From National Disability Data Disorder to National Disability Data System?

David Stapleton

May 28, 2009
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

<table>
<thead>
<tr>
<th>Improve Existing Data Collection and the Use of Existing Data</th>
</tr>
</thead>
<tbody>
<tr>
<td>Include common disability measures in all federal surveys</td>
</tr>
<tr>
<td>Study the common measures</td>
</tr>
<tr>
<td>Expand and improve matching of administrative data</td>
</tr>
<tr>
<td>Improve survey methods and increase uniformity</td>
</tr>
<tr>
<td>Make small changes to instruments</td>
</tr>
<tr>
<td>Coordinate special population surveys</td>
</tr>
<tr>
<td>Produce new statistics</td>
</tr>
<tr>
<td>Invest in documentation</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Collect New Data</th>
</tr>
</thead>
<tbody>
<tr>
<td>Develop survey supplements</td>
</tr>
</tbody>
</table>
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