

# **Reorienting Disability Research**

National Council on Disability

April 1, 1998

National Council on Disability  
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## **Reorienting Disability Research**

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## LETTER OF TRANSMITTAL

April 1, 1998

The President  
The White House  
Washington, DC 20500

Dear Mr. President:

On behalf of the National Council on Disability (NCD), I am pleased to submit a report entitled *Reorienting Disability Research*. The report synthesizes recommendations by researchers and consumers toward a disability statistics policy that is more meaningful and useful in light of the paradigm shift precipitated by the Americans with Disabilities Act of 1990, which NCD originally proposed.

For many years, disability research has appeared to be essentially a scientific exercise, based on academic procedures applied in an area of health care. People with disabilities have learned, however, that underlying values and assumptions have guided research in ways that are not necessarily important or helpful to them as the ultimate beneficiaries. Choices are made, either consciously or not, at each stage of research design, collection, and dissemination that affect the utility of the research to individuals with disabilities. Given limited federal resources, which questions should be studied? How should they be studied? What should be done with the results?

This report recommends action steps to reorient the answers to these questions based on the thinking that disability is a natural part of the human experience; that people with disabilities should participate in the production and consumption of research about them; and that disability data should be an integral part of population statistics and socioeconomic measures of progress. NCD stands ready to work with you and stakeholders outside the government to see that the agenda set out in the attached report is implemented.

Sincerely,

Marca Bristo  
Chairperson

(The same letter of transmittal was sent to the President Pro Tempore of the U.S. Senate and the Speaker of the U.S. House of Representatives.)



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## **ACKNOWLEDGMENT**

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## BACKGROUND

This document is the product of a yearlong initiative sponsored by the National Council on Disability (NCD) and the National Institute on Disability and Rehabilitation Research (NIDRR) of the U.S. Department of Education. It was prompted by the National Council on Disability's Disability Policy Summit in April 1996 and subsequent release of the report *Achieving Independence: The Challenge for the 21<sup>st</sup> Century* in July 1996. At the Policy Summit, people with disabilities articulated their keen interest in disability statistics and identified a need for changes in federal data collection activities. Their interest in disability statistics reflects their recognition that such data are often used in policy decisions and that better data will enhance their ability to pursue changes in government policies that will benefit people with disabilities. Recommendations to improve data collection are included in *Achieving Independence*.

NCD was prompted by the disability community to go beyond the *Achieving Independence* recommendations and initiate in-depth dialogue with policy makers, people with disabilities, and researchers about how such changes could be achieved. It was determined that the next step would be a document targeted to federal disability policy makers in Congress and the Administration, outlining specific action steps that could be taken to improve the nation's disability data collection activities. NIDRR initiated the development of this document by funding a synthesis of disability data recommendations that had been made by various bodies in the recent past. This synthesis was reviewed by members of the Interagency Subcommittee on Disability Statistics and used as the basis for a meeting held on June 13, 1997, in Washington, D.C. More than 45 researchers, people with disabilities, and policy makers attended that meeting, entitled "How Consumers Can Maximize Their Influence on and Use of Disability Data: A Dialogue Among Consumers, Data Producers and Data Analysts." A significant portion of the meeting was focused on discussing the synthesis and offering suggestions for improvement. This report is the product of that meeting.

It is intended to inform policy makers in Congress and the Administration about action steps they could take to improve disability data collection activities of the Federal Government. While the

report does not purport to represent consensus among the disability community, researchers, and policy makers, it does offer a synthesis of recent thinking on this topic.

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# INTRODUCTION

Data related to people with disabilities have increasingly gained the interest of policy makers, the disability community, and researchers over the past decade. Calls for greater policy and program accountability and effective planning, both within and outside of government, have fueled an interest in disability-related data. Policy issues on the forefront of the disability agenda, such as long-term services and employment, require relevant measures, accurate data, routinely repeated measures, sophisticated analysis, and both broad and well-targeted dissemination.

Changes in federal data collection activities are likely to be long-term efforts with significant political and resource considerations. Cost implications of developing new questions or expanding sample sizes are not to be ignored. The politics of negotiating new or replacement questions must be a consideration in carrying out any recommendations.

During the past several years, numerous conferences and workshops have been held to discuss the status of disability-data-related activities of the Federal Government, including data collection and statistical reporting of disability. The purpose of this report is to synthesize the recommendations of those groups and present action steps for implementing changes in federal data collection activities.

The following action steps address six areas of primary importance in disability statistics: orienting disability data collection activities to the new paradigm of thinking about disability, improving organizational structure, refining current data collection efforts, using existing data, developing new data collection instruments, and broadening dissemination.



# **ORIENTING DISABILITY DATA COLLECTION ACTIVITIES TO THE NEW PARADIGM OF THINKING ABOUT DISABILITY**

With the enactment of the Americans with Disabilities Act (ADA) in 1990, a new paradigm of thinking about disability was firmly established in law and policy. Moving away from the medical model that usually forms the foundation of disability policy, this new paradigm offers a civil rights orientation that focuses on societal barriers to full participation rather than the functional impairments of the individual. The disability community has embraced ADA as its declaration of independence, one that articulates a vision of an accessible and equitable society. However, the vast majority of data collection activities of the Federal Government retain the medical bias and have not yet adopted the new paradigm. Examples of medical bias are found in questions about work in population-based surveys such as the Decennial Census and the Current Population Survey (CPS). Questions in those surveys focus on the individual's impairment and functional level but fail to identify barriers in society and the environment—such as discrimination and lack of accommodations in the workplace—that are potential obstacles to employment, assuming instead that the obstacles to employment reside solely with the individual as a result of the impairment itself.

Ideally, disability measures should also tell us about participation with and without accommodations. ADA recognizes the need for and emphasizes the use of accommodations to enable people with disabilities. Measuring the use of accommodations will not only indicate the gross level of need; it is also the best indicator of how well we are meeting ADA goals.

With the enactment of ADA, people with disabilities established themselves as a minority group with civil rights protections comparable to those available to other protected groups, such as ethnic and racial minorities, women, and the elderly. As a minority group, people with disabilities increasingly seek to have data about themselves that are comparable to data collected

about other protected groups. For example, through the CPS, the Bureau of Labor Statistics collects and disseminates data each month about the employment rate of other protected groups; such data are collected and disseminated only yearly about people with disabilities.

The following action steps are recommended to infuse the disability paradigm embodied in ADA into federal data collection activities.

**1. Use ADA as the basis for the definition of disability in federal surveys.**

ADA requires viewing disability as dynamic rather than static, as an interaction between an individual with an impairment and the environment rather than as a deficit of an individual. Definitions of disability need to be changed to reflect this orientation. In addition, questions about disability issues should be integrated into questions being asked of all respondents. For example, disability-related support needs could be included in a list of support needs in a question asked of all respondents, not just those who have identified themselves as having an impairment.

**2. Operationalize the nation's goals for people with disabilities, as articulated in ADA, so that data can be collected about the extent to which society is moving toward reaching those goals.**

ADA states that the nation's proper goals for people with disabilities are (1) equality of opportunity, (2) full participation, (3) independent living, and (4) economic self-sufficiency. Statistical measures should be developed for each of these goals. Data should be regularly collected to determine whether the nation is moving toward these goals. The government should dedicate resources to this effort.

**3. Breakdowns by disability should be included in all federal data collections that collect data on gender and race/ethnicity.**

Where data are collected, analyzed, and reported about other protected groups, this should also be collected, analyzed, and reported about people with disabilities. Such data activities are a



matter of both equity and good research. We recognize that there are unique issues involved in obtaining adequate samples of people with disabilities, but they should be resolvable with creative sampling techniques, larger samples, or both.

**4. Methodological research on the survey definition of disability and its subtypes, on sampling issues, and on participation criteria should be ongoing.**

Disability data collection is an evolving field. A formidable amount of work remains to improve the validity and accuracy of disability statistics. The constant methodological research being done in fields such as economics, physics, and medicine has proven invaluable for improving research results in those fields. Equal attention should be given to disability-related research to ensure that upcoming substantive research will be conducted appropriately.

**5. Ensure that people with disabilities are integrally included in planning, developing, and carrying out disability-related data collection activities at all levels, from local to international.**

People with disabilities should be a part of designing and refining data collection instruments, determining questions that will guide analysis, and developing dissemination strategies. Too often, data are generated that are irrelevant or unusable by people with disabilities. People with disabilities are often unaware of what is available. Inaccessible formats prevent meaningful use. People with disabilities should be provided financial support for their participation in the provision of data (e.g., responding to surveys and requests for information), the development of data activities, and the utilization of data. Information should be available in accessible formats in all phases of data collection activities.



## **IMPROVING ORGANIZATIONAL STRUCTURE**

Numerous federal agencies and interagency entities are involved in disability data collection activities. Furthermore, most federal surveys operate with particular constituencies, both inside and outside of government, and in political environments. Coordination and collaboration are challenging but essential for effective data collection activities.

The following action steps are recommended to improve organizational structure.

**6. Create a central coordination mechanism, such as a task force or committee, to effectively manage disability data efforts.**

Because of the complexity of this task, the range of interest involved, and the need to make sound recommendations, this must be a high-ranking task force or committee that includes representation from the federal and state governments, the disability communities, research communities, and providers of services. Its charge should be to develop a plan within a delimited time span of about one year. This entity should work in conjunction with the Interagency Subcommittee on Disability Statistics.

**7. Develop a mechanism for all federal agencies to exchange information regularly with the Department of Health and Human Services (HHS) Data Council, which reviews and clears all HHS surveys. The Interagency Subcommittee on Disability Statistics should be integrally involved in this effort.**



## REFINING CURRENT DATA COLLECTION EFFORTS

The Federal Government routinely carries out several large surveys. Appendix I includes a partial list of those surveys and a brief description of their purposes. Numerous conferences and reports have outlined recommendations for improving the disability questions in those surveys. A compilation of those recommendations follows each survey description in the appendix.

The following actions steps are recommended to refine current data collection efforts.

### **8. Revise census questions for the Year 2000 Census to reflect the ADA definition. Include such questions in the short form.**

Numerous federal agencies have been working to revise the 1990 census questions on disability for use in the Year 2000 Census. Efforts should proceed until questions are developed that reflect the new paradigm of thinking about disability embodied in ADA. Questions about disability should be included on the short form only if sufficient space can be given or questions developed that will accurately capture the full disability community in the space available.

### **9. Continue active participation, including people with disabilities, in the revision of the International Classification of Impairments, Disabilities, and Handicaps (ICIDH), to promote an international standard and uniform coding schemes that include a measure of the disabled individual's participation in society and the accessibility of the environment.**

Utilization of an internationally accepted classification system promotes meaningful international data exchange and analysis. During the past few years, the U.S. government has been actively involved in the ICIDH revision process, which includes the development of measures of societal participation and access. The ICIDH was revised in April 1997 into the ICIDH-2 beta version. The beta version is scheduled for review and approval by the World Health Organization's World Health Assembly in April 1999.

**10. Expand the monthly Current Population Survey questionnaire to include questions on the employment of people with disabilities.**

Currently the Bureau of Labor Statistics collects data about the employment of people with disabilities only once a year, in the March supplement. Data about the employment of other protected groups are collected and reported on a monthly basis. Including people with disabilities in this monthly collection and analysis would bring public attention to the problem of the high level of unemployment among people with disabilities. Questions used in the Current Population Survey should be reviewed to ensure that they are consistent with the new paradigm of disability and that they will accurately capture work information for people with disabilities.

**11. Develop and refine a constellation of disability indicators that will comprise Goals 2010 for the forthcoming Healthy People 2010 effort.**

**12. Integrate data on people with disabilities into all existing or proposed data collection efforts being carried out through major government initiatives.**

This action would include information-gathering efforts related to such programs as the school-to-work transition program, health care, and welfare reform to enable determination of the impact of these programs on people with disabilities. Surveys about topics such as crime and tourism should include questions about people with disabilities. A goal is to have at least one "global disability indicator" on every federal, state, and small-area survey funded by the Federal Government.

**13. Ensure that the broadest range of people with disabilities (including children, those with hidden disabilities, and minorities with disabilities) are sampled.**

To understand the unique aspects of all people with disabilities, it is critical that all groups be adequately sampled. Frequently, too few people with a particular disability or of a particular age or ethnicity are sampled to allow for statistically sound analysis.

## USING EXISTING DATA

The following action steps are recommended to make better use of existing data.

**14. Ensure extensive analysis of data from the disability supplement to the National Health Interview Survey.**

**15. Require coordination and linking of data with and across federal and state systems as a way of ensuring quality, accuracy, efficiency, and confidentiality of data.**

There is currently a large amount of duplication among data collection efforts, as well as significant gaps in data collection. Improved coordination of efforts could eliminate duplication and identify gaps. Linkage of data sets would facilitate effective research into complex questions.

**16. Evaluate data elements of state systems for data elements common to both federal and state data banks and identify minor modifications that could establish additional common data elements, including key demographic, disability, service and cost variables.**

Many informational needs (such as characteristics of low-prevalence populations and outcome efforts) cannot be addressed via federal data efforts. Significant data on needs, programs, outcomes, and efficacy are found at state and local levels more often than at the federal level. The Federal Government should take the initiative to identify, synthesize, and make available the significant amount of data that exist at state and local levels. The government should examine new disability data collections funded by National Centers for Environmental Health to be used soon in 16 states on their Behavioral Risk Factors Surveillance System survey. It should ask state health departments for their experience in making state estimates and evaluate the State and Local Area Integrated Telephone Survey, the new National Center for Health Statistics (NCHS) National Health Interview Survey (NHIS) designed to greatly enhance state estimates. It should review recently published techniques for making small-area estimates (such as *Indirect Estimators in U.S. Federal Programs*, edited by W. L. Schiabile and published by

Springer-Verlag), and it should note the level of individual unit analysis currently permitted on NCHS public use tapes.

**17. Backcode additional surveys to the ICIDH or ICIDH-2 beta version or both, to produce roughly comparable disability data now from data collected previously with no goal of being comparable to any national or international standard.**

Apply algorithms used in the successful backcoding efforts of the Department of Education, the United Nations Statistical Division's DISTAT project, and the National Center for Medical Rehabilitation Research's Research Archive on Disability in the United States.



## **DEVELOPING NEW DATA COLLECTION INSTRUMENTS**

The following action steps are recommended to develop new data collection instruments.

**18. Establish focus groups on the emerging issues and needs of persons with disabilities in the topical areas of major surveys before data collection instruments are planned.**

It is not enough to have people review completed surveys; key constituencies must also be involved in defining the purpose and research questions of a study. Guidelines in NIDRR's Participatory Action Research (PAR) Report should be followed.

**19. Develop a framework for the collection of employment data on persons with disabilities that allows (1) description of the employment patterns of persons with disabilities and (2) assessment of individual characteristics and work environments that account for these patterns.**

These data should allow for an analysis of how disability affects the ability to work. Data should be collected on functional limitations, duration of impairment, age of onset, and human capital. In addition, the work environment should be analyzed in terms of its impact on disability and work.

**20. Use an extensive set of indicators that can be reported monthly or annually to determine the progress in the employment situations of people with disabilities.**

A labor utilization framework goes beyond collecting data on unemployment; it also collects data on part-time work, income compensation, and the degree to which people are fully employed in the labor force with respect to their human capital characteristics. These types of measures would extend insight into the nature of work disability.

**21. Design well-written questions to measure work disability that separate the notions of employment and disability.**

Work limitations must be described in the data, not by inference, as a function of environmental barriers and accommodation, including transportation, along with individual impairment. Both the National Center for Health Statistics and the Bureau of Labor Statistics have cognitive laboratories that are experienced in question design and could help address this issue.

**22. Government surveys should collect the following employment-related data for people with disabilities: age, gender, race, region, veteran status, use of assistive technology, use of accommodations, productivity measures with accommodations, workplace flexibility, characteristics of the employer and the job, promotions and training, social support, transportation, access to benefits (including pensions, health insurance, and leave), qualifications for employment (including education and literacy), condition and impairment data (including severity, change over time, and age of onset), labor force patterns, level of awareness of public programs, impact of health insurance, motivational factors, social supports for employment, family resources, income, and assets.**

Some of these items will require the development of new survey questions or the redesign of existing questions to reflect the new disability paradigm and to ensure the accuracy of the results.

**23. Develop questions to determine the extent to which people with disabilities have access to the services and supports they need, including assistive technology, long-term support services, accessible community-based housing, and rehabilitation services.**

**24. Develop questions about voter registration and participation by people with disabilities, and routinely monitor these activities.**

**25. Develop and pilot-test measures for household and living arrangement classifications that could be incorporated into the sample frame enumeration used in the census and other surveys.**

**26. Ensure that any new disability questions reflect variations in ethnic cultural understanding of disability.**



## **BROADENING DISSEMINATION**

The following action steps are recommended to broaden dissemination.

### **27. Ensure that data and data analyses are disseminated in alternative formats and that they are accessible to people with all disabilities.**

Formats such as Braille, large print, and computer disks will enable blind and visually impaired people to participate in all phases of disability research. Particular attention should be given to presentation of quantitative data commonly formatted in tables, graphs, and so on. Information should be formatted in a manner suitable for screen readers and other devices used by people with disabilities.

Access issues also apply for people with impairments that do not involve reading print. Methods needed to ensure everyone's participation in research depend on the specific research techniques used for most of the sample; for example, a telephone survey needs to accommodate direct participation by people with hearing and speech impairments.

To put teeth into recommendations concerning accessible materials, grants and contracts should be required to show what time and budget allocations will be made to accomplish the goal; peer review and agency review criteria should be established.

### **28. Federal agencies should develop requirements for dissemination of data and data analyses so they are widely available to the disability community, researchers, and other interested parties.**

Federal agencies could require contractors and grantees, as a part of an award stipulation, to produce an ASCII database of raw data, a file of data definitions, and files of relevant data and study documentation (properly cleaned, formatted, and disidentified) for the sponsoring government agency at the end of the project period. The agency could then determine whether to

directly redistribute the data and documentation for secondary statistical analysis and educational purposes or to release the files to another organization for public access.

## **Appendix I**

### **Major Surveys**

#### **American Housing Survey**

The American Housing Survey (AHS) is conducted every other year by the American Housing Survey Branch of the Bureau of the Census. In 1995, the sample consisted of approximately 61,000 units. The sample areas, called primary sampling units, are stratified by region and urban/rural location. Both national estimates and estimates of selected metropolitan areas are available. Housing units form the sampling unit. An important feature of these surveys is that generally the same housing units remain in the sample year after year, and it is the housing unit rather than its occupants that is followed.

#### Recommendations for improving the American Housing Survey

- Improve the health and disability status section.
- Add a section to the instrument to obtain information on supportive services in special units.
- Develop a subsample of specialized housing units to permit the national profiling of trends in these settings.
- Structure the questionnaire and code the results to ICIDH-2.

#### **National Health Interview Survey and Disability Supplement**

The National Health Interview Survey (NHIS) is a continuous national survey sponsored by the National Center for Health Statistics. It provides data on acute conditions, limitations of activities, injuries, occupational disability, physician and dental visits, and selected chronic conditions. It also provides standard demographic information and some housing data. In

1994-95, a supplemental survey on disability was conducted to obtain additional information on the living arrangements and caregiver resources of this population. The survey instrument for the supplement includes questions on activities of daily living (ADL) and instrumental activities of daily living (IADL), mental retardation and developmental disabilities; physical, emotional, and cognitive impairments; transportation; employment barriers; home access and accommodation; and use of services.

#### Recommendations for improving the National Health Interview Survey and Disability Supplement

- Implement a regular schedule for fielding the disability supplement.
- Add a more complete housing component, perhaps using the American Housing Survey format for categorizing special places housing within the disability supplement.
- Extend the quality-of-care questions to all ages among the disability group. (Presently, many of the quality-of-care items apply to the age 70+ population only.)
- Structure the questionnaire and code the results to ICIDH-2.

#### **Decennial Census of Population and Housing**

The Decennial Census encompasses the entire U.S. population. It provides data accumulated at the census tract level on household demographics, income by source, labor force participation, occupation, and type of dwelling. The number and relationships of persons in each household are also compiled. Included among the many tabulations and tape files is a summary statistics file representing a 100 percent count of persons in group quarters. The group quarters category includes persons in institutions and noninstitutions.



### Recommendations for improving the Decennial Census of Population and Housing

- The most practical change would be to clarify the enumeration process for the multitude of specialized living arrangements and to create data files and tabulations that are specific to the settings.
- The housing or living arrangements categories should be consistent with those in the American Housing Survey. The Bureau of Census conducts the AHS, the NHIS, and the Decennial and Current Population surveys, reducing the barrier to the creation of common definitions and cross-identification.
- Consider adding questions applicable to specialized living settings that describe the physical and staff characteristics of facilities, as well as the services provided.
- Structure the questionnaire and code the results to ICIDH-2.

### **Medicare Current Beneficiary Survey**

The Medicare Current Beneficiary Survey (MCBS) is sponsored by the Health Care Financing Administration as an ongoing, multipurpose survey conducted among a probability sample of Medicare beneficiaries. Also collected are data on health conditions, functional status, health care utilization, and demographics, including income and vital statistics. To date, there has been only one survey round in which a supplementary interview was conducted with a particular set of survey recipients; in this case those receiving home health care.

### Recommendations for improving the Medicare Current Beneficiary Survey

- The addition of a more detailed housing classification would enhance the utility of MCBS for tracking supportive housing arrangements.
- The ability to organize living arrangement information by the health and functional status of household members would be useful in differentiating licensed from unlicensed supportive housing arrangements.

- Consider periodic supplemental surveys of specialized housing as a means of expanding knowledge of the population living in such settings.
- Data analysis should recognize that the sample is restricted to persons covered by Medicare and is not necessarily representative of the disability community as a whole.
- Structure the questionnaire and code the results to ICIDH-2.

### **Social Security New Beneficiary Survey**

This survey, sponsored by the Social Security Administration, provides longitudinal data on disability and aging of new beneficiaries under Title 11 (workers with disabilities). Personal interviews are conducted with a random sample of noninstitutionalized beneficiaries and their spouses. The first wave was collected in 1982, and the second wave was conducted in 1992. Data collected include demographics, employment and income, health conditions that limit ability to do work, and limitations of activities (ADL and IADL). There are also data on long-term care in residential facilities.

#### Recommendations for improving the Social Security New Beneficiary Survey

- The housing, living arrangements, and services section of the instrument should be brought into alignment with whatever changes are made in the Medicare Current Beneficiary Survey.
- Like the MCBS, the Social Security Beneficiary Survey is directed only at a specific service population. Therefore, the problem of excluded individuals cannot be easily addressed.
- Structure the questionnaire and code the results to ICIDH-2.

## **Survey of Income and Program Participation (SIPP)**

SIPP is a panel survey of the economic conditions of people in the United States. It is designed to provide detailed information about income distribution and about federal and state income transfer and service programs. It also provides information about limiting conditions among respondents 15 years and older. Disability data for children ages 0 through 14 are obtained from their parents. SIPP contains information on economic and social variables of persons with disabilities that are not usually included in health surveys that ask about disability.

### Recommendations for improving the Survey of Income and Program Participation

- Include better data on impairment in SIPP, perhaps by using International Classification of Diseases codes, so that the specific impairment can be more accurately linked to the employment outcome experienced by the person in a workplace.
- Use SIPP as a complementary data source to the Current Population Survey (CPS) to describe the employment patterns of persons with work disabilities. The CPS is used to provide the monthly unemployment rate for persons in the United States. Extending that set of indicators would allow reporting not only on the unemployment rate but also on the levels of full employment among persons with and without disabilities.
- Structure the questionnaire and code the results to ICIDH-2.



## **Appendix II**

### **Mission of the National Council on Disability**

#### **OVERVIEW AND PURPOSE**

NCD is an independent federal agency led by 15 members appointed by the President of the United States and confirmed by the U.S. Senate.

The overall purpose of NCD is to promote policies, programs, practices, and procedures 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 inclusion and integration into all aspects of society.

#### **SPECIFIC DUTIES**

The current statutory mandate of NCD includes the following:

- ☐ Reviewing and evaluating, on a continuing basis, policies, programs, practices, and procedures concerning individuals with disabilities conducted or assisted by federal departments and agencies, including programs established or assisted under the Rehabilitation Act of 1973, as amended, or under the Developmental Disabilities Assistance and Bill of Rights Act; as well as all statutes and regulations pertaining to federal programs that assist such individuals with disabilities, in order to assess the effectiveness of such policies, programs, practices, procedures, statutes, and regulations in meeting the needs of individuals with disabilities.
  
- ☐ Reviewing and evaluating, on a continuing basis, new and emerging disability policy issues affecting individuals with disabilities at the federal, state, and local levels and in the private sector, including the need for and coordination of adult services, access to personal assistance services, school reform efforts and the impact of such efforts on

individuals with disabilities, access to health care, and policies that operate as disincentives for individuals to seek and retain employment.

- ☐ Making recommendations to the President, the Congress, the Secretary of Education, the Director of the National Institute on Disability and Rehabilitation Research, and other officials of federal agencies regarding ways to better promote equal opportunity, economic self-sufficiency, independent living, and inclusion and integration into all aspects of society for Americans with disabilities.
- ☐ Providing the Congress, on a continuing basis, with advice, recommendations, legislative proposals, and any additional information that the Council or the Congress deems appropriate.
- ☐ Gathering information about the implementation, effectiveness, and impact of the Americans with Disabilities Act of 1990 (42 U.S.C. 12101 et seq.).
- ☐ Advising the President, the Congress, the Commissioner of the Rehabilitation Services Administration, the Assistant Secretary for Special Education and Rehabilitative Services within the Department of Education, and the Director of the National Institute on Disability and Rehabilitation Research on the development of the programs to be carried out under the Rehabilitation Act of 1973, as amended.
- ☐ Providing advice to the Commissioner with respect to the policies and conduct of the Rehabilitation Services Administration.
- ☐ Making recommendations to the Director of the National Institute on Disability and Rehabilitation Research on ways to improve research, services, administration, and the collection, dissemination, and implementation of research findings affecting persons with disabilities.

- ☐ Providing advice regarding priorities for the activities of the Interagency Disability Coordinating Council and reviewing the recommendations of this Council for legislative and administrative changes to ensure that such recommendations are consistent with the purposes of the Council to promote the full integration, independence, and productivity of individuals with disabilities.
- ☐ Preparing and submitting to the President and the Congress an annual report titled *National Disability Policy: A Progress Report*.
- ☐ Preparing and submitting to the President and Congress an annual report containing a summary of the activities and accomplishments of the Council.

## **INTERNATIONAL**

In 1995, NCD was designated by the Department of State to be the official contact point with the U.S. government for disability issues. Specifically, NCD interacts with the special rapporteur of United Nations Commission for Social Development on disability matters.

## **CONSUMERS SERVED AND CURRENT ACTIVITIES**

While many government agencies deal with issues and programs affecting people with disabilities, NCD is the only federal agency charged with addressing, analyzing, and making recommendations on issues of public policy that affect people with disabilities regardless of age, disability type, perceived employment potential, economic need, specific functional ability, status as a veteran, or other individual circumstance. NCD recognizes its unique opportunity to facilitate independent living, community integration, and employment opportunities for people with disabilities by ensuring an informed and coordinated approach to addressing the concerns of persons with disabilities and eliminating barriers to their active participation in community and family life.

NCD plays a major role in developing disability policy in America. In fact, it was NCD that originally proposed what eventually became ADA. NCD's present list of key issues includes

improving personal assistance services, promoting health care reform, including students with disabilities in high-quality programs in typical neighborhood schools, promoting equal employment and community housing opportunities, monitoring the implementation of ADA, improving assistive technology, and ensuring that persons with disabilities who are members of minority groups fully participate in society.

## **STATUTORY HISTORY**

NCD was initially established in 1978 as an advisory board within the Department of Education (Public Law 95-602). The Rehabilitation Act Amendments of 1984 (Public Law 98-221) transformed NCD into an independent agency.



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