

National Council on Disability: 20 Years of Independence



National Council on Disability
July 26, 2004

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Dedication

This report is dedicated to Americans with disabilities and their families, who contribute to their communities and the nation.

Acknowledgments

The National Council on Disability would like to thank Professor Robert L. Burgdorf Jr. of the David A. Clarke School of Law at the University of the District of Columbia for his assistance in drafting this report.

NCD would also like to thank NCD Chairperson Lex Frieden and former Chairpersons Joe Dusenbury, Sandra Swift Parrino, and Marca Bristo for their input.

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Introduction

Twenty years ago, a minuscule advisory body in the Department of Education (ED), known then as the National Council on the Handicapped, was elevated to the status of an independent federal agency. The legislation that made what is now called the National Council on Disability (NCD) independent also gave it an ambitious agenda that greatly exceeded its size and modest resources. Among other duties, it was charged with reviewing all federal laws and programs affecting people with disabilities and assessing the extent to which those laws and programs encouraged the establishment of community-based services; promoted full integration in the community, schools, and the workplace; and contributed to the independence and dignity of people with disabilities. NCD was then directed to use this assessment to recommend legislative proposals to increase incentives and eliminate disincentives in federal programs. Finally, NCD was to present this information in a report to the President and Congress. To complete this imposing task, NCD's 15 part-time Council members and its small staff were given two years.

These responsibilities were in addition to other ongoing, statutorily mandated duties such as establishing general policies for and overseeing research activities sponsored by the National Institute on Disability and Rehabilitation Research (NIDRR); reviewing and evaluating federal rehabilitation programs; and advising the President, Congress, the Commissioner of Rehabilitation, the appropriate Assistant Secretary of ED, and the Director of NIDRR on the development of programs carried out under the Rehabilitation Act. In periodic revisions to NCD's statutory mission, Congress has not only continued most of the original duties assigned to NCD but has added more. In 1992, for example, NCD was asked to "review and evaluate 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 the individuals to seek and retain employment."

Out of a profound sense of the importance of its mission, unwavering optimism about the future of Americans with disabilities, and perhaps, at times, an underestimation of the massive tasks it undertook, NCD has never shied away from its designated duties. NCD believes that this determination has produced an impressive body of accomplishments. In some ways, NCD has been a "mouse that roared." NCD is aware that during its 20 years it has been fortunate in having highly capable Council members, officers, and staff as well as the consistent support of Congress and the various administrations it has served.

The period since 1984 has been an important one in the evolution of the status and rights of people with disabilities in the United States. Although the 1970s have been characterized as a shift "from charity to rights," when individuals with disabilities sought to establish through court cases and protest actions that they were entitled to basic civil and human rights, the past two decades have seen equal opportunity, independent living, integration, and full participation—values specifically adopted in NCD's statutory purpose—emerge as the official

objectives of the Federal Government's laws, programs, and policies. Such progress has placed NCD front and center in offering recommendations for achieving these objectives and for identifying ways in which current efforts are falling short.

NCD's key contribution has been to serve as a focal point within the Federal Government for issues affecting people with disabilities. NCD fields thousands of telephone calls, e-mail messages, and letters each year from concerned individuals and organizations, and its award-winning Web site (www.ncd.gov) receives more than 4 million hits annually. NCD disseminates important disability-related information through its monthly *NCD Bulletin*, special mailings, articles, special reports, annual reports, brochures, position papers, alerts to other disability organizations, the Internet, and ongoing interaction with the news media.

No report of manageable size could cover all of NCD's activities and products. Accordingly, this report describes only the highlights and mentions some of the Council's most significant activities, publications, and initiatives. In doing so, the report must omit many significant NCD efforts. Just to cite two examples, the report does not attempt to describe the early and ongoing work that NCD has done to review and evaluate federal rehabilitation programs and to oversee and establish general policies for the research activities of NIDRR.

NCD believes that it has made a small but significant contribution to the evolution of American policy concerning individuals with disabilities. This report commemorates the high points and ongoing efforts of its 20 years of work as an independent federal agency, with a sense that much has been accomplished but much more remains to be done.

National Council on Disability Members and Staff During the Dusenbury Era

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Origins, Initial Configuration, and First Steps: The Dusenbury Era

A. Conceptual Sources

The concept of NCD existed at least as far back as 1972, when Congress introduced legislation to extend and expand the Vocational Rehabilitation program. The new provisions established (1) an Office for the Handicapped in the Department of Health, Education, and Welfare (DHEW) to analyze program operations, develop long-range projections for providing comprehensive services, encourage coordinated and cooperative planning, and promote scientific research to “bring about the full integration of handicapped individuals into all aspects of society”; (2) a National Advisory Council on Rehabilitation of Handicapped Individuals within DHEW to review the operation and administration of rehabilitation programs and provide policy advice to the Secretary of DHEW and the Commissioner of Rehabilitation Services; and (3) a National Commission on Transportation and Housing for Handicapped Individuals to identify and eliminate barriers to the mobility of individuals with disabilities and to develop proposals to promote adequate transportation and housing for such individuals. After President Nixon twice vetoed the legislation due to budgetary and programmatic concerns, Congress eliminated the proposed agencies as part of a legislative compromise with the President.

Similar ideas emerged from meetings of the White House Conference on Handicapped Individuals in May 1977, the first major opportunity for people with disabilities to have a voice in shaping policy for people with disabilities. Among the recommendations adopted by the delegates were partially overlapping calls for the appointment of (1) a presidential spokesperson on the handicapped, who would make recommendations to the President and speak with “a high degree of authority to government agencies and the public on issues related to handicapped persons”; (2) a special advisor to the President for affairs of the handicapped, who would communicate directly with the President and cabinet members, ensure interdepartmental cooperation and coordination, and influence recommendations and legislative proposals; and (3) a President’s Ombudsman Council, which would “establish a direct channel for all handicapped concerns to the highest office.” The proposal for presidential spokesperson expressly declared that “he or she should be independent of any existing agency or department.”

B. Creation of the Council Within DHEW

In the 1978 amendments to the Rehabilitation Act of 1973, Congress added a new title to the Act that established a National Council on the Handicapped within DHEW. The Council was made up of 15 presidential appointees and was charged with establishing general policies for, and reviewing the operation of, the newly created National Institute of Handicapped Research, later to be renamed the National Institute on Disability and Rehabilitation Research (NIDRR). The Council also advised DHEW and the Commissioner of Rehabilitation Services on rehabilitation policies and programs. In addition, the Council was assigned many of the broader duties that it would later retain as an independent federal agency. One of its responsibilities involved

reviewing and evaluating the effectiveness of “all policies, programs, and activities” concerning individuals with disabilities conducted or assisted by federal departments and agencies. The Council was also charged with making recommendations to the Secretary of DHEW, the Commissioner of Rehabilitation Services, and NIDRR respecting ways to improve research and administration of services, and with facilitating the implementation of programs based upon research findings. As a specific work product, the Council was directed to submit an annual report to the President, Congress, and the Secretary of DHEW containing a statement of the current status of research concerning people with disabilities in the United States, a review of the activities of the Rehabilitation Services Administration and NIDRR, and such recommendations as the Council considered appropriate.

The first chairperson of the Council was Dr. Howard Rusk, a rehabilitation pioneer and founder of the Institute of Rehabilitation Medicine at New York University Medical Center. He was appointed by President Jimmy Carter on November 6, 1979. On May 1, 1980, President Carter appointed the remaining members: Elizabeth M. Boggs, Mary P. Chambers, Nelba R. Chavez, Jack G. Duncan, Nanette Fabray, Donald E. Galvin, Judith E. Heumann, John P. Hourihan, Thomas C. Joe, Odessa Komer, Edwin O. Opheim, J. David Webb, and Henry Williams. Primarily, staff was detailed from ED. When President Reagan took office in 1981, he replaced the existing Council with new members. On October 4, 1982, he selected as chairperson of the Council Joe Dusenbury, previously the commissioner of the South Carolina Vocational Rehabilitation Services and president of the National Rehabilitation Association.

C. Chairperson Dusenbury and the *National Policy for Persons with Disabilities*

After becoming chairperson, Joe Dusenbury appointed two vice chairpersons—Justin Dart and Sandra Swift Parrino—to help direct Council activities. The Council members turned immediately to the task of the annual report, and decided that they should develop an ambitious proposal for disability policy. They also decided that if the report were to have any legitimacy, it needed to be the product of a nationwide effort based on grassroots input. Accordingly, Justin Dart began conducting consumer forums around the country—the first of many such campaigns. Using his own funds, Dart traveled to every state to discuss disability policy and obtain feedback for the Council’s policy report. He met with more than 2,000 people, including people with disabilities and their parents, government officials, disability professionals, and other interested individuals. Among the most frequently cited problems forum participants described were discrimination and the inadequacy of laws to protect the rights of people with disabilities.

Dart and Dusenbury took the feedback from the public forums to heart in designing the NCD report, in which the spirit and content of human, civil, and disability rights are pervasive. People throughout the country reviewed various iterations of the document, ensuring that the final product was truly national in origin. Adopted by unanimous vote of the Council in August 1983, the *National Policy for Persons with Disabilities* built on the independent living philosophy: the pursuit of “maximum independence, self-reliance, productivity, quality of life potential and equitable mainstream social participation.” Although individuals must assume primary

responsibility for their lives, the report said, the Federal Government had a critical role to play. The report identified 22 different policy areas in need of attention, including accessibility issues, employment, education, and research. Part of the government's obligation, the report contended, was "to develop a comprehensive, internally unified body of disability-related law which guarantees and enforces equal rights and provides opportunities for individuals with disabilities." As the report declared, "In matters of fundamental human rights, there must be no retreat."

In a letter to the Council after receiving the *National Policy*, President Reagan declared:

The fact that so much care was taken to include the concerns of handicapped individuals across America makes this a valuable document. It will provide us with the guidance needed as we chart our course through the Decade of the Disabled and beyond. We must all work together to make sure that people with disabilities achieve the greatest possible access to our society, find maximum independence, and have the opportunity to develop and use their capabilities.

In addition to developing the *National Policy*, Chairperson Dusenbury, along with then-Executive Director Harvey Hirshi, advocated that the Council should be made an independent agency, so that it could exercise its judgment without bureaucratic interference and restraints. Congress granted this request in the 1984 amendments to the Rehabilitation Act, explaining that "the Council has not been able to meet congressional intent for an independent body to advise on all matters in the Government affecting handicapped individuals."

D. Perspectives of Chairperson Dusenbury

As I think back on my years on the Council, I give Ronald Reagan great credit for agreeing to appoint a group of unselfish and unwavering advocates for people with disabilities. I take full credit for choosing Justin Dart and Sandra Swift Parrino as vice chairpersons. Both were known for their persistence and supported the idea of a national policy on disability. We organized the Council into committees, and every member of the Council bought into the plan to involve the disabled community in the creation of a national policy statement. Justin Dart visited every state to get input. The Council put the statement together and took great pride in forwarding the statement to the White House. All members of Congress received copies.

Congress intended the Council to be independent, but some members of the administration wanted the Council to be an advisory body to ED, which at that time was itself in jeopardy. They refused to allow us much leeway, and it became apparent that the Council must become independent if it were to succeed in fulfilling the congressional mandate. Key members of the House and Senate from both political parties supported independence, and at our request they got the legislation passed.

The Council accomplished much during my time as chairperson, but I consider establishing the Council as an independent federal agency to be my greatest accomplishment.

National Council on Disability Members and Staff During the Parrino Era

Members

Sandra Swift Parrino, Chairperson
Justin W. Dart Jr., Vice Chairperson
Hunt Hamill, Vice Chairperson
Kent Waldrep Jr., Vice Chairperson

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H. Latham Breunig, Ph.D.
Larry Brown, Jr.
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Mary Ann Mobley Collins
Joe S. Dusenbury
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Deborah Shuck, Staff Assistant
Joyce Turner, Secretary
Lorraine Williams, Student Assistant

Toward Independence: The Parrino Era and the ADA Proposal

A. The Council as an Independent Federal Agency

The Council became an independent agency within the Federal Government on February 22, 1984. Although he had played a key role in bringing about the Council's independence, Joe Dusenbury did not chair the agency in its new status. Before the Council realized its independence, President Reagan named one of the former vice chairpersons, Sandra Swift Parrino, to be the new chairperson.

In granting the Council independence, Congress recognized the potential for a centralized evaluation of a patchwork of disability programs as had been recommended by the White House Conference on Handicapped Individuals. Accordingly, the 1984 law that made the Council an independent agency also mandated that it produce a comprehensive analysis of federal disability programs and policy by February 1, 1986. To some extent, interested members of Congress viewed the 1986 report as a test of the Council's mettle that would determine its future and continued funding. Chairperson Parrino felt that the Council's reputation—indeed, its very existence—would depend largely on the reception the report received in the White House and on Capitol Hill.

Congress called for the report to present a “priority listing” of federal disability programs according to the number of individuals served and the programs' costs. To determine whether the Federal Government was promoting dependence or independence for people with disabilities, Congress also directed the Council to assess the degree to which federal disability programs promote or discourage the establishment of community-based services for individuals with disabilities, their integration into the community, schools, and the workplace; and their independence and dignity.

Representative Steve Bartlett (R-TX) appeared before the Council on April 30, 1984, to explain the significance of the challenge that lay ahead. “You are to advise Congress in a whole new approach, a whole new concept,” he said, “on how to decrease dependence and increase independence.” This, Bartlett suggested, represented what the disability community knew and what Congress was only reluctantly recognizing: “Sometimes federal laws or provisions in federal laws are the worst enemy of independence.” According to NCD's minutes, Bartlett emphasized that “Congress is not looking for more programs, more maintenance grants, and larger appropriations.” Instead, the Council should “look for ways to convert existing maintenance dollars to help recipients achieve independence.” Patricia Owens, associate commissioner for disability in the Social Security Administration, reinforced this approach in an appearance before the Council, saying, “The administration wants a program that encourages people to return to work.” Disability policy therefore involved more than just improving the lives of persons with disabilities; curtailing dependence would also help minimize the federal cost of

disability. By reviewing federal programs, the Council's proposals might actually reduce government expenditures.

B. Initial Steps

The Council, although officially independent, remained part of the Federal Government, subject to the administration, which controlled its financial disbursements and supplied many of its administrative needs, and to Congress, which controlled both its statutory mission and its appropriations. The Council's transformation to independent agency status, however, heralded a decisive shift. Congress had now prioritized recommendations concerning the entire sweep of disability policy over such particularized responsibilities as overseeing NIDRR. In addition, the Council's new identity as an independent think tank gave disability issues enhanced stature as a major policy area. "For the first time, disability as an issue is institutionalized, by statute, in the structure of the Federal Government," said John Doyle, who left his post with the Senate Subcommittee on the Handicapped for six months to help the Council in its transition. The actions of the disability community were clearly gaining attention, and the themes of independence and community integration were working their way into national policy directives. The agency had truly become a "National Council" on disability. (Although it was not until 1988 that the agency's name was changed from the National Council on the Handicapped to the National Council on Disability, this report uses the acronym NCD to describe the Council from its inception as an independent federal agency.)

Chairperson Parrino welcomed the heightened responsibilities for NCD. Under her leadership, the Council met quarterly to advance its ambitious statutory responsibilities. Shortly before the Council officially became independent, Parrino and Vice Chairperson Justin Dart Jr. recruited Lex Frieden, an independent-living leader who had founded the Independent Living Research Utilization Program, to serve as the Council's executive director. Frieden assumed NCD's reins in December 1984 and immediately turned to the task of finding high-quality staff to support him. He hired Ethel Briggs, who had extensive experience in vocational rehabilitation, as an adult services specialist. (Years later—beginning in April 1990—she would become NCD's executive director.) Attorney Robert L. Burgdorf Jr. filled the research specialist position, and Naomi Karp, on detail from NIHR, joined the staff as children's services specialist. Joyce Turner was hired as secretary; then, after a few months, Brenda Bratton assumed the job. Marilynne Gisin continued in her previous role as executive assistant. Having acquired independence, additional staff, and a \$500,000 budget, NCD was now able to face its growing responsibilities with increased zeal.

NCD's quarterly meetings were held around the country, often in conjunction with "consumer forums" designed to solicit the views of those in the disability community. Although NCD attended to the requirements to monitor NIDRR and RSA and considered various initiatives raised by its members, it increasingly turned its attention to preparing the 1986 report, which imposed heightened work demands.

C. The *Toward Independence* Report

At the quarterly NCD meeting on January 23, 1985, Chairperson Parrino declared that “the contribution of this Council and its continued existence will rest almost entirely on the content of our February 1986 Report to the President and how it is judged by the president and the Congress.” She urged NCD members to unite in a common purpose and pledge their support. In April, recognizing that preparation for NCD meetings and consumer forums dominated NCD’s time, Frieden convinced the Council to clear the table and focus almost exclusively on the report.

As a foundation for developing the report, NCD had made significant efforts to obtain grassroots input. As in 1982, Justin Dart personally financed another series of public forums, visiting every state to learn what issues were most important to people with disabilities. The Council sought additional information on the status and views of Americans with disabilities. At the time, no substantive national survey data on people with disabilities existed. Noting this gap, Council member Jeremiah Milbank suggested a national poll of people with disabilities. With the assent of the other NCD members, Milbank contacted the polling agency Louis Harris and Associates, which agreed to conduct the study. NCD staff and members, along with other experts in the disability community, contributed to the development of the questions and structure of the survey. The International Center for the Disabled (ICD), for which Milbank served as Chairman of the Board, provided most of the funding. Preliminary data and findings of the survey helped inform NCD’s 1986 report. The final, official version of the survey report, *The ICD Survey of Disabled Americans: Bringing Disabled Americans into the Mainstream*, was published in March 1986.

“The purpose of the survey,” explained ICD Executive Director John Wingate, “was to obtain data on disabled people’s experiences and attitudes that would provide a clear information framework of NCD’s recommendations on public policy for disabled people.” The nationwide survey was based on 1,000 telephone interviews with a national sample of noninstitutionalized persons with disabilities aged 16 and older. Although other organizations had conducted surveys of people with disabilities, this was the first comprehensive national survey that solicited their own perceptions of their conditions, their obstacles, and their quality of life. It provided solid data documenting the extent of the problems faced by people with disabilities and unearthed fruitful directions for policy development.

The Harris poll report presented a series of significant, quantified findings about Americans with disabilities:

- 40 percent did not finish high school, compared with 15 percent in the nondisabled population.
- 50 percent reported annual household incomes less than \$15,000, compared with 25 percent among the nondisabled population.
- 56 percent reported that disability prevented desired levels of social and community participation.

- 49 percent identified lack of transportation as a barrier to social and community participation.
- 67 percent aged 16 to 64 were not working; 66 percent of those not working said they would like to be employed.
- 95 percent advocated increased public and private efforts to educate, train, and employ people with disabilities.
- 74 percent supported implementing antidiscrimination laws affording disabled people the same protections as other minorities.

Such findings documented what were previously subjective assessments. The survey was a ringing endorsement of initiatives to help Americans with disabilities find work and live independent lives. The poll affixed numbers to real and pressing problems and provided a sound foundation for NCD's recommendations.

In June, NCD members held working sessions to determine the focus of Council's report. To make the scope of the report manageable, Frieden and Burgdorf presented Council members with a list of 41 potential topics and recommended that they choose 8 to 10 of them. Drawing on the issues addressed in the 1983 *National Policy for Persons with Disabilities* as well as the input received at consumer forums, the Council pared down the list of potential topics to 10: equal opportunity laws, employment, disincentives to work under Social Security laws, prevention of disabilities, transportation, housing, community-based services for independent living, educating children with disabilities, personal assistant services, and coordination of disability services and programs. Council members noted that the first topic was consistently discussed at the consumer forums and declared it to be of "central importance." However, to make the concept more palatable to a wider audience, including the Reagan administration, Burgdorf recast the issue as "equal opportunity laws" rather than as "civil rights."

After the Council members chose the 10 topic areas, Frieden assigned staffers and a few consultants to develop detailed papers on each of the topics; these papers were to document problems and present draft recommendations for solutions to the President and Congress. The topic papers were then presented to the Council members for their feedback and revision. During 1985, NCD devoted its consumer forums to soliciting feedback about the various topic papers. In addition, Frieden regularly consulted with disability organizations from around the country. The extensive, nationwide outreach helped give the disability community a sense of ownership of NCD's activities and its upcoming report. By the end of 1985, NCD had crafted more than 400 pages of policy analyses that it would ultimately publish as a detailed appendix to the 1986 report. Because of logistical problems posed by meeting only four times a year, much of the responsibility for designing the structure and overall form of the report fell to Frieden and Burgdorf, under the guidance of the Council's officers.

In January 1986 Burgdorf, at Frieden's direction, synthesized the topic papers into a short, readable report presenting 45 recommendations to the President and Congress. Following NCD's statutory directive, the report included a "List of Federal Programs Affecting Persons with Disabilities in Order of Expenditure," which was developed by NCD consultant Frank Bowe.

One fact that the list brought to light was that the annual federal expenditure on disability benefits and programs was more than \$60 billion, of which more than \$57 billion was going to public aid programs. Such programs are premised on the dependency of the people who receive benefits, in that eligibility is based on their inability to engage in substantial gainful activity or their significantly low income. This finding provided an economic rationale for the report's recommendations. In her cover letter transmitting the report to the President and congressional leaders, Chairperson Parrino indicated that, by following the Council's recommendations, "current federal expenditures for disability can be significantly redirected from dependency-related approaches to programs that enhance independence and productivity of people with disabilities, thereby engendering future efficiencies in federal spending."

Based on its assessment of federal laws and programs, NCD drew three general conclusions:

1. Approximately two-thirds of working-age people with disabilities do not receive Social Security or other public assistance income.
2. Federal disability programs overemphasize income support and underemphasize initiatives for equal opportunity, independence, prevention, and self-sufficiency.
3. Federal policy should emphasize programs that encourage and assist private-sector efforts to promote opportunities and independence for individuals with disabilities.

At the suggestion of Council member Jeremiah Milbank Jr., the report also featured a large fold-out chart portraying key federal programs serving people with disabilities and their corresponding legislative committees. The chart illustrated the pervasiveness and complexity of federal programs affecting people with disabilities. The core of the report addressed the 10 topic areas NCD had selected. Each section presented a brief overview of the problems being addressed and then laid out NCD's recommendations, followed by a succinct rationale and explanation that represented a distillation of the more detailed explanation and commentary provided on each topic. The 45 recommendations represented the best current ideas on addressing problems in each topic area.

The report's primary recommendation was for the advancement of equal opportunity laws for people with disabilities. Although Congress had previously enacted some narrow antidiscrimination laws protecting people with disabilities, the report noted that such laws paled in comparison to federal measures prohibiting race and gender discrimination. NCD therefore proposed that Congress "enact a comprehensive law requiring equal opportunity for individuals with disabilities, with broad coverage and setting clear, consistent, and enforceable standards prohibiting discrimination on the basis of handicap." The proposal also delineated what such a law should entail. NCD member Kent Waldrep even suggested a name for such a law—the Americans with Disabilities Act (ADA).

The report's title, *Toward Independence*, echoed the subtitle of a book by disability rights advocate and NCD consultant Frank Bowe, *Rehabilitating America: Toward Independence for Disabled and Elderly People*. The title therefore not only reflected NCD's statutory mandate to assess the extent to which federal programs "contribute to the independence and dignity" of individuals with disabilities but also signified NCD's endorsement of the independent living philosophy that had emerged within the disability community. NCD viewed facilitating independence through equal participation as the overriding objective of its recommendations.

Ethel Briggs worked with the staff at the U.S. Government Printing Office (GPO) to ensure that *Toward Independence* and its large appendix would be printed in a timely fashion and would be included in GPO's *Catalog of U.S. Government Publications*.

NCD officially presented *Toward Independence*, accompanied by letters of transmittal, to President Reagan, Vice President and President of the Senate George H. W. Bush, and Speaker of the House James C. Wright on February 1, 1986. NCD also scheduled a press release for January 28, 1986. On that day, however, media attention was focused on the explosion of the space shuttle *Challenger*. The *Challenger* tragedy also caused the cancellation of another scheduled Council function: a meeting with President Reagan to present the report in person. Consequently, Vice President Bush and White House adviser Boyden Gray met with Parrino, Dart, Milbank, and Frieden. The Vice President displayed considerable interest in NCD's report. A scheduled 10-minute photo-op evolved into a substantive discussion that lasted nearly an hour. Mr. Bush recounted his personal experience with the disabilities of family members. He also showed himself to be familiar with the content of the report, talking about education and equal opportunity laws in detail. The meeting ended with the Vice President's promise that he would pass the report along to President Reagan.

Although NCD's planned press conference and meeting with President Reagan were canceled, the agency's third public relations event went on as planned: a reception on Capitol Hill, where many members of Congress gathered to accept the report. Senator Lowell Weicker, Senator Paul Simon, Representative Steve Bartlett, and Representative Major Owens, among others, offered remarks. NCD ultimately distributed more than 20,000 copies of *Toward Independence* to legislators, government officials, disability advocates, and disability organizations. As NCD Executive Director Paul Hearne, Frieden's successor, observed in 1988, NCD's preparation of *Toward Independence* and instigation of the *ICD Survey* helped "put the Council on the map."

Although the report was completed on time, Frieden had hired Frank Bowe to write another report in case the staff report was not completed by the deadline established by Congress.

D. From *Toward Independence* to *On the Threshold* and the Draft ADA

In fall 1986, Congress amended the statutory provisions governing NCD. It clarified NCD's overall mission as follows: "The purpose of the National Council is to promote the full integration, independence, and productivity of handicapped individuals in the community,

schools, the workplace and all other aspects of American life.” It also gave NCD a specific directive to issue by January 30, 1988, and annually thereafter, a report to the President and the Congress “on the progress that has been made in implementing the recommendations contained in ... *Toward Independence*.” Frieden assigned Dr. Andrea Farbman, NCD’s public affairs specialist, the lead responsibility for developing the 1988 report. The report, *On the Threshold of Independence*, was issued on January 29, 1988, beating the statutorily imposed deadline by one day.

On the Threshold examined the reception given to the *Toward Independence* report and summarized recent statistical data, including information derived from the 1986 Harris poll and a second such poll of employers. The report then reviewed the 10 topic areas addressed in *Toward Independence* and described accomplishments or significant developments in each area.

NCD found that about 80 percent of the 45 recommendations offered in *Toward Independence* had been either partially or fully accomplished. *On the Threshold* noted, however, that although “[m]any doors to independence have been opened, others remain closed or only partially opened.” Despite the apparent progress, a glaring exception was the Council’s primary recommendation to enact a comprehensive federal law prohibiting discrimination on the basis of disability. Congress had not responded at all to this recommendation.

After seeing no progress on the ADA recommendation for nearly a year, Council members became impatient. They concluded that the only way to overcome legislative inertia was for NCD to take the lead. At one point, Chairperson Parrino asked Burgdorf whether he could draft such a law for the Council; he responded that he would welcome the opportunity. The framework for such a law was already sketched out in some ways. In 1984, Burgdorf and Chris Bell had published a “statutory blueprint” for such a law in the American Bar Association’s *Mental and Physical Disability Law Reporter*. In *Toward Independence*, Burgdorf had expanded on the blueprint by specifying various elements that the law should include. Early in 1987, Burgdorf began drafting an ADA bill. In the ensuing months, NCD members reviewed draft after draft of the proposal. By August 1987, they had accepted an internal draft of the bill and began circulating it to various stakeholders and disability rights experts for their input, and, it was hoped, their support.

NCD’s initial plan was to hand over its ADA proposal to some supportive member or members of Congress who could then claim responsibility for having drafted the legislation. This approach bogged down, however, when legislators, unsure of the breadth of support for the ADA proposal, were reluctant to take the forefront. As the press deadline for the 1988 report neared, the Council decided to include the ADA draft in *On the Threshold*. Once it was featured prominently in the report, the text of the ADA legislative proposal attracted the attention of grassroots members of the disability community, who asked their organizations and their congressional representatives to take a position in favor of it.

For congressional sponsorship, Parrino turned first to Senator Weicker, who was one of the disability community’s greatest supporters in the Senate and with whom NCD had a

longstanding relationship. Early in 1987, during a meeting with Parrino, Weicker had indicated a willingness to support disability rights legislation if NCD drafted a proposal. After *On the Threshold of Independence* came out, he agreed to sponsor the bill. For the ADA to succeed, Weicker emphasized that the bill would have to be introduced simultaneously in both houses of Congress. He recommended that NCD contact Representative Tony Coelho, a high-ranking member of the House leadership who had epilepsy and had encountered discrimination firsthand. Chairperson Parrino and Council member Roxanne Vierra met with Coelho, who agreed to sponsor the legislation in the House. After NCD made some revisions to the legislation at the suggestion of the members of Congress and of Washington disability groups, Weicker and Coelho introduced the Americans with Disabilities Act bills in April 1988.

In his April 28, 1988, introductory remarks, Senator Weicker called the legislation “historic,” and said that it “will establish a broad-scoped prohibition of discrimination and will describe specific methods by which such discrimination is to be eliminated.” He compared the conditions faced by people with disabilities to those faced by minorities in the 1960s. Congress had responded by enacting civil rights laws that prohibited discrimination because of race or national origin in access to public accommodations, use of transit, employment opportunities, services of state and local governments, and housing. “Yet, today,” Weicker noted, “it is not unlawful for these same establishments to exclude, mistreat, or otherwise discriminate against people because of their disabilities.” He contended that discrimination on the basis of disability was “just as intolerable as other types of discrimination that our civil rights laws forbid.” The following day, Representative Coelho joined Weicker by introducing an identical bill to the floor of the House of Representatives. Civil rights for persons with disabilities had entered the national legislative agenda.

E. NCD’s Role in Passage of the ADA

Although in many ways the ADA’s introduction in Congress amounted to passing the baton from NCD to congressional sponsors and the disability community, NCD’s role did not end there. At several stages, current and former NCD members and staff persons played significant roles in moving the legislation ahead. Although NCD could present legislative proposals and justify its recommendations by offering “technical information,” federal law at the time prevented employees of federal agencies from personally lobbying members of Congress. In lieu of formal lobbying, NCD members made presentations in their hometowns and in their professional circles. Chairperson Parrino met extensively with officials in the White House and helped pave the way for favorable action on the ADA by the Bush administration. She also presented important congressional testimony on several occasions.

The ADA was introduced too late in the 100th Congress to have any serious chance of passage. The most that could be hoped for was to have congressional hearings to focus attention on the discrimination encountered by people with disabilities and to highlight the need for legislation to address the problem. These hopes were fulfilled on September 27, 1988, when Chairperson

Parrino testified at a joint congressional hearing. The senators and representatives present for the hearing congratulated Parrino and the Council for developing the ADA bill.

In November 1988, NCD issued *Implications for Federal Policy of the 1986 Harris Survey of Americans with Disabilities*. The report examined the Harris poll results in detail and made 31 policy recommendations based on the data collected in the poll. The report found that the responses documented the existence of discrimination in the job market and workplace, in educational opportunities, in access to public buildings and public bathrooms, in transportation, in insurance, and in social person-to-person contacts. NCD also noted that “[t]he survey found great support for legal protection against discrimination on the basis of disability,” with 75 percent of participants responding in favor of such protection. The report also found that 68 percent of Americans with disabilities were unaware of the limited civil rights protection that was then available to them. Such data buttressed NCD’s conviction that the ADA was needed; accordingly, NCD made a strong recommendation: “Congress should enact the Americans with Disabilities Act of 1988 to establish a strong and clear requirement of equal opportunity for individuals with disabilities, paralleling the civil rights protections afforded other minorities and women.”

When the 100th Congress expired without either house acting on the ADA legislation, various efforts were begun to prepare the legislation for enactment during the next Congress. One such initiative was Representative Major Owens’ Congressional Task Force on the Rights and Empowerment of Americans with Disabilities, which sought to gather evidence on the extent and nature of discrimination on the basis of disability. The chairperson of the Task Force was former NCD Vice Chairperson Justin Dart, its coordinator was former NCD Executive Director Lex Frieden, and Sandra Swift Parrino was a member.

Before reintroducing the ADA legislation in the 101st Congress, congressional supporters, in consultation with national disability consumer organizations, revised the proposal, adding specificity and some policy compromises. The revised ADA bills were introduced in the new Congress on May 9, 1989, with Senator Tom Harkin as the sponsor in the Senate and Representative Coelho as the sponsor in the House of Representatives. Eventually, both houses passed the legislation, and, after two joint conference committees to reconcile differences between the Senate and House, the House approved the final version of the bill on July 12, 1990, and the Senate followed suit on July 13, 1990.

When President Bush signed the ADA into law on July 26, 1990, Parrino and Dart were next to him on the dais. Many former and current members and staff of NCD were among the more than 3,000 spectators who gathered on the South Lawn of the White House for the signing ceremony. In his signing statement and remarks, the President described how as Vice President he had “personally accepted” the *Toward Independence* report, credited NCD for its role in developing the ADA, and specifically acknowledged both Dart and Parrino. He praised the ADA as an “historic new civil rights Act . . . the world’s first comprehensive declaration of equality for people with disabilities.”

F. International Advocacy

Chairperson Parrino and Executive Director Ethel D. Briggs represented the United States at many international meetings, including the Meeting of Experts in Finland and China. The Standards for Equalization of Opportunities for Persons with Disabilities were drafted at the meeting in Finland. NCD represented the United States at the United Nations Center for Social Development in Vienna several times. In 1990, 1991, and 1992, Parrino was a delegate at the Third Committee on Social Development at the United Nations. In 1991, the People's Republic of China invited NCD to assist it in its efforts to help people with disabilities. As the request of the government of Czechoslovakia, NCD was invited to conduct the Eastern European Conference on Disabilities for participants from Czechoslovakia, Hungary, and Poland.

G. Perspectives of Chairperson Parrino

I was chairperson of NCD from 1983 to 1993, beginning with a minuscule budget, one staff member, and a one-room office in the basement of the Department of Education's Switzer Building. The outstanding members of NCD took on the herculean task of meeting their obligations and fulfilling their federal mandate. Kent Waldrep served superbly as vice chairperson for my entire tenure, and I am deeply indebted to him for his insight, loyalty, and commitment. We all learned quickly how difficult it can be serving two masters, the President who appointed us and the Congress to whom we had to report to for our budget.

The Council was made up of a handful of disability activists appointed by the President and confirmed by the Senate. Every member who served during this time was either a person with a disability, the parent or spouse of a person with a disability, or a career professional in the field of disability; thus, all had firsthand experience with living with a disability in America.

With the help of Senator Lowell Weicker and others, NCD became an independent federal agency in 1984 under a new congressional mandate. This new status gave the Council the legitimacy and stature to define disability policy in America. Weicker staff member John Doyle was "loaned" to NCD for six months to get the Council up and running, and he did a superb job.

Despite a small budget and limited staff, NCD conducted public hearings and consumer forums across the country aimed at getting input from people with disabilities and effectively reviewing all federal laws and programs affecting persons with disabilities. Council member Justin Dart traveled across the country to discuss disability issues with consumers. The information gathered from these hearings and forums enabled Council members and Executive Director Lex Frieden to conclude that equal opportunity laws were urgently needed to protect the rights of people with disabilities and create a level playing field.

Another important achievement was the now famous Harris poll, the first-ever survey of people with disabilities. In 1986, Council member Jeremiah Milbank Jr. conceived the idea of the Harris poll and arranged independent financing for this groundbreaking survey. The Council brought in consumer advisors to work with Council members and staff on the survey.

In 1986, the Council presented to the President and Congress its landmark report *Toward Independence*, which recommended an equal opportunity law as a top priority. The legislation was then formulated by Council members and put into draft form by Robert Burgdorf Jr.

After receiving no feedback from Congress or the administration on the proposed antidiscrimination law, the Council began to develop a strategy to move its agenda forward. That agenda began with my visit to Senator Weicker in 1987 asking him to be the chief sponsor in the Senate of what was then called the Americans with Disabilities Act of 1986. Council member Roxanne Vierra and I paid a similar visit to Representative Tony Coelho and asked him to be the chief sponsor of the ADA in the House. The ADA legislation was dropped into the Senate and the House of Representatives in April 1988.

In 1988, the Council successfully influenced Congress to authorize and appropriate funds to create a nationwide Disability Prevention Program at the Centers for Disease Control. This effort was organized by Council member Michael Marge. This success led the agency to write the Disability Prevention Act of 1991 (the Silvio O. Conte Disabilities Act).

In addition to its mandated duties, NCD organized several important consumer advisory groups to work in the areas of civil rights, minorities, Native Americans, primary and secondary disability prevention, and personal attendant care.

I was honored to serve as chairperson of NCD under Presidents Reagan and Bush and privileged to work with the dedicated and gifted members of the Council, who are the unsung heroes of this celebration. This Council was the driving force behind the creation and passage of the ADA. On July 26, 1990, I was present on the podium at the White House ceremony when President Bush signed the ADA into law. I represented the Council members and staff who had worked so diligently on behalf of all Americans with disabilities.

National Council on Disability Members and Staff During the Bristo Era

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Janice Mack, Administrative Officer
Jamal Mazrui, Program Specialist

Moira Shea, Senior Legislative and Economic Advisor (on detail)
Pam O’Leary, Sign Language Interpreter
Brenda Bratton, Executive Secretary
Stacey S. Brown, Staff Assistant
Carla Nelson, Office Automation Clerk

Challenges in Achieving Independence: NCD Under Chairperson Bristo

In May 1994, President Clinton named Marca Bristo—the founder of Access Living, Illinois’ first independent living center—chairperson of NCD. NCD was entering its second decade as an independent federal agency. Its agenda in the previous decade had centered primarily on the policy proposals presented in the *National Policy for Persons with Disabilities and Toward Independence*. The first years of the 1990s were largely dominated by the enactment of the ADA and its various sections, the issuance of regulations to implement it, and early enforcement efforts. The early 1990s also produced an ADA backlash similar to that during the initial implementation of the Civil Rights Act in the 1960s. The principal expression of this backlash was found in the charge of some opponents that the ADA constituted an unfunded mandate. This, of course, revealed a fundamental misunderstanding of the ADA’s nature. The ADA is, at its core, civil rights legislation grounded in the freedoms guaranteed in the Bill of Rights. As such, the rights and freedoms codified in the ADA should not be subject to a debate on their cost any more than the rights of women, minorities, or religious groups would be. This fact was recognized in 1994 in the Senate debate regarding unfunded mandates.

NCD took the lead in countering this backlash by organizing a group of disability leaders and political appointees with disabilities. Part of the strategy included a media response team to share negative media portrayals and respond to each story. NCD also determined that it would visit every state, the District of Columbia, and the U.S. Virgin Islands to hear directly from consumers and those involved in ADA implementation about the degree to which the law has affected their quality of life. Through this serious and substantial outreach effort, the NCD hoped to determine whether, and how much, the ADA had changed the nature of American culture. Has a society in which people with disabilities historically did not have equal opportunities, were excluded, and were kept in dependency become a society in which people with disabilities have equal opportunities, are included, and are empowered both socially and economically? NCD also attempted to understand the nature of complaints lodged by critics of the ADA within the context of the actual life experiences of people with disabilities covered under the Act.

NCD’s 1995 report *Voices of Freedom: America Speaks Out on the ADA* concluded that the ADA was beginning to create positive and, at times, dramatic changes in the lives of people with disabilities. The backlash began to subside, and under Chairperson Bristo’s leadership, NCD undertook a number of ambitious initiatives.

A. The National Summit on Disability Policy

A priority of the new Council was a comprehensive reassessment of disability policy based on the input and perspectives of leaders in the disability community. Accordingly, NCD decided to host the National Summit on Disability Policy. The summit, attended by 300 disability leaders

from every state and the District of Columbia, took place from April 27 to April 29, 1996, in Dallas. People with a variety of disabilities and their families attended. About 20 percent of the participants were members of culturally diverse populations, including Native Americans, African Americans, Asian Americans, and Hispanic Americans. Participants represented disability organizations, service-providing organizations, academia, and federal, state, and local governments. Federal officials provided technical assistance and background information. The summit placed special emphasis on youth with disabilities; 20 people aged 13–22 participated fully, providing a glimpse of tomorrow’s leadership and invigorating the dialogue. Attendees assessed the status of disability policy and ADA enforcement in 1996.

Led by volunteer facilitators chosen from among the participants, summit participants met in policy working groups for three days. They were asked to address 11 policy areas chosen by NCD and a Summit Advisory Committee after a review of the topics addressed in *Toward Independence* and the priorities reported by the President’s Committee on Employment of People with Disabilities in *Operation People First*. The groups brainstormed their policy areas, assessing the current state of affairs and debating how future policy could best promote the goal of independence.

The summit was an example of democracy in action. Reminiscent in some ways of the 1977 White House Conference on Handicapped Individuals, the summit offered knowledgeable people from around the country the opportunity to provide direct input into the federal policy-making process. The attendees proved themselves effective and thoughtful analysts and contributors. The recommendations generated by the working groups were supplemented by suggestions from disability leaders who could not attend the summit and were reviewed and fine-tuned by NCD. The result was more than 120 recommendations in the 11 designated areas of disability policy.

B. The *Achieving Independence* Report

Out of the results of the National Summit on Disability Policy, NCD developed the report *Achieving Independence: The Challenge for the 21st Century*. The report assessed the nation’s progress in achieving equal opportunity and empowerment between 1986 and 1996 and presented recommendations that set an agenda for the next decade.

Based on the summit, NCD drew three broad conclusions about the state of disability policy in America:

1. Disability policy has made steady progress over the decade in empowering people with disabilities; however, this progress is threatened, compromised, and often undermined by a lack of understanding and support in the Congress and among particular segments of society.

2. Most public policy affecting people with disabilities does not yet promote the goals of ADA—equality of opportunity, full participation, independent living, and economic self-sufficiency.
3. Most Americans with disabilities remain outside the economic and social mainstream of American life.

In response to the shortcomings of current disability policy, NCD identified the following overarching themes that underpin the specific recommendations presented in the report:

1. Existing laws should be more vigorously enforced.
2. People with disabilities should direct policy and decision-making when they are affected by the outcome.
3. Outreach and awareness campaigns must be launched to educate the public about the human and societal benefits of achieving independence for people with disabilities and the important role that civil rights and community-based supports play in promoting independence.
4. Incentives for the inclusion of people with disabilities in all aspects of society must be further developed and implemented.
5. Principles of universal design should be universally applied.
6. Systems, services, and supports for people with disabilities must be further developed as a part of the mainstream of community life.
7. Accurate data about people with disabilities should be regularly collected, analyzed, and reported.

After presenting disability demographics and discussing some basic concepts of independent living, disability rights, and disability culture, the body of the report presented an assessed disability policy in 11 areas: policy coordination, civil rights, education, employment, Social Security and other income maintenance, health insurance and health care, long-term services in the community, technology, housing, transportation, and international issues. In each of these areas, the report presented specific recommendations. Summit participants also had the opportunity to organize additional groups to discuss emerging issues or issues not sufficiently included in the 11 policy areas. The discussions of nine of these groups were summarized in an appendix to the report: multiple chemical sensitivities, complementary medicine, Native Americans, crossover between health care and long-term services, targeted versus integrated managed care, research, disability culture, physician-assisted suicide, and genetics issues.

In discussing future challenges, *Achieving Independence* sounded an optimistic note:

Advances in policy, science and technology are available to support independence as never before. The challenge of achieving independence is a challenge of mustering the political will to move forward. Progress requires a dedicated commitment from all sectors of society—policy makers, people with disabilities and their allies, state and local government officials, nonprofit organizations, the private sector and the media. The achievement of independence for people with disabilities is a test of the very tenets of our democracy. It is a test we can pass.

C. The Disability Civil Rights Monitoring Project

One of the primary themes to emerge from the National Summit on Disability Policy was the need for stronger and more consistent enforcement of federal civil rights laws for people with disabilities. In fact, the overarching recommendation from the summit was that existing civil rights laws should be more vigorously enforced. The participants recommended that NCD should

- work with the responsible federal agencies to develop strategies for greater enforcement of existing disability civil rights laws “consistent with the philosophy of” the ADA; and
- continue working “toward elimination of contradictory laws, regulations and programs [and] promote coordination and commonality of goals across agencies.”

In response to these recommendations, NCD launched a policy initiative in 1997 called the Disability Civil Rights Monitoring Project. In carrying out this monitoring effort, NCD undertook in-depth studies of federal enforcement of disability civil rights laws in the areas of education, equal opportunity, ADA, employment, public accommodations, housing, air travel, and Internet technology.

NCD initially focused on the Federal Government’s compliance, enforcement, and public information efforts regarding the ADA, Part B of the Individuals with Disabilities Education Act (IDEA), the Air Carrier Access Act of 1986 (ACAA), Section 504 of the Rehabilitation Act, and the Fair Housing Act as amended by the Fair Housing Amendments Act of 1988. NCD selected the Disability Rights Education and Defense Fund to conduct an assessment and to develop a draft report on federal enforcement of the ADA, Part B of IDEA, and the ACAA. For the Fair Housing Act, NCD contracted with the National Fair Housing Alliance and the Bazelon Center for Mental Health Law. Based on the material developed by these contractors, NCD produced reports that came to be referred to collectively as the Unequal Protection Under Law series.

On March 18, 1999, NCD produced its first report in the series, *Enforcing the Civil Rights of Air Travelers with Disabilities: Recommendations for the Department of Transportation and Congress*. The ACAA prohibits discrimination against people with disabilities in the provision of air transportation services and is enforced by the U.S. Department of Transportation (DOT). It applies to most domestic U.S. carriers and airports as well as the contractors they employ who serve the public. Overall, NCD found that “although things have improved since ACAA was

passed in 1986, people with disabilities continue to encounter frequent, significant violations of the statute and regulations. When they complain, they encounter an enforcement effort that is both inconsistent and limited in scope.” The report identified deficits both in the statute itself and in DOT’s enforcement activities. It was sharply critical of DOT’s performance, declaring that “ACAA implementation and enforcement efforts over the past 12 years have been so lacking in several essential areas as to constitute nonenforcement.” It identified “an extreme lack of resources” as having undermined “DOT’s capacity to develop and maintain a credible enforcement program or to adequately support ACAA implementation.” The report declared flatly that “DOT’s budget and staff for ACAA enforcement are drastically inadequate.”

To correct the deficiencies it had identified, NCD made 30 recommendations. In addition to better funding and increased involvement of people with disabilities in DOT’s policy-making and rule-making processes, the report offered specific recommendations for structural, administrative, policy, and regulatory improvements in ACAA enforcement activities. The report also concluded that, in part because DOT’s regulation and enforcement mechanism was so weak, an effective private right of action for violations of the ACAA was especially important: “If ACAA’s nondiscrimination mandate is to be realized, the disability community will have to use private right of action to create effective incentives.” Accordingly, NCD recommended that Congress should amend the ACAA to

- establish a statutory private right of action and permit the award of attorney’s fees and compensatory and punitive damages to successful plaintiffs;
- authorize the Access Board, in consultation with the Federal Aviation Administration (FAA), to develop standards for accessible cabin interiors and for any equipment related to air travel access, including boarding assistance equipment;
- expand DOT’s authority to conduct public education activities geared to consumers with disabilities and the general public, conduct regular ACAA compliance monitoring with the airlines, levy fines when an individual informal complaint investigation indicates that a violation has occurred, and to impose civil penalties for findings of pattern and practice violations; and
- include foreign air carriers operating in the U.S. travel market and using U.S. airport facilities within the scope of the law and its implementing regulation.

The second report growing out of the Disability Civil Rights Monitoring Project, *Back to School on Civil Rights*, was issued on January 25, 2000, and addressed enforcement of IDEA. Overall, NCD found that “federal efforts to enforce the law over several administrations have been inconsistent, ineffective, and lacking any real teeth.” It found that states had failed to ensure compliance with the core civil rights requirements of IDEA at the local level and that children with disabilities and their families were far too often required to file complaints to ensure compliance with the law. It took the Federal Government to task for “fail[ing] to take effective action to enforce the civil rights protections of IDEA when federal officials determine that states

have failed to ensure compliance with the law.” Also, despite recent improvements, ED’s “formal enforcement of IDEA has been very limited.”

After reviewing ED’s monitoring reports of states between 1994 and 1998, NCD found that

Every state was out of compliance with IDEA requirements to some degree; in the sampling of states studied, noncompliance persisted over many years.

Notwithstanding federal monitoring reports documenting widespread noncompliance, enforcement of the law is the burden of parents who too often must invoke formal complaint procedures and due process hearings, including expensive and time-consuming litigation, to obtain the appropriate services and supports to which their children are entitled under the law. Many parents with limited resources are unable to challenge violations successfully when they occur. Even parents with significant resources are hard-pressed to prevail over state education agencies (SEA) and local education agencies (LEA) when they or their publicly financed attorneys choose to be recalcitrant.

The Department of Education has made very limited use of its authority to impose enforcement sanctions such as withholding of funds or making referrals to the Department of Justice, despite persistent failures to ensure compliance in many states.

ED has not made known to the states and the public any objective criteria for using enforcement sanctions, so that the relationship between findings of noncompliance by federal monitors and a decision to apply sanctions is not clear.

Back to School on Civil Rights presented an array of recommendations to the President and Congress to advance a more aggressive, credible, and meaningful federal approach to enforcing IDEA. Key among these recommendations was that Congress should amend IDEA to create a complaint-handling process administered by the Department of Justice (DOJ) to address systemic violations; provide DOJ with independent authority to investigate and litigate IDEA cases; and require ED and DOJ to consult with students with disabilities, their parents, and other stakeholders to develop objective criteria for defining “substantial noncompliance,” the point at which a state that fails to ensure compliance with IDEA’s requirements is referred to DOJ for legal action. The report also recommended that ED

- establish and use national compliance standards and objective measures for assessing state progress toward better performance outcomes for children with disabilities and for achieving full compliance with IDEA, and
- develop a range of enforcement sanctions to be triggered by specific indicators and measures indicating a state’s failure to ensure compliance.

The report also proposed that an amount equal to 10 percent of any increase in funding under Part B of IDEA should be allocated to DOJ and ED to enhance enforcement, complaint handling, and technical assistance infrastructure.

The third report generated by the Disability Civil Rights Monitoring Project, *Promises to Keep: A Decade of Federal Enforcement of the Americans with Disabilities Act*, was released on June 27, 2000. This report addressed federal compliance, enforcement, technical assistance, and public information activities for Titles I through IV of the Americans with Disabilities Act. It examined DOJ's ADA enforcement activities, the Equal Employment Opportunity Commission (EEOC), DOT, and the Federal Communications Commission. For each agency, the report reviewed

- complaint processing methodologies and their outcomes,
- proactive compliance activities,
- regulatory and policy development activities,
- litigation activities and the focus and impact of litigation choices,
- administrative organization for enforcement,
- staff training for ADA enforcement,
- technical assistance activities and public information aimed at covered entities and at people with disabilities, and
- leadership in addressing key issues of ADA interpretation and enforcement as new issues surface and in response to the interests and needs of the disability community.

The report also discussed the ADA technical assistance activities of three additional agencies: the Architectural and Transportation Barriers Compliance Board (Access Board), NIDRR, and the President's Committee on the Employment of People with Disabilities.

NCD found that although the Executive Branch had consistently asserted strong support for the civil rights of people with disabilities, the federal agencies charged with enforcement and policy development under the ADA had been overly cautious, reactive, and lacking any coherent and unifying national strategy. The report observed that enforcement efforts took a case-by-case approach rather than an approach based on compliance monitoring and a cohesive, proactive enforcement strategy. In addition, enforcement agencies had not consistently taken leadership roles in clarifying frontier or emergent issues—issues that, even after nearly 10 years of enforcement experience, continue to be controversial, complex, unexpected, and challenging. NCD attributed some of the leadership and enforcement deficiencies noted in the report to the bureaucratic culture of particular agencies, which have hewed to their traditional mission and circumspectly defined their constituency. In some circumstances, the agencies feared taking positions on new or controversial issues or were too concerned about the potential backlash of a strong position. In sum, NCD took the agencies to task for providing “halting, reactive leadership.”

A critical finding of the report was that many of the shortcomings in federal enforcement of the ADA were inexorably tied to chronic underfunding and understaffing of the responsible

agencies. These factors, combined with undue caution and a lack of coherent strategy, undermined enforcement of the ADA in its first decade. As a result, in some areas the destructive effects of discrimination continued without sufficient challenge, and the weak enforcement environment contributed to problematic federal court decisions unjustly narrowing the scope of the ADA's protections. The body of the report detailed the deficiencies of each agency's enforcement processes and activities. In all, the report presented 69 formal findings regarding ADA enforcement and made 104 recommendations for improving ADA enforcement.

Among the overarching recommendations in *Promises to Keep* were the following:

- DOJ should provide robust and assertive leadership for ADA implementation and develop a strategic vision and plan for ADA enforcement across the Federal Government.
- DOJ, DOT, EEOC, and the Title II referral agencies should strengthen methods for the timely and effective enforcement of the ADA.
- Federal enforcement agencies should engage in more outreach, training, and collaboration with the disability community.
- DOJ, EEOC, and the other federal agencies charged with ADA enforcement should promote proactive messages for media coverage of the ADA.

In August 1994, NCD members and staff began meeting with representatives of the disability community and officials of Microsoft Corporation to discuss access to Windows-based software for people with disabilities, especially people with severe visual impairments.

As a result of that meeting, in 1995 NCD established Tech Watch, a community-based, cross-disability consumer task force on technology. The 11-member task force, under the leadership of NCD member Bonnie O'Day, advised NCD on issues relating to emerging technology legislation and helped monitor compliance with civil rights legislation, such as Section 508 of the Rehabilitation Act of 1973, as amended.

With the advice of Tech Watch, NCD issued *The Accessible Future*, the fourth report generated by the Disability Civil Rights Monitoring Project, on June 21, 2001. The report addressed the status of federal enforcement of key laws—the ADA, Section 255 of the Telecommunications Act of 1996, and Section 508 of the Rehabilitation Act, as amended—and how such enforcement relates to electronic and information technology (E&IT), particularly the Internet, the World Wide Web, and select information/transaction machines. NCD observed that access to such information and technology developments is “a double-edged sword that can release opportunities or sever essential connections” for people with disabilities.

An overriding principle recognized in the report was that access to electronic and information technology is a civil right. Measuring federal implementation against this standard, NCD concluded from documentary and empirical research that individual leadership and commitment

on the part of federal agency officials and staff was the primary reason for their relative success, particularly internally, in implementing pro-accessibility measures. The report documented various steps agencies have taken to enhance E&IT accessibility that are worthy of emulation. Among the major findings of the report were the following:

The adverse and predictable results of E&IT inaccessibility on the lives of people with disabilities constitute discrimination, albeit unintentional, where technology that could substantially reduce the disparity exists but is not used.

Existing civil rights laws appropriately take costs into account in determining whether particular E&IT-oriented accommodations or accessibility strategies are too costly. But they do so in ways that accentuate the size and visibility of such costs while concealing the costs of access denial.

The current legal framework for E&IT accessibility is actually a patchwork of laws covering certain categories of technology in some settings, other categories in other settings, but nowhere reflecting an overview or comprehensive assessment of either the issues or the solutions.

Without partnership with government and consumers, the marketplace is not well suited to redressing the E&IT access gap on its own. Normal competitive pressures do not operate to encourage fully accessible design of mainstream E&IT products, although the latent demand for such devices is considerable.

Changes in technology and in the interpretation of all civil rights laws emanating from the courts will require the rethinking of both our definition of E&IT and our approach to advocacy on behalf of its heightened accessibility.

The report presented an assortment of concrete recommendations calculated to help “to make the electronic bridge to the 21st century available to all Americans.”

The release of *The Accessible Future* was highly publicized and generated numerous articles and editorials about electronic and information technology access for people with disabilities. The report has proven to be highly influential. It is one of the most frequently downloaded reports on the NCD Web site. The report was translated into Spanish by the Spanish government.

Both before and after the report’s release, NCD worked in various concrete ways to get the Federal Government, private industry, and consumers to join forces to increase access to E&IT for people with disabilities. In addition to meeting with Microsoft, for example, NCD staff met with staff at the Congressional Office of Compliance to help ensure that full coverage of the ADA and the Rehabilitation Act is extended to all instrumentalities of Congress, including the Government Printing Office, General Accounting Office, Library of Congress, and other congressional offices. NCD recommended that all congressional offices and instrumentalities comply with Section 508 of the Rehabilitation Act of 1973, which requires accessibility of the

Federal Government's electronic and information technology. Subsequently, the Congressional Office of Compliance voted to approve a motion that all Web sites maintained by instrumentalities of Congress must comply with Section 508. Accordingly, the Government Printing Office, using information provided by NCD, began revising 30,000 archived Web pages to comply with Section 508 accessibility standards.

Even before the release of *The Accessible Future*, NCD had addressed the role of technology and initiatives for making technological systems and tools accessible to people with disabilities in such reports as *Access to the Information Superhighway and Emerging Information Technologies by People with Disabilities* (1996), *Guidance from the Graphical User Interface (GUI) Experience: What GUI Teaches About Technology Access* (1996), *Access to Multimedia Technology by People with Sensory Disabilities* (1998), and *Federal Policy Barriers to Assistive Technology* (2000). In May 1997, following NCD's recommendations to improve accessibility of graphical user interface systems (such as systems using icons and a mouse), Microsoft Corporation released a long-awaited technology called Active Accessibility, which standardized the way Windows applications communicate with adaptive equipment such as the screen reader programs used by blind people. This new technology was a response to the crisis people with disabilities, particularly visual disabilities, were facing because of the rapid deployment of graphical user interfaces. NCD encouraged Microsoft to incorporate accessible technology into its future Windows operating systems and other related applications. In the fall of 1997, IBM and Sun Microsystems made public commitments to make Java-based applications accessible to people with disabilities. NCD encouraged technology vendors to incorporate accessibility into the design stage of their products.

At the formal event marking the release of *The Accessible Future* in 2001, representatives of Microsoft, Hewlett Packard, Compaq, Motorola, and Cingular Wireless endorsed the goal of making their technology accessible to people with disabilities. Each company described concrete examples of the progress made in improving the accessibility of its products and services. These examples included, most notably, Microsoft's release of Windows 2000, which included an accessibility wizard that allowed users to customize the operating system to meet their needs, and Office XP, which featured basic speech recognition capabilities.

On November 6, 2001, NCD issued the fifth report resulting from the Disability Civil Rights Monitoring Project, *Reconstructing Fair Housing*. It examined the U.S. Department of Housing and Urban Development's (HUD's) efforts to enforce provisions of the Fair Housing Amendments Act of 1988 (FHAA) and Section 504 of the Rehabilitation Act that prohibit discrimination on the basis of disability. Overall, NCD's findings revealed that HUD's enforcement efforts had been underfunded and understaffed and lacked a consistent strategy and direction.

The study disclosed that in the late 1990s HUD had lost control of its own enforcement process, with investigations taking nearly five times as long as Congress mandated and with scarcely 100 cases per year concluding with findings of discrimination. NCD observed that enforcement of civil rights laws had been hampered by the failure of Congress and HUD to provide the level of

resources that effective enforcement requires. Inconsistent and inadequate funding has caused various problems for HUD, particularly in staffing and special enforcement initiatives. In NCD's view, however, a larger problem was HUD's failure to provide consistent national leadership and management of the fair housing enforcement process. As a result, NCD found, "the promises of the fair housing laws have been empty for many Americans, with and without disabilities."

The report presented 102 detailed findings and made 86 recommendations for improvement of HUD's administrative enforcement and compliance activities. The report broadly summarized the recommendations as falling into the following major categories:

- The administration, HUD, and Congress must improve the enforcement of disability rights guaranteed by FHAA and Section 504 of the Rehabilitation Act, ensure compliance by federal grantees, and make enforcement of disability rights laws a priority.
- The administration, HUD, and Congress must ensure that current and future HUD budgets are increased so that adequate resources are devoted to enforcing housing-related civil rights laws and ensuring compliance by federal grantees.
- HUD must provide better guidance on the meaning of housing-related disability civil rights laws, including the FHAA and Section 504, and must dramatically improve its collection of data about enforcement and compliance activities.
- HUD must improve its identification and dissemination of best practices concerning education, enforcement, and compliance activities.
- The administration, Congress, and HUD (including its Office of Disability Policy and National Consumer Advisory Committee) must work together to regain public trust in governmental enforcement and compliance activities.

NCD outlined the overall challenges facing HUD in improving its efforts as follows:

As detailed in this report ... much more needs to be done. HUD needs to work continuously with its various stakeholders to ensure that management and program reforms recommended in this report are implemented. HUD needs to work alongside NCD as part of this process. HUD also needs to ensure that its work in this regard incorporates the knowledge generated by the Interagency Council on Community Living, as well as the groundbreaking work being conducted around the Olmstead Initiative by the Department of Health and Human Services. It is time to restructure fair housing.

During Chairperson Bristo's tenure, NCD engaged in numerous other activities as part of its Disability Civil Rights Monitoring Project. These included issuing a summary of the holdings and implications of the Supreme Court's ADA rulings (*Supreme Court Decisions Interpreting the Americans with Disabilities Act*), a summary of major federal laws prohibiting discrimination

on the basis of disability (*A Guide to Disability Rights Laws*), and a paper on the implications of the Supreme Court's ruling in *Alexander v. Sandoval* (*The Sandoval Ruling*).

In addition, pursuant to its statutory duty to "make recommendations to ... officials of ... Federal entities" regarding "equal opportunity for all individuals with disabilities" and "achiev[ing] ... inclusion and integration into all aspects of society," NCD supplied information in friend of the court (*amicus curiae*) briefs to the Supreme Court in four cases. First, in *Olmstead v. L.C.*, NCD described how prohibiting unnecessary segregation and isolation of people with disabilities in various contexts, including state and local government facilities that provide treatment and habilitation services, was a central concern of the ADA proposal from its inception. Second, in *Board of Trustees of the University of Alabama v. Garrett*, NCD submitted an *amicus curiae* brief to the Supreme Court describing the extensive record of state and local governments in denying equal protection and due process to individuals with disabilities and the appropriateness of the ADA's measures to address and remedy this inequity. NCD also recounted the 25 years of methodical congressional study, measured legislative steps, and finely tuned negotiation that led to the enactment of the ADA.

In *Toyota Motor Manufacturing, Kentucky, Inc. v. Williams*, the Supreme Court considered the breadth of the scope of protection afforded under the ADA. NCD filed an *amicus curiae* brief in which it contended that a narrow interpretation of the term "disability" in the ADA would exclude many people whom Congress intended to protect. Recognizing that discrimination on the basis of disability takes place in various ways against people with various types of disabilities, Congress had adopted an inclusive, three-prong definition of "disability." NCD condemned as "draconian" and "erroneous" the "stereotypical view of disability" that would extend ADA protection only to those who "are so severely restricted that they are unable to meet the essential demands of daily life." In *Chevron U.S.A. Inc. v. Echazabal*, NCD told the Supreme Court that the "direct threat to self" defense created by EEOC was "directly contrary to a plain and natural reading of the Act, and is inconsistent with the clearly expressed intent of Congress." In NCD's view, such a defense allows employers to unilaterally bar or dismiss from jobs qualified workers who do not pose a health or safety risk to others and whose purported risk to themselves may be based on speculative, paternalistic, and stereotypic assumptions by the employer.

NCD also monitored developments in the education of students with disabilities and the implementation of IDEA, both before and after its prominent *Back to School on Civil Rights* report. IDEA, like the ADA, experienced a significant backlash that NCD fought at every opportunity. NCD offered input on proposed legislative and regulatory changes and advocated for optimal educational rights and opportunities for students with disabilities. It periodically issued formal reports on educational issues and the implementation of IDEA: *Inclusionary Education for Students with Disabilities: Keeping the Promise* (1994), *Improving the Implementation of the Individuals with Disabilities Education Act: Making Schools Work for All of America's Children* (1995), *Discipline of Students with Disabilities: A Position Statement* (1998), and *Individuals with Disabilities Education Act Reauthorization: Where Do We Really Stand?* (2002). Through these and other efforts, NCD maintained a high profile as an advocate for the educational rights of pupils with disabilities.

D. Political Appointees with Disabilities

Following recommendations from its 1996 report *Achieving Independence: The Challenge for the 21st Century*, NCD for the first time began to convene meetings of political appointees with disabilities, who then collaborated on common issues. The appointees agreed to focus on a single issue—the employment of people with disabilities. This collaboration led to significant and positive results, such as the Ticket to Work and Work Incentives Improvement Act (TWWIA) and an executive order creating the Presidential Task Force on the Employment of Adults with Disabilities.

E. Ticket to Work and Work Incentives Improvement Act

Both the National Summit on Disability Policy and the *Achieving Independence* report identified the need for legislation to create programs to “ensure a fundamental level of support for working-age adults with disabilities who are in economic need,” with the proviso that “[t]his support should lead to employment as the desired outcome whenever possible.” Such support would include services such as “housing, personal assistance services, assistive technology and vocational rehabilitation, that are necessary to ensure independent living and self-determination.” In *Achieving Independence*, NCD advanced the idea of “tickets” for beneficiaries, who would then be able to select services from a “broker” that would receive program funds for helping individuals find and keep a job—a concept that was particularly promoted by Council member Bonnie O’Day.

Consumers and advocates expanded upon the employment recommendations from that report during a 1997 working conference. Most of the 40 conference participants were or had been Supplemental Security Income (SSI) recipients or Social Security Disability Insurance (DI) beneficiaries, and all were knowledgeable about disability employment issues. The participants identified barriers to employment faced by individuals with disabilities and generated a series of proposals for overcoming those barriers. To find out what the rest of the disability community thought of the proposals, NCD took oral and written testimony from hundreds of individuals with disabilities, their families, and advocates in 13 hearings nationwide.

In 1997, NCD expanded upon the “ticket” concept in its report *Removing Barriers to Work: Action Proposals for the 105th Congress and Beyond*. The report declared that

Congress should create a “ticket” or “voucher” program that enables SSI recipients and DI beneficiaries to select and buy services leading to employment. Individuals should be allowed to choose from a wide array of service providers, including educational institutions, training facilities, job-coaching services, and assistive technology.

NCD added that “[s]ervices covered by any voucher proposal should include the purchase of technology or equipment, tuition for college or vocational school, or other training and support

needed to work. SSI recipients and DI beneficiaries should control the allocation of those vouchers.”

The ticket concept was incorporated into concrete legislative proposals in the 105th Congress in the form of the proposed Ticket to Work and Economic Self-Sufficiency Act in the House and the Work Incentives Improvements Act proposal in the Senate, both of which gained the administration’s support and almost became law. The return-to-work bills captured the attention of people with disabilities, their families, and advocates across the country as news of them arrived by e-mail, fax, telephone, and letter. The progress made on this issue in the 105th Congress afforded a solid foundation for the passage of such legislation in the next Congress, and on December 17, 1999, President Clinton signed the TWWIIA. In addition to features designed to increase work incentives and opportunities for people with disabilities, the new law sought to reduce disincentives to working for SSI and DI recipients. TWWIIA reduced disincentives to working in two ways: by providing new opportunities for obtaining vocational services through the issuance of the “ticket to work” and by creating new ways to retain health insurance after leaving the benefit rolls. The Ticket to Work and Self-Sufficiency Program, which was established in Title I of the TWWIIA, modernized the disability employment services system by allowing SSI or DI beneficiaries to go to any public or private provider of their choice for vocational rehabilitation and other covered services. The program, administered by the Social Security Administration (SSA), became operational in January 2001.

TWWIIA allowed people with disabilities to keep their Medicare coverage for four and a half years while still working; it also created a support system for them by developing one-stop shops where they can find employment and resolve benefit questions. According to SSA, the goal of TWWIIA is “to give disability beneficiaries the opportunity to achieve steady, long-term employment by providing them greater choices and opportunities to go to work if they choose to do so.” The legislation “removes barriers that previously influenced people’s choices between healthcare coverage and work.” NCD continued to work with administration officials to promote the vigorous and effective implementation of TWWIIA. In his “New Freedom Initiative” announced on February 1, 2001, President Bush included swift implementation of TWWIIA as a specific objective.

F. Input into the Establishment of the President’s Task Force on the Employment of Adults with Disabilities.

Another employment-related need identified by the National Summit on Disability Policy and reflected in *Achieving Independence* was that “the President should issue an executive order directing the Secretary of Labor to promote the employment of people with disabilities and to establish employment goals for people with disabilities.” In addition, the report stated that there should be an assessment of “our nation’s efforts to employ people with disabilities in the context of current and future labor market trends, both nationally and locally,” conducted by “the Secretary of Labor and the chairman of PCEPD [the President’s Committee on Employment of People with Disabilities], in conjunction with representatives from business, labor, people with

disabilities and labor market economists,” culminating in “recommendations for maximizing the employment of people with disabilities.”

Consistent with these recommendations, President Clinton signed an Executive Order on March 13, 1998, that established the Presidential Task Force on the Employment of Adults with Disabilities (PTFEAD). PTFEAD’s mandate was to “evaluate existing federal programs to determine what changes, modifications, and innovations may be necessary to remove barriers to employment opportunities faced by adults with disabilities” and to review such issues as “reasonable accommodations, inadequate access to health care, lack of consumer-driven, long-term supports and services, transportation, accessible and integrated housing, telecommunications, assistive technology, community services, child care, education, vocational rehabilitation, training services, employment retention, promotion and discrimination, on-the-job supports, and economic incentives to work.”

In the FY 2001 budget process, Congress provided funding for a new Office of Disability Employment Policy in the Department of Labor (DOL). The programs and staff of the former PCEPD were incorporated into this new office. NCD has been an active member of PTFEAD since its inception.

G. International and Foreign Affairs Issues

Another area addressed in *Achieving Independence* concerned international issues involving people with disabilities. The summit participants made several recommendations concerning social and economic development, foreign assistance, and the inclusion of people with disabilities in all aspects of foreign policy, and they recommended that U.S. foreign policy recognize the human and civil rights of people with disabilities. In 1995, the State Department designated NCD the official contact for disability issues in the U.S. government, and the United States Mission to the United Nations “advised that the contact point within the U.S. government for disabilities issues is the ... National Council on Disability.” As part of this role, NCD interacts with the special rapporteur of United Nations Commission for Social Development on disability matters.

To meet these responsibilities, NCD developed and issued *Foreign Policy and Disability* (1996), which measured the extent to which U.S. disability rights laws are extended in international settings through the activities of three key U.S. foreign policy agencies: the State Department, the U.S. Agency for International Development (USAID), and the United States Information Agency (USIA). It examined the employment, accessibility, and outreach policies and programs of these agencies and the attitudes of their officials in light of U.S. disability rights law and democratic principles; its goal was to assess the effect of American foreign policy and programs on people with disabilities in the United States and abroad. The report’s major finding was that the United States did not have a comprehensive foreign policy on disability. It declared that “[t]hose responsible for creating and implementing U.S. overseas policies and programs generally lack awareness of disability issues, cannot articulate our national policies with respect to people with disabilities, do not incorporate the interests of people with disabilities into U.S. foreign policy

objectives, and do not see the importance of U.S. disability advances and achievements for people with disabilities in other countries.”

Among the major recommendations of the report were

- creating a comprehensive foreign policy on disability to advocate for people with disabilities through activities at the international level;
- extending U.S. disability law by legislation or executive order to include, without ambiguity, the international operations of the U.S. government;
- employing domestic standards of nondiscrimination in U.S.-sponsored international activities;
- training U.S. foreign affairs agencies and their contractors to plan for programmatic accessibility; and
- establishing the principle that no U.S. international activity should have a lower standard of inclusion than its domestic correlate.

Secretary of State Madeleine Albright acknowledged the significance of the *Foreign Policy and Disability* report when, in remarks to the International Leadership Forum for Women with Disabilities on June 16, 1997, she declared,

Here in the United States, the Americans with Disabilities Act has made us a leader in promoting full participation by persons with disabilities. But a year ago, when NCD issued a report asking whether our foreign policy had a coherent approach to disability, the answer was no. This is not an acceptable answer and, fortunately, it is not an answer that will remain accurate for very long.

Within a matter of weeks, USAID will be issuing a new policy and action plan on disability and development. That document will express the agency’s commitment to reach out and include persons with disabilities in its programs and place this issue prominently on our development agenda with governments that receive our aid.

True to Secretary Albright’s words, on September 12, 1997, USAID issued its policy paper on disability, which affirmed the organization’s commitment to nondiscrimination against people with disabilities and described steps it would take to implement its policy on disability, which is “to promote the inclusion of people with disabilities both within USAID programs and in host countries where USAID has programs.”

During the mid- to late 1990s, NCD worked with the State Department toward developing an official disability inclusion policy applicable to every major area of State Department operations. During the same period and continuing into the first years of the next decade, NCD met with

representatives from the governments of Argentina, Great Britain, Japan, Saudi Arabia, Slovakia, Finland, New Zealand, Australia, and Germany. NCD also had discussions with organizations involved in international disability issues, including the United States Council on International Rehabilitation, the International Labor Organization, and the European Disability Forum, and participated in numerous international conferences such as USIA/Mobility International USA, the Inter-American Convention on Disabilities, the International Conference on Accessibility, the Global Workshop on Children with Disabilities, the International Leadership Forum for Women with Disabilities, the International Summit on Employment, the United Nations Conference on Human Settlements, the Third Paralympic Conference, the U.N. World Summit for Social Development, the European Union/U.S. conference on “Harnessing the Information Society to Raise Employment Levels for People with Disabilities,” and the Fifth World Assembly of Disabled Peoples’ International.

Congress has periodically sought NCD’s advice on international disability issues. For example, during NCD’s fiscal year 2001 appropriations hearings, Representative John Porter’s questions to Vice Chairperson Kate Pew Wolters included inquiries about the status of people with disabilities internationally, and whether Congress was effective in helping people with disabilities “worldwide.”

In January 1997, the State Department’s Permanent Mission to the Organization of American States (OAS) invited NCD to participate in the development of the U.S. Government’s comments on a draft “Inter-American Convention for the Elimination of All Forms of Discrimination by Reason of Disability.” The convention’s primary objective was to prohibit disability discrimination throughout the hemisphere. In response, NCD consulted with representatives of the State Department and DOJ to try to reach consensus on comment language. This process culminated in official comments on behalf of the U.S. government that were presented to the OAS Working Group on Disabilities on April 28, 1997. Thereafter, led by Council member Dr. Yarker Andersson with the legal/technical assistance of Robert Burgdorf Jr., NCD provided comments on successive drafts of the proposed convention.

After some thorny issues had arisen over the ensuing months, OAS decided to convene a “Meeting of Experts to Examine the Draft Inter-American Convention” on March 3–4, 1998. NCD was part of the U.S. delegation at the meeting and contributed significantly to the discussions and drafting of alternative language, particularly concerning the definitions of disability and of discrimination on the basis of disability. Although the experts appeared close to consensus on many of the important issues, the political representatives of the member governments were unable to agree, and a replacement version of the convention was not adopted at that time. The draft convention remained stalled until April 30, 1999, when the Committee on Juridical and Political Affairs of OAS adopted a revised version. In July 1999, OAS ratified the Inter-American Convention on the Elimination of All Forms of Discrimination Against Persons with Disabilities. The convention entered into force when it was ratified by at least six countries, but it is legally binding only in countries that have themselves ratified it. Although NCD has encouraged Congress to adopt the convention, it has yet to do so.

In 1997, NCD established a consumer-oriented task force known as International Watch to share information on international disability issues and advise NCD's International Committee on developing proposals to promote foreign policy consistency with the values and goals of the ADA. In October 2000, International Watch was reconstituted and formally chartered as a Federal Advisory Committee to NCD. International Watch has provided NCD with considerable information and expertise on issues affecting the rights of persons with disabilities abroad. With International Watch's guidance, NCD issued its *Summary of International Watch Recommendations for NCD Consideration and Action* (2000), which addressed foreign policy and international disability issues.

NCD also facilitated the beginning of a roundtable series on disability inclusion in foreign assistance programs that includes USAID, InterAction, the State Department, the World Bank, and various nongovernmental disability rights organizations. The roundtable series sought to identify and address issues that would encourage constructive engagement of the State Department and USAID on disability inclusion in their foreign assistance programs. The first such roundtable was held on February 11, 2002.

Through International Watch, NCD has responded to a call from disability rights groups to promote an International Convention on the Human Rights of Persons with Disabilities. NCD served as a consciousness-raising force within the disability community in the convention's early stages. On April 8, 2002, NCD convened a Summit on Human Rights and Disability that involved leaders and experts in the fields of disability and human rights as well as others with experience in treaty processes. Building on the summit, on June 12, 2002, NCD sponsored A Call for Worldwide Recognition of the Human Rights of People with Disabilities, a forum of U.S. grassroots disability organizations, to discuss their role in the development of an International Convention on the Rights of People with Disabilities. To describe to a broad audience the need for such a convention, what form it might take, and what it might accomplish, in 2002 NCD issued several documents, including *An International Disability and Human Rights Convention: What You Need to Know About International Human Rights Law and Efforts to Gain Equality and Justice for People with Disabilities in the U.S. and Abroad*; *A Reference Tool: Understanding the Potential Content and Structure of an International Convention on the Human Rights of People with Disabilities*; and a white paper, *Understanding the Role of an International Convention on the Human Rights of People with Disabilities*. Through these publications and through various formal and informal activities, NCD lent its strong support to the development of an International Convention on the Rights of People with Disabilities.

H. Cultural Diversity

A vital and ongoing concern of NCD is the lack of inclusion and other unmet needs of culturally diverse people with disabilities. NCD has found that key information related to the rights and services available to people with disabilities is not reaching a large segment of the population, especially members of culturally diverse populations and people living in rural communities. To address such concerns, NCD undertook a number of initiatives, studies, and outreach actions.

In August 1997, NCD conducted a roundtable in Atlanta on outreach to minority and rural residents. More than 100 participants discussed the challenges and barriers minorities and rural residents with disabilities face to the full enjoyment of their rights and possible approaches for improving outreach to these groups. NCD published the findings in *Outreach to Minorities with Disabilities and People with Disabilities in Rural Communities* (1997). In January 1998, NCD conducted a public hearing in New Orleans on meeting the needs of children and youth with disabilities from minority and rural communities in Louisiana. In August 1998, NCD held a public hearing in San Francisco that focused on meeting the needs of people with disabilities from diverse cultural populations. Information from these three meetings helped inform NCD's 1999 report *Lift Every Voice: Modernizing Disability Policies and Programs to Serve a Diverse Nation*. The report presented an array of findings and recommendations for addressing barriers facing culturally diverse individuals with disabilities: employment, public accommodations, transportation, culturally competent service delivery, citizenship, resources, and accurate demographic data. The executive summary of this report was released at the White House Forum on Disability and Cultural Diversity that also celebrated the ninth anniversary of the passage of the ADA. The forum, convened by the White House and NCD with support from the Leadership Conference on Civil Rights, focused on how to improve outcomes in education, employment, and civil rights enforcement for people with disabilities from diverse cultural backgrounds.

Judge Hughey Walker, NCD vice chairperson and chair of the Subcommittee on Cultural Diversity Issues, became concerned by growing evidence that the benefits won for the disability community under the ADA and other federal laws and programs were not reaching everyone equally. In response, Walker suggested a meeting to bring together people with disabilities from diverse cultures and members of national civil rights organizations to find common ground and generate action plans that could advance disability rights and civil rights reciprocally. Out of this suggestion, NCD hosted Think Tank 2000. The event, held May 18–20, 2000, in Washington, D.C., grew out of numerous reports prepared for NCD and testimony from citizens during stakeholder hearings in Jackson, Mississippi; San Francisco; Atlanta; and New Orleans.

More than 70 people attended the meeting, including people with disabilities from diverse cultures, their supporters, and members of national civil rights organizations. Also present were national disability rights supporters such as Representative James Clyburn, chair of the Congressional Black Caucus; Representative Major Owens, who helped steer the ADA through the House; Bill Lann Lee, acting assistant U.S. attorney general for civil rights; Milton Little, vice president of the National Urban League; and Wade Henderson, executive director of the Leadership Conference on Civil Rights. Participants came from all areas of the country and included Native Americans, African Americans, Asian Americans and Pacific Islanders, Hispanic Americans/Latinos, and Caucasians.

Think Tank 2000 participants were asked to formulate an action plan for working collaboratively on rights issues that are of mutual concern to the disability and civil rights communities. By the end of the meeting, participants had formed an organization, Leadership Coalition Unlimited; decided on their first action (creating a listserv to maintain communication among participants and other interested parties); and agreed to other prioritized actions that could create a critical

mass of advocates for disability rights, civil rights, and human rights. The proceedings and outcomes of the event were summarized in *Carrying on the Good Fight: Summary Paper from Think Tank 2000—Advancing the Civil and Human Rights of People with Disabilities from Diverse Cultures* (2000). The report presented a collection of action steps to address the following priority areas: cultivating leadership development, removing educational barriers, providing equal opportunity and access to employment, upholding human rights and civil rights, and expanding voter registration and voter participation.

Some of the strategies that came out of these meetings were decisions by the participants to

- stay in touch and share information through a listserv;
- develop an advocacy toolkit with attention to different cultural needs;
- build coalitions from bottom to top, beginning in local communities; and
- establish a leadership task force composed of people from traditional civil rights areas, public- and private-sector organizations, and the disability community.

The next step was to incorporate the messages and concerns articulated at Think Tank 2000 into NCD's overall civil and human rights agenda. NCD convened a second group in June 2000, the Civil Rights Retreat, to build on the Think Tank 2000 plan of action and the reports generated by NCD's Disability Civil Rights Monitoring Project. The meeting was attended by experts from diverse cultural, professional, and disability backgrounds, and the attendees were charged with mapping out the elements of a 10-point Strategic Action Plan for more effective civil rights enforcement.

The resulting strategy, which was published as *Closing the Gap: A Ten-Point Strategy for the Next Decade of Disability Civil Rights Enforcement*, represented a collective effort by people from diverse backgrounds to reach past their own community perspectives to understand and help each other on the road to full equality, affirming that power comes from unity. The proposed plan called for cooperation at all levels, from all public- and private-sector interest groups, including the administration; Congress; grassroots advocates; state and local government agencies; and education, business, religious, professional, and civic organizations. The plan presented an ambitious and wide-ranging strategy, addressing such issues as

- working with and finding a common agenda with other human rights and civil rights activists;
- forming cross-cultural coalitions of technical and information experts to develop multiformat, multilanguage information and training systems;
- forming action coalitions to facilitate the election of disability-friendly national leaders;

- seeking strong presidential leadership to give disability issues and the enforcement of disability rights laws high priority and high visibility within the administration;
- promoting effective accountability of civil rights enforcement agencies, including increasing stakeholder involvement with monitoring and advisory groups;
- mobilizing action coalitions across civil and human rights groups to design and carry out a comprehensive strategy for making legal resources available and securing successful court actions;
- ensuring that forms of alternative dispute resolution result in settlements that are fair and consistent with the spirit and intent of the complainants' legal rights;
- countering negative media coverage and winning the media battle;
- acknowledging and honoring persons who uphold the values of equality of opportunity and inclusion; and
- engaging, identifying, training, and supporting new leaders with disabilities.

NCD posted the plan for public input on its Web site and sought additional input through 14 regional briefings that included outreach to people from diverse cultures. Feedback from community members included, for example, suggestions that training for grassroots groups, including youth and young adults in high school and college, should include information on civil rights and how to participate in local, state, and federal policy-making, and that young people should be encouraged to join older leaders to become effective self-advocates and leaders.

On August 11, 2000, the President issued Executive Order 13166, "Improving Access to Services for Persons with Limited English Proficiency (LEP)." Before the Executive Order was signed, NCD's Web site was already using an automatic translation service known as Babel Fish, which translates Web pages to and from English, French, German, Italian, Portuguese, and Russian. After the Order was issued, NCD published its *Implementation Plan for Executive Order 13166—Improving Access to Services for Persons with Limited English Proficiency* (2000), which was approved by DOJ. This plan enunciated NCD's strategy for improving access to services for persons with limited English proficiency.

On January 16, 2001, NCD chartered a Cultural Diversity Advisory Committee to provide advice and recommendations on issues affecting people with disabilities from culturally diverse backgrounds. The committee is charged with identifying issues, expanding outreach, infusing participation, and elevating the voices of underserved and unserved segments of the population. It also assists NCD in developing federal policy that addresses the needs and advances the civil and human rights of people from diverse cultures.

I. Outreach to Youth

As a complement to its work on cultural diversity, NCD emphasized reaching out to young people and addressing the issues that affect them. In 1998 NCD released *Grassroots Experiences with Government Programs and Disability Policy: Proceedings from a Public Hearing in New Orleans, Louisiana*, which made recommendations on issues facing children with disabilities and their families from minority and rural communities in Louisiana. In 2000, NCD released *Transition and Post-School Outcomes for Youth with Disabilities: Closing the Gaps to Post-Secondary Education and Employment*, which analyzed research on the status of transition, postsecondary education, and employment outcomes over the past 25 years for 14- to 22-year-olds with disabilities; identified what had worked and what should work in light of unmet needs and unserved populations; and presented recommendations for national, state, and local community action.

In June 1999, NCD coordinated the National Leadership Conference for Youth with Disabilities, its third annual youth conference. The conference was sponsored by SSA, ED, the U.S. Department of Health and Human Services (HHS), PTFEAD, and the President's Committee on Employment of People with Disabilities, with the Mitsubishi Electric America Foundation as the primary private sponsor. The conference, which brought together more than 125 young people, succeeded in its three primary aims:

- serving as a forum for youth to learn from national disability leaders about national disability policy, civil rights, the public policy process and leadership, employment opportunities, and related programs available to them;
- encouraging young people to identify barriers to their economic independence, provide input to the public policy process, and identify future programs to support economic independence and leadership among all youth with disabilities; and
- creating solidarity and community among the participants, and building the confidence and resolve to take action.

The success of the National Leadership Conference led to the development of the National Youth Leadership Network (NYLN). NYLN, which is supported by ED, DOL, HHS, SSA, and NCD, is a five-year, research-oriented project to involve 16- to 24-year-olds with disabilities in formulating and evaluating the programs and services that affect their lives. Its ultimate goal is to develop the next generation of leaders in the disability community. Under the aegis of NYLN, the National Leadership Conference for Youth with Disabilities has continued as an annual event.

In January 2000, NCD formed a Youth Advisory Committee (YAC) to advise NCD on issues affecting the lives of children and youth. NCD sought such input to ensure that NCD's activities and policy recommendations responded adequately to the needs of youth with disabilities, particularly regarding critical civil rights legislation such as IDEA. In November 2001, YAC released its first formal document, *Speak Out: Youth and Young Adults with Disabilities*. YAC

has produced several other informative documents as well as providing ongoing input and perspectives on the Council's activities.

J. Assisted Suicide and the Value of the Lives of People with Disabilities

In 1997, NCD took on a controversial issue when it decided to take a position on physician-assisted suicide. In its report *Assisted Suicide: A Disability Perspective Position Paper*, NCD sought to present a coherent and principled stance on these issues drawn from the input and viewpoints of individuals with disabilities. To arrive at its position, NCD examined the following factors:

- Rights, services, and options
- The reality and prevalence of discrimination
- Deprivation of choices and the importance of self-determination
- Others' underestimation of life quality
- The fallibility of medical predictions
- Eschewing the medical model of disabilities
- The impact of disability onset on emotional state and decision-making
- The reality of living with pain and bodily malfunction
- Divergent interests of those involved in assisted suicide decisions

After studying the effects of these factors, NCD found that the benefits of physician-assisted suicide apply only to the small number of people who have an imminently terminal condition; are in severe, untreatable pain; wish to commit suicide; and are unable to do so without a doctor's involvement. NCD recognized the substantial danger of permitting physician-assisted suicide, including the already-prevalent pressure on people with disabilities to end their lives and the insidious appropriation by others of the right to make that choice for them—compounded by the growth of managed care and the rationing of health care services and financing. NCD also described society's devaluation of the lives of people with disabilities, noting the example of the Netherlands, where people with disabilities experienced coercion and involuntary "euthanasia." NCD explained the difficulty of crafting adequate procedural safeguards, which inevitably would place unacceptable control in the hands of medical and legal "experts," and the many societal barriers that continue to limit life choices for people with disabilities. The report declared that "society should not be ready to give up on the lives of its citizens with disabilities until it has made real and persistent efforts to give these citizens a fair and equal chance to achieve a meaningful life." Based on these realities, NCD opted to declare its opposition to physician-assisted suicide.

NCD's position on this issue, which was shared by other national organizations such as the National Council on Independent Living (NCIL), was widely publicized and quite influential. The executive editor of the journal *Issues in Law and Medicine*, which reprinted NCD's *Position Paper* verbatim, wrote that the report "provides an invaluable disability perspective in opposition to assisted suicide that still needs to be heard."

The dangers of undervaluing the lives of people with disabilities were spotlighted some months later by Peter Singer, an ethics professor at Princeton University. In his book *Practical Ethics*, Singer argued that some people with disabilities have lives that are not worth living and that infants with disabilities may be killed ethically because they are not sentient beings. NCD decided to take on this deplorable viewpoint and joined Princeton Students Against Infanticide, Not Dead Yet, and others to protest Singer's appointment. In remarks she delivered at a protest event at Princeton on April 17, 1999, Bristo condemned Singer's stance in no uncertain terms: "Singer's core vision, that the life of a person with a disability is worth less than the life of a person without a disability, and therefore it is okay to kill infants with disabilities if that is what the parent wants to do, amounts to a defense of genocide Condoning the murder of infants is wrong. Devaluing the life of a human because of her disability is discriminatory, hateful, and bigoted."

K. Other Issues

Under the leadership of Chairperson Bristo, the Council became involved in a number of other issues—some new and some ongoing. NCD issued reports dealing with mental health issues, including *Position Paper on Patients' Bill of Rights Legislation* (2001) and *From Privileges to Rights: People Labeled with Psychiatric Disabilities Speak for Themselves* (2001). In 1997, NCD presented the first Justin Dart Freedom Award. The award, a bronze copy of Dart's famous cowboy hat, was given to the Leadership Conference on Civil Rights for its critical role in supporting and assisting the passage of the ADA.

For many years, NCD has recognized the harmful effects of discrimination based on individuals' genetic information and has supported the creation of federal legislation prohibiting genetic discrimination as well as the enforcement of existing legislation that may prohibit certain types of genetic discrimination. NCD addressed genetic discrimination in several broader reports, including *Achieving Independence: The Challenge for the 21st Century* (1996), *Promises to Keep: A Decade of Federal Enforcement of the Americans with Disabilities Act* (2000), and its 1997 and 2000 Annual Reports. In 2002, NCD issued two publications focused solely on genetic discrimination. In its *Position Paper on Genetic Discrimination Legislation*, NCD recommended enacting new federal legislation to prohibit genetic discrimination. The report documented several considerations that supported the need for such legislation; they were presented under the following topic headings:

- Recent Advances in Genetic Research Have Brought Increasing Potential for Genetic Discrimination
- Genetic Discrimination Is a Historical and Current Reality
- Genetic Discrimination Undermines the Purposes of Genetic Research and Testing
- Genetic Test Information Has Little Value for Purposes of Making Employment Decisions and Insurance Decisions

- Existing Laws Are Insufficient to Protect Individuals from Genetic Discrimination

The report concluded that “[i]n light of the inadequacies of federal and state law to address genetic discrimination issues, comprehensive federal legislation that specifically addresses these issues is necessary.”

The report then listed certain principles that NCD believed were critical for guiding any federal legislation addressing genetic discrimination. NCD issued these legislative principles, in revised and edited form, in a separate document titled *Principles for Genetic Discrimination Legislation*.

L. Perspectives of Chairperson Bristo

When I finally made it through the yearlong confirmation process and was sworn in by Vice President Gore as chairperson of NCD, I remember being daunted by two things: NCD had been the birthplace of the ADA; how could we top that? And, no one with a disability had held this post before, a fact which carried with it a special responsibility.

These two ideas profoundly shaped the Council’s vision, mission, and activities during my eight-year tenure. First, we did not try to “top” the ADA; rather, we worked to implement, defend, and monitor its enforcement. We recognized that the really difficult work lay ahead as we attempted to infuse the values embedded in the ADA into other areas of public policy.

Second, as a person with a disability, I understood the absolute necessity of giving voice to the disability community in everything we did. This was made considerably easier by President Clinton, who appointed an activist Council of true disability rights leaders. Further, the record numbers of people with disabilities appointed by the President throughout government gave us access to trusted colleagues with whom we could collaborate. NCD convened the political appointees with disabilities, and together we worked on initiating the Ticket to Work and Work Incentives Improvement Act, creating the Presidential Task Force on Employment of Adults with Disabilities, forming the Office of Disability Employment Policy at DOL as well as many other policy initiatives.

All of our work rested on the “nothing about us without us” approach to public policy. The historic summit in Dallas resulted in the report *Achieving Independence*, which served as our road map. Most of the rest of our work also cascaded out of that gathering of 300 of the nation’s most well-regarded leaders of the disability community. We gave voice to perspectives and constituents who too often have been left out of the policy equation, particularly youth, people from diverse cultural backgrounds, and members of the psychiatric survivor movement.

Bringing to light the difficulties faced by people with disabilities is not always welcomed. I look back with pride and deep respect for my fellow Council members and staff who, undeterred by the criticism they bore for taking politically unpopular positions, epitomized the spirit of an

independent agency. Our civil rights enforcement series, Unequal Protection Under the Law, was controversial in its forthrightness, and, unfortunately, many of its core findings remain true today.

The influence that NCD has had on our nation over the past 20 years has been profound. I know that my fellow Council members and I are proud to have played a part in shaping the policy agenda on behalf of people with disabilities.

National Council on Disability Members and Staff During the Frieden Era

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The Current Council, Investing in Independence, Righting the ADA, and the 21st Century: NCD Under Chairperson Frieden

In April 2002, President Bush named Lex Frieden, former executive director of NCD, to be its chairperson, and he was sworn in in September of that year. Frieden is senior vice president at The Institute for Rehabilitation and Research (TIRR) in Houston, director of TIRR's Independent Living Research Utilization Program, and a professor of physical medicine and rehabilitation at Baylor College of Medicine. Under his leadership, NCD has continued many of the initiatives and directions begun under previous chairpersons and instituted a various new activities and initiatives.

A. Transition to the Bush Administration and the President's New Freedom Initiative

Even before President Bush took office in January 2001, the outgoing Council sought to facilitate the transition to the new administration in regard to disability policy matters. During his presidential campaign, Bush had articulated several themes regarding his vision and objectives regarding persons with disabilities. These themes were ultimately crystallized in his New Freedom Initiative (NFI), in which he articulated a number of proposals addressing Americans with disabilities, including the following:

- a commitment to end discrimination through strong, steadfast support for and enforcement of disability civil rights laws;
- full workforce integration of Americans with disabilities;
- expanded access to technology for Americans with disabilities to increase opportunities for productivity, full participation, and independent living; and
- increased access into community life for Americans with disabilities by pursuing strong and coordinated implementation of the *Olmstead* decision.

NCD decided to assist the incoming administration by translating these objectives into recommended actions based on NCD's experience with federal disability policy issues. Accordingly, in January 2001, NCD issued *Investing in Independence: Transition Recommendations for President George W. Bush*. The report invited the new administration to draw on NCD's research to learn how and where executive agencies can act to the maximum benefit of their constituents. Based on insights NCD had gained in the 1996 National Summit on Disability Policy, Think Tank 2000, the Civil Rights Retreat (2000), other meetings and forums NCD had conducted between 1996 and 2000, and the reports that drew on them, NCD offered the incoming President a series of recommendations to

- advance the federal commitment to quality education for all children, including children and youth with disabilities, through strengthened compliance and enforcement of IDEA;

- implement key recommendations identified by PTFEAD to significantly reduce the 75 percent unemployment rate among individuals with disabilities;
- ensure that general education, health, workforce development, housing, and other programs include appropriate services to individuals with disabilities (especially for cases in which the authority to develop service systems has been substantially returned to the states);
- establish a system of health care that supports the needs of people with disabilities for continued work opportunities, prevention of secondary conditions, and long-term care supports that allow them to live in their homes or in the least restrictive environment;
- take national and international steps to ensure access to technology and participation in the global technological economy;
- preserve and enhance funding for programs that further inclusion, integration, independent living, and economic self-sufficiency of people with disabilities through the next decade under the goals and spending limits of the Balanced Budget Act;
- encourage the adoption of universal design concepts and create timely guidance and mechanisms to ensure continuous improvements to accessibility in the environment (i.e., physical structures and pathways, transportation, and technology); and
- establish a foreign policy that supports the goals of access, civil and human rights, inclusion, and poverty reduction for people with disabilities throughout the world.

NCD expressed the belief that its recommendations were consistent with and incorporated President Bush's NFI.

Overall, the transition report called for the new President to exercise "strong leadership" to achieve a disability-friendly administration. The report noted President Bush's campaign statement that "ending discrimination is just the beginning of full participation" and his promise that the NFI would "expand opportunities for people with disabilities to pursue the American dream." NCD stated that its recent evaluations of the enforcement status of key civil rights laws (e.g., ADA, IDEA, and ACAA) indicated a need for comprehensive, cohesive federal leadership strategies for effective implementation. NCD recommended an interagency effort to coordinate the activities of federal enforcement agencies; provide continual and substantial input of disability, civil rights, and human rights communities into developing and monitoring the implementation of enforcement agency action plans; and establish a mechanism for citizen feedback and agency response to resolve concerns and achieve accountability.

NCD also called upon the new administration to "oppose any legislative or judicial weakening of disability civil rights protections by Congress or the Courts," and quoted then-Governor Bush's statement in a June 21, 2001, interview with *Business Week Online*:

Let me lay this principle out. No law should undermine the Americans with Disabilities Act. The ADA must stand. The ADA is a good law. I want your readers and followers to

know that George W. Bush, the son of President Bush who signed the Americans with Disabilities Act, fully supports the ADA in spirit and in law. I would not do otherwise. There is a role to enhance the ADA: I want to make sure the law is fully complied with. The Federal Government has made a commitment to protecting civil rights. The ADA is a civil-rights legislation.

NCD noted that in the same interview, Governor Bush said that in regard to the constitutionality of the ADA, he “believe[d] in the full force and effect of the ADA.”

Thereafter, the report offered more specific recommendations for addressing numerous issues, presented under the broad headings of (1) strengthening compliance with disability civil rights laws, (2) cultural diversity, (3) increasing independent living, and (4) providing access to community living. NCD expressed its hope that the initiatives contained in the report would “offer the new administration opportunities to reinvigorate federal enforcement of disability, civil, and human rights laws so that more Americans with disabilities and their families can realize the dream of equal access to full participation in American society.”

In February 2001, President Bush formally announced the NFI as part of his administration’s official policy, and he committed his administration to ensuring the rights and inclusion of people with disabilities in all aspects of American life. In the NFI, President Bush stated, “Too many Americans with disabilities remain outside the economic and social mainstream of Americans life.”

By Executive Order 13217, issued on June 18, 2001, the President declared the commitment of the United States to community-based alternatives for people with disabilities and required the Attorney General; the Secretaries of HHS, ED, DOL, and HUD; and the Commissioner of SSA to work cooperatively with the states to ensure that the *Olmstead v. L.C.* decision would be implemented in a timely manner.

In its *Olmstead* decision, the Supreme Court had ruled that in appropriate circumstances the ADA requires that people with disabilities be placed in a community-integrated setting whenever possible. The Court had concluded that “unjustified isolation,” for example, institutionalization when consulting physicians deem community treatment equally beneficial, “is properly regarded as discrimination based on disability.” The Executive Order directed federal agencies to work together to tear down the barriers to community living. As a result, various federal departments entered into joint efforts with states and others to provide elderly people and people with disabilities with the necessary supports to participate fully in community life.

In its public policy education role, NCD has worked to disseminate information about the NFI to the disability community and to the families and colleagues of individuals with disabilities. In its advisory role to the administration and Congress, NCD has provided information and suggestions about concrete ways to achieve NFI objectives.

B. Investing in Independence Studies

Under Chairperson Frieden's leadership, NCD has undertaken a new series of studies in response to the NFI that focus on such topics as consumer-directed health care, universal design (products designed to be usable by all people, to the greatest extent possible, without the need for adaptation or specialized design), implementation of the *Olmstead* decision, long-term services and supports, increasing the employment of Social Security beneficiaries, employment-related and return-to-work initiatives, tax incentives, delinquency prevention and juvenile justice, and American Indians and Alaska Natives with disabilities. These studies will comprise the Investing in Independence series. Through a targeted examination of key supports and resources, NCD will provide the President, Congress, and other federal agencies with practical information to shape federal policy development, refinement, and change consistent with the centerpiece initiatives presented in the NFI.

The NFI contains strong, sound ideas but requires concrete Federal Government action and coordination as well as adequate congressional funding. Through its efforts, NCD hopes to help the administration fulfill the proposals presented in the NFI to ensure that all Americans have the opportunity to learn and develop skills, engage in productive work, choose where to live, and participate in community life. The first three studies in the Investing in Independence series were completed in 2003; they addressed the implementation of the *Olmstead* decision, American Indians and Alaska Natives with disabilities, and delinquency prevention and juvenile justice.

The study of the implementation of the *Olmstead* decision exemplifies the type of assistance NCD has been and will be providing. The Supreme Court's decision in *Olmstead v. L.C.* mandated systemic change with major implications for national and state-funded residential options for people with severe physical and mental disabilities. NCD's study focused on evaluating *Olmstead* implementation in terms of (1) the extent of unnecessary institutionalization in the United States, (2) the continuing barriers to community placement, and (3) the resources and service models that facilitate community integration. The study looked at both the Federal Government's implementation efforts and the strategies states and key stakeholders are using to develop consensus on a coordinated action plan, identify and commit the necessary resources for community-based service options, and sustain collaborative action toward creating real choice for people with disabilities living in institutions. The results of the study were issued in *Olmstead: Reclaiming Institutionalized Lives*, which was published on August 19, 2003. This unabridged online version included extensive information NCD had collected on individual states' experiences in the planning and implementation of the *Olmstead* decision. On September 29, 2003, NCD issued in both electronic and hard copy forms an abridged version of the report without the extensive state-by-state information.

Overall, the report concluded that "progress to varying degrees has occurred in the implementation of the *Olmstead* decision," but added that "given the many areas where progress has not yet been achieved," further efforts were necessary to increase public awareness of *Olmstead*, to clarify the applications and implications of the decision to relevant entities, and to provide the resources necessary to encourage and ensure effective adherence to the decision's

spirit and intent. The report labeled the extent of unnecessary institutionalization of people with disabilities in the United States “daunting.” NCD found that “[r]esearch and experience have shown that the great majority of people who live in large congregate settings could be supported safely and effectively and enjoy a higher quality of life in a typical home in the community.” It also noted that longitudinal studies of community placement had documented these favorable outcomes and established that people with significant disabilities benefit most from community placement.

With the advantages of home and community placements clear, the data regarding unnecessary institutionalization were troubling:

Yet, 106,000 persons with developmental disabilities lived in public and private institutions and more than 1,300,000 elders and persons with disabilities lived in nursing facilities in the year 2000. In addition, data on the outcomes of consumer-directed mental health services and intensive case management models show that most of the 58,000 persons currently confined in psychiatric institutions could be supported in their own homes in the community. The persons who fill the more than 800,000 licensed board and care beds in the United States could also live in the community.

The report identified the single biggest barrier to community integration in the United States as the lack of affordable and accessible housing. It also found that housing subsidy programs for people with disabilities were inadequate because of systemic problems and disproportionate underfunding. Other significant barriers to community integration were the lack of meaningful collaboration between human services agencies and housing agencies, high unemployment rates among people with significant disabilities, the low wages and benefits that severely limit the availability of personal assistants and other direct-support professionals, the low reimbursement rates for community services, the lack of quality health care, and the absence of dependable transportation. The report added that “the institutional bias of the Title XIX (Medicaid) program, in which home- and community-based waiver-funded services and personal care are optional whereas nursing facility services are required and financial eligibility rules for institutional residents are more generous than those for people living in their own homes, greatly compounds the problem.”

At the state level, the report catalogued specific examples of promising practices in the design, delivery, and financing of community services in such measures as the form and content of states’ *Olmstead* plans, overcoming incentives to unnecessary institutionalization, identification and transition of people with disabilities from institutions, the use of trusts and fine funds to finance transition costs and start-up of community services, housing strategies, single-point-of-entry systems, and initiatives to increase community integration beyond institutional closure.

NCD presented a series of recommendations for the Federal Government, including the following:

- HHS and the Centers for Medicare and Medicaid Services (CMS) should provide more explicit guidance on the implementation of *Olmstead v. L.C.*
- CMS should determine whether the states are adequately identifying residents of Medicaid-funded and -certified facilities that can handle and benefit from community living.
- HHS should refocus its Real Choice Systems Change grant program as a true system change project by shifting from funding demonstration projects to funding change that affects entire service systems.
- HHS should require the states to identify all institutionalized people in the state and their need for community services.
- CMS should use its waiver approval authority to require the states to minimize institutional bias in the choice between institutional and home- or community-based waiver services.
- HHS should give federal financial assistance to states to provide small grants to people with disabilities for transition costs from institutions to community.

In releasing the report, NCD Chairperson Lex Frieden commented,

The *Olmstead* decision has become a powerful impetus for a national effort to increase community-based alternatives and eliminate unjustified institutional placements. Ultimately, only comprehensive amendments to Title XIX of the Social Security Act, similar to the amendments proposed in the Medicaid Community-based Attendant Services and Supports Act (MiCASSA), will overcome the institutional bias within the Medicaid program. Our nation will be much more prosperous when it makes real the right of people with disabilities to live in the most integrated setting.

On August 1, 2003, NCD issued *People with Disabilities on Tribal Lands: Education, Health Care, Vocational Rehabilitation, and Independent Living*. The study examined research on issues that affect people with disabilities living in Indian Country. It was developed and guided to completion in collaboration with American Indian and Alaska Native (AI/AN) representatives of people with disabilities, their families, and tribal community leaders. The report discussed the perspectives of AI/AN people with disabilities, tribal leaders, and federal agency representatives identified as productive in meeting the needs of people with disabilities residing in tribal lands. It also included an assessment of and recommendations for improvements in government-to-government (state to sovereign tribal to U.S. government) relationships needed for effective coordination across existing federally funded projects and programs. In addition, NCD developed a toolkit that provides resources for consumers; tribal communities; and people at state, local, and federal levels: *Understanding Disabilities in American Indian and Alaska Native Communities: Toolkit Guide*.

The *People with Disabilities on Tribal Lands* report noted the unique needs of AI/AN populations: their rate of disabilities is disproportionately higher than that of all population groups, and this situation is compounded by factors such as high poverty, elevated school dropout rates, geographic isolation from state or local district rehabilitation and health care, and limited employment options. Overall, the study documented that AI/AN people with disabilities who live in tribal lands are not receiving the services to which they are entitled. Based on a review of the literature and interviews with tribal officials and federal program administrators, the report discussed barriers and challenges that hamper or prevent the development of meaningful government-to-government relationships regarding issues affecting people with disabilities in Indian Country. The study identified the following major barriers: fragmentation of services across federal agencies and offices; lack of federal staff knowledge of tribal sovereignty and the federal trust responsibility to AI/AN people; limited enforcement of laws protecting people with disabilities in tribal lands; lack of clarity about legal enforcement options; limited local tribal planning to protect and support people with disabilities; and lack of involvement of tribal leaders and tribal members in the design, development, and implementation of programs.

The report provided recommendations in each of five major categories:

- fulfilling the federal trust responsibility to AI/AN tribes and the national mandate for the elimination of discrimination against people with disabilities;
- ensuring meaningful consultation with and involvement of people with disabilities and tribal leaders;
- providing tribes with better access to federal resources and funded programs;
- developing cultural competence within federal agencies and increasing agencies' interaction with tribes; and
- including disability issues among tribal priorities and federal initiatives in tribal communities.

A major conclusion of the study was that “effective collaboration among sovereign tribal governments and federal and state programs is key to successfully addressing the issues and needs of tribal members with disabilities and descendants living in Indian Country. AI/AN people with disabilities and advocates must be invited to the table for key conversations regarding application of disability policies, initiatives, and program development and resource allocation.” As NCD stated, “Unless and until this government-to-government collaboration occurs, AI/AN people with disabilities will continue to remain locked out of the protections and services guaranteed to all Americans with disabilities.”

On May 1, 2003, NCD published *Addressing the Needs of Youth with Disabilities in the Juvenile Justice System: The Status of Evidence-Based Research*, which evaluated the status of key policies and programs that affect children and youth with disabilities, who have often been

overlooked by service and research programs. This study grew out of NCD's awareness that children and youth with disabilities have increasingly become overrepresented in the juvenile justice system and that a significant proportion of youth in the juvenile justice system have education-related disabilities and are eligible for special education and related services under IDEA. The study identified a tremendous gap in empirically based knowledge about children and youth with disabilities, especially those who are either at risk of delinquency or involved in the juvenile justice system. This information vacuum leaves behind a spectrum of largely unanswered questions involving distinct sets of policy issues ranging from the potentially conflicting philosophies underlying existing laws to what is known about effective prevention, intervention, and delinquency management strategies and efforts to ensure that the rights and needs of children and youth with disabilities are addressed. In response to this information gap, the report recommended "research that focuses on establishing the true prevalence of youth with disabilities of different types among at-risk populations in schools and across all stages of the juvenile justice system; the needs/services gap, including compliance with disability law; the causes of overrepresentation, where it exists, of youth with disabilities in the juvenile justice system, especially correctional facilities; and effective systems-level and program-level approaches, including federal laws, for addressing the needs of these youth, including particular attention to the types of programming most effective for youth from diverse racial/ethnic and cultural backgrounds."

Other major recommendations in the report were the following:

- identifying a range of strategies to enforce and promote compliance with federal disability law as it relates to children and youth with disabilities who are at risk of delinquency;
- increasing funding and resources to schools and the juvenile justice system to ensure that youth with disabilities receive appropriate services;
- designating a single federal agency whose sole focus is to ensure that the rights and needs of youth with disabilities entering or in the juvenile justice system are addressed; and
- undertaking a comprehensive assessment, including research studies, to determine the most effective programs and policies in schools, communities, and the juvenile justice system while ensuring that a balanced approach is taken to funding diverse programs and policies.

In its letter transmitting the report to President Bush, NCD expressed the hope that "your administration can use the findings and recommendations from this research study to help shape the scope and direction of future federal initiatives designed to tackle delinquency prevention and juvenile justice," and offered NCD's assistance in working with federal agencies and other stakeholders inside and outside the government to devise strategies for delinquency prevention and juvenile justice that work.

In addition to these three completed reports, the study of employment-related and return-to-work initiatives, under way at the time this report goes to press, illustrates the information NCD intends to provide through its Investing in Independence initiative. NCD has undertaken an examination of the way SSA is administering its SSI and DI programs and, in particular, its efforts to heighten its focus and effectiveness on transitioning beneficiaries to work. This study is designed to address the following questions:

- What are the evidence-based practices that promote the return to work of working-age beneficiaries of the DI and SSI programs?
- What policy changes are needed, given recent trends in program participation and employment?
- Are there proven and documented practices that work best for some populations of people with disabilities and not others?
- Which factors ensure that documented and evidence-based practices could be adapted or adopted by SSA and other entities that seek to ensure the employment of people with disabilities?

In 2005, NCD plans to evaluate the effectiveness of labor market interventions in addressing the employment of people with disabilities. The high number of people with disabilities who are unemployed or underemployed has been a chronic problem in the United States. The Federal Government has had to take a multifaceted approach (e.g., legislation, rehabilitation, employment programs, and work incentives) to increase the number of active labor market measures that are directed at the problems of unemployment and underemployment. In some instances, the Federal Government has partnered with businesses and industries in using various labor market interventions. The Federal Government and the private sector believe that these interventions will be instrumental in helping people with disabilities gain employment or improve their employment earnings potential. NCD is interested in determining the accuracy of these claims; the effectiveness of the different interventions and programs in place; the subgroups of people with disabilities who would benefit the most; and the roles, expectations, experiences, benefits, and level of employer satisfaction. This NCD study will examine the effectiveness of the aforementioned types of labor market interventions on increasing the employment of people with disabilities in the United States.

Similarly, NCD intends to evaluate the current use of tax incentives for businesses and places of public accommodation as well as personal federal tax provisions of particular interest to people with disabilities. This study will evaluate the ability of business incentives and other provisions such as individual exemptions and deductions to encourage increased opportunity and accessibility. It will also make recommendations for increasing availability, awareness, and use of these incentives. The study will evaluate the extent to which tax credits, personal exemptions (such as medical deductions and the standard deduction available for individuals who are blind), and other financial incentives have been or could be used to increase access to employment,

housing, transportation, health care, long-term services, and technology. A recent General Accounting Office report found that tax credits have had a limited effect on the employment of people with disabilities, noting that a very small proportion of corporate and individual taxpayers with a business affiliation use the tax credits that are available to encourage the hiring, retention, and accommodation of workers with disabilities and that information on the effectiveness of incentives is limited and inconclusive. It is probable that there is an equal lack of information and understanding of financial incentives that promote a range of independent living activities. NCD will seek information on the extent to which these incentives reduce society's costs. The study will examine the implications of expanding tax credits or deductions and assess whether better coordination of government efforts, clarification of tax incentive provisions, and increased outreach and education would increase usage.

In March 2004, NCD awarded a contract to the National Disability Institute, a program of the National Cooperative Bank Development Corporation, to conduct a research study examining critical issues surrounding the configuration, financing, and delivery of long-term services and supports financing and systems reform. This research will focus on (1) current level(s) and type(s) of involvement by the Federal Government in a range of systems and financing for long-term services and supports, (2) current and projected future needs for long-term services and supports among people with disabilities and the elderly, (3) gaps in long-term services and supports, (4) key features of future financing and systems reforms for long-term care, (5) locales that have incorporated indicators of cohesive and comprehensive reform into their policy and service systems, (6) major challenges and barriers that locales face in moving toward financing and systems reform for cohesive and comprehensive long-term services and supports, and (7) promising policy levers and policy changes. Through this research, NCD will focus its attention and resources on an impending crisis in American domestic policy.

Through such studies, NCD expects to provide the administration and Congress with concrete information and suggested approaches for making disability policy decisions and achieving maximum community integration for Americans with disabilities.

NCD has also stood ready to speak up in favor of measures that would further the implementation of the NFI. Thus, NCD commended the administration for its proposed New Freedom Initiative Medicaid Demonstrations Act of 2003, which would help Americans with disabilities transition from nursing homes or other institutions into community-based living settings. NCD noted that in its 2002 report *National Disability Policy: A Progress Report* it had recommended that people with disabilities have appropriate input into the allocation of funds in CMS's budget to assist with demonstration projects and a range of community-based activities throughout the life of the initiative. In NCD's view, the administration's 2003 proposals reflected NCD's recommendations by addressing barriers to home- and community-based care under Medicaid. The legislation would address a number of important issues vital to a person's ability to live in the community through the following proposed demonstration projects: Money Follows the Individual Rebalancing Demonstration, Demonstration on Respite for Caregivers of Adults, Demonstration on Respite for Caregivers of Children with Substantial Disabilities, Demonstration to Address Shortages of Community Direct Care Workers, and Demonstration of Home and Community-

Based Alternatives to Psychiatric Residential Treatment Facilities for Children. In addition, the bill contains proposed changes that would give states the option of providing Medicaid home- and community-based services for up to 90 days while final Medicaid eligibility is being determined and that would remove disincentives for people with disabilities to return to work by protecting the Medicaid health insurance coverage of spouses, if those spouses also have a disability.

NCD Chairperson Frieden declared,

NCD applauds the President's new legislative proposal, which will help eliminate many barriers to full participation in community life for people with disabilities. NCD supports the President's commitment to changing policies that unnecessarily confine people with disabilities to living in institutions. Helping people with disabilities who want to live in their own homes by providing community-based programs that foster independence and community participation is good public policy. Congress should act quickly to enact this proposal.

C. Monitoring Enforcement and Reauthorization Input

Despite having shifted its primary focus from studying the federal implementation and enforcement of civil rights laws to addressing more broadly those federal policies and programs that advance the independence, integration, and the full participation of people with disabilities in society, NCD has also continued its civil rights monitoring efforts. In February 2003 NCD issued *Rehabilitating Section 504*, a study of federal enforcement of Section 504 of the Rehabilitation Act of 1973. The report focused on the enforcement activities of five key federal agencies: ED, DOL, HHS, the State Department, and DOJ. NCD found that although the Federal Government consistently asserted its strong support for the civil rights of people with disabilities, the federal agencies charged with enforcement and policy development under Section 504 had, to varying degrees, lacked any coherent and unifying national leadership, coordination, accountability, and funding. NCD research documented the following kinds of deficiencies:

Agencies have not maintained consistency in their Section 504 programs' operational leadership and have given a low priority to the enforcement of Section 504, and there are significant differences in their enforcement efforts.

[N]one of the agencies examined for this report [has] initiated funding terminations to enforce Section 504 against grantees that violate the law.

Agencies have given low priority to collecting and analyzing Section 504 program data, and there are major differences in their data efforts. None of the agencies [has] developed information systems that comprehensively collect, aggregate, or summarize detailed information about complaints or compliance reviews and their outcomes.

Agencies have not received and have not been able to devote sufficient funding and resources to their Section 504 programs.

All five agencies, with the exception of the Department of State, have invested significant resources in providing written and verbal technical assistance to their grant recipients.

Rehabilitating Section 504 provided recommendations for addressing the shortcomings that had hindered Section 504 compliance and enforcement. Among the suggested strategies and approaches, NCD recommended that the Federal Government conduct periodic and thorough Section 504 self-evaluations, improve the collection and dissemination of data about Section 504 enforcement efforts, bolster DOJ resources and guidance to federal agencies on Section 504 enforcement, and apply successful practices in Section 504 technical assistance and enforcement used by federal agencies.

In January 2003, NCD began monitoring the 2003 reauthorization of five laws important to people with disabilities: Temporary Assistance for Needy Families (TANF), the Workforce Investment Act (WIA), IDEA, the Transportation Equity Act, and the Higher Education Act (HEA). During 2003, NCD published *TANF and Disability—Importance of Supports for Families with Disabilities in Welfare Reform* and forwarded it to the congressional committees handling TANF reauthorization. On March 11, 2004, NCD released an op-ed article on the reauthorization of the TANF program, in which it declared,

It will be important that the new law establish policies that reflect both the intention and desire of people with disabilities to work and the reality that some individuals may have significant work circumstances requiring long-term assistance.

While the TANF program is not specifically directed towards individuals with disabilities, research data indicate far-reaching effects of this program on people with disabilities. The General Accounting Office numbers are startling—over 40 percent of TANF recipients have at least one physical or mental impairment or they have a child with a disability, and eight percent of TANF families have both an adult and a child with a disability. TANF's work requirements and lifetime limits to benefits, which are key elements of welfare reform, pose challenges for state and local agencies as they attempt to address the unique needs of families with individuals with a disability. These challenges must be directly addressed in the reauthorization of TANF if welfare reform is to be meaningful for a large number of TANF recipients. If TANF is to truly help people with a disabilities fulfill their potential and move to work, the proper supports must be in place and continue as they exit the TANF program.

NCD sent a letter to the congressional committees with jurisdiction over WIA reauthorization, particularly addressing the reauthorization of the Vocational Rehabilitation Act. NCD also sent letters to the congressional committees with jurisdiction over IDEA reauthorization regarding (1) NCD's responses to H.R.1350, the House version of IDEA reauthorization, and NCD's recommendations for IDEA reauthorization; (2) the proposed use of vouchers for students with

disabilities in the Parental Choice Act, along with a policy paper NCD had issued in 2003, *School Vouchers and Students with Disabilities*; and (3) effective implementation and enforcement of IDEA. NCD provided oral and written testimony at a joint hearing of the House Committee on Transportation and Infrastructure and the House Committee on Education and the Workforce on “Coordination of Human Services Transportation.”

During 2003, NCD also completed a study of access to higher education for people with disabilities, *People with Disabilities and Postsecondary Education*, which included recommendations for reauthorization of the HEA. It provided a summary of the paper to the congressional committees with jurisdiction over the reauthorization of the HEA. In March 2004, NCD followed up by issuing a *Higher Education Act Fact Sheet* to assist Congress in its deliberations. NCD also published *Students with Disabilities Face Financial Aid Barriers* (2003) to highlight the difficulties facing some students with disabilities in paying for college and graduate school.

D. The “Righting the ADA” Initiative

In fall 2002, NCD took its special responsibility as originator of the ADA and its ongoing statutory mission to monitor the ADA’s implementation to a new level. The Council inaugurated a major initiative to suggest remedial approaches to address serious problems created by court decisions interpreting and applying the ADA. Spurred by concerns expressed at a series of meetings with ADA stakeholders, NCD became increasingly troubled by a series of Supreme Court decisions that take restrictive and antagonistic approaches to the ADA, with the result that the civil rights of people with disabilities have been significantly diminished. NCD’s initiative, which eventually was called “Righting the ADA,” documents and explains the problems that such decisions create, ultimately seeking to advance legislative proposals to reverse their impact. The initiative began with the development of a series of policy briefing papers published on NCD’s Web site that explain the problematic aspects of the Supreme Court decisions and describe their negative implications. To date, 19 such papers have been issued under the title Policy Brief Series: Righting the ADA Papers; they are found on the NCD Web site at <http://www.ncd.gov/newsroom/publications/policybrief>. Several more papers will be added to the series, and more may become necessary, depending on future Supreme Court rulings on the ADA. The series of briefs will culminate in a comprehensive report that will present legislative proposals and options for remedying the damaging effects of the Supreme Court’s decisions.

NCD also issued several other reports that, while they were not formally part of the Righting the ADA series, provided additional information regarding ADA enforcement and implementation. In 2003 NCD issued a paper discussing a pending ADA case that could have major ramifications on the efficacy and breadth of the ADA—*Tennessee v. Lane: The Legal Issues and the Implications for People with Disabilities*. Also in 2003, NCD issued *Application of the ADA to the Internet and the Worldwide Web*, which incorporates both NCD’s ongoing interest in technology issues and its ADA monitoring function.

E. International Efforts and the U.N. Convention

NCD has continued to play a leading role in seeking to promote foreign policy consistency with the values and goals of the ADA and the NFI. NCD has been designated by the State Department as the official liaison with the special rapporteur on disability at the United Nations and as a representative to the Third Committee on Social Development and Human Rights regarding the development of U.S. foreign policy on disability issues. In September 2003, NCD issued *Foreign Policy and Disability: Legislative Strategies and Civil Rights Protections To Ensure Inclusion of People with Disabilities*. The report was a follow-up to NCD's 1996 *Foreign Policy and Disability* report, which identified barriers to access for people with disabilities in U.S. foreign assistance programs. In the 2003 report, NCD concluded that the inclusion of people with disabilities in U.S. foreign policy will occur only when specific legislation is enacted to achieve that purpose. The report reviewed a number of models that Congress has adopted for linking human rights and foreign policy that could be adapted to ensure the inclusion of people with disabilities. In particular, the report recommended that Congress amend the Foreign Assistance Act to (1) ensure the inclusion of people with disabilities in all U.S. programs by requiring every U.S. agency operating abroad to operate in a way that is accessible and inclusive of people with disabilities, (2) establish a disability advisor at the State Department, and (3) create an office on Disability and Development at USAID.

The report was released at a very well attended event on Capitol Hill that featured a press conference and briefing. Speakers at the press conference included Senator Tom Harkin, Representative Jim Langevin of the Bipartisan Disabilities Caucus, and NCD member Kathy Martinez. The featured speakers at the briefing included, in addition to NCD members Milton Aponte and Kathy Martinez, Eric Rosenthal of Mental Disability Rights International and Arlene Kanter of Syracuse University School of Law, who had helped write the report for NCD. Following up on the report, NCD staff met with several congressional offices, including the staff of Representatives Doug Bereuter, Diane Watson, and Amory Houghton and Senator Richard Shelby to discuss the report and proposals to incorporate disability language into the Iraq and Afghanistan reconstruction/appropriation bills. NCD also met with Senator Harkin's staff to follow up on the report's recommendation of a Millennium Challenge Account, which would establish a new development agency and would tie development assistance to countries that demonstrate performance in specified areas.

NCD's report and follow-up helped precipitate an amendment to the Foreign Operations appropriations bill to require that, in determining a country's eligibility for funds, the Millennium Challenge Account include as one of its criteria the country's commitment to providing opportunities for people with disabilities. When Senator Harkin offered this amendment, he asked that the executive summary from NCD's report, along with the report transmittal letter from Lex Frieden, be read into the *Congressional Record*. The Millennium Challenge Act of 2003 was enacted as Title II of the Consolidated Appropriations Act, 2004 (Pub. L. 108-199); it established the Millennium Challenge Corporation (MCC). A provision of the Act (Sec. 607(b)(1)(B)) establishes that one of the criteria for a country's eligibility for funds through the Millennium Challenge Account is "respect [for] human and civil rights, including the rights of people with

disabilities.” Later language requires that eligibility determination “be based, to the maximum extent possible, upon objective and quantifiable indicators of a country’s demonstrated commitment to the criteria in subsection (b).”

Another section of the Consolidated Appropriations Act (Section 587) added a new provision with the heading “Disability Access.” It requires the Administrator of USAID to “seek to ensure that programs, projects, and activities administered by USAID in Afghanistan comply fully with USAID’s *Policy Paper: Disability* issued on September 12, 1997.” It directs the Administrator to submit by December 31, 2004, a report to the Appropriations Committee describing how the needs of people with disabilities were met in the development and implementation of USAID programs, projects, and activities in Afghanistan. In addition, the act requires the Administrator, in consultation with other appropriate departments and agencies, the Architectural and Transportation Barriers Compliance Board, and nongovernmental organizations with expertise in the needs of people with disabilities, to develop and implement, within 180 days of enactment of the Act, appropriate standards for access for people with disabilities for construction projects funded by USAID.

Title II of the Emergency Supplemental Appropriations Act for Defense and for the Reconstruction of Iraq and Afghanistan, 2004, titled “Iraq and Afghanistan Reconstruction and International Assistance,” contains a provision that requires the Administrator of the Coalition Provisional Authority to “seek to ensure that programs, projects and activities funded under this heading, comply fully with USAID’s *Policy Paper: Disability* issued on September 12, 1997.” In accordance with the new statutory requirements, the requests for proposal (RFPs) for Iraq reconstruction have begun to contain the following language under “Special Contract Requirements”:

B. COMPLIANCE WITH UNITED STATES AGENCY FOR INTERNATIONAL DEVELOPMENT (USAID) DISABILITY POLICY MEMORANDUM

The contractor shall follow the guidance provided in the United States Agency for International Development (USAID) *Disability Policy Paper*, dated September 12, 1997. The objectives of the USAID policy on disability are: (a) to enhance the attainment of United States foreign assistance program goals by promoting the participation and equalization of opportunities of individuals with disabilities in USAID policy, country-and sector strategies, activity designs and implementation; (b) to increase awareness of issues of people with disabilities both within USAID programs and in host countries; c) to engage other U.S. government agencies, host country counterparts, governments, implementing organizations and other donors in fostering a climate of nondiscrimination against people with disabilities; and (d) to support international advocacy for people with disabilities.

Another major recommendation to Congress and the administration in the 2003 *Foreign Policy and Disability* report was to support the drafting of a new U.N. Convention on the Rights of

People with Disabilities in the spirit of the ADA and other civil rights laws that would promote the full inclusion of people with disabilities in society. This recommendation reiterated a position in favor of such a convention that NCD had announced in September 2001. Under Chairperson Frieden's leadership, the Council has taken an increasingly visible and important role in facilitating U.S. support and involvement in the development of a convention. In February 2003, NCD cosponsored (with the U.S. International Council on Disabilities, the World Bank, and Yoshiko Dart) a meeting in Washington, D.C., to provide up-to-date information to the disability community on the development of a United Nations convention on the rights of people with disabilities and efforts to promote a disability-inclusive foreign assistance policy in the United States. On May 8, 2003, Representative Tom Lantos introduced H. Cong. Res. 169, expressing the belief of Congress that the United States should play a leading role in drafting a U.N. convention that affirms the rights of people with disabilities. The bill was cosponsored by Representatives Henry Hyde (R-IL) and Jim Langevin; it was referred to the House Committee on International Relations. Representative Lantos's office asked for NCD's comments on the resolution. In its advisory role to Congress, NCD recommended that Resolution 169 be supported as drafted.

On June 12, the House Committee on International Relations passed Resolution 169 by unanimous consent.

The convention was discussed before a U.N. ad hoc committee in June 2003. On June 16, the first day of the ad hoc meeting, NCD Chairperson Lex Frieden and former NCD member John D. Kemp were guests on Voice of America's "Talk to America," a daily international call-in talk show. The show focused on the importance of a U.N. convention for the human rights of people with disabilities. On June 24, Frieden conducted a news conference at the U.N. to focus attention on such a convention. During the press conference, Frieden said, "Many countries still require the guidance of international compacts to ensure the human rights of people with disabilities. NCD further believes that, as the world evolves into a global society, it is important to have meaningful international standards and structures in place to protect people with disabilities from discrimination and abuse."

In October 2003, NCD issued *UN Disability Convention—Topics at a Glance: History of the Process*, which summarized the process of trying to develop the convention and provided an update on recent developments. Frieden, in his joint roles as chairperson of NCD and president of Rehabilitation International, moderated a panel discussion on the importance of the U.N. convention on the human rights of people with disabilities during the 2003 observance of International Day of Disabled Persons on December 3 at U.N. headquarters in New York City. On January 21, 2004, NCD sent a letter to House Majority Leader Tom DeLay requesting his assistance in scheduling Resolution 109 for a vote as soon as possible. NCD expressed its view that "it would well serve the people of the United States to be involved in this historic process and ensure that this Convention is consistent with the Americans with Disabilities Act and the U.S. Constitution. The United States is a leader on disability around the world. We must continue to show our leadership through U.S. support and involvement in the proposed Convention so as to protect, preserve, and enforce the rights of people with disabilities everywhere."

On March 30, 2004, the U.S. Congressional Human Rights Caucus held a briefing on the U.N. Convention on the Human Rights of People with Disabilities. NCD member Kathy Martinez was among those testifying. Other witnesses included Ambassador Luis Gallegos, Permanent Representative of Ecuador to the United Nations and Chair of the U.N. Ad Hoc Committee drafting the convention; Richard Thornburgh, former U.S. Attorney General and vice chairman of the World Committee on Disability; and Alan Reich, president of the National Organization on Disability and chairman of the World Committee on Disability.

F. Other Activities, Pending Issues, and the Future

NCD continued to devote attention to mental health issues and services. In September 2002, it issued *The Well Being of Our Nation: An Inter-Generational Vision of Effective Mental Health Services and Supports*. The report examined some of the root causes of the mental health crisis and sought to “connect the dots” concerning the dysfunction of a number of public systems that are charged with providing mental health services and supports for children, youth, adults, and seniors. One of the most significant findings of the report was that children and youth who experience dysfunction at the hands of mental health and educational systems are much more likely to become dependent on failing systems that are supposed to serve adults. Similarly, adults whose mental health service and support needs are not met are very likely to become seniors who are dependent on failing public systems of care. In this way, hundreds of thousands of children, youth, adults, and seniors experience poor services and poor life outcomes, literally from cradle to grave. While recognizing that no single antidote exists for the current dysfunction of the public mental health system, the report declared that “visionary leadership, adequate funding and expansion of proven models (including consumer-directed programs) are essential ingredients.” Most important, the report called for “a dramatic shift in aspirations for people with psychiatric disabilities.”

Along with holding the meetings and issuing the reports on AI/AN people with disabilities, discussed above, NCD engaged in other activities related to diversity and participation by culturally diverse populations. In 2003, it issued a revised and updated version of *Language Assistance Plan for Implementation of Executive Order 13166—Improving Access to Services for Persons with Limited English Proficiency*. Also in 2003, NCD created a Cultural Diversity Initiative (CDI). Guided by NCD’s Cultural Diversity Advisory Committee, the CDI consists of three related projects designed to promote within federal agencies public awareness, advocacy, networking, policy-making, and research about people with disabilities from diverse cultures. The CDI’s primary goal is to provide definitive information about promising practices for successful outreach to people with disabilities from diverse cultures in relation to their rights and opportunities under various civil rights laws. A secondary goal is to promote capacity-building among federal agencies for integrating issues that affect people with disabilities from diverse cultures into the federal agenda. Immediate benefits include contributing to the knowledge base and understanding among federal agencies about how to meaningfully include people with disabilities from diverse cultures in agency activities.

The three separate but interrelated projects of the CDI are research, the development of a “toolkit,” and a national forum. The research aspect of the CDI involved reviewing existing literature on outreach to people with disabilities from diverse cultures, including social marketing and outreach efforts by federal agencies and nonprofit organizations. This effort resulted in the publication of *Outreach and People with Disabilities from Diverse Cultures: A Review of the Literature*. The toolkit project aims to develop specific resources federal agencies can use to enhance their outreach to people with disabilities from diverse cultures. This toolkit will include fact sheets on federal disability policies; information on designing and managing strategic outreach initiatives; and models of promising outreach policies, programs, and products.

The “Outreach for All Forum” was designed to bring about face-to-face dialogue among people with disabilities, their advocates, and federal officials. Its purpose was to give life to the idea of grassroots-government collaboration and to prompt communication about outreach approaches and practices. On July 28, 2003, NCD hosted the forum in Washington, D.C., as a working meeting that brought together people from various cultures across the country with senior officials from nine federal agencies and one White House initiative. Sixty people spent a full day in work sessions that focused on finding ways to create a two-way street for people with disabilities who come from diverse communities and government agencies that have a responsibility for providing appropriate services and for supporting empowerment and movement toward full participation in society.

The participants were an array of people with and without identified disabilities, including youth. NCD also brought to the table government officials from ED, HHS, HUD, DOJ, DOL, DOT, SSA, FCC, EEOC, and the White House Initiative on Asian and Pacific Islanders with Disabilities. The forum was further enriched by diverse heritages among many of the federal agency representatives who were also people with disabilities.

During the forum work sessions, participants developed recommendations for the cultural diversity resource toolkit and for an outreach road map of suggested actions beyond the forum. Among the recommendations were calls for (1) a presidential order clarifying the need and role for federal agencies around outreach as national demographics shift and (2) interagency efforts to address ways the Federal Government can provide more accessible programs and services through seamless, culturally sensitive, and simplified processes. The results of the proceedings were summarized in *Outreach for All Forum Summary Paper: Paths to Support Individual Empowerment of People with Disabilities from Diverse Cultures*.

Work on many of the issues described in previous sections of this report continues. The Investing in Independence series, a key initiative of the current Council, is still in its early stages; various critical studies are under way or in the planning stages. NCD is also in the process of developing a pivotal report as part the “Righting the ADA” initiative; it will document and explain the problems created by negative ADA decisions of the Supreme Court and present legislative proposals to reverse their impact. Such proposed legislation will seek to return the ADA to its original course by (1) reinstating the scope of protection the Act affords, (2) restoring certain previously available remedies to successful ADA claimants, and (3) repudiating or limiting

certain inappropriate and harmful defenses that have been grafted onto the carefully crafted standards of the ADA. NCD will continue to monitor and respond to future significant court decisions as they arise. In April 2004 NCD published an RFP for a study of ADA's impact on people with disabilities and the effects of the Supreme Court's ADA decisions on them. This study will provide additional information, data, and guidance for the continuing development and promotion of the "Righting the ADA" initiative.

In January 2004, NCD issued *Improving Federal Disability Data* and revisited an issue that has been an ongoing concern of the Council since its inception—getting better data on disabilities from the U.S. Census process. The report stressed the importance of having accurate data:

Census data are used by educators, policymakers, and community leaders and directly affect funding for many programs critical to individuals with disabilities, including programs for health care, transportation, employment training, and housing. Federal, state, and county governments use Census information to guide the annual distribution of hundreds of billions of dollars in critical services and supports.

NCD observed, however, that Census efforts regarding disability data remain inadequate: "While there have been some improvements in the use of a few disability questions and interview methodology in the Decennial Censuses for the past 30 years, those improvements have been small and incremental." Among the major recommendations were that (1) Congress should legislatively require an official and accurate enumeration of Americans with disabilities through the Decennial Census and through related national Census-like efforts such as the American Community Survey, (2) the Census Bureau should immediately revise Census questions for the Year 2010 Census (and the American Community Survey) to reflect the ADA definition of disability, and (3) the Bureau of Labor Statistics (BLS) should finish with all due haste its redesign of disability employment questions for the BLS Current Population Survey. NCD will continue to push for Federal Government agencies to obtain and disseminate better data on disabilities.

NCD expects to continue playing a major role in advocating for a U.N. Convention on the Rights of People with Disabilities in the hope of helping the U.N. embrace the fundamental objectives of independence, integration, equality, and full participation of people with disabilities.

G. Perspectives of Chairperson Frieden

Having served as the executive director of NCD at its inception as an independent agency and now having the privilege of serving as its chairperson, I have what might be called a long view of Council history.

The Council plays a unique role in reviewing, recommending, and implementing policies affecting the lives of people with disabilities. I am proud to observe that since its founding, the Council has maintained its steadfast commitment to ensuring equal opportunity for people with

disabilities and improving their quality of life. The Council has never compromised its independence, and it has routinely and respectfully sought the diverse views of all sectors of the disability community.

The Council continues to receive approbation for its role in conceiving the ADA. Less visible has been the extent of the Council's influence on other very important disability issues. Without question, Council efforts over the past 20 years have had a profound effect on the ability of people with disabilities to be full participants in the American way of life.

For two decades, the Council has brought issues affecting the lives of people with disabilities to the attention of public policymakers, produced dozens of insightful reports, and generated scores of well-conceived and well-received recommendations for the consideration of legislators and administrators. It has served four presidents and their administrations; Congress; and, most important, people with disabilities, their families, and advocates throughout our great land.

NCD has been well served by its members—some of them high-profile heroes of the disability rights and independent living movements as well as numerous others who are less well-known but equally heroic, committed, and knowledgeable members of our community. The Council's effectiveness may also be attributed to another factor: richness in diversity. Throughout its history, NCD has been characterized by diversity among its members and staff—diverse disability types, races, economic backgrounds, experiences, and areas of expertise. The Council has always been one of the most broadly representative units of government.

The Council's job will never be done. Despite improvements in our laws and policies, and despite the progress that we as a nation have made, we have many troublesome challenges yet to face. People with disabilities face great challenges in their search for employment and economic self-sufficiency. We are struggling to secure adequate health care and rehabilitation. Housing and transportation, fundamental to living independently, remain difficult to obtain and are largely unavailable in some areas of the country. Personal assistance is vital for maintaining the health, mobility, and productivity of many people with disabilities, yet we cannot ensure the provision of these services to most people in our communities who need them. Mental health services, like other disability services, are badly fragmented, and, in large part, they are built upon outdated paradigms that foster dependence rather than independence. These are among the challenges faced by people with disabilities every day, and it is the Council's duty to see that they remain before the President and his administration, Congress, and the public at large.

I predict the Council will have an even more important role in future events than it has had in the past. Our society faces many new questions about the implications of disability in regard to changing demographics, expanding knowledge of human processes and genetics, breakthrough discoveries in science and technology, and the changing role of America in the global society. The opportunities and uncertainties that these changes are bringing call for even greater thoughtfulness and leadership from the Council. NCD members and staff are working now to address these challenges and opportunities, and it will continue to do so in the future.

I have the honor and privilege of serving with 14 very dedicated members, and we are fortunate to be working with an equally dedicated staff. Our work together has been productive, and we are in the process of developing many important recommendations for improving the status and the quality of life of people with disabilities as well as helping President Bush bring to life the vision that he has conveyed in the New Freedom Initiative.

To paraphrase the late Justin Dart, who, I am pleased to say, also served as a Council member, we are with you, we are part of you, we love you. Together, we shall achieve our goals of independent living, economic self-sufficiency and prosperity, and full participation in society.

NCD Reports

In addition to the numerous meetings, discussions, consultations, comments, briefings, press events, awards, conferences, and various other activities in which NCD has engaged, NCD has generated a huge quantity of documents over the past 20 years. NCD's award-winning Web site makes available a large selection of different kinds of written products, including news releases, media advisories, articles, presentations, speeches, testimony, audiovisual broadcasts, correspondence, "NCD in the News" updates, and monthly issues of the *NCD Bulletin*. This section does not attempt to recount or summarize all these diverse documents, although they are often significant and informative. What follows is a list of the principal reports issued by NCD. The papers issued as part of the Righting the ADA series are listed separately.

National Council on Disability Publications

1984

National Policy for Persons with Disabilities—Executive Summary

1986

Toward Independence: An Assessment of Federal Laws and Programs Affecting Persons with Disabilities—With Legislative Recommendations

1988

On the Threshold of Independence

Implications for Federal Policy of the 1986 Harris Survey of Americans with Disabilities

1989

The Education of Students with Disabilities: Where Do We Stand?

1991

The Impact of Exemplary Technology-Support Programs on Students with Disabilities

1992

Wilderness Accessibility for People with Disabilities: A Report to the President and the Congress of the United States on Section 507(a) of the Americans with Disabilities Act

1993

Furthering the Goals of the Americans with Disabilities Act Through Disability Policy Research in the 1990s: Summary of Proceedings

Meeting the Unique Needs of Minorities with Disabilities: A Report to the President and the Congress

ADA Watch—Year One: A Report to the President and the Congress on Progress in Implementing the Americans with Disabilities Act

Progress in Advancing the Status of People with Disabilities Around the World: The Work of the United States Delegation to the Thirty-Third Session of the Commission for Social Development of the United Nations

Serving the Nation's Students with Disabilities: Progress and Prospects

Sharing the Risk and Ensuring Independence: A Disability Perspective on Access to Health Insurance and Health-Related Services

Study on the Financing of Assistive Technology Devices and Services for Individuals with Disabilities

1994

Inclusionary Education for Students with Disabilities: Keeping the Promise

Making Health Care Reform Work for Americans with Disabilities: Summary Information on Five "Town Meetings" on Health Care Reform

1995

Disability Perspectives and Recommendations on Proposals to Reform the Medicaid and Medicare Programs

Voices of Freedom: America Speaks Out on the ADA

Improving the Implementation of the Individuals with Disabilities Education Act: Making Schools Work for All of America's Children

The Americans with Disabilities Act: Ensuring Equal Access to the American Dream

1996

Access to the Information Superhighway and Emerging Information Technologies by People with Disabilities

Foreign Policy and Disability

Achieving Independence: The Challenge for the 21st Century

Improving the Implementation of the Individuals with Disabilities Education Act: Making Schools Work for All of America's Children—Supplement

Guidance from the Graphical User Interface (GUI) Experience: What GUI Teaches About Technology Access

Cognitive Impairments and the Application of Title I of the Americans with Disabilities Act

1997

National Disability Policy: A Progress Report (July 26, 1996–October 31, 1997)

Removing Barriers to Work: Action Proposals for the 105th Congress and Beyond

Outreach to Minorities with Disabilities and People with Disabilities in Rural Communities

Equality of Opportunity: The Making of the Americans with Disabilities Act

Impact of the Welfare Reform Legislation on Legal Immigrants with Disabilities

Assisted Suicide: A Disability Perspective Position Paper

1998

National Disability Policy: A Progress Report (November 1, 1997–October 31, 1998)

Grassroots Experiences with Government Programs and Disability Policy

Discipline of Students with Disabilities: A Position Statement

Reorienting Disability Research

Brief Amicus Curiae of the National Council on Disability in Support of Respondents

Access to Multimedia Technology by People with Sensory Disabilities

1999

Lift Every Voice: Modernizing Disability Policies and Programs to Serve a Diverse Nation

Implementation of the National Voter Registration Act by State Vocational Rehabilitation Agencies

Annual Report to the President and Congress, Volume 19, Fiscal Year 1998

Enforcing the Civil Rights of Air Travelers with Disabilities: Recommendations for the Department of Transportation and Congress

2000

Implementation Plan for Executive Order 13166—Improving Access to Services for Persons with Limited English Proficiency

Transition and Post-School Outcomes for Youth with Disabilities: Closing the Gaps to Post-Secondary Education and Employment

Carrying on the Good Fight: Summary Paper From Think Tank 2000—Advancing the Civil and Human Rights of People With Disabilities From Diverse Cultures

Closing the Gap: A Ten-Point Strategy for the Next Decade of Disability Civil Rights Enforcement

Brief Amicus Curiae of the National Council on Disability in Support of Respondents

Promises to Keep: A Decade of Federal Enforcement of the Americans with Disabilities

A Guide to Disability Rights Laws

New Paradigms for a New Century: Rethinking Civil Rights Enforcement

Federal Policy Barriers to Assistive Technology

National Disability Policy: A Progress Report (November 1, 1998–November 19, 1999)

National Council on Disability, Summary of International Watch Recommendations for NCD Consideration and Action

2001

Action Strategies for Effective Coalitions

Reconstructing Fair Housing

Brief Amicus Curiae of the National Council on Disability in Support of Respondents, Toyota v. Ella Williams

The Sandoval Ruling

The Accessible Future

National Disability Policy: A Progress Report, November 1999–November 2000

Position Paper on Patients' Bill of Rights Legislation

Inclusive Federal Election Reform

Applied Leadership for Effective Coalitions

Investing in Independence: Transition Recommendations for President George W. Bush

Annual Performance Report to the President and Congress—Fiscal Year 1999

Back to School on Civil Rights

From Privileges to Rights: People Labeled with Psychiatric Disabilities Speak for Themselves

2002

The Well Being of Our Nation: An Inter-Generational Vision of Effective Mental Health Services and Supports

An International Disability and Human Rights Convention: What You Need to Know About International Human Rights Law and Efforts to Gain Equality and Justice for People with Disabilities in the U.S. and Abroad

A Reference Tool: Understanding the Potential Content and Structure of an International Convention on the Human Rights of People with Disabilities

National Disability Policy: A Progress Report, December 2000–December 2001

Individuals with Disabilities Education Act Reauthorization: Where Do We Really Stand?

White Paper—Understanding the Role of an International Convention on the Human Rights of People with Disabilities

Annual Performance Report to the President and Congress Fiscal Year 2001

Supreme Court Decisions Interpreting the Americans with Disabilities Act

Supreme Court Decisions Interpreting the Americans with Disabilities Act (chart)

Position Paper on Genetic Discrimination Legislation

Principles for Genetic Discrimination Legislation

Brief Amicus Curiae of the National Council on Disability in Support of Respondents, Chevron U.S.A. Inc. v. Mario Echazabal

2003

UN Disability Convention—Topics at a Glance: History of the Process

Outreach and People with Disabilities from Diverse Cultures: A Review of the Literature

Students with Disabilities Face Financial Aid Barriers

Olmstead: Reclaiming Institutionalized Lives (unabridged online version)

People with Disabilities and Postsecondary Education—Position Paper

Foreign Policy and Disability: Legislative Strategies and Civil Rights Protections To Ensure Inclusion of People with Disabilities

Tennessee v. Lane: The Legal Issues and the Implications for People with Disabilities

Olmstead: Reclaiming Institutionalized Lives (abridged version)

Understanding Disabilities in American Indian and Alaska Native Communities: Toolkit Guide

People With Disabilities on Tribal Lands: Education, Health Care, Vocational Rehabilitation, and Independent Living

National Disability Policy: A Progress Report, December 2001–December 2002

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Conclusion

With the emergence of the disability rights and independent living movements, NCD has attempted to live up to its statutory mandate to be a voice within the Federal Government for “policies, programs, practices, and procedures that

- guarantee equal opportunity for all individuals with disabilities, regardless of the nature or severity of the disability; and
- empower individuals with disabilities to achieve economic self-sufficiency, independent living, and inclusion and integration into all aspects of society.”

It has also sought to fulfill its role as 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, functional ability, veteran status, or other individual circumstance.

The preceding pages highlight much of what NCD has contributed to public policy concerning the ways that people with disabilities are treated and affected by government programs and activities. NCD is proud of its accomplishments and looks forward to helping people with disabilities achieve the American dream—a future that entails equal opportunity, self-sufficiency, inclusion, integration into all aspects of society, and a full measure of independence.

Appendix

Mission of the National Council on Disability

Overview and Purpose

The National Council on Disability (NCD) is an independent federal agency with 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 significance 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, 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 act as disincentives for individuals to seek and retain employment.
- Making recommendations to the President, Congress, the Secretary of Education, the director of the National Institute on Disability and Rehabilitation Research, and other officials of federal agencies about 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 Congress, on a continuing basis, with advice, recommendations, legislative proposals, and any additional information that NCD or Congress deems appropriate.
- Gathering information about the implementation, effectiveness, and impact of the Americans with Disabilities Act of 1990 (ADA) (42 U.S.C. § 12101 et seq.).
- Advising the President, 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 of the Rehabilitation Services Administration with respect to the policies and conduct of the administration.
- Making recommendations to the director of the National Institute on Disability and Rehabilitation Research on ways to improve research, service, 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 NCD's purpose of promoting the full integration, independence, and productivity of individuals with disabilities.
- Preparing and submitting to the President and Congress an annual report titled *National Disability Policy: A Progress Report*.

International

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

Consumers Served and Current Activities

Although 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, veteran status, 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 people 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, NCD originally proposed what eventually became the 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 the ADA, improving assistive technology, and ensuring that those persons with disabilities who are members of diverse cultures fully participate in society.

Statutory History

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

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