. Surveys are the primary source of information on people with disabilities served by these programs, especially the SIPP (Table 9.1), but construction of state-level statistics on participation is problematic for those programs not explicitly included in the ACS, because of small sample sizes. Also, as with the disability income-support programs, income from unemployment insurance, family assistance, and public assistance are underreported in SIPP and the CPS (Coder and Scoon-Rogers 1996).

PROGRAM PARTICIPATION STATISTICS FOR STATES

In this section we present a few state-level statistics on program participation for working-age people with disabilities in 2005. The statistics on participants are all publicly available from agency sources. Our innovation is to compare the number of participants in each state program to an estimate of the size of the state’s household population of people with disabilities.

Ideally, we would like to know what percentage of those individuals meeting a program's eligibility criteria in each state are actually in the program (i.e., the state's "participation rate"). Survey-based estimates of such rates are often produced for nondisability programs (e.g., TANF and food stamps), made possible by the fact that surveys collect family demographic and financial information that can be used to approximate eligibility criteria. Participation rates are not available for disability programs, however, because surveys do not collect the detailed medical information needed along with financial information to determine eligibility for disability programs. The difficulties of collecting such information became all too apparent in the 1990s, when SSA's effort to collect such data encountered technical obstacles and escalating costs that eventually led to the termination of the project.²⁴

It is possible, however, to produce state statistics on the number of participants relative to the estimated size of the working-age household population with any self-reported disability, hereafter, "participation ratios." The number in the denominator is an estimate of the size of a broader population than those eligible to participate, namely those who would self-report disability based on the ACS questions. The population estimates are from the 2005 ACS (see Weathers 2009). It seems reasonable to assume that variation in participation ratios reflects variation not only in unobserved participation rates but also in the ratio of persons eligible for the program relative to the number of persons with any disability. Although variation in estimated participation ratios across states is almost certainly higher than variation in actual participation rates, it also seems likely that variation in participation rates accounts for a substantial share of variation in the estimated ratios.

The ratios presented below are for SSDI, SSI, Medicare, Medicaid, and state VR services. We also discuss, but do not present state statistics for, VC and VP. These statistics are all derived from data available in administrative and survey sources described in the previous section.²⁵ The ratios are subject to several limitations, in addition to the fact that the denominator includes many people with disabilities who are not eligible for the program. First, the denominator is a survey-based estimate, which is therefore subject to sampling error. Second, some participants might not be represented in the denominator, either because survey respondents who are participants failed to report their disability

or because they do not reside in the household population, and therefore are outside the 2005 ACS sampling frame (She and Stapleton 2009). Third, each statistic is constructed with data from two or more sources, and the sources are usually not fully consistent with respect to the reference date, state (the state recorded in an administrative record might not match actual state of residence), age group categories, or possibly other factors, as detailed in the footnotes to Appendix 9A.

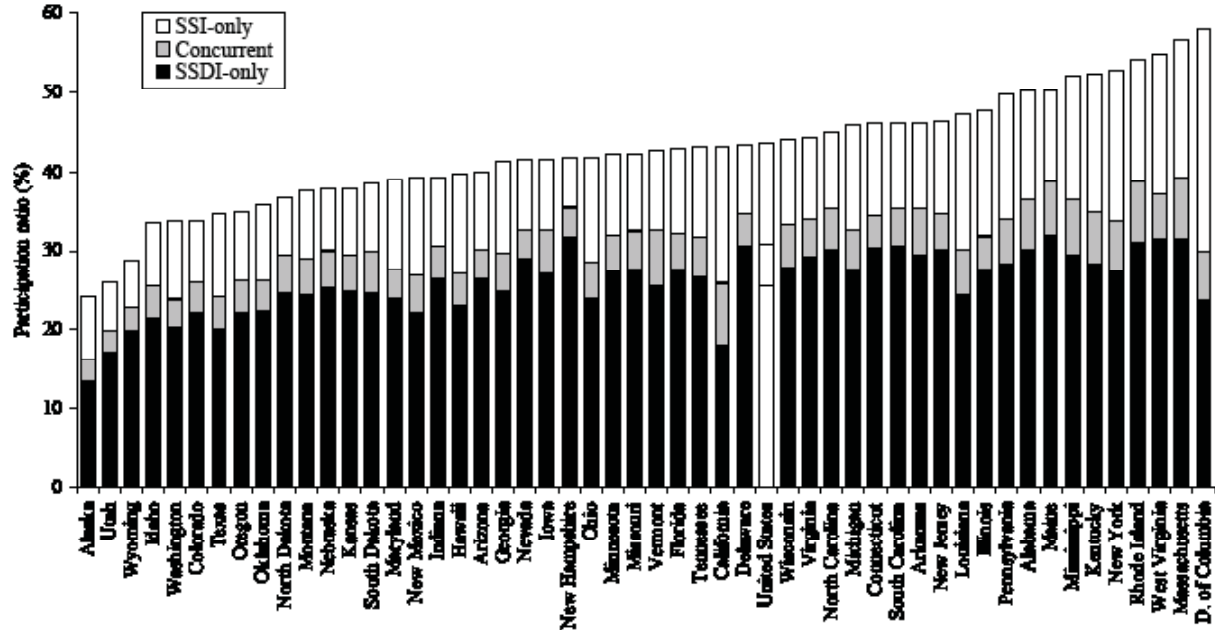
Estimated participation ratios for SSDI and SSI are displayed in Figure 9.2. The ratios are expressed as the number of participants per 100 persons in the household population with self-reported disabilities. The height of each bar is the combined participation ratio for the two programs, the bottom section of the bar (black) is the SSDI-only participation ratio, the middle section (gray) is the concurrent participation ratio, and the top section (white) is the SSI-only participation ratio. The states are ordered by the total participation ratio, and a clear bar for the United States as a whole appears near the middle.

The range of the total SSDI and SSI participation ratio is remarkably wide, from 28 percent or lower in Alaska, Utah, and Wyoming, to 55 percent or higher in West Virginia, Massachusetts, and the District of Columbia. Thus, the highest participation ratios are more than twice as large as the lowest. There is also considerable variation in the distribution of participants across the three program categories.

State-level participation ratios for Medicare and Medicaid are presented in Figure 9.3. The Medicaid figures are especially subject to error because the data are reported in a manner that makes separation of working-age adult enrollees with disabilities from child enrollees with disabilities problematic.²⁶ “Dual-eligible” participants are those enrolled in both programs. For ease of comparison to Figure 9.1, we have also plotted the SSDI/SSI participation ratio and ordered the states by that variable.

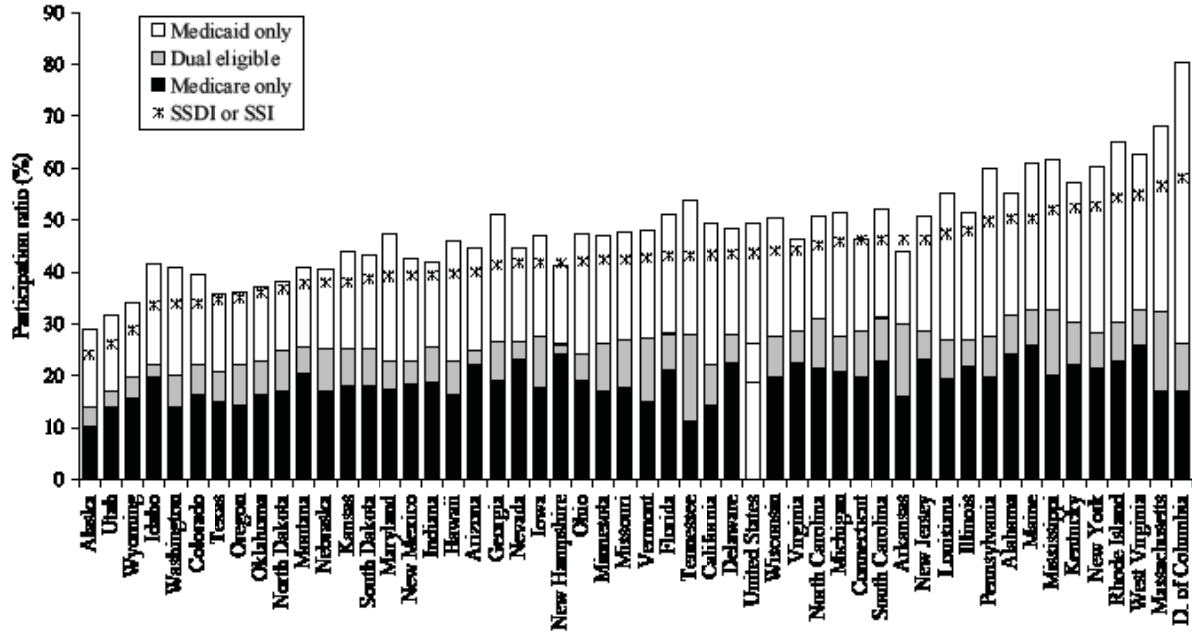
The pattern of Medicare and Medicaid enrollment across states is quite similar to that of SSDI and SSI participation, reflecting the links between these programs. There is, however, substantial variation across states that is not attributable to this variation, reflecting the extent to which Medicaid covers individuals with disabilities who are not SSI participants. In some states, participants in Medicare or Medicaid exceed participants in SSDI or SSI by a substantial margin, most likely

Figure 9.2 Ratio of SSDI and SSI Participants to the Working-Age Household Population (Aged 18–64) with Disabilities, by State, 2005



NOTE: The denominator of the participation ratios is the 2005 ACS estimate of the size of the working-age household population with disabilities, many of whom are not eligible for either SSDI or SSI.
 SOURCE: Authors' estimates based on the 2005 ACS and SSA published statistics for December 2005. See Appendix 9A for original data, assumptions, and sources.

Figure 9.3 Ratio of Medicare and Medicaid Enrollees to the Working-Age Household Population (Aged 18–64) with Disabilities, by State, 2005



NOTE: The denominator of these participation ratios is the ACS estimate of the size of the working-age household population with disabilities, many of whom are not eligible for either Medicare or Medicaid.

SOURCE: Authors' estimates. See Appendix 9A for original data, assumptions, and sources.

because of enrollment in optional Medicaid categories that vary across states, including medically needed programs, MBI, and programs for which the state agencies have obtained Medicaid waivers. Some states also offer coverage to people with disabilities through state-only Medicaid categories. Variation in participation ratios for these two programs across states is even greater than the variation in participation in SSDI or SSI; only 28.4 percent of Alaskans with disabilities are enrolled in one of these programs, compared to 68 percent in Massachusetts and 80 percent in the District of Columbia. As with the SSA programs, the highest participation ratios are more than twice as large as the lowest ratios.

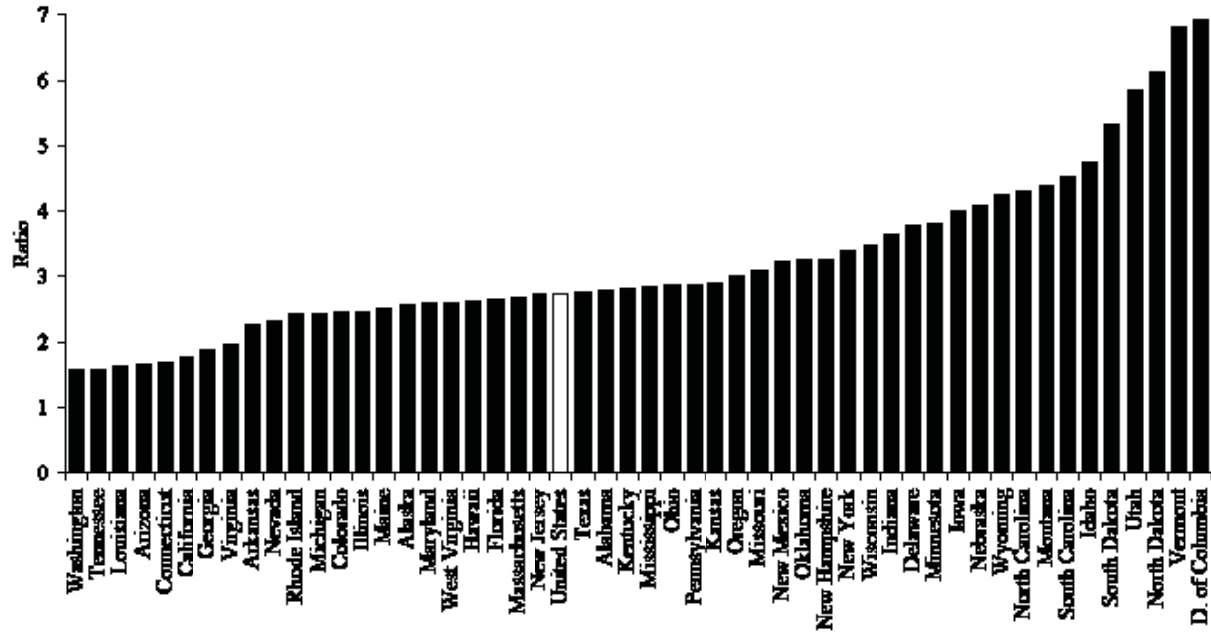
The numerator of the VR participation ratio is the number of cases closed in 2005 by the state VR agency (Figure 9.4). The VR participation ratio is conceptually different than those for the SSA and CMS programs. VR closures represent the flow of participants through relatively short-term VR programs, whereas participants in the SSA and CMS programs reflect the stocks of participants—that is, the number on the rolls at a point in time—in these agencies' long-term programs.

The VR participation ratio varies from 1.6 in Washington, Tennessee, and Louisiana to 6.8 in Vermont and 6.9 in the District of Columbia. Relative variation in VR participation ratios is even larger than relative variation in ratios for SSA and CMS programs; the largest VR ratios are more than three times as large as the smallest ones.

We attempted to develop state-level participation ratios for VC and VP based on DVA statistics and the ACS estimates of the number of working-age veterans with disabilities in each state (Appendix 9A). We found, however, that our methodology produces VC participation ratios well in excess of 100 percent in three states: Alaska, Hawaii, and Virginia. The apparent reason is that the state VC and VP statistics do not reflect migration of veterans from states where they first received benefits to their current state of residence.

In summary, state-level participation ratios for the major federal and federal-state programs are difficult to construct and have substantial limitations. The constructed statistics show that participation of people with disabilities in these programs varies widely across states, a fact that should be of considerable interest to people concerned about the distribution of resources for these programs and how public policy

Figure 9.4 Ratio of the Number of State VR Cases Closed to the Estimated Working-Age Household Population (Aged 18–64) with Disabilities, by State, Fiscal Year 2005



NOTE: The denominator of the VR participation ratio is the ACS estimate of the size of the working-age household population with disabilities. The numerator, VR closures, is the number of cases closed during the fiscal year, as reported to RSA by state VR agencies. The VR closure statistics used to construct these ratios include a small share of closures for clients who are outside the defined working-age range.

SOURCE: Authors' estimates. See Appendix 9A for original data, assumptions, and sources.

and program administration affect participation. At least some of this variation is likely caused by factors other than variation in underlying participation rates, including state demographic, geographic, and cultural factors. But the variation also raises a number of very interesting policy questions. Are substantial numbers of people in low participation ratio states not receiving benefits they are both medically and financially eligible for or is the participation ratio low because many of those who are medically eligible are not financially eligible?²⁷ If it is the latter, are those medically eligible but not participating financially ineligible because they work and their earnings are too high? Or have they not worked enough in the past to qualify for SSDI and they have income from other sources or assets that make them ineligible for SSI? Is there a very large pool of medically eligible nonparticipants who would likely become participants if their financial circumstances deteriorated? Answers to these and other questions about the causes of variation in participation ratios would likely have important policy implications.

DATA INITIATIVES

In this section we summarize several significant initiatives by federal agencies to make administrative data on program participants with disabilities more useful for research and other purposes. We first describe two recently developed longitudinal research files based on single-agency administrative data. These files are making it possible for researchers to better understand the dynamics of program participation and are supporting the evaluation of several important policy initiatives. We then summarize SSA, CMS, and RSA efforts to match data across agencies. These efforts are providing important opportunities to learn about participants in one program (e.g., VR clients) from the data of other programs (e.g., SSDI and SSI), and how innovations in one program (e.g., the MBI for workers with disabilities) affect the participants in other programs (e.g., SSDI beneficiaries). Finally, we discuss recent efforts to match survey data to administrative data. Such matches expand knowledge about program participants and also provide opportunities to study the dynamics of participation.

Program administrators encounter significant obstacles in the pursuit of efforts like those described here—the absolute need to protect the privacy of individual participants, the challenges of interagency cooperation, technical issues such as ensuring accurate matches, and tight research budgets.²⁸ The fact that substantial progress is being made on several fronts, despite these obstacles, attests to the value that the agency administrators place on enhancing data on disability program participants.

Research Files Derived from Administrative Data

SSA has supported the development of a longitudinal analytical data file containing an extensive record for each person who has been eligible, as an adult, to receive SSDI or SSI benefits in at least one month from 1996 forward. Each record contains the individual's benefit history from 1994 forward. SSA and Mathematica Policy Research, Inc. staff initially developed the Ticket Research File (TRF) to support the evaluation of the Ticket to Work (TTW) program. The TRF is by far the largest longitudinal file with detailed information about people with severe disabilities ever assembled. A very large share of all working-age people with significant disabilities is represented in the file, as is evident from the fact that the number of working-age SSDI or SSI beneficiaries in December 2005 was equal to 44 percent of the ACS-based estimate of the number of working-age people with disabilities in the household population (Figure 9.2).

The 2006 version of the TRF contains a record for every working-age adult who participated in SSDI or SSI for at least one month from January 1996 through December 2006—more than 19 million beneficiaries. The TRF data are extracted from numerous SSA administrative files. An important feature of the TRF is that data from SSI and SSDI sources are combined into a single TRF record for each beneficiary. The longitudinal variables include monthly benefit payments, program eligibility, use of program work incentives, Employment Network²⁹ service enrollment, state of residence, and disability diagnosis codes. Other variables include date of birth, sex, race/ethnicity, and mortality. Hildebrand et al. (2007) provide documentation for the most recent version of the TRF. Currently, the TRF can be used only by SSA staff and

authorized contractors. Staff can also match the TRF to IRS earnings data.

Many statistics generated from the TRF appear in the TTW evaluation reports (Thornton et al. 2004, 2006, 2007) and in several articles in the *Journal of Vocational Rehabilitation*.³⁰ In addition, SSA and its contractors are using the file to support other research efforts at SSA, including the Benefit Offset National Demonstration, Youth Transition Demonstrations, Accelerated Benefits Demonstration, and the State Partnership Initiative. The data have also been used to support a HUD assessment of the housing needs of people living with HIV/AIDS. Government Accountability Office (2007) analyzes outcomes for VR clients using TRF data matched to RSA 911 data, and CMS is using it for several projects under a matching agreement with SSA described later in this chapter.

Under a 2003 mandate from Congress, CMS has expanded its effort to make Medicare data available to researchers studying chronic conditions, through the establishment of the Chronic Condition Warehouse.³¹ These are longitudinal records for samples of beneficiaries having one of 21 specified conditions. They are based on data extracted from the claim records for a random 5 percent of the beneficiaries from 1999 to 2004, expanded to 100 percent of beneficiaries from 2005 forward. These are research identifiable files; like the Medicare RIF data described earlier, they can only be accessed with permission and in a secure setting.

As mentioned previously, CMS has developed an analytical Medicaid file, called MAX, and made it available to researchers in a controlled manner. MAX data are currently available for all states from 1999 through 2002. Similar State Medicaid Research Files are available for 30 states from 1992 to 1998. As with the Medicare RIF data, the MAX data include information researchers need to construct longitudinal records. The primary source file for MAX is the Medicaid Statistical Information System; MAX incorporates a number of refinements to that data, which improves its utility for researchers and analysts.³²

Cross-Agency Matches of Administrative Data

One way to address the paucity of data on program interactions is to match administrative data from multiple programs. Many states have been engaged in matching activities for years, but their efforts have largely focused on data for low-income parents and children. The Substance Abuse and Mental Health Treatment Administration, for example, has supported state efforts to match Medicaid data with state mental health agency data.

Three federal agencies, SSA, CMS, and RSA, have recently established two-way agreements for matching data on participants in their respective programs. These efforts are already bearing significant fruit for the disability research of the agencies involved.

SSA and CMS have an interagency agreement to support projects that require matched SSA and CMS administrative data. IRS earnings data held by SSA can be used under this agreement provided that the work is conducted by a qualified SSA employee. The two agencies and their contractors are conducting several disability studies under these agreements. The CMS-funded study of the MBI program is using data from the TRF that is linked to Medicaid and Medicare eligibility and claims data (Liu, Ireys, and Thornton 2008). This study will also link CMS data with SSA's earnings records to study the employment profiles of MBI participants before and after entering this program. Another CMS-funded project has merged extracts from the TRF with Medicare and Medicaid data to study Medicare beneficiaries with behavioral health problems. A third CMS-funded study is analyzing enrollment dynamics in the Medicaid, SSI, and SSDI programs, with special attention to participation patterns of beneficiaries in states where Medicaid enrollment is not automatic for SSI recipients.

These studies are just the tip of the iceberg of research that will take advantage of 1) the existence of well-developed longitudinal analytic extracts for SSA programs (TRF) and CMS programs (Medicare RIF and MAX) and 2) the interagency-sharing agreement. The infrastructure that these two agencies have developed makes it feasible for them to support longitudinal research involving participants in SSDI, SSI, Medicare, and Medicaid.

SSA and RSA have a similar interagency agreement to support projects that require matched SSA and RSA administrative data. SSA's TTW evaluation has used RSA 911 data matched to the TRF to study the extent to which VR agencies are obtaining ticket assignments from their SSDI and SSI clients and to study the impact of TTW on service enrollment.

The GAO used SSA TRF records matched to Social Security earnings records and RSA 911 records to examine the earnings of SSDI and SSI clients of state VR agencies in the year after VR closure (GAO 2007). This appears to be the first published analysis of post-closure VR client earnings based on administrative records. Among other things, the GAO used the data to produce state-level earnings statistics, examine the sensitivity of earnings outcomes to the state's economic environment, and identify VR practices that appear to increase client earnings. The Office of Special Education and Rehabilitative Services in the Department of Education is currently using the data to examine long-term employment and benefit outcomes of transition-age youth receiving VR services. Westat, Inc. is matching these data to survey data from the RSA-sponsored Post Vocational Rehabilitation Experiences Study for data validation purposes.

Matches between Survey and Administrative Data

One important way to address limitations on program participation data in surveys is to match survey data records to administrative records. Such matches can also add important longitudinal information to a cross-sectional survey, potentially including the entire history of participation in a program and, in some cases, earnings. The matched data can also be used to study the reliability of the survey data. Survey-administrative data matches also make it possible to learn much more about the characteristics and activities of program participants that cannot be learned from administrative data alone—because information in the administrative data is essentially limited to that which has an administrative purpose.

Survey-administrative data matches require the consent of the survey respondents as well as common identifiers in the files to be matched. Confidentiality rules also limit researcher access to matched data.

SSA and the Census Bureau have matched numerous years of data from both the CPS and the SIPP to SSA administrative records (including IRS earnings records) and, in some years, to CMS Medicare records.³³ These data have been used extensively to study the characteristics and behavior of people with disabilities, as well as other populations.

A few examples from the substantial disability literature illustrate the value of the matched SIPP and CPS data to disability research. Lahiri et al. (1995) used the matched SIPP data to study how characteristics of program applicants affect outcomes at each stage of SSA's disability determination process. Stapleton et al. (2001–2002) used the matched SIPP data to study the transition of participants in the Aid to Families with Dependent Children program onto SSI in the early 1990s, just prior to welfare reform. Davies et al. (2001–2002) developed a model of financial eligibility for SSI that SSA uses to simulate how changes to the SSI means test would affect program participation and expenditure. Bound, Burkhauser, and Nichols (2003) used the data to track the incomes of working-age SSI and SSDI applicants. Honeycutt (2004) used both the matched SIPP data and the matched CPS data to study the participation of SSDI awardees in other public and private support programs prior to the SSDI award.

Researchers must obtain Census Special Sworn Status to use the matched SIPP and SSA data, have their specific project approved by the Census Bureau and the relevant agencies, and access the data through the restricted-access data facilities operated by the Census Bureau. These requirements substantially limit the use of the matched data. To address this limitation, yet continue to meet confidentiality requirements, the Census Bureau has recently developed a "synthetic" SIPP file, which is available to researchers without substantial restriction.³⁴ The individual records in this file do not correspond to real people. Instead, they were generated in a fashion that makes statistics produced from the file match the statistics that would be produced from the original data. The current file is based on the SIPP panels from 1990 through 1996 and the matched SSA and IRS data.

The SIPP data should continue to be an important source of information on disability in future years, and the Census Bureau is trying to improve their data collection efforts to address concerns regarding

attrition, program accuracy, and timeliness. The Census is currently in the field with the 2004 SIPP, which is scheduled to continue through the first quarter of 2008, and is funded to conduct a 2008 SIPP panel, which will extend from February 2008 through January 2012. The data collection methods and content will generally be similar to earlier SIPP panels. The one notable exception, described in more detail below, is that the 2008 SIPP panel will use a different methodology for collecting personal information, which should increase the match rate between the SIPP and SSA administrative records. The Census Bureau is planning to reengineer the SIPP to be a more efficient and cost-effective data collection effort by 2011.³⁵ The reengineering process should result in better and more timely disability data. The Census Bureau plans to continue to collect the same set of detailed functional limitation information as in earlier panels, and the use of administrative data should enhance its ability to collect more accurate information on disability program outcomes.

The National Center for Health Statistics has an extensive program to match SSA, Medicare, and National Death Index administrative data to the surveys for which it is responsible, including the NHIS, the National Health and Examination Study, the Longitudinal Study on Aging, and the National Nursing Home Survey.³⁶ This is a relatively new effort, and disability research using these data is just starting to emerge. One example is Riley's (2006) use of the matched NHIS, SSA, and Medicare data to analyze the health insurance and access to care of SSDI beneficiaries during their 24-month waiting period from SSDI entitlement to Medicare entitlement.

HRS data have also been matched to SSA and Medicare administrative data,³⁷ and they can be used to study working-age people with disabilities over the age of 50, as well as Social Security retirees (Mitchell, Olson, and Steinmeier 2000). SSA has been collaborating with the Census to match SSA records with the ACS data (Obenski and Prevost 2004; Haines and Greenberg 2005). If successful, the match could support the production of a wide array of descriptive statistics on SSDI and SSI beneficiaries for states and metropolitan areas.

Matched survey and administrative data are limited by the accuracy and completeness of the matches. The match rate for the SIPP declined substantially after 1996, primarily because it required respondents to

report their SSNs, and a larger and larger share of respondents refused. In 2004, 35 percent of the SIPP respondents refused to cooperate. Similarly, 38 percent of NHIS respondents in 1998 and 23 percent of CPS respondents in 2003 refused to cooperate.³⁸ Starting in 2006, the Census adopted a methodology that substantially increases the match rate. The interviewer no longer asks for permission to use the respondent's SSN and instead offers the respondent an opt-out postcard that can be mailed in to prevent the match. The match is now made on the basis of name, sex, birth date, and address information. Algorithms are used to identify highly probable matches, and much higher match rates are being achieved. Informed consent requirements prevent the Census Bureau from applying the same methods to the earlier surveys.

CONCLUSION

There is an abundance of administrative and survey data available about working-age people with disabilities who participate in the federal and federal-state programs servicing this population. Despite some significant limitations, these data provide important information about participants in these programs, even at the state level, and have proved to be a rich source for research on the dynamics of disability and program participation. Furthermore, current efforts to improve the quality of these data, primarily through matches between survey and administrative data and between administrative data from different agencies, are already yielding significant dividends. It is very important to maintain the momentum of these efforts.

We are especially encouraged by recent efforts to match administrative data to survey data. It is apparent from historical experience that such matches are the only cost-effective way to obtain high quality participation and benefit information in survey data, as well as extensive socioeconomic information about program participants. The effort to match survey and administrative data has been expanded considerably in recent years, and it is greatly improving the availability of data and statistics on disability program participants. The decline in the match rate after the early 1990s threatened the value of the match effort, but

recent efforts by the Census appear to have addressed that threat. We are encouraged by the early Census-SSA effort to match ACS data with SSA records. Among other things, that match would make it possible to generate extensive, reliable information about the characteristics of program participants at the state level.

As discussed in this chapter, state-level program statistics are extremely important for tracking the status of people with disabilities and understanding the consequences of changes in state policy and economic environments. The agencies produce substantial state-level statistics, but we recommend that the agencies consider routine publication of more such statistics, individually or, better, collaboratively—taking advantage of their matched data files. Statistics broken down by characteristics such as age, sex, and impairment would be helpful because the effects of various aspects of the state environment might be quite different for various beneficiary groups. To some extent, program statistics for such subgroups can be matched to subgroup population estimates from the ACS. Thus, for instance, it would be possible to produce state-level participation ratios, like those presented in this chapter, by age and sex. It would be interesting to know the extent to which the reported cross-state variation in participation ratios can be explained by variation in the demographic composition of those who self-report disabilities in the ACS and how much cross-state variation remains within the demographic groups.

Age-specific estimates would be particularly helpful for working-age Medicaid enrollees with disabilities because current statistics include some children. More extensive state-level statistics on employment, earnings, and use of SSA work incentive programs would also be of considerable value, especially for SSDI beneficiaries, because such statistics are already produced for SSI recipients. Statistics on participation in multiple programs could potentially be generated from data that have been matched across agencies.

Existing administrative data would have much greater value for the production of information on people with disabilities if they were more accessible to those who have the resources and capabilities to produce such information outside the agencies. As we have discussed, however, providing access to researchers in a manner that protects individual pri-

vacy is a very challenging and costly task, so it should be no surprise that access is more limited than many outside the agencies would like.

The long-term CMS effort to make Medicare data available to researchers is a model that other agencies might do well to follow. The value of the health research that has been conducted with these data is enormous, and the fact that CMS has sustained the program over many years has made it a resource that health researchers have come to rely on. The CMS investment places a considerable direct burden on the agency's budget, but its value to the programs and the people they serve is undoubtedly much greater. Researchers and analysts outside the agency use the data extensively to produce information that helps guide both public health policy and the administration of Medicare, Medicaid, and other programs.

Other agencies would also do well to examine the model that the CMS Medicare Current Beneficiary Survey provides for the collection of data on program participants. The SSA, DVA, and RSA have all invested heavily in special purpose research, but they do not have continuous efforts to survey their programs' participants. A continuous effort would help the agencies and others monitor the well-being of program participants and provide data that can support the design and evaluation of programmatic changes, and it would reduce the need for special-purpose surveys.

Program participation information is critical for monitoring the status of people with disabilities and for supporting the development of better programs and policies. The considerable value of the currently available program participation data and statistics is being significantly increased by current data improvement efforts. Although cost will always be a limiting factor, the value of these data improvement efforts is extremely high, and we would encourage their continuation and expansion.

Appendix 9A

Table 9A.1 Population and Program Data for the Working-Age Population (Aged 18–64) with Disabilities in 2005, by State

State	Working-age population ^b	People with disabilities ^c	SSDI ^d	SSI ^e	SSDI or SSI ^f	Medicare ^g	Medicaid ^h	Medicare or Medicaid ⁱ	Veterans with disabilities ^j	Veterans' Comp. beneficiaries ^k	Veterans' Pension beneficiaries ^k	VR closures ^l
Total ^a	180,308,000	22,229,000	6,838,148	4,016,727	9,688,845	5,809,035	6,821,880	10,973,000	2,652,413	1,611,699	138,382	609,502
Alabama	2,784,000	490,000	179,203	98,836	245,804	155,136	151,341	270,000	61,403	37,751	2,871	13,628
Alaska	428,000	62,000	10,006	6,683	14,967	8,667	11,738	18,000	8,146	9,568	237	1,592
Arizona	3,508,000	414,000	124,731	55,295	165,051	102,199	93,718	185,000	58,485	36,809	2,435	6,921
Arkansas	1,665,000	308,000	108,717	51,675	142,324	92,293	85,351	135,000	45,266	20,559	2,352	6,946
California	21,876,000	2,297,000	594,961	578,944	993,472	510,432	803,317	1,132,000	220,986	135,053	11,580	40,591
Colorado	2,929,000	290,000	75,221	33,981	98,185	64,393	68,138	115,000	44,919	35,414	1,742	7,117
Connecticut	2,122,000	208,000	71,701	32,748	95,729	59,725	54,912	96,000	20,586	10,135	676	3,496
Delaware	521,000	62,000	21,505	7,947	26,899	17,275	16,116	30,000	7,200	5,048	253	2,341
District of Columbia	327,000	36,000	10,780	12,304	20,880	9,382	22,912	29,000	3,378	2,467	394	2,493
Florida	10,419,000	1,292,000	415,927	197,811	555,720	362,727	387,504	659,000	174,621	121,744	9,301	34,099
Georgia	5,656,000	707,000	210,245	116,203	292,053	187,038	225,074	360,000	89,396	67,011	4,879	13,375
Hawaii	779,000	74,000	20,032	12,293	29,314	16,913	22,040	34,000	7,926	8,884	432	1,949
Idaho	874,000	118,000	30,096	14,191	39,513	25,907	25,718	49,000	18,795	10,326	567	5,607
Illinois	7,730,000	773,000	246,120	155,020	368,999	208,717	229,506	397,000	79,538	36,564	4,674	19,054
Indiana	3,746,000	502,000	153,188	63,861	197,120	127,811	116,936	211,000	69,349	28,904	2,203	18,369
Iowa	1,786,000	200,000	65,071	28,977	83,291	55,111	58,941	94,000	27,585	11,841	1,349	8,009
Kansas	1,658,000	194,000	57,108	25,130	73,528	48,575	49,954	85,000	24,019	15,222	1,390	5,619
Kentucky	2,597,000	496,000	173,362	118,946	259,745	149,750	174,214	283,000	55,993	26,059	2,820	13,973
Louisiana	2,748,000	437,000	131,908	100,522	206,831	117,490	156,994	241,000	45,522	24,054	3,685	7,098
Maine	834,000	126,000	48,817	22,885	63,243	41,118	44,399	77,000	20,303	12,275	1,195	3,182
Maryland	3,451,000	352,000	97,238	53,781	137,802	80,180	106,129	167,000	38,518	32,594	1,727	9,169

Massachusetts	3,952,000	415,000	163,210	104,301	234,641	133,968	213,190	283,000	39,694	25,440	1,790	11,106
Michigan	6,192,000	805,000	263,081	146,604	368,601	221,416	247,762	415,000	100,153	37,828	4,811	19,655
Minnesota	3,179,000	302,000	96,494	44,793	127,624	79,181	90,466	142,000	38,043	25,376	1,623	11,483
Mississippi	1,747,000	318,000	116,304	71,253	165,166	104,190	132,145	196,000	33,194	16,646	1,874	9,042
Missouri	3,530,000	526,000	171,034	76,973	222,604	141,971	156,274	250,000	68,251	31,285	3,431	16,253
Montana	580,000	76,000	21,959	10,224	28,711	19,343	15,570	31,000	12,483	8,513	779	3,344
Nebraska	1,054,000	118,000	35,408	14,864	44,618	29,678	28,032	48,000	14,336	10,301	884	4,811
Nevada	1,490,000	143,000	46,655	17,909	59,494	37,761	30,821	64,000	23,177	16,786	1,548	3,339
New Hampshire	826,000	95,000	33,713	9,502	39,662	24,720	16,139	39,000	12,760	9,002	354	3,095
New Jersey	5,261,000	484,000	167,528	78,665	224,064	138,993	133,589	246,000	41,207	23,555	1,238	13,194
New Mexico	1,170,000	172,000	46,438	29,461	67,367	39,138	41,464	73,000	27,350	16,606	1,360	5,578
New York	11,741,000	1,315,000	444,862	334,873	693,966	369,614	512,907	794,000	112,574	54,019	6,487	44,609
North Carolina	5,268,000	748,000	264,082	110,939	336,720	230,624	220,475	380,000	88,191	67,949	3,738	32,319
North Dakota	393,000	42,000	12,365	5,135	15,437	10,374	8,925	16,000	5,650	4,652	354	2,571
Ohio	6,970,000	941,000	268,629	167,931	394,134	226,908	267,876	447,000	114,099	50,846	8,087	26,947
Oklahoma	2,149,000	361,000	94,842	48,675	129,397	81,762	74,957	134,000	51,120	32,465	3,669	11,727
Oregon	2,271,000	302,000	79,133	38,446	105,422	67,076	65,680	109,000	48,905	24,519	2,919	9,112
Pennsylvania	7,413,000	934,000	317,000	199,599	464,476	256,267	374,221	559,000	121,565	48,031	5,895	26,800
Rhode Island	645,000	80,000	31,016	18,549	43,331	24,112	33,765	52,000	9,440	4,997	399	1,946
South Carolina	2,588,000	396,000	140,239	61,520	182,350	123,278	116,118	206,000	53,706	33,757	2,610	17,967
South Dakota	461,000	53,000	15,801	7,495	20,488	13,427	13,378	23,000	6,728	6,316	572	2,826
Tennessee	3,739,000	617,000	195,240	101,866	265,932	172,349	261,718	331,000	69,930	39,154	3,858	9,814
Texas	13,832,000	1,646,000	397,752	238,539	570,348	341,079	344,751	591,000	192,114	149,377	12,265	45,444
Utah	1,490,000	155,000	30,686	13,999	40,473	26,524	27,305	49,000	16,092	9,327	580	9,065

(continued)

Table 9A.1 (continued)

State	Working-age population ^b	People with disabilities ^c	SSDI ^d	SSI ^e	SSDI or SSI ^f	Medicare ^g	Medicaid ^h	Medicare or Medicaid ⁱ	Veterans with disabilities ^j	Veterans' Comp. beneficiaries ^k	Veterans' Pension beneficiaries ^k	VR closures ^l
Vermont	400,000	52,000	16,956	8,831	22,155	14,185	17,316	25,000	5,129	3,218	252	3,544
Virginia	4,667,000	518,000	175,800	77,710	229,048	147,725	122,048	239,000	66,865	71,325	2,638	10,239
Washington	3,978,000	537,000	127,988	72,661	181,501	107,990	143,532	219,000	79,722	57,704	2,850	8,444
West Virginia	1,129,000	236,000	87,721	55,304	129,408	77,240	86,804	148,000	31,899	13,538	2,093	6,151
Wisconsin	3,429,000	360,000	120,189	58,128	158,599	98,679	111,639	182,000	46,063	26,780	2,406	12,576
Wyoming	326,000	44,000	10,086	3,945	12,638	8,624	8,064	15,000	7,028	4,105	257	1,873

^a Total does not include U.S. territories.

^b Estimates for 2005 are based on the ACS. <http://www.disabilitystatistics.org> (accessed August 3, 2007).

^c Estimates for 2005 are based on the ACS, from <http://www.disabilitystatistics.org> (accessed August 3, 2007).

^d SSDI estimates for December 2004 from http://www.socialsecurity.gov/policy/docs/statcomps/di_asr/2004/sect01.html#table8 (accessed August 3, 2007).

^e SSI estimates for December 2004 from http://www.socialsecurity.gov/policy/docs/statcomps/ssi_asr/2004/sect02.html#table9 (accessed August 3, 2007).

^f Calculated by adding SSDI and SSI, then subtracting concurrent beneficiaries. Concurrent beneficiary data for December 2004 from http://www.socialsecurity.gov/policy/docs/statcomps/ssi_asr/2004/sect04.html#table18 (accessed August 3, 2007).

^g Medicare enrollees with disabilities (SSDI beneficiaries plus a relatively small number with end stage renal disease). July 2005 estimates from <http://www.cms.hhs.gov/MedicareEnRpts/Downloads/05Disabled.pdf> (accessed August 8, 2007).

^h Medicaid enrollees with disabilities, FY 2004. Original source: the State Health Facts Web site. Medicaid Enrollment from <http://www.statehealthfacts.org/comparetable.jsp?ind=198&cat=4&yr=27&typ=1&sort=a&o=a>. Medicaid Distribution by Enrollment Category from <http://www.statehealthfacts.org/comparetable.jsp?ind=200&cat=4&yr=27&typ=2>. Medicaid enrollment was multiplied by the percent in the disability category to obtain the numbers reported. Some states appear to include some Medicaid enrollees under the age of 18 in this category, but the number of such enrollees is not reported. Both accessed August 8, 2007.

ⁱ Calculated as the number enrolled in Medicare plus the number enrolled in Medicaid minus the estimated number of Medicaid beneficiaries with dual entitlement to Medicaid. The latter was estimated as the number of working-age people on Medicaid (previous column) times

the percentage of dual eligible beneficiaries in the Medicaid disability category from State Health Facts (see footnote h).

^j Veterans with disabilities living in the household population in 2005, estimated from the 2005 ACS.

^k Veterans' Compensation data were only available for veterans under age 75, and pension data were only available for those under age 70. For each, we estimated the number under age 65 by multiplying the value reported by the ratio of veterans under age 65 to veterans in the age range for the reported statistic. Veterans' Compensation and Pension data for FY 2005 from http://www.vba.va.gov/bln/dmo/reports/fy2005/2005_abr.pdf (accessed August 3, 2007). Veterans as of September 30, 2005 are from <http://www1.va.gov/vetdata/docs/11.xls> (accessed August 3, 2007).

^l VR closures for FY 2005 from Monitoring Tables—113 and 2—2005, available at <http://rsamis.ed.gov/choose.cfm?menu=spreadsheets> (accessed January 15, 2008). Closures for the approximately 3 percent of clients under age 18 or over age 64 are included because we have not found published state statistics by age.

Notes

1. In this chapter we define the working-age population as persons aged 18–64. We use a broader age range than in the other chapters because most published administrative statistics for program participants use this range.
2. Goodman and Stapleton (2007) found that federal expenditures to support working-age people with disabilities totaled \$226 billion in 2002, or 11.3 percent of all federal outlays, up from 6.1 percent in 1984.
3. SSI also provides income support to children with disabilities and to people age 65 or older in low-income households. See SSA's Annual Statistical Supplement to the Social Security Bulletin for details (SSA 2007a).
4. The SSI employment and earnings statistics appear in the annual report SSI Disabled Recipients Who Work. http://www.ssa.gov/policy/docs/statcomps/ssi_workers/2004/index.html#toc (accessed October 4, 2007). The most recent data are for 2004.
5. Whereas contractors for SSA with appropriate security clearances can access SSA programmatic data, only SSA employees with appropriate clearances can access the IRS earnings data.
6. See SSA's Performance and Accountability Report for FY2006 (SSA 2007b).
7. The statistic for SSI includes both children and working-age adults with disabilities, which are not reported separately; it does not include aged claimants (SSA 2007a).
8. See, for example, Burkhauser, Butler, and Weathers (2002) and Burkhauser, Butler, and Gumus (2004).
9. See Parsons (1991) and Stapleton et al. (1998).
10. See Table 4.B10 in the 2006 Supplement (SSA 2007a).
11. Some benefit discrepancies are caused by benefit adjustments, but most are due to respondent reporting error (Sears and Rupp 2003).
12. A related survey, the Ticket Participant Survey, collects data on participants in Ticket to Work, and subsamples of participant respondents are being followed for two or three years. SSA plans to release public-use files from the NBS in the near future. Statistics from the survey appear in Thornton et al. (2006, 2007) and in several articles in a special issue of the *Journal of Vocational Rehabilitation* 27(2), 2007.
13. The data contain extensive information on demographics, employment, health, income, medical expenditures, and functional capacity. Administrative data have been added to the survey data. SSA makes the data available to researchers through a set of public-use files, the New Beneficiary Data System, available at <http://www.socialsecurity.gov/policy/docs/microdata/nbds/index.html> (accessed August 1, 2007).
14. The 24-month Medicare waiting period is waived for beneficiaries with amyotrophic lateral sclerosis ("Lou Gehrig's disease").
15. See Centers for Medicare and Medicaid Services (n.d.a)

16. See Centers for Medicare and Medicaid Services (n.d.b). See Gimm et al. (2008) for information on the Medicaid Buy-in program.
17. See Research Data Assistance Center (n.d.c).
18. An informative discussion of the history of survey measurement of health insurance appears in Nelson and Mills (2001).
19. The data are provided by the CMS-funded Research Data Assistance Center. See Research Data Assistance Center (n.d.b).
20. The public-use files are available from Employment and Disabilities Institute (n.d.).
21. The Veterans Benefits Administration is responsible for the administration of all the benefit programs other than health. Descriptions of their programs can be found in Veterans Benefits Administration (2006). The Veterans' Health Administration administers VHC. See Veterans Health Administration (n.d.).
22. See Sengupta, Reno, and Burton (2007) and Sengupta and Reno (2007).
23. These statistics were designed to omit lump-sum payments, although some survey respondents might have misreported them during the survey year as annual income.
24. This project was initially called the Disability Examination Study and then renamed the National Study of Health and Activities. See Wunderlich, Rice, and Amado (2002) for discussion of the plans for this survey.
25. The population and participation counts underlying these statistics are provided in Appendix 9A.
26. The original state enrollment tabulations have four mutually exclusive categories: "children" (under age 19), "adults" (aged 19–64), "elderly" (age 65+), and "disabled" (under age 65). Unfortunately, the "disabled" category includes some children as well as adults. We subtracted the number of SSI children in the state to obtain an estimate for adults only. Also, the "adult" age range in the administrative statistics (aged 19–64) does not exactly coincide with the more conventional age range we have adopted for the "working-age" population (aged 18–64).
27. The medical eligibility criteria for SSDI and SSI are the same among states; the financial criteria differ.
28. These challenges were heightened after the theft of data on more than 25 million veterans from a government analyst's home in 2006. See the testimony of then-Secretary of Veterans Affairs R. James Nicholson before the House Veterans' Affairs Committee, June 29, 2006 (Nicholson 2006).
29. Employment Networks are the provider entities servicing beneficiaries under Ticket to Work; they include state VR agencies as well as many private providers.
30. Vol. 27, No. 2, 2007.
31. See Research Data Assistance Center (n.d.a).
32. Claims and enrollment data in the MAX files reflect final adjustments; claim dates in MAX reflect date of service, rather than date of filing or payment; and Medicare enrollment information for dual eligible beneficiaries has been added from the CMS Medicare enrollment data. See Wenzlow et al. (2007).

33. A history of this effort appears in Haines and Greenberg (2005). SSA data have been matched to March CPS data for 1991, 1994, and 1996 through 2006.
34. See U.S. Census Bureau (n.d.).
35. The four goals of the reengineering effort include 1) a reduction in data collection costs, 2) improved accuracy in collection of data elements, 3) timeliness in file production, and 4) relevance to policy research. To achieve these goals, the Census plans to use an annual data collection to reduce the number of interviews (currently being conducted quarterly), increase its efforts to reduce attrition rates and use administrative data to verify program data elements, improve their internal processing of data collection, and draw samples from the ACS.
36. Details can be found from National Center for Health Statistics (n.d.a).
37. Details can be found at <http://hrsonline.isr.umich.edu/rda/> (accessed August 23, 2007).
38. Bates (2005) reported that the refusal rate for the SIPP increased from 12 percent in 1996 to 35 percent in 2004 and that the refusal rate for the CPS increased from 10 percent in 1994 to 23 percent in 2003. The NHIS refusal rate increased from 19 percent in 1994 to 38 percent in 1998. See National Center for Health Statistics (n.d.b).

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