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

David C. Stapleton

*Mathematica Policy Research*

Craig V.D. Thornton

*Mathematica Policy Research*

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David C. Stapleton and Craig Thornton

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

**T**he 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 this set of programs has become increasingly difficult as more people seek benefits, as the programs face greater budget pressures, and as efforts have risen to foster better service integration among programs. Yet the data that could inform administrators and policymakers remain a morass of program-specific data sets and largely uncoordinated surveys. 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 data on program participants, these efforts could be enhanced considerably by the creation of a National Disability Data System (NDDS).

The 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 and conflicting incentives. Policymakers trying to address those 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? Does the overall service system adequately meet their needs?

Many of these questions cannot be answered adequately despite the fact that the federal government collects voluminous data on Americans with disabilities every year. A primary reason? Federal data collection and analysis activities for this population are only loosely coordinated among the numerous agencies that collect them. In this article, we discuss why an NDDS might greatly increase the value of the multitude of federal disability data collection efforts. We draw heavily on several chapters from *Counting Working-Age People with Disabilities: What Current Data Tell Us and Options for Improvement*

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(Houtenville et al. 2009), which was published this year by the Upjohn Institute. See p. 7 for more information about the book.

### Background

Millions of people in the United States live with serious impairments or disability. A long history of legislation reflects the broad public concern over their well-being. In particular, the 1990 Americans with Disabilities Act (ADA) sets out society's intent to include these individuals fully in employment and public life, and a wide array of programs have been enacted to provide direct assistance. In 2005, 9.7 million working-age people with disabilities received income from Social Security Disability Insurance (DI) or

Supplemental Security Income (SSI) programs, both administered by the Social Security Administration (SSA). Approximately 10.9 million people with disabilities were enrolled in Medicare or Medicaid. Furthermore, many also receive supports for housing, food, employment services, transportation, and other goods and services from a range of federal, state, and local disability-focused programs, and an unknown but large number received income from such broadly targeted assistance programs as Unemployment Insurance and Temporary Assistance for Needy Families (Stapleton, Wittenburg, and Thornton 2009).

Most federal data about the characteristics, well-being, and activities of people with disabilities come from two major sources: surveys and administrative records. 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. In addition, there have been eight recent special-topic surveys that include large samples of people with disabilities and 14 occasional surveys of specific disability subpopulations. Administrative data systems are maintained by SSA, the Centers for Medicare and Medicaid Services (CMS), the Department of Veterans' Affairs, and the Rehabilitation Services Administration (RSA—responsible for overseeing state vocational rehabilitation programs) and contain substantial individual data about the millions of people participating in their programs.

### Disability Data Are Increasingly Valuable

Legislation passed in the last two decades—most notably the ADA and 1999 Ticket to Work and Work Incentives Improvement Act—increased the value of the data and stimulated important efforts to improve it. Efforts to understand the effect of the ADA brought attention to significant limitations in employment statistics for people with disabilities,

ultimately leading to improvements in the identification of people with disabilities in the CPS. Similarly, the agencies responsible for implementing the multiple initiatives of the Ticket Act have seen the need for new data collection efforts (for example, SSA's first survey of all working-age DI and SSI recipients), bilateral agency agreements to match administrative data (between SSA and CMS, and SSA and RSA), improvements in the matching of SIPP and CPS records to SSA records, and, for the first time, the matching of SSA and CMS records and the NHIS and other health surveys.

### **Incentives for Cooperation Are Limited and the Challenges Are Formidable**

It has proven to be extremely difficult to combine data from multiple agencies in order to develop a broad perspective on the people served by any single agency. Staff at individual agencies must reconcile conflicting missions and objectives, address privacy issues, negotiate and enforce rights to access and use, resolve incompatible definitions, and obtain sufficient funding. Consequently, 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 the responsible agencies could not agree on common measures. Finally, at the urging of Congress and the Office of Management and Budget (OMB), the U.S. Department of Labor and the Census Bureau implemented common measures for the CPS and ACS in 2008. These measures are gradually making their way into other surveys.

### **Does the Value of the Data Warrant Greater Investment?**

Because responsibility for serving and surveying people with disabilities is spread over many agencies, the country tends to underinvest in data about this group. Even though the agencies would likely benefit from having a comprehensive perspective on the people they serve and the disability population

in general, they tend to collect only data pertinent to their own specific mission and programs. As a result, we have many data systems focused on narrow aspects of the population, but few that can support a fuller analysis of the well-being of this population. Nor do we have sufficient data to understand how the various support programs overlap or interact.

Growing demands on the various support programs combined with intense budget pressures have created a growing consensus about the need to have better data to support better program assessment and development. 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 have all expressed interest in better disability data, as

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have people with disabilities and their organizations, disability vendor and insurer organizations, and researchers.

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

Much more could be done to enhance the data at a low cost: 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 are relatively low cost, and some would pay dividends by reducing the need for, or making it easier

to conduct, occasional national disability data surveys (Stapleton, Livermore, and She 2009). Such low-cost enhancements seem like worthwhile investments given the sheer size and complexity of federal and state expenditures to support the working-age population with disabilities.

An NDDS would be a way to coordinate and enhance the various efforts to improve disability data. At its simplest, an NDDS would be a group that guides, provides technical assistance, and supports agency efforts to improve disability data and data use policies. A more extensive system might archive data from multiple sources, produce matched files, make data available to the agencies and other authorized parties through a systematic process that duly protects privacy, quickly provide policymakers with tabulations to inform decisions, create public use files that are cleaned of personally identifiable information, produce and disseminates numerous statistics based on matched data, and provide disability research support to the agencies and other authorized parties.

Most importantly, an NDDS could provide a vehicle for agencies and organizations with broad perspectives on disability policy (such as Congress and OMB), to work with agencies such as SSA, CMS, and others that have more focused responsibilities. An NDDS could bring together the many narrow data sets in order to provide the comprehensive perspective and information required by all agencies to develop a more effective and responsive disability system. The wider perspective provided by a functioning NDDS 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.

Existing 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 upon. The challenge is to expand on the significant gains of sporadic and isolated efforts by creating a well-organized, permanent NDDS. The value of improved data has never been higher than it is now. So while

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.

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*Age People with Disabilities: What Current Data Tell Us and Options for Improvement*, Andrew J. Houtenville, David C. Stapleton, Robert R. Weathers II, and Richard V. Burkhauser, eds. Kalamazoo, MI: W.E. Upjohn Institute for Employment Research, pp. 381–418.

*David C. Stapleton is the director of the Center for Studying Disability Policy at Mathematica Policy Research, Inc., and Craig Thornton is Mathematica's managing director for health research.*