



Disability Policy Research Brief

Center for
Studying
DISABILITY POLICY



Number 09-03 • May 2009

Is It Time to Establish a National Disability Data System?¹

David Stapleton and Craig Thornton

There is a growing divergence in the United States between the demands placed on our system for assisting people with disabilities and the data required to manage and refine that system. Currently, the federal government spends more than \$226 billion a year on some 200 programs that provide income, health insurance, housing, and a wide array of services to millions of working-age people with disabilities (Goodman and Stapleton 2007; Government Accountability Office 2005). Managing these programs has become increasingly difficult as more people seek benefits, the programs face greater budget pressures, and there are increasing efforts to integrate services across programs. Yet the data that could help administrators and policymakers address these issues, particularly regarding service coordination, remain in a morass of program-specific data sets and largely uncoordinated surveys. In fact, it is not even possible to obtain accurate counts of the aggregate number of people being served or the extent to which people draw on multiple programs. While substantial progress is being made to improve the database for program monitoring and development, these efforts could be enhanced considerably with the creation of a National Disability Data System (NDDS).

Existing programs provide invaluable services to people with disabilities, and in many ways they work well. Yet there is dissatisfaction with many elements of these programs, particularly with program fragmentation. Policymakers trying to address these concerns are faced with a host of questions: how will new rules in one program affect use and expenditures of other programs? Do the number and characteristics of people being served vary substantially across states and over time? Are eligible people making effective use of all the programs that might help them? Is there a comprehensive profile of the people being served by each program? Does the overall service system adequately address the needs of people with disabilities?

Many of these questions cannot be answered despite the fact that the federal government collects voluminous data on Americans with disabilities every year. Answering these important questions is difficult because federal data collection and analysis activities for this population are only loosely coordinated across numerous agencies. Different definitions of disability, program-specific statistics, lags in data availability, and similar factors inhibit effective management of programs as well as efforts to better integrate the range of benefit and service offerings.

In this issue brief, we seek to stimulate discussion about the value of establishing an NDDS in order to improve existing data systems and add new data. This system would be designed to improve the coordination of federal data collection and analysis efforts, help agencies and others gain a more comprehensive understanding of those served, and provide information that is critical for program monitoring and improvement. This brief draws heavily on several chapters in a recently published book, *Counting Working-Age People with Disabilities: What Current Data Tell Us and Options for Improvement* (Houtenville et al. 2009).

Background

Most federal expenditures to support the working-age population with disabilities are for income support and health care (95.5 percent in 2002). In 2005, 9.7 million working-age people with disabilities received income from Social Security

¹ The writing of this brief was supported by the Department of Education's National Institute on Disability and Rehabilitation Research through its Rehabilitation Research and Training Center on Disability Demographics and Statistics grant to Cornell University (No. H133B031111). The contents do not necessarily represent the policies of the Department of Education or any other office of the federal government (Edgar, 75.620 [b]).

Disability Insurance (DI) or Supplemental Security Income (SSI) programs, both administered by the Social Security Administration (SSA). In addition, 1.6 million received veterans' compensation from the Department of Veterans Affairs (DVA), and an unknown but large number received income from two federal-state programs targeted at broader populations: Unemployment Insurance and Temporary Assistance for Needy Families. Approximately 10.9 million were enrolled in Medicare or Medicaid, and most veterans with disabilities received veterans' health benefits. Remaining expenditures were spread across an array of smaller programs to pay for housing, food, employment services, transportation, and other necessities.

Federal disability data are drawn from two major sources: surveys and administrative records (Table 1). The major national household surveys—the American Community Survey (ACS), Current Population Survey (CPS), National Health Interview Survey (NHIS), and Survey of Income and Program Participation (SIPP)—include substantial samples of people with disabilities. Livermore and She (2007) identify 8 special-topic surveys that also include samples of people with disabilities, plus 14 surveys of specific subpopu-

lations with disabilities, most of which are not conducted on a regular basis. In addition, SSA, the Centers for Medicare and Medicaid Services (CMS), DVA, and the Rehabilitation Services Administration (RSA—responsible for overseeing state vocational rehabilitation programs) have administrative processes to collect substantial individual data about participants in their disability programs. The Department of Labor (DOL) also collects individual data on participants in the federal-state workforce development programs.

Existing Disability Data Are Increasingly Valuable

Existing data are already used to support program operations, measure performance, conduct evaluations and research, and analyze policy proposals. Legislation passed in the last two decades—most notably the 1990 Americans with Disabilities Act (ADA) and the 1999 Ticket to Work and Work Incentives Improvement Act (Ticket Act)—heightened the value of the data and stimulated important efforts to improve it. For instance, analyzing the impact of the ADA on employment brought attention to significant limitations in employment statistics for people with dis-

Table 1. Summary of Federal Disability Data Sources

Major National Household Surveys	
American Community Survey	National Health Interview Survey
Current Population Survey	Survey of Income and Program Participation
National Household Surveys on Specific Topics	
American Housing Survey	Medical Expenditure Panel Survey
American Time Use Survey	National Health and Nutrition Examination Survey
Behavioral Risk Factor Surveillance System	Panel Study of Income Dynamics
Consumer Expenditure Survey	Survey of Consumer Finances
Surveys of Subpopulations	
National Longitudinal Study of Adolescent Health	National Beneficiary Survey
National Longitudinal Survey of Youth	Medicare Current Beneficiary Survey
Health and Retirement Study	NHIS—Disability Supplement
Longitudinal Study of the Vocational Rehabilitation Services Program	
Surveys of Nonhousehold Populations	
Nursing Home Minimum Data Set	Survey of Inmates in State Correctional Facilities
National Nursing Home Survey	Survey of Inmates in Federal Correctional Facilities
Survey of Inmates in Local Jails	National Survey of Homeless Assistance Providers and Clients
ACS (includes the nonhousehold population from 2006 forward)	
Administrative Data from Major Federal and Federal-State Disability Programs	
SSA: DI and SSI data	
CMS: Medicare and Medicaid enrollment and claims	
RSA: State vocational rehabilitation service agency closure data	
DVA: Veterans' health, compensation, pensions, and vocational rehabilitation program data	
Equal Employment Opportunity Commission data	

Source: Stapleton et al. (2009).

abilities. This prompted the Bureau of Labor Statistics to improve identification of people with disabilities in the CPS and to add employment statistics for people with disabilities to its monthly employment reports.

Similarly, the architects of the Ticket Act recognized that those who receive benefits from multiple programs (such as income support, health care, food stamps, and housing subsidies) face multiple work disincentives. The Ticket Act addressed these disincentives through multiple initiatives, most notably SSA's Ticket to Work program and the Medicaid Buy-Ins implemented in many states. The evaluations of these and other programs required new data sets. For example, SSA conducted its first survey of all working-age DI and SSI recipients, focusing on work-related issues and participation in multiple programs. Similarly, CMS, which required data it did not normally have about the earnings, benefit receipt, and employment of Buy-In participants, obtained data about these outcomes from SSA under an inter-agency agreement (see Box 1).

The growing importance of information about the population served by these programs has also motivated efforts to match survey data to administrative data. For example, the Census Bureau and SSA have improved the matching of SIPP and CPS records to SSA records. For the first time, the National Center for Health Statistics (NCHS) has collaborated with SSA and CMS to match NHIS and other NCHS survey records to SSA and CMS administrative data.

Incentives for Cooperation Are Limited, and the Challenges Are Formidable

Each agency has incentives to work with other agencies to improve disability data, but they face formidable barriers to such cooperation. Agencies that wish to collaborate must reconcile conflicting missions and objectives, address privacy issues, negotiate and enforce rights to access and use, resolve incompatible definitions, and absorb costs. As a result, even seemingly simple data improvements have been slow to materialize. For instance, the value of including common disability measures in federal surveys has been recognized for years, but because the responsible agencies have differing reasons for collecting disability data, they could not agree on common measures. However, at the urging of Congress and the Office of Management and Budget (OMB), DOL and the Census Bureau implemented common measures for the CPS and ACS in 2008.

These measures are gradually making their way into other surveys, including the NHIS and SIPP.

Does the External Value of the Data Warrant Greater Investment?

The fact that external entities pushed for the development of common measures illustrates a general point: disability data have extensive value to the entities that are not responsible for collecting them—a value that is not fully factored into the decisions of the responsible agencies. The external value of the data is high because the agencies involved serve a large common population; the actions of each agency affect individuals served by others, the services delivered by others, and expenditures on those services. There is also growing recognition that the most difficult disability policy issues cut across offices and levels of government. The White House (particularly OMB), Congress and its committees and agencies (notably the Congressional Budget Office and the Government Accountability Office), and the executive and legislative branches of state governments all have a significant interest in disability data, as do people with disabilities and their organizations, disability vendor and insurer organizations, and nongovernment researchers.

The value of the data to these external entities raises an important question: is the value high enough to warrant a more substantial investment in a coordinated effort to improve the data? As pointed out in Stapleton et al. (2009), much more could be done to enhance the data: expanding matching efforts to include multiagency matches, matching ACS data to administrative data, improving survey methods to ensure that subjects with disabilities are uniformly included, modifying instruments to capture disability-related information, increasing use of special-topic and special-population supplements, expanding responsible access to administrative data, and producing statistics drawn from longitudinal and matched data. Many improvements have relatively low cost, and some would pay dividends by reducing the need for, or making it easier to conduct, occasional national disability data surveys.

The extent to which the agencies responsible for the data will pursue these improvements is likely to be restricted by the specific mission of each organization as well as competing internal demands for administrative resources in an era of fiscal restraint. However, the data improvements, including those made possible by an NDDS, could help each agency

Box 1. Tracking Medicaid Buy-In Outcomes

The Medicaid Buy-In posed a challenge to CMS because the agency's administrative data did not include the key program outcome of employment. CMS addressed this challenge by having states submit identifying information for all their Buy-In enrollees. This information was used to extract detailed enrollment, use, and expenditure data from the Medicaid files already at CMS. CMS also made use of an agreement with SSA that let them merge SSA administrative data about receipt of cash disability benefits, employment, and use of work incentives. In this way, CMS, the states, and policymakers were able to learn more about the people served by the Buy-In than they would have using only CMS centralized data. In addition, CMS reduced the reporting burden on the states and improved states' monitoring efforts by letting them request custom data analyses.

advance the management of its own programs. The improvements could also help administrators and policymakers better understand how these programs interact, identify high-value opportunities for administrative and policy improvements, and support the design of such improvements. The sheer size of federal and state expenditures to support the working-age population with disabilities, combined with the complexity of these programs and the numerous challenges related to program fragmentation, suggests that the external value of the data is more than sufficient to warrant an externally supported, coordinated effort to improve disability data—that is, to establish a National Disability Data System, or NDDS.

What Might an NDDS Look Like, and How Much Would It Cost?

An NDDS could take many forms with respect to content, functionality, financing, governance, administration, privacy protections, and access, and the cost will vary accordingly. At the low-cost end would be a system that guides the development of disability data policy, archives data from multiple sources, produces matched files, helps policymakers find the most relevant data to meet their needs, and makes data available to the agencies and other authorized parties through a systematic process that duly protects privacy. At the high-cost end would be a system that supports program operations in near real time, enables policymakers to quickly obtain tabulations to inform decisions, links administrative data from multiple agencies so that each can get a comprehensive perspective on the people they serve, creates public use files that are cleaned of personally identifiable information, produces and disseminates statistics based on matched data, and

provides disability research support to the agencies and other authorized parties. The cost may range from a few million dollars per year for a modest system to tens of millions or more for an ambitious system.

Developing an NDDS would build on the numerous efforts to improve disability data that have been outlined above as well as other efforts currently underway. Those efforts, and the information they have generated, show that it is possible to improve the data, demonstrate the value of improvements, and provide valuable experience to build on. The challenge is to build on the significant gains of sporadic and isolated efforts by creating a well-organized, permanent system. Such a system could improve the data and make it easier for agency staff and various decision makers to quickly obtain needed information. The next step may be to identify specific informational gains that the many stakeholders might realize from an NDDS and to develop options for the governance, administration, content, privacy protection, functions, and financing of a system designed to maximize those gains.

There is a widely recognized need to think broadly about the many federal and federal-state programs that serve people with disabilities. A wider perspective will likely lead to significant gains in program administration and to improvements in disability policy that would foster better matching of services and benefits to the needs of people with disabilities. There is also growing recognition of the need for accurate, timely, and comprehensive data to inform and guide these efforts. The value of improved data has never been higher than it is now. Although the challenges to improving the data are substantial, they pale in comparison to the likely consequences of failing to do so, both for people with disabilities and for taxpayers.

References

- Goodman, N., and D.C. Stapleton. “Federal Expenditures for Working-Age People with Disabilities.” *Journal of Disability Policy Studies*, vol. 18, no. 2, 2007, pp. 66–78.
- Government Accountability Office. “Federal Disability Assistance: Wide Array of Needs to Be Examined in Light of 21st Century Challenges.” GAO-05-626. Washington, DC: GAO, June 2005.
- Houtenville, A.J., D.C. Stapleton, R.R. Weathers II, and R.V. Burkhauser (editors). *Counting Working-Age People with Disabilities: What Current Data Tell Us and Options for Improvement*. Kalamazoo, MI: The Upjohn Institute for Employment Research, 2009.
- Livermore, G.A., and P. She. “Limitations of the National Disability Data System.” Ithaca, NY: Cornell University, Rehabilitation Research and Training Center on Disability Demographics and Statistics, 2007.
- Stapleton, D.C., G.A. Livermore, and P. She. “Options for Improving the National Disability Data System.” In *Counting Working-Age People with Disabilities: What Current Data Tell Us and Options for Improvement*, edited by A.J. Houtenville, D.C. Stapleton, R.R. Weathers II, and R.V. Burkhauser. Kalamazoo, MI: The Upjohn Institute for Employment Research, 2009.

For more information about this brief, contact Center director David Stapleton at (202) 484-4224.

For more information about the Center for Studying Disability Policy, go to www.DisabilityPolicyResearch.org.

Center for Studying Disability Policy Mathematica Policy Research 600 Maryland Ave., SW, Suite 550 Washington, DC 20024-2512 (202) 484-9220	Princeton Office P.O. Box 2393 Princeton, NJ 08543-2393 Phone: (609) 799-3535	Washington Office 600 Maryland Ave., SW Suite 550 Washington, DC 20024-2512 Phone: (202) 484-9220	Cambridge Office 955 Massachusetts Ave. Suite 801 Cambridge, MA 02139-3226 Phone: (617) 491-7900	Ann Arbor Office 555 S. Forest Ave. Suite 3 Ann Arbor, MI 48104-2583 Phone: (734) 794-1120	Oakland Office 505 14th Street Suite 800 Oakland, CA 94612-1475 Phone: (510) 830-3700
---	--	---	--	--	---

Visit the Center for Studying Disability Policy website at www.DisabilityPolicyResearch.org.

Visit Mathematica’s website at www.mathematica-mpr.com. Mathematica® is a registered trademark of Mathematica Policy Research, Inc.