



National Council on Disability

An independent federal agency making recommendations to the President and Congress to enhance the quality of life for all Americans with disabilities and their families.

Testimony

Of

*Ms. Pat Pound
NCD Member*

*Information Policy, Census, and National Archives Subcommittee
Oversight and Government Reform Committee*

*“Does Federal Statistical Data Adequately Serve People Living with
Disabilities?”*

*Wednesday, June 4, 2008
2154 Rayburn HOB
2:00 P.M.*

“Does Federal Statistical Data Adequately Serve People Living with Disabilities”

Good afternoon. My name is Pat Pound. On behalf of the National Council on Disability, I want to thank you for allowing us to provide testimony to the members of this very distinguished Congressional Subcommittee today.

NCD is an independent federal agency, composed of 15 members appointed by the President and confirmed by the Senate. NCD's purpose is to promote policies and practices that guarantee equal opportunity for all individuals with disabilities, regardless of the nature or severity of the disability, and to empower individuals with disabilities to achieve economic self-sufficiency, independent living, and integration into all aspects of society.

The history of the United States has been marked by a constant evolution to open more doors, break down more barriers, extend basic human rights, and improve the quality of life to more and more people. The development of our current federal disability policy framework dates back to the early 20th century, starting with the Social Security Act in 1935, which established federal old age benefits and grants to states for assistance to people who were elderly or blind, and to children with physical disabilities. While other policies and legislation were enacted after the Social Security Act of 1935, the bulk of our nation's disability policy framework has been put into place during the second half of the 20th century.

For example, the first generation of disability legislation occurred in the 1960s. In 1965, Social Security Amendments were passed, establishing Title XVIII (Medicare) and Title XIX (Medicaid) that provided hospital and medical insurance protection to persons with disabilities.

The second generation of disability legislation occurred in the 1970s. For example, the passage of the Rehabilitation Act of 1973 provided the first major statutory expression in the form of Section 504, through which Congress prohibited discrimination toward qualified individuals with disabilities by recipients of federal funds.

The third generation of disability legislation occurred in the 1980's. The major theme involved extending civil rights' antidiscrimination protections in areas of peoples' lives. In 1986, Congress passed the Air Carriers Access Act, which protects people with disabilities against discrimination by air carriers.

1331 F Street, NW ■ Suite 850 ■ Washington, DC 20004

202-272-2004 Voice ■ 202-272-2074 TTY ■ 202-272-2022 Fax ■ www.ncd.gov

The fourth generation of disability legislation in this country began during the 1990s. The major themes were consumer empowerment and individual choice. In 1990, Congress passed the Americans with Disabilities Act (ADA) under which it is illegal to discriminate against individuals with disabilities in both the public and private sectors: employment, access to public accommodations, transportation and telecommunications.

NCD Research and Perspective

NCD is proud that during the past 50 years, advocates, policymakers, and a variety of public and private organizations have undertaken significant efforts to improve the lives of people with disabilities, culminating in the passage or improvement of legislation such as the Americans with Disabilities Act (ADA), various sections of the Rehabilitation Act, the Individuals with Disabilities Education Act, the Ticket to Work and Work Incentives Improvement Act, and others.

Notwithstanding these various pieces of legislation and policies, NCD has also noted that insufficient effort and progress has been made to measure and reflect upon the overall performance, effectiveness and impact of these laws and policies on the lives of people with disabilities. This conclusion is based on various NCD policy evaluations over the past six (6) years, for example:

- In a 2002 report, NCD noted problems that continued to be associated with widely used disability employment data from the Current Population Survey and with some disability data from the 2000 Census. NCD also indicated its concern that the collection of valid and reliable employment or other data about Americans with disabilities arising from a series of Supreme Court decisions over the previous three years could likely raise the potential for dramatically narrowing the legal standards for who is a person with a disability and confound federal data collection efforts. (See, National Disability Policy: A Progress Report)
- In a 2003 report, NCD found that federal agencies have given low priority to collecting and analyzing Section 504 program data, and there were major differences in their data efforts. None of the agencies have developed information systems that comprehensively collect, aggregate, or summarize detailed information about complaints or compliance reviews and their outcomes. (See, Rehabilitating Section 504)
- In a 2004 paper, NCD expressed its interest and support for improving two federal disability-related data collection efforts that are directly related to the Decennial Census: the U.S. Census Bureau's American Community Survey (ACS), and the Bureau of Labor Statistics' Current Population Survey (CPS). (See, Improving Federal Disability Data)
- In a 2005 report, NCD indicated a grave concern over a lack of data that presents a complete and accurate picture of the costs for Long-term Services and Supports (LTSS) for families with children or adults with disabilities as a key finding. (See, The State of 21st Century LTSS)

- In a 2006 report, NCD noted a need to modify current performance measures being used by OMB to assess individual program strengths and weaknesses to focus on cross-department and agency collaboration to enhance livable community outcomes. (See, Creating Livable Communities).
- In a 2007 report, NCD described a surprising absence of ongoing, systematic data collection about the ADA, the result of which is significant knowledge gaps about the impact of the ADA. (See, The Impact of the ADA)

Similarly, several assessments from the Government Accountability Office (GAO) support our conclusion, including:

- In a 2005 report, the Government Accountability Office (GAO) conducted a review of 200 federal programs located in 20 agencies that served individuals with disabilities. As a result of its review, and as indicated in this 2005 report, GAO identified the need to transform many of the programs it reviewed to keep pace with the changing expectations and challenges of the 21st century. (See, Federal Disability Assistance)
- In 2007, GAO convened a forum to address some of the key issues related to modernizing federal disability policy. The forum brought together a diverse array of experts, including employers; advocate groups, researchers, and academia; and federal officials. As indicated in a report of the proceedings, most participants at the GAO 2007 forum on modernizing disability programs agreed, and a key GAO recommendation noted, that multiple indicators were needed to measure the success of disability programs and that these measures should include not only economic measures such as income and employment, but quality of life measures as well. (See, Highlights of a Forum: Modernizing Federal Disability Policy).

As a result of the analyses and findings just discussed, NCD concluded that more needs to be done on the national level, particularly to address the need for a relevant disability information system.

In 2008, NCD released a report entitled, *Keeping Track: National Disability Status and Program Performance Indicators*. This NCD report identifies and describes three major objectives for the U.S. government to improve the life of millions of people with disabilities. First, it lays out a roadmap for the federal government to improve the status of its information policy and program performance accountability system.

Second, *Keeping Track* includes a set of statistical social indicators that NCD believes are currently able to measure the progress of people with disabilities in important areas of their life, over time. The report includes 18 indicators determined by stakeholders to measure "quality of life" using both objective and subjective measures. The indicators span a variety of life domains, including employment, education, health status and health care, financial status and security, leisure and recreation, personal relationships, and crime and safety. Collectively they can create a holistic representation of the lives of people with disabilities.

Third, this report also provides or serves as a mechanism for installing the set into a key national indicator system which is currently under consideration by the federal government. This prospective national indicator system is known as the "State of the USA" (SUSA) (previously known as the "Key National Indicator Initiative").

Conclusion

The landscape of American government is rich with disability policies and programs designed to address identifiable national issues, at least, over the past 50 years. Some of these policies and programs have worked well; some have not achieved the results intended. It is imperative that Congress work to design a national disability information system that is effective. Based on NCD's scrutiny of federal policies and programs, we recommend that:

1. The Federal Government establish and fund a coalition of disability policy-makers and advocates to: 1) develop a fuller set of indicators that are important to people with disabilities, building on the indicators outlined in this report (See, *Keeping Track*, Chapter 5); and 2) ensure that disability is included as a subgroup characteristic as the SUSA is developed. The SUSA offers an important opportunity to integrate disability into a larger national indicator system. When completed, the SUSA will offer individuals who are looking for disability data relatively easy access to the data. It will highlight the importance of including disability as a subgroup in analyzing the relative status and progress of the population and highlight gaps in data about people with disabilities.
2. Promote a standard set of disability questions. Some important federal surveys have no disability measures. When measures are included, they vary across surveys, often yielding inconsistent and confusing results. A common core of disability questions on all federal surveys would improve comparability and improve the national discourse about disability programs and policy.
3. Fully disseminate disability data. Federal agencies and other organizations that conduct national surveys, such as the US Census Bureau of Labor Statistics and the U.S. Department of Health and Human Services Administration on Healthcare Research and Quality, should provide comparisons of people with and without disabilities in their aggregated data reports and should, where sufficient data exists, offer comparisons of people with disability by gender, race, and other socio-demographic characteristics.
4. Administrative records of all means-tested programs should include a disability indicator. Programs that serve individuals with disabilities, such as One-Stop Employment Centers, and TAN F, should collect data on the number of individuals with disabilities who use their programs and compare outcomes between program users with and without disabilities. We recommend that the Interagency Committee on Disability Research (ICDR) develop a workgroup to establish criteria on which the indicator is based.
5. Expand the Job Training Common Indicators. NCD should ask the Department of

Labor to explore options within its administrative data collection system to add questions to the Job Training Common Indicators that more adequately capture concepts important to the focus groups, including choice in job; whether the job uses the employee's full talents and abilities; whether the wage is appropriate given their qualifications; the extent to which they are satisfied with job conditions (including place, facility, co-workers, schedule requirements, accommodations, and opportunities for advancement); and whether they have meaningful opportunities to make choices about the conditions of their work.

6. Agencies should consider the effects of programs on non-participants. Agencies should include participation rates for eligible individuals (or potentially eligible individuals) and measures of well-being for those who are denied services in their GPRA and PART outcome measures. Improved survey data on people with disabilities would help support such measures.

Thank you all very much for listening.