

From National Disability Data Disorder to National Disability Data System?

David Stapleton

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Overview

- **There are numerous ways to improve disability data—some inexpensive, some not.**
- **The growing value of the data has led to significant improvements.**
- **Fragmentation of responsibilities creates difficult challenges.**
- **Could/should we move from “national disability data disorder” to a National Disability Data System (NDDS)?**

Options for Improvement

Improve Existing Data Collection and the Use of Existing Data

Include common disability measures in all federal surveys

Study the common measures

Expand and improve matching of administrative data

Improve survey methods and increase uniformity

Make small changes to instruments

Coordinate special population surveys

Produce new statistics

Invest in documentation

Collect New Data

Develop survey supplements

Example 1: Common Measures

- **In the past, federal surveys**
 - Each had their own questions for identifying people with disabilities, or
 - Included no such questions
- **Rationale: relevance to the responsible agencies**
- **Result: a Tower of Babel**
- **Change is underway, but challenges remain**

Example 2: Matching

- **Information about many individuals is captured in multiple data sources.**
 - Administrative data for multiple programs and years
 - Surveys
- **Before the 1990s, matching was rare as each agency followed its own mission.**
- **The value of matching is high.**
 - Richness of information about people served
 - Participation in multiple programs
 - Dynamics
- **Change is underway, but challenges remain.**



Example 3: Survey Supplements

- **An efficient way to collect disability data from subgroups**
- **The value of disability supplements is high**
 - **Cross-cutting issues**
 - **Limitations of other data**
- **Change is underway**
 - **1994–95 National Health Interview Survey Disability Supplement**
 - **Again?**
- **Challenges remain**

Themes

- **Value of cross-cutting data is high and growing.**
 - Focus on people, not programs
- **Improvements are occurring, but slowly.**
- **Technology would support more improvements.**

Themes (cont'd.)

- **Improvements are hindered by fragmentation.**
 - **Diverse agency responsibilities**
 - **Privacy issues**
 - **Governance**
 - **Competing demands for resources**
 - **Inefficiencies**
- **Interests of the agencies are sometimes sufficient to overcome the challenges, but this is often not the case.**

Should We Invest More in Disability Data?

- An agency is likely to invest in the data when the value of the investment *to the agency* is sufficient relative to the costs of overcoming the challenges.
- From each agency's perspective, the agency's investment is presumably optimal.
- From a social perspective, investment is likely suboptimal if external entities value the data more than the agencies do.

External Entities

- **Consumer groups**
- **Taxpayers**
- **The White House**
 - **Office of Management and Budget, Domestic Policy Council, Council of Economic Advisers**
- **Congress**
 - **Congressional Budget Office, Government Accountability Office, Congressional Research Service, committees**
- **State and local governments**
- **Producers of goods and services**
- **Researchers**

An Investment Option: An NDDS

- **Mission: to improve the value of federal disability data collection and analysis**
 - Create order out of disorder
 - Make better use of existing data
 - Lead cross-cutting improvements in data collection
 - Govern usage
 - Expand access in a manner that is
 - Responsible
 - Systematic
 - Transparent
 - Use resources more efficiently

Is It Time to Establish an NDDS?

- **Yes:**
 - Improve performance while reducing cost
 - Address cross-cutting disability policy issues
- **No:**
 - The challenges of fragmentation are too high
 - It is too expensive in a time of fiscal restraint
- **Maybe: depends on what the NDDS is**

What Would an NDDS Look Like?

- **Content**
- **Functions**
- **Governance**
- **Financing**
- **Administration**
- **Privacy and access**

Is it Time to Start?

- **Building an NDDS would take time**
 - Start with low-hanging fruit
 - Build confidence
 - Systematically address challenges
- **Next steps?**

Contact Information

**David Stapleton, Director
Center for Studying Disability Policy
Mathematica Policy Research, Inc.
600 Maryland Ave., SW, Suite 550
Washington, DC 20024
(202) 484-4224**

dstapleton@mathematica-mpr.com

www.DisabilityPolicyResearch.org