# National Council on Disability Government Performance and Results Act Annual Report to the President and Congress Fiscal Year 2005



June 26, 2006

## **National Council on Disability**

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

Annual Performance Report to the President and Congress—Fiscal Year 2005

This report is also available in alternative formats and on NCD's award-winning Web site (http://www.ncd.gov).

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The views contained in this report do not necessarily represent those of the Administration, as this agency and NCD documents are not subject to the A-19 Executive Branch review process.

In accordance with 31 USC Sec. 1116 (f), this program performance report was prepared solely by federal employees.

# **Letter of Transmittal**

June 26, 2006

The President The White House Washington, DC 20500

Dear Mr. President:

The National Council on Disability (NCD) is pleased to submit its *Annual Performance Report* to the President and Congress—Fiscal Year 2005, as required by the Government Performance and Results Act (31 USC Sec. 1116).

As a unique independent federal agency and leader in the development and analysis of disability policy, NCD conducted a wide variety of activities in Fiscal Year (FY) 2005, with an authorized budget of \$3,021,070.

This report compares actual performance with the projected levels of performance set out in NCD's annual performance plan. As a public policy agency making recommendations to the President and Congress, NCD is pleased to inform you that the findings of this report show a positive link between the allocated resources and NCD's performance. NCD's assessment review showed that it was successful in meeting its goals and achieving its intended results.

NCD's FY 2005 activities promoted the full participation of people with disabilities in all areas of society by increasing access to assistive and universally designed technologies, expanding educational and employment opportunities, and promoting increased access into daily community life—the core of your New Freedom Initiative. These efforts were based on NCD's strategic goals: 1) Make evidence-based public policy recommendations that can enhance the lives of people with disabilities of all ages and backgrounds; 2) Educate the public and elected officials on disability issues; 3) Promote effective delivery of federal services and programs to all people with disabilities, particularly unserved and underserved populations such as people from diverse cultures, rural residents, and youth; and 4) Maintain NCD's status as a high performance organization.

Through its efforts, NCD was able to have a significant impact on the lives of people with disabilities and their families all over the world. Today, there are more than 54 million Americans with disabilities, 20 percent of the U.S. population. About half of these individuals have a severe disability, affecting their ability to see, hear, walk, or perform other basic functions of life.

With your support, NCD will continue to make recommendations that enhance the quality of life for all Americans with disabilities and their families, promote economic opportunity, support a compassionate society, and provide assistance to the most vulnerable among us.

Sincerely,	
Ethel D. Briggs Executive Director	
(The same letter of transmittal was sent to the Pre Speaker of the U.S. House of Representatives)	esident Pro Tempore of the U.S. Senate and the

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My Administration is committed to tearing down the barriers to equality that face many of the 54 million Americans with disabilities...My New Freedom Initiative will help Americans with disabilities by increasing access to assistive technologies, expanding educational opportunities, increasing the ability of Americans with disabilities to integrate into the workforce, and promoting increased access into daily community life.

President George W. Bush in the Forward to the New Freedom Initiative

# **Executive Summary**

#### **Background**

The National Council on Disability (NCD) is an independent federal agency making recommendations to the President and Congress on issues affecting 54 million Americans with disabilities. NCD is composed of 15 members appointed by the President and confirmed by the U.S. Senate.

### **Statutory History**

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

#### **Consumers Served and Current Activities**

While many government agencies deal with issues and programs affecting people with disabilities, NCD is unique in that it is the only federal agency charged with addressing, analyzing, and making recommendations on issues of public policy that affect people with disabilities regardless of age, disability type, perceived employment potential, economic need, specific functional ability, status as a veteran, or other individual circumstance. NCD recognizes its unique opportunity to facilitate independent living, community integration, and employment opportunities for people with disabilities by ensuring an informed and coordinated approach to addressing the concerns of 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, it was NCD that originally proposed what eventually became the Americans with Disabilities Act (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 and enforcement of ADA, improving assistive technology, and ensuring that people with disabilities from culturally diverse backgrounds fully participate in society.

In its 1986 report, *Toward Independence*, NCD first proposed that Congress should enact a civil rights law for people with disabilities.

In 1990, the Americans with Disabilities Act (ADA) was signed into law by President George H. W. Bush. Since that time, the ADA has been instrumental in guaranteeing equal opportunity for

people with disabilities in employment, public accommodations, transportation, state and local government services, and telecommunications. In 1992, Congress modified NCD's authorizing legislation, Title IV of the Rehabilitation Act of 1973, giving NCD a monitoring role in the enforcement, implementation, and effectiveness of the ADA.

In FY 2005, NCD continued its review and evaluation of new and emerging policy issues that affect people with disabilities. NCD continued to identify the overall needs and concerns of people with disabilities by conducting hearings, forums, and conferences throughout the country, and by responding to thousands of telephone, e-mail, and written inquiries on the ADA and other disability civil rights issues.

Major activities for FY 2005 included publishing several significant reports such as:

- The Civil Rights of Institutionalized Persons Act: Has It Fulfilled Its Promise? (August 2005)
- The Current State of Transportation for People with Disabilities in the United States (June 2005)
- Saving Lives: Including People with Disabilities in Emergency Planning (April 2005)
- National Disability Policy: A Progress Report (December 2004)
- Livable Communities for Adults with Disabilities (December 2004)
- Righting the ADA (December 2004)
- Design for Inclusion: Creating a New Marketplace (October 2004)
- Consumer-Directed Health Care: How Well Does It Work? (October 2004).

In addition, NCD's Web site received approximately 12 million hits in FY 2005—an NCD record. Additionally, nearly 500,000 reports were downloaded from the NCD site during the fiscal year—another record, producing huge savings to the taxpayer in lower costs in printing, postage, handling, storage, etc.

NCD's FY 2005 activities promoted the full participation of people with disabilities in all areas of society by increasing access to assistive and universally designed technologies, expanding educational and employment opportunities, and promoting increased access into daily community life—the core of President Bush's New Freedom Initiative. These efforts were based on NCD's strategic goals: 1) Make evidence-based public policy recommendations that can enhance the lives of people with disabilities of all ages and backgrounds; 2) Educate the public and elected officials on disability issues; 3) Promote effective delivery of federal services and programs to all people with disabilities, particularly unserved and underserved populations such as people from diverse cultures, rural residents, and youth; and 4) Maintain NCD's status as a high performance organization.

Through its efforts, NCD was able to have a significant impact on the lives of people with disabilities and their families all over the world.

### NATIONAL COUNCIL ON DISABILITY ACTIVITIES FOR FY 2005

## **Increasing Access through Technology**

## **NCD Releases Universal Design Report**

October 28, 2004, Washington, DC

The National Council on Disability (NCD) released its report, *Design for Inclusion: Creating a New Marketplace* 

(http://www.ncd.gov/newsroom/publications/2004/online\_newmarketplace.htm), and a white paper, which called on the designers and manufacturers of electronic and information technology (E&IT) to incorporate universal design processes when developing their E&IT products. The report demonstrates how designing with access in mind can significantly increase the size of targeted markets for E&IT.

NCD's report analyzes six product lines from the telecommunications, software, consumer electronics, and digital services industries for accessibility and usability: ATM machines, cell phones, distance learning, personal digital assistants, televisions, and voice recognition software.

## **Next Steps**

#### REPORT IMPLEMENTATION

NCD will continue to conduct studies on emerging issues such as information technology and service. NCD will continue with its follow-up work on implementing the recommendations made in its Investing in Independence series of reports. NCD will provide an ongoing assessment of how these recommendations are being implemented. As part of this assessment, NCD also will identify and describe systems, programs and models demonstrating successful partnerships between the Federal Government and state, local or private organizations to effectively implement and enforce these laws.

## **Expanding Educational Opportunities for Youth with Disabilities**

**Individuals with Disabilities Education Act Burden of Proof: On Parents or Schools?** August 9, 2005

NCD released *Individuals with Disabilities Education Act Burden of Proof: On Parents or Schools?* a position statement on *Schaffer v. Weast*, which is pending in the Supreme Court of the United States (http://www.ncd.gov/newsroom/publications/2005/burdenofproof.htm).

The Individuals with Disabilities Education Act does not specify whether parents or school districts have the burden of proof in special education litigation. It is NCD's position that school

districts, not parents, should have the burden of proof in issues about IEPs, placement, eligibility, and other matters related to appropriate education.

In *Schaffer v. Weast*, the United States Court of Appeals for the Fourth Circuit held that "parents who challenge an IEP . . . have the burden of proof in the administrative hearing." The court noted that the ". . . circuits are split—and splintered in reasoning—on this question." The split revolves around the Tatro / Alamo Heights line of cases contrasted with the Lascari / Oberti line of cases. Five circuits have assigned the burden of proof, the Tatro / Alamo Heights rule, to parents. Five other circuits, following the Lascari / Oberti rule, assign the burden to schools. The United States Supreme Court agreed to resolve the split between the Circuits.

If a parent disputes an IEP, the courts agree that it is the parent's burden to "place in issue the appropriateness of the IEP." The next issue is whether the parent has the burden of proving that the IEP is not appropriate or whether the school district has the burden of proving that the IEP is appropriate.

There are several competing principles. Should the party attacking the terms of an IEP bear the burden of showing why the IEP is not appropriate? Or should the party that prepared the IEP and has greater expertise and resources have the burden of proving that the IEP is appropriate?

If a statute is silent regarding which party has the burden of proof, the complainant usually has the burden of proof. The U. S. Supreme Court has issued several decisions about burden of proof in the absence of statutory guidance. In most cases, the Court, relying on the policy and history of the statute and concerns of fundamental fairness, has been consistent in assigning the burden of proof to the party more likely to have access to the information that explains its actions in order to arrive at a result that is "right" and "just."

This paper reviews the history of special education, special education law, the *Mills* case, which formed the backbone of the procedural safeguards in the Individuals with Disabilities Education Act, special education burden of proof cases, and U. S. Supreme Court cases.

Brian Schaffer, Peter Mills and Bill Dunstan are children with disabilities whose cases were decided by different courts. Their own educational and legal processes are typical of the circumstances in which parents and schools disagree. Because the burden of proof was assigned to Bill Dunstan, the outcome in his case was not fair or right; it was unjust.

The release of the NCD position statement caused one of the counsels for the respondents to petition the Court to dislodge the NCD position statement and other material from the Court's view. On August 25, the Court granted the plaintiff's motion to lodge these documents, including NCD's position statement, for the record.

#### IMPROVING EDUCATIONAL OUTCOMES FOR STUDENTS WITH DISABILITIES

As a follow-up to its 2004 paper "Improving Educational Outcomes for Students with Disabilities," NCD will conduct a formal evaluation of federal and state education agencies' implementation of both the No Child Left Behind Act (NCLBA) and the Individuals with Disabilities Education Act (IDEA). By FY 2006, ample time will have passed since passage of NCLBA and the reauthorization of IDEA for this research to be undertaken.

The range of research activities necessary for this project will include, but not be limited to: (a) interviews with a range of stakeholders including key Departmental managers and staff, Congressional staff members, national and state community leaders, students with disabilities and family members; (b) reviews of federal and state educational data systems for NCLBA and IDEA; (c) examinations of all relevant Departmental reports, memos, policy guidance, etc. as well as all relevant Congressional testimony, reports, etc.; (d) other pertinent materials, such as federal and state case law; (e) federal and state education agencies' technical assistance activities related to NCLBA and IDEA; (f) federal and state level professional development and management activities related to NCLBA and IDEA; (g) federal and state level knowledge transfer and diffusion activities related to NCLBA and IDEA; (h) federal and state level knowledge transfer and diffusion activities related to NCLBA and IDEA; and (i) monitoring and enforcement of NCLBA and IDEA by the Federal Government and states.

NCD expects that this research and report will be used by policymakers and the public to refine and strengthen the ongoing implementation of the two laws, and serve as one source for data-based decision making by educational leaders and policymakers during the next cycle of reauthorization of the federal laws.

## **Integrating Americans with Disabilities into the Workforce**

# **Workforce Investment Act Reauthorization Recommendations** March 17, 2005

In 1998, Congress passed the Workforce Investment Act (WIA), creating authority for the Workforce Development System, a federal employment services program, which provides assistance through One-Stop Centers across the nation. This system replaced a number of smaller federally supported employment programs, consolidating the funds into what was intended to be a more user-friendly, universally accessible system of employment services. The Rehabilitation Act was included as a separate program with separate funding under the new Act. Title IV of WIA now carries the authority for the Rehabilitation Act in its entirety and throughout the Act creates a number of opportunities for interaction between the State Vocational Rehabilitation (VR) system and the One-Stop Centers. For example, the State VR program is identified as one of several "partners" in the One-Stop system. The Act also makes clear that One-Stop Centers

are to be available and accessible to individuals with disabilities and includes non-discrimination language that specifically references disability.

Originally slated for reauthorization in 2003, WIA now appears to be on track in both the House and Senate to move forward in 2005. With so much of importance to the disability community in the Act, NCD offered to the 108th Congress detailed recommendations. NCD observations and input are offered as a guide to disability-related issues for the current reauthorization process. They can be found at

http://www.ncd.gov/newsroom/publications/2005/workforce\_investment.htm.

## **Financial Incentives Study**

March 31, 2005

NCD published a presolicitation notice in Federal Business Opportunities (<a href="http://www.fedbizopps.gov">http://www.fedbizopps.gov</a>) to conduct a Financial Incentives Study for people with disabilities.

NCD is conducting a series of interrelated studies aimed at improving the employment of people with disabilities and factors that impact daily activities, including work. The first two studies that will address both public and private policies and initiatives are the Social Security/Transitioning to Work Study and the Employment Study. As the third study in the NCD series, the proposed Financial Incentives Study should: (a) identify among other tasks what factors influence the use of financial incentives by employers, employees and potential employees who are people with disabilities; (b) assess what is needed to address those factors to increase the use of existing incentives and/or create new incentives; (c) look within and beyond the workplace regarding the potential role of financial incentives in the increased hiring of and/or use by people with disabilities with respect to aspects of living that also impact obtaining and maintaining meaningful daily living opportunities and choices, including employment (e.g., affordable and accessible assistive technology, housing, transportation, health care, personal assistants and other supports); (d) set forth a model that provides economic analysis of benefits to costs for employers, and (e) as appropriate, reflect connections with NCD's Social Security and employment studies. This could include final report recommendations for necessary legislative, regulatory and administrative changes or new actions that benefit both employers and people with disabilities. The estimated contract is for 12 months.

#### **Next Steps**

#### **EMPLOYMENT STUDY**

Over the past 30 years, a range of laws have been enacted in the United States such as the Workforce Investment Act, and other related federal laws and domestic policy initiatives, to improve the employment status of Americans with disabilities. Periodic reports (e.g., Census 1990 and 2000) and survey findings (e.g., Harris Interactive 1994, 1998, and 2002) indicate that the intended employment outcomes are not yet being achieved. NCD will continue to build upon its 2004 and 2005 employment research work and carry forward its thorough review of federal

laws and programs aimed at employing people with disabilities to determine the status and impact of these efforts. NCD will continue to focus on the following questions: (a) what do employment programs do to individualize their services and supports for individuals with a range of disabilities; and (b) how are entities carrying out the accommodations provision of Section 504 and the Americans with Disabilities Act?

Current public policies and procedures addressing the employment of people with disabilities are not coordinated and often conflict. The research for this project will include, but not be limited to, analyzing existing public policies that impact the employment of people with disabilities and determining how they conflict or complement each other; developing a consistent national public policy agenda that supports the employment of people with disabilities; looking at innovative ways to eliminate inconsistencies in federal agency policy; as well as examining ways to stimulate discussion about private sector involvement supporting the employment of people with disabilities.

In July 2005, NCD awarded this research initiative to Rutgers University, to examine both public and private policies aimed at improving the employment of people with disabilities.

#### SOCIAL SECURITY STUDY

NCD completed its research evaluating the effectiveness and direction of federal social security benefits programs that support people with disabilities. NCD examined in detail the impact of the Supplemental Security Income and Social Security Disability Insurance benefits programs on people with disabilities, particularly with respect to how these programs support transitioning or returning beneficiaries to work. The study incorporated the expertise of key stakeholders, including consumers, service providers, employers, and other community organizations. The study's recommendations and findings are slated for release in November 2005.

## **Promoting Full Access to Community Life**

## NCD Releases Consumer-Directed Health Care Report October 26, 2004

NCD released its report, *Consumer-Directed Health Care: How Well Does It Work?* (http://www.ncd.gov/newsroom/publications/2004/consumerdirected.htm). The report offers a clear picture of the strengths and limitations of our Federal Government's current research agenda related to consumer-directed health care for Americans with disabilities. It sheds light on the relationship between consumer-directed health care and practice. It also provides a basis for policymakers who use health research evidence to make informed policy decisions (e.g., about MiCASSA, Money Follows the Person, *Olmstead*, and Real Choice Systems Change Grants) in keeping with the intent of the New Freedom Initiative.

## **NCD Releases Righting the ADA**

December 1, 2004

NCD released its report Righting the ADA

(<a href="http://www.ncd.gov/newsroom/publications/2004/righting\_ada.htm">http://www.ncd.gov/newsroom/publications/2004/righting\_ada.htm</a>) at a news conference at the National Press Club in Washington, DC, calling on the Administration and Congress to support legislation that will "right" the course of the Americans with Disabilities Act (ADA) and protect the civil rights of people with disabilities.

Over the past two years, NCD conducted an in-depth analysis of the Supreme Court's interpretations of the ADA. NCD has determined that, while some of the Court's decisions have clearly liberated people with disabilities, e.g., *Tennessee v. Lane, Martin v. PGA Tours*, and *Olmstead v. L.C.*, several of the Court's rulings involving the ADA depart from the core principles and objectives of the ADA. NCD's report *Righting the ADA* provides an analysis of the problematic rulings, describes the resulting impact on people with disabilities, and offers legislative proposals designed to restore the ADA to its original intent.

The purpose of the ADA is 'to provide a clear and comprehensive national mandate for the elimination of discrimination against individuals with disabilities.' The provisions of the ADA addressing architectural, transportation, and communication accessibility have changed the face of American society in numerous concrete ways, enhancing the independence, full participation, inclusion, and equality of opportunity for Americans with disabilities. However, the provisions of the ADA that have been narrowed by Court rulings currently do not provide the same scope of opportunities and protections expressed by those involved in the creation and passage of the ADA. Legislation is urgently needed to restore the ADA to 'assure equality of opportunity, full participation, independent living, and economic self-sufficiency' for Americans with disabilities.

The report contains NCD's legislative proposal, entitled, "ADA Restoration Act," which is intended to restore the protections of the Americans with Disabilities Act that have been restricted by several U.S. Supreme Court decisions over the past few years.

# NCD Makes Recommendations on Livable Communities for Adults with Disabilities December 2, 2004

NCD released its report *Livable Communities for Adults with Disabilities* at a Congressional briefing, calling on the Administration and Congress to develop a cohesive public policy agenda for livable communities for adults with disabilities.

The briefing was co-sponsored by the Congressional Bipartisan Disabilities Caucus, the Congressional Livable Communities Task Force, and NCD.

The advances in America's policy and programs on behalf of citizens with disabilities have been inspiring. Notwithstanding the individual social policy and legislative achievements of the past 50 years on behalf of Americans with disabilities, however, we need to establish a cohesive

public policy agenda in the coming years. We need a common vision, with clear objectives, that speaks to the strength of our commitment to our citizens and the quality of their lives, and one that addresses the challenges facing us in the years ahead.

Communities in the United States are faced with increasingly difficult choices and decisions about how to grow, plan for change, and improve the quality of life for adults with disabilities as well as elders who may develop disabilities as they grow older. People are living longer today than ever before and the population of people aged 65 and older is growing rapidly. One in five people in the United States will be over the age of 65 by 2030. Currently, more than 4.7 million Americans aged 65 years or older have a sensory disability involving sight or hearing, and more than 6.7 million have difficulty going outside the home. As the population of elders grows, it is possible that the number of people aged 65 and older with disabilities will also grow, particularly those 75 years of age and older.

Livable Communities for Adults with Disabilities, NCD's report, offers a compelling vision for our nation. It articulates the elements of a livable community, highlights existing examples of livable communities in the United States today, which can serve as models for others, and describes how communities can develop and sustain their livability features. The report was developed with the advice of a consumer advisory committee of people from around the country.

NCD's recommendations are in line with President Bush's emphasis in the New Freedom Initiative on community integration, participation, and enhancement of the independence of people with disabilities at home, at work, and throughout the course of their daily lives.

## **NCD Notes Progress in Disability Policy**

December 9, 2004

NCD released its annual report, *National Disability Policy: A Progress Report* (<a href="http://www.ncd.gov/newsroom/publications/2004/ProgressReport2004.htm">http://www.ncd.gov/newsroom/publications/2004/ProgressReport2004.htm</a>), noting progress has been made, but gaps remain.

The report covers the period from December 2002 through December 2003. It reviews federal policy activities by issue areas, notes input by other federal agencies on their progress where it has occurred, and makes further recommendations where necessary, primarily to the executive and legislative branches of the Federal Government.

NCD has observed examples of progress in disability policy and the broader policy arena. Among these are the findings and recommendations of the President's New Freedom Commission on Mental Health in its report on recovery from mental illnesses and a proposed transformation of the nation's approach to mental health care; the Department of Health and Human Services' funding of several model projects (Demonstration to Improve the Direct Service Community Workforce) designed to develop and implement programs that recruit and retain personal assistance workers for people with disabilities and people who are aging; and critical attention to the needs and inclusion of people with disabilities in preparation for

emergency situations, such as the Department of Homeland Security's work and coordination with other agencies.

Examination of the status of disability policy discloses that incremental progress made in some areas is clouded by other major barriers and challenges that continue to block paths available to the general population. Gaps in necessary services and supports remain to the extent that, as stated in NCD's 2002 report on progress, far too many Americans with disabilities are undereducated and unemployed.

NCD encourages all government agencies and Congress to use NCD's work as a reference point and source of data for recommendations and in future investigations of disability policy issues.

## **Cruise Ships and ADA**

February 8, 2005

The U.S. Supreme Court heard oral arguments in *Spector v. Norwegian Cruise Line Ltd.* (No. 03-1388), a case that will determine whether foreign-flagged cruise ships serving U.S. ports must comply with the public accommodations provisions contained in Title III of the Americans with Disabilities Act (ADA).

On February 8, NCD published a paper examining the *Spector* case in detail and concluded that the plain and expansive language of Title III evidences a congressional intent to require cruise ships to comply with Title III. Cruise ship owners and operators claim that they and their ships are exempt from ADA because all of their ships are, with few exceptions, foreign-flagged, and, historically under international law, a seagoing vessel need only comply with the laws of the flagging nation when it comes to the regulation of a ship's internal operations. The paper explains that compliance with Title III would not impinge on the internal management prerogatives of cruise lines or conflict with the United States' obligations under international law. Moreover, the contemporary practice of flying what is known as a "flag of convenience" is simply a business decision that only marginally implicates the sovereign interests of the flagging nation. In stark contrast, however, the United States has a significant interest in ending invidious discrimination against persons with disabilities by cruise lines—particularly when cruise lines are headquartered in the United States, base their ships in U.S. ports, draw their clientele almost exclusively from the United States, and advertise and solicit most of their passengers in the United States. In passing ADA, Congress sought to guarantee "full participation" by persons with disabilities in all aspects of American life. The Supreme Court has an opportunity in Spector to give force and effect to Congress' unequivocal intent by refusing to exempt foreignflagged cruise ships from Title III of ADA. To do otherwise would place the Court's imprimatur upon the discriminatory practices of inaccessible cruise lines and write segregation on the basis of disability into American law.

## **NCD Conducts ADA Impact Forums**

March 25, 2005

As a part of a year-long study, NCD is sponsoring five public forums around the country to gather testimony from people with disabilities, their families, and their advocates on the impact the Americans with Disabilities Act of 1990 (ADA) has had on their lives.

Fifteen years ago, ADA was hailed as a major civil rights law guaranteeing equal opportunity for Americans with disabilities to participate more fully in their communities, to have greater access to goods and services, and to enjoy more employment opportunities. To what extent ADA has achieved its goals of equality of opportunity, full participation, independent living, and economic self-sufficiency for people with disabilities remains an open question, one the public forums will address.

Representing a diversity of regions, populations, and ethnicities, the five sites for the public forums are: Iowa City, Iowa, Los Angeles, California, Houston, Texas, Savannah, Georgia, and Washington, DC.

In addition to holding public forums, the NCD's ADA Study Team is conducting focus groups and interviews with individuals with disabilities, employers, service providers, business and trade association representatives, and other stakeholders who have been directly affected by ADA. Rounding out the research activities, the ADA Study Team is also conducting an environmental scan to collect data on such ADA impact statistics as number of curb cuts, number of telephone relay calls, number of reasonable accommodations provided by employers, and other indicators to determine whether the law has brought about significant change in the past 15 years.

The ADA Study Team is being advised by a blue ribbon panel of nationally and internationally recognized experts on disability policy.

### **Emergency Planning**

April 15, 2005

NCD released a report (<a href="http://www.ncd.gov/newsroom/publications/2005/publications.htm">http://www.ncd.gov/newsroom/publications/2005/publications.htm</a>) recommending immediate federal changes in emergency planning for people with disabilities. Saving Lives: Including People with Disabilities in Emergency Planning, provides an overview of steps the Federal Government should take to build a solid and resilient infrastructure that will enable the government to include the diverse populations of people with disabilities in emergency preparedness, disaster relief, and homeland security programs. This infrastructure would incorporate access to technology, physical plants, programs, and communications. It also would include procurement and emergency programs and services.

All too often in emergency situations the legitimate concerns of people with disabilities are overlooked or swept aside. In areas ranging from the accessibility of emergency information to the evacuation plans for high-rise buildings, great urgency surrounds the need for responding to the concerns of people with disabilities in all planning, preparedness, response, recovery, and mitigation activities. The homeland security terrorist event of September 11, 2001, as well as the

recent energy blackouts in the U.S. Northeast and Midwest and, more recently, the natural disaster hurricane events in Florida and the tsunami event of December 26, 2004, underscore the need to pay attention to the concerns raised in this report.

The decisions the Federal Government makes, the priority it accords to civil rights, and the methods it adopts to ensure uniformity in the ways agencies handle their disability-related responsibilities are likely to be established in the early days of an emergency situation and be difficult to change if not set on the right course at the outset. By way of this report, NCD offers advice to assist the Federal Government in establishing policies and practices in these areas. This report provides examples of community efforts with respect to people with disabilities, but by no means does it provide a comprehensive treatment of the emergency preparedness, disaster relief, or homeland security program efforts by state and local governments.

## **Key Findings**

- Disaster management activities appear to have many access mistakes in common. People
  with disabilities frequently encounter barriers to physical plants, communications, and
  programs in shelters and recovery centers and in other facilities or devices used in
  connection with disaster operations such as first aid stations, mass feeding areas, portable
  payphone stations, portable toilets, and temporary housing.
- Many of these barriers are not new. Information and lessons learned are not shared across agency lines, and thus experience does not enlighten the development of new practices. Many accessibility lessons learned during previous disasters are not incorporated in subsequent planning, preparedness, response, and recovery activities. This should not be perceived as a post-9/11 problem. Segments of the disability community have reported problems in helping to develop and benefiting from emergency services over many decades.
- People with disabilities are left out of preparedness and planning activities. These activities include analyzing and documenting the possibility of an emergency or disaster and the potential consequences or impacts on life, property, and the environment.

## **Key Recommendations**

- DHS should establish a Disability Access Advisory Group, in addition to the Interagency Coordinating Council on Emergency Preparedness, made up of qualified people with disabilities and others with disability-specific disaster experience who meet regularly with senior officials to discuss issues and challenges.
- The DHS Directorate of Emergency Preparedness and Response should integrate information on people with disabilities into general preparedness materials. It also should inform readers and information users on how to get access to more customized materials.

- The DHS Office of Civil Rights and Civil Liberties should regularly issue guidance for state and local emergency planning departments to reinforce their legal obligation to comply with ADA and Section 504 and 508 of the Rehabilitation Act in planning for, operating, and managing programs and services such as Citizen Corps, shelters, and other disaster services.
- The FCC should develop stronger enforcement mechanisms to ensure that video programming distributors, including broadcasters, cable operators, and satellite television services, comply with their obligation to make emergency information accessible to people with hearing and vision disabilities, that it acts immediately on violations, and that it is proactive on Section 255 hearing aid compatibility.

#### Mediation and ADA

May 10, 2005

The U.S. Equal Employment Opportunity Commission (EEOC), the National Council on Disability (NCD), and the U.S. Department of Justice (DOJ) jointly released two new publications addressing how to ensure that mediation of equal employment opportunity disputes is accessible to people with disabilities. The publications are available on all three agencies' Web sites at <a href="https://www.eeoc.gov">www.eeoc.gov</a>, <a href="https://www.eeoc.gov">www.ncd.gov</a>, and <a href="https://www.ada.gov">www.ada.gov</a>.

The documents, entitled *Questions and Answers for Mediation Providers: Mediation and the Americans with Disabilities Act* and *Questions and Answers for Parties to Mediation: Mediation and the Americans with Disabilities Act*, address the obligations of all private and public sector mediation providers, including employers that offer their employees mediation as a benefit of employment. The documents are written in a question-and-answer format and discuss topics such as: types of reasonable accommodations that may be necessary to make mediation accessible to people with disabilities; best practices for ensuring that mediation is accessible; the confidentiality of medical information disclosed during mediation; and, recommended types of ADA training for mediators.

### **ADA Implementation**

May 16, 2005

NCD published a request for proposals on Federal Business Opportunities (<a href="http://www.fedbizopps.gov">http://www.fedbizopps.gov</a>) for an Americans with Disabilities Act (ADA) Implementation Project (Solicitation Number NCD05-04).

NCD is responsible for gathering information about the implementation, effectiveness, and impact of ADA. NCD's work in this area over the past three years has focused on identifying problems or gaps in ADA implementation and understanding what factors enhance or impede ADA implementation. In the 2003-2004 "Righting the ADA" project, NCD analyzed the effects of unfavorable Supreme Court interpretations in ADA cases and developed legislative recommendations for restoring ADA to its original intent. NCD is currently conducting an ADA

impact study, gathering information about the impact of ADA and determining whether the law's goals are being achieved. Building on findings from this earlier work, NCD would like to bring together ADA stakeholders to develop recommendations on how to improve ADA implementation and make its goals a reality for individuals with disabilities.

The contractor will establish a mechanism whereby ADA stakeholders, including people with disabilities, businesses, employers, state and local governments, and federal agencies, can engage in a national dialogue on ADA and examine strategies for more effectively implementing it. The contractor must demonstrate the ability to successfully identify and reach out to relevant stakeholders, facilitate consensus building among groups with different perspectives and interests, and assist NCD in developing an effective public information and awareness campaign. Based on stakeholder input, the contractor will prepare a final report with specific recommendations for improving ADA implementation.

The estimated contract period is 12 months.

# Same Struggle, Different Differences: Civil Rights Policy Forum June 9, 2005

NCD sponsored a civil rights forum entitled "Same Struggle, Different Difference." The forum was held to encourage greater collaboration and communication among disability advocates and the broader civil rights coalition on common policy priorities. The forum was organized as a result of NCD's cooperative agreement with the American Association of People with Disabilities with the support of the Leadership Conference on Civil Rights, AARP, and NCD's Cultural Diversity Advisory Committee. More than 90 individuals from 47 civil rights and disability rights organizations participated in the forum. A summary of the forum activities with follow-up opportunity for participating organizations' consideration and action is posted at: <a href="http://www.ncd.gov/newsroom/publications/2005/forum\_summary.htm">http://www.ncd.gov/newsroom/publications/2005/forum\_summary.htm</a>. In addition, workgroup notes summarized from forum discussions among national and state level civil and disability rights representatives are posted at:

http://www.ncd.gov/newsroom/advisory/cultural/group\_notes.htm. A related resource directory on disability and diversity, drawn from NCD's Cultural Diversity Initiative toolkit, is posted at: <a href="http://www.ncd.gov/newsroom/advisory/cultural/resource\_directory.htm">http://www.ncd.gov/newsroom/advisory/cultural/resource\_directory.htm</a>.

# NCD Reissues Statement of Opposition to Assisted Suicide Legislation June 9, 2005

NCD reissued its statement opposing the legalization of assisted suicide.

In 1997, NCD issued *Assisted Suicide: A Disability Perspective* (http://www.ncd.gov/newsroom/publications/1997/suicide.htm), as part of its role as the principal agency within the Federal Government charged with the responsibility of providing cross-disability policy analysis and recommendations regarding government programs and policies that affect people with disabilities. At the time the position paper was issued, the U.S.

Supreme Court was preparing to rule on appeals from the Second and Ninth Circuit Courts, each of which had declared assisted suicide a constitutional right.

After a thorough review of the forms of discrimination people with disabilities experience in American society, the Council decided to oppose legalization of assisted suicide, concluding that:

Current evidence indicates clearly that the interests of the few people who would benefit from legalizing physician-assisted suicide are heavily outweighed by the probability that any law, procedures, and standards that can be imposed to regulate physician-assisted suicide will be misapplied to unnecessarily end the lives of people with disabilities.... At least until such time as our society provides a comprehensive, fully-funded, and operational system of assistive living services for people with disabilities, this is the only position that the National Council on Disability can, in good conscience, support.

In the eight years since the position paper was issued, the U.S. Supreme Court has overturned the Second and Ninth Circuits and ruled that there was no constitutional right to assisted suicide, but that the states could experiment with state laws allowing it. There has been an opportunity to observe the implementation of the Oregon assisted suicide law, and the evolution of cultural attitudes toward so-called "mercy killing," of both the medical and non-medical variety. Jack Kevorkian was convicted of second degree murder for euthanizing a man with ALS; utilitarian euthanasia advocate Professor Peter Singer was hired for a prestigious bioethics chair at Princeton University; two movies favorably depicting euthanasia of people with quadriplegia won Oscars; and numerous courts upheld the right of a guardian to starve and dehydrate a severely brain injured but healthy woman in Florida.

The U.S. Supreme Court has agreed to hear a case this year about the Oregon Death with Dignity Act. Congress has also begun taking a look at federal legislation to address laws governing surrogate decisions to withhold life-sustaining treatment in the aftermath of the *Schiavo* case. Accordingly, in the context of the current public debate, NCD reaffirms its position opposing the legalization of assisted suicide by reissuing its 1997 position paper along with a statement of its reasons for doing so (<a href="http://www.ncd.gov/newsroom/publications/2005/assisted\_suicide.htm">http://www.ncd.gov/newsroom/publications/2005/assisted\_suicide.htm</a>).

The Council's position paper carefully examined the many forms of discrimination and devaluation people with disabilities experience in today's society. The struggle to implement the social vision embodied in ADA continues. In view of the aging of our population, policymakers should turn to the disability rights movement for its expertise in cost-effective services to enhance self-determination and independence. While study and consensus building continue with respect to the formulation of public policies in the aftermath of the *Schiavo* case, some principles recently expressed to a Congressional subcommittee by attorney, parent, and advocate Rud Turnbull seem clear:

• Disability is a natural part of the human experience and in no way diminishes the right of individuals to participate in or contribute to society.

- The nation's policy for people with disabilities is to ensure their equal protection under the law, advance their self-determination, and promote their independent living.
- Discrimination against any person with a disability, regardless of the nature or severity of the disability, is morally and legally indefensible.
- When medical care is clearly beneficial, it must be provided.
- It is impermissible to take into account the anticipated or actual limited potential of a person, or their lack of resources.
- The person's disability itself must never be the basis for a decision to withhold treatment.

It is critical to fully implement the rights of people with disabilities, old and young, to choose home- and community-based, long-term-care services, consistent with Title II of the ADA and the U.S. Supreme Court decision in *Olmstead*. If individuals with disabilities feel that they have lost control of their lives, been devalued because of their impairments, and become a burden to others, the appropriate response from society is to support him or her to live independently in the community. Legalized medical killing solely based on disability should be rejected. People with disabilities are not better off dead, and society is not better off without them.

## **NCD Makes Transportation Recommendations**

June 13, 2005

NCD released its report *The Current State of Transportation for People with Disabilities*, stating that improvements have been made in transportation for people with disabilities, but more remains to be done.

The report was developed with the input of individuals with disabilities and transportation professionals from around the country. The purpose in undertaking this project was to develop a better understanding of access to transportation and mobility for people with disabilities, including access to traditional public transportation systems, private transportation services, alternative transportation initiatives, and the pedestrian environment; to identify transportation barriers as well as promising practices and models; and to develop recommendations in keeping with the goals of President Bush's New Freedom Initiative to "expand transportation opportunities for people with disabilities."

There have been many advances in America's transportation systems and services for citizens with disabilities, particularly since the passage of the Americans with Disabilities Act of 1990. The U.S. Department of Transportation and the nation's public transportation industry are to be applauded for their part in bringing about this progress. However, research reveals that many barriers to transportation continue to exist that prevent the full inclusion and full participation of people with disabilities in society.

The report highlights industry best practices and successful initiatives that can serve as models for communities for enhancing transportation and mobility for people with disabilities. This report also sets forth a variety of recommendations for service improvements and for additional

research that will lead to greater options for the 6 million Americans with disabilities who have difficulties obtaining the transportation they need to live independent and productive lives.

## **ADA 15th Anniversary**

July 25 and 26, 2005

NCD and its federal partners observed the 15th ADA anniversary with two events. More than 700 people attended an invitation-only reception at the John F. Kennedy Center for the Performing Arts in Washington, D.C., where former President George H. W. Bush was the keynote speaker. Also speaking were Health and Human Services Secretary Michael O. Leavitt, Labor Secretary Elaine L. Chao, Housing and Urban Development Secretary Alphonso Jackson, Transportation Secretary Norman Y. Mineta; Tom Harkin, U.S. Senator (D-IA), and Steny Hoyer, U. S. Representative (D-MD); Lex Frieden, NCD chairperson; and Janice M. Tuck, Chair, U.S. Access Board.

During the program President George H. W. Bush awarded the George Bush Medal for the Empowerment of People with Disabilities to Allan Reich, president emeritus, National Organization on Disability; Dr. I. King Jordan, president, Gallaudet University; and Representative Steny Hoyer (D-MD).

The medal is intended to reinforce the nation's commitment to keeping the promise of the ADA to all Americans and to encourage the spirit of ADA throughout the world.

Past recipients include: Senator Tom Harkin (1994); Ed Roberts and Bengt Lindqvist (1996); and Elizabeth Boggs, Justin Dart, Jr., Evan J. Kemp, Jr., Joshua Teke Malinga, Dick Thornburgh, and Patrisha A. Wright (2000).

The second event was an ADA seminar that took place on July 26 at the Marriott at Metro Center in Washington, D.C. More than 300 people participated in the seminar, which included an opening plenary session, six ADA-related workshops, and a closing plenary session. Speakers included Homeland Security Secretary Michael Chertoff, Transportation Secretary Norman Y. Mineta, Equal Employment Opportunity Commission Chair Cari M. Dominguez, and Social Security Administration Commissioner Jo Anne Barnhart. The seminar agenda can be found at <a href="http://www.ncd.gov/newsroom/publications/2005/anniversary\_event2.htm">http://www.ncd.gov/newsroom/publications/2005/anniversary\_event2.htm</a>.

On July 26, NCD released its latest paper *NCD and the Americans with Disabilities Act: 15 Years of Progress*, which describes NCD's role in the passage of the ADA and the continuing efforts of the Council in evaluating the implementation, effectiveness and impact of the ADA.

# **Civil Rights of Institutionalized Persons Act Recommendations** August 8, 2005

NCD's report *The Civil Rights of Institutionalized Persons Act: Has It Fulfilled Its Promise?* (http://www.ncd.gov/newsroom/publications/2005/personsact.htm), examines the U.S.

Department of Justice's (DOJ) enforcement of the Civil Rights of Institutionalized Persons Act (CRIPA), which was enacted by Congress in 1980 to protect the rights of people in state-run nursing homes, mental health facilities, institutions for people with intellectual and developmental disabilities, and correctional facilities for children and adults. NCD's findings reveal that DOJ has enforced the statute unevenly—performing well in some areas but poorly in others.

This report provides recommendations for ways DOJ could better protect the rights of people in institutions, including adopting strategic and multifaceted enforcement, broadening the breadth of investigations, resolving cases through enforceable consent decrees, increasing technical assistance to states to help them comply with federal laws, increasing federal agency coordination to support human and civil rights, making better use of the press, and including more and consistent data in its annual reports to Congress.

### **Emergency Planning Recommendations**

September 7, 2005

NCD issued a series of papers with recommendations in the aftermath of Hurricane Katrina, because people with disabilities have unique needs that must be surveyed and responded to immediately. In order to evacuate the large number of survivors from the New Orleans area, as well as from other areas of Louisiana, Mississippi and Alabama, people with disabilities were often forced to abandon their wheelchairs, walkers and other medical equipment. People who are blind, who may no longer have a service animal or cane to help them navigate, will require assistance in navigating a new environmental landscape. People who are deaf or hard of hearing will need visual access to emergency information. People in need of personal assistance services may now no longer have access to such services both as the result of separation from attendants during the evacuation process or due to not knowing how to obtain and fund the cost of qualified individuals in the locations where they now find themselves and, consequently, nursing home care in an institutional setting is often seen as the only remaining viable alternative to living in shelters. People with mental health needs, whose access to treatment and medications may have been disrupted, are in critical need of treatment and/or medication. In addition, mental illness symptoms are often exacerbated in times of crisis, and many individuals, even those not directly affected by the hurricane, may need assistance in identifying and accessing available resources.

- NCD recommends that President Bush designate a high-level official within Department of Homeland Security/FEMA to resolve issues around disability access or related issues.
- NCD recommends that FEMA coordinate with HHS' Substance Abuse and Mental Health Services Administration (SAMHSA), which is equipped to train mental health workers and other human services providers who assist survivors following a disaster. The SAMHSA Disaster Technical Assistance Center was established to provide assistance to jurisdictions planning for or facing an emergency event. SAMSHA should also continue to work with mental health providers and consumers to develop and implement a plan for providing or continuing services.

- Many organizations and individuals have stepped up to provide donated equipment. For example, several Centers for Independent Living (CILs) are in the process of obtaining a substantial amount of durable medical equipment (DME). FEMA and the agencies working with people with disabilities need to know about these DME resources that have been obtained and about other disability-specific resources and services that will most definitely benefit incoming people with disabilities. NCD urges FEMA to assist with immediate shipment of donated equipment.
- NCD urges the Federal Communications Commission to work with agencies to designate Telecommunications Relay Services (TRS) personnel, Public Safety Answering Point (PSAP) personnel, and captioners as essential personnel to ensure that they can travel to and from their designated facilities to provide continuity of services for persons with hearing and speech disabilities. Without trained personnel to provide these intermediate services, individuals with hearing and speech disabilities will be denied their rights to accessible communications and will not have access to public alert and warning information during and after an emergency.
- NCD recommends that FEMA coordinate with HHS to ensure that comprehensive medical approaches are used to address the health care and medical needs of individuals with disabilities across the lifespan of the Hurricane Katrina disaster.
- NCD urges the Department of Transportation to coordinate with state and local governments to provide expedited eligibility to vocational rehabilitation services, paratransit services and specialized telecommunication assistance programs. A multi-agency, cross-disability proposal for disability specific funds should be developed to support on-going activities in the Gulf region.
- Shelters and facilities must be accessible to people with disabilities and to people who
  have expertise in providing services to people with disabilities. NCD recommends that
  the Justice Department issue a statement on the legal requirements for accessible shelters
  and facilities. NCD recommends that DHS issue a statement and operational guidance
  encouraging accessibility.
- NCD recommends that the Department of Education (ED) coordinate with state and local school districts to ensure that students with disabilities are included in ED's plans to work with states and local communities to welcome students with disabilities and get them enrolled into schools as quickly as possible. NCD urges the use of "emergency" assessment procedures by qualified school professionals to provide a record of general functioning for temporary provision of special education and related services. Plans for regular evaluation need to be established within a reasonable time frame after enrollment by state and local school districts to avoid over identification of children from diverse racial and cultural backgrounds as children with disabilities. Counseling and other mental health services need to be made available to all evacuated children and families through schools and collaboration with health departments.
- FEMA/CMS/HHS should immediately determine the location and status of residents of long-term care facilities, including nursing home and group home populations, and assess and respond to their immediate needs to ensure that they are receiving the necessary range of services and supports. NCD also recommends that CMS consider the impact of the implementation of Medicare Part D.

- HHS and HUD have each established toll free hotlines. HUD has established a single toll-free number (1-888-297-8685) to help disaster victims with all housing concerns. Assistance is available from 7 a.m. to 8 p.m., CST, seven days a week. HHS has established a crisis hotline for people in crisis in the aftermath of Hurricane Katrina. By dialing 1-800-273-TALK (1-800-273-8255), callers will be connected to a network of local crisis centers across the country that are committed to crisis counseling. Callers to the hotline will receive counseling from trained staff at the closest certified crisis center in the network. However, it is strongly recommended that these hotlines be made accessible to deaf and hard of hearing consumers immediately by also establishing a TTY/TDD telephone number. NCD also recommends that HUD consider housing vouchers and other low income housing be set aside for people with disabilities, and provide help in locating accessible housing.
- The Secretary of Veterans Affairs should request VA hospitals across the country to assist in providing outdated or unneeded wheelchairs and other useful durable medical equipment, currently in VA storerooms, to the relief effort. The VA should also coordinate with the network of veteran's homes and other veterans' organizations, like VFW and American Legion chapters, whose members could provide donations to, or assist with, equipment drives.

## **Next Steps**

#### DISABILITY DEMOGRAPHICS AND DATA

In an effort to identify valid federal data and to describe the status of the U.S. population of Americans with disabilities, NCD will conduct research that results in a product entitled Americans with Disabilities: Key Indicators of Quality Lives. The research and resultant report and database will focus on several important areas in the lives of people with disabilities - population, economics, education, employment, housing, health status and health care, to name a few areas.

Federal agencies have created various disability data collection efforts to focus on different aspects of people's lives. None have collaborated to create a comprehensive set of quality-of-life indicators that can be followed over time. By following these holistic data trends, more accessible information could be available to target efforts that can improve the lives of Americans with disabilities.

The research for this project would include, but not be limited to: (a) identifying existing federal disability data collection efforts; (b) reviewing and evaluating data efforts identified in item 'a' for validity, reliability, and utility by various stakeholders; (c) identifying and, to the extent feasible, examining emerging federal disability data collection systems for validity, reliability, and potential utility to various stakeholders; (d) defining the features and key components of a federal disability data indicator system; (e) identifying and describing the availability/unavailability of existing federal disability data to populate that indicator; and (f)

determine future steps needed to create and implement such an indicator system for the federal government. NCD expects that this research and report will stimulate discussions by policymakers and the public, encourage exchanges between the data and policy communities, and foster improvements in Federal data collection on Americans with disabilities. By examining a broad range of indicators, researchers, policymakers, service providers, and the Federal Government can better understand the quality-of-life areas that are improving for Americans with disabilities and the areas that require more attention and effort.

As indicated previously, NCD's priorities are based upon recommendations from stakeholders and are based upon the goals and objectives outlined in NCD's strategic plan. Research studies and projects are commissioned by NCD when it is necessary to enlist the support of outside individuals and groups who possess expertise not available within NCD itself. Given the limited size of our agency, the judicious use of external research studies and projects substantially enhances our capability to meet our basic mandate 'to provide expert advice to the Administration and Congress on disability policy issues.

#### **EMERGING ISSUES**

NCD will continue to conduct studies on emerging issues such as information technology and services. In addition, NCD will work on policy priorities related to international, mental health and cultural diversity issues.

#### **ADVISORY COMMITTEES**

NCD has three advisory committees. They are the Cultural Diversity Advisory Committee, International Watch, and the Youth Advisory Committee. All NCD advisory committees are governed by the Federal Advisory Committee Act (FACA), 5 U.S.C. App. 2, which was enacted to promote good government values such as openness, accountability and balance of viewpoints consistent with administrative efficiency and cost-containment.

#### **Cultural Diversity Advisory Committee**

The purpose of NCD's Cultural Diversity Advisory Committee (CDAC) (<a href="www.ncd.gov/newsroom/advisory/cultural/cultural.html">www.ncd.gov/newsroom/advisory/cultural/cultural.html</a>) is to provide advice and recommendations to NCD on issues affecting people with disabilities from culturally diverse backgrounds. Specifically, the committee will help identify issues, expand outreach, infuse participation, and elevate the voices of underserved and unserved segments of this nation's population. This will help NCD develop federal policy that will address the needs and advance the civil and human rights of people from diverse cultures.

CDAC's charter was renewed for two years on January 14, 2005.

#### **International Watch**

The purpose of International Watch (IW)

(www.ncd.gov/newsroom/advisory/international/international.html) is to share information on international disability issues and to advise NCD on the development of policy proposals that will advocate for a foreign policy that is consistent with the values and goals of the Americans with Disabilities Act. IW has two working groups: International Convention on the Human Rights of People with Disabilities; and Inclusion of People with Disabilities in Foreign Assistance Programs.

IW's charter was renewed for two years on October 1, 2004.

### **Youth Advisory Committee**

The purpose of the Youth Advisory Committee (YAC) (<a href="www.ncd.gov/newsroom/advisory/youth/youth.html">www.ncd.gov/newsroom/advisory/youth/youth.html</a>) is to provide advice to NCD on various issues such as NCD's planning and priorities. NCD is seeking this type of input in order to make sure NCD's activities and policy recommendations respond to the needs of youth with disabilities.

YAC's charter was renewed for two years on October 27, 2005.

#### INFORMATION DISSEMINATION

Information dissemination continued to grow at record levels for NCD, as it responded to thousands of telephone calls, e-mail messages, and letters from concerned people and organizations about disability issues. During the year, NCD also received thousands of news clips from its news clipping service, reflecting a high degree of interest by the media in NCD's initiatives and activities. This symbiotic relationship between NCD and the media helps disseminate important disability-related information that affects all Americans with disabilities and their families.

In addition, NCD published its monthly newsletter, *NCD Bulletin*, which reaches more than 13,000 people and organizations by U.S. Mail and listserv. All NCD publications are available in alternative formats, such as Braille, large print, and audiocassette. This information is also available at NCD's award-winning Internet Web site (<a href="www.ncd.gov">www.ncd.gov</a>), which now receives more than 4 million hits per year and a record number of first-time visitors.

## **NCD WEB SITE**

During FY 2005, NCD increasingly relied on its ability to provide cost-effective and efficient dissemination of its work through the use of information technology (i.e., its Web site). For example, during the fiscal year, NCD's Web site received in excess of 12 million hits, including an increasing number of first-time visitors.

An increasing number of visitors to NCD's Web site are interested in downloading copies of NCD's reports, policy briefs, and other pertinent outcomes. During FY 2005, approximately 500,000 reports were downloaded, saving thousands of dollars in printing and approximately \$60,000 in postage. This is another NCD fiscal year record and fully supports the President's expanded electronic government management initiative to improve the government's ability to serve its citizens. Some NCD documents are also available in Spanish, Chinese, and Vietnamese. All NCD Web documents can be roughly translated into multiple languages other than English with the use of a free Web translator.

## NCD QUARTERLY MEETINGS

As required by Section 400 of the Rehabilitation Act of 1973, as amended, NCD met on four occasions during FY 2005.

November 29–December 1, 2004, Washington, DC March 9–11, 2005, Honolulu, HI May 9, 2005, Washington, DC July 25–27, 2005, Washington, DC

#### PERFORMANCE RESULTS

Aligned with the President's Management Agenda (PMA), several key disciplines were highlighted in NCD's work during Fiscal Year 2005.

NCD identified the agency-wide results that were desired, outlined strategies to achieve them and worked assertively to realize those defined goals. A focus on results was not new for NCD; however, self-assessment and accountability with respect to specific and measurable outcomes were given more conspicuous positions.

Based on work plan goals and needs, NCD identified necessary additional knowledge, skills and abilities within its own small staff and began to look at ways to make greater and more efficient use of its personnel. Policy team staff leaders were more actively engaged in development of the agency work plan and related activities. Efforts were made to capitalize on the strengths that individuals brought to the workplace. These efforts included regular staff as well as contractors and unpaid interns who contributed commendably to the work of policy team research, related projects and agency advisory committees. NCD's outreach to gather perspectives from underserved and unserved citizens (e.g., youth and people from diverse cultures) continued in the agency's ongoing efforts to make broadly informed public policy recommendations. Collaboration and team work across policy and administrative staff also saw a level of improvement and support through training opportunities, flexible assignments and alternate work

locations. Policy team meetings were also open routinely to administrative personnel who were encouraged to participate in discussions.

NCD continued its long-standing and successful practice of determining when services outside the federal government were beneficial for reaching the agency's identified goals. Strides were also made in the ongoing evaluation of how work (e.g., research and related projects) progressed toward the stated agency goals and written cooperative agreements with outside contractors. The improvements in this area resulted in recognizing, and aggressively taking steps to remove, low-performing contractors in a timely manner. Outreach was expanded to solicit and continue to attract highly qualified vendors.

Management and implementation of NCD's work plan and related activities were enhanced by greater collaboration among members of the agency's policy and administrative teams. The effectiveness of this practice was shown in improved procedures for justifying and allocating funds within a small budget. Other staff input from policy and administration aspects also resulted in a number of practices and systems developed and implemented as checks and balances. The policy team also developed a process for in-house collection of impact indicators related to NCD's work products and related activities. Continued self-assessment will aid ongoing improvements in how the agency carries out its mission.

Many NCD project and program objectives reflect the expectation that the policy work supported at NCD will and should influence and have an impact on the policy process. Within projects and programs, for example, NCD staff promote various means of linking research to policy, and research supported is often reported to have enhanced decision makers' awareness of policy options or to have been otherwise taken into account in policy processes.

# **NCD Authorizing Statute**

# TITLE IV, REHABILITATION ACT OF 1973, AS AMENDED--NATIONAL COUNCIL ON DISABILITY

### **Establishment of National Council on Disability**

Sec. 400. (a)(1)

- (A) There is established within the Federal Government a National Council on Disability (hereinafter in this title referred to as the "National Council"), which shall be composed of fifteen members appointed by the President, by and with the advice and consent of the Senate.
- **(B)** The President shall select members of the National Council after soliciting recommendations from representatives of—
- (i) organizations representing a broad range of individuals with disabilities; and
- (ii) organizations interested in individuals with disabilities.
- (C) The members of the National Council shall be individuals with disabilities, parents or guardians of individuals with disabilities, or other individuals who have substantial knowledge or experience relating to disability policy or programs. The members of the National Council shall be appointed so as to be representative of individuals with disabilities, national organizations concerned with individuals with disabilities, providers and administrators of services to individuals with disabilities, individuals engaged in conducting medical or scientific research relating to individuals with disabilities, business concerns, and labor organizations. A majority of the members of the National Council shall be individuals with disabilities. The members of the National Council shall be broadly representative of minority and other individuals and groups.
- (2) The purpose of the National Council is to promote policies, programs, practices, and procedures that—
- (A) guarantee equal opportunity for all individuals with disabilities, regardless of the nature or severity of the disability; and
- **(B)** empower individuals with disabilities to achieve economic self-sufficiency, independent living, and inclusion and integration into all aspects of society.
- (b)(1) Each member of the National Council shall serve for a term of 3 years, except that the terms of service of the members initially appointed after the date of enactment of the Rehabilitation, Comprehensive Services, and Developmental Disabilities Amendments of 1978

shall be (as specified by the President) for such fewer number of years as will provide for the expiration of terms on a staggered basis.

- (2)(A) No member of the National Council may serve more than two consecutive full terms beginning on the date of commencement of the first full term on the Council. Members may serve after the expiration of their terms until their successors have taken office.
- **(B)** As used in this paragraph, the term "full term" means a term of 3 years.
- (3) Any member appointed to fill a vacancy occurring before the expiration of the term for which such member's predecessor was appointed shall be appointed only for the remainder of such term.
- (c) The President shall designate the Chairperson from among the members appointed to the National Council. The National Council shall meet at the call of the Chairperson, but not less often than four times each year.
- (d) Eight members of the National Council shall constitute a quorum and any vacancy in the National Council shall not affect its power to function.

#### **Duties of National Council**

## Sec. 401. (a) The National Council shall—

- (1) provide advice to the Director with respect to the policies and conduct of the National Institute on Disability and Rehabilitation Research, including ways to improve research concerning individuals with disabilities and the methods of collecting and disseminating findings of such research;
- (2) provide advice to the Commissioner with respect to the policies of and conduct of the Rehabilitation Services Administration;
- (3) advise the President, the Congress, the Commissioner, the appropriate Assistant Secretary of 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 this Act;
- (4) provide advice regarding priorities for the activities of the Interagency Disability Coordinating Council and review the recommendations of such Council for legislative and administrative changes to ensure that such recommendations are consistent with the purposes of the Council to promote the full integration, independence, and productivity of individuals with disabilities:
- (5) review and evaluate on a continuing basis—

- (A) policies, programs, practices, and procedures concerning individuals with disabilities conducted or assisted by Federal departments and agencies, including programs established or assisted under this Act or under the Developmental Disabilities Assistance and Bill of Rights Act of 2000; and
- **(B)** all statutes and regulations pertaining to Federal programs which assist such individuals with disabilities:

in order to assess the effectiveness of such policies, programs, practices, procedures, statutes, and regulations in meeting the needs of individuals with disabilities;

- (6) assess the extent to which such policies, programs, practices, and procedures facilitate or impede the promotion of the policies set forth in subparagraphs (A) and (B) of section 400(a)(2);
- (7) gather information about the implementation, effectiveness, and impact of the Americans with Disabilities Act of 1990 (42 U.S.C. 12101 et seq.);
- (8) make recommendations to the President, the Congress, the Secretary, the Director of the National Institute on Disability and Rehabilitation Research, and other officials of Federal agencies or other Federal entities, respecting ways to better promote the policies set forth in section 400(a)(2);
- (9) provide to the Congress on a continuing basis advice, recommendations, legislative proposals, and any additional information that the National Council or the Congress deems appropriate; and
- (10) 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.
- (b)(1) Not later than October 31, 1998, and annually thereafter, the National Council shall prepare and submit to the President and the appropriate committees of the Congress a report entitled *National Disability Policy: A Progress Report*.
- (2) The report shall assess the status of the Nation in achieving the policies set forth in section 400(a)(2), with particular focus on the new and emerging issues impacting on the lives of individuals with disabilities. The report shall present, as appropriate, available data on health, housing, employment, insurance, transportation, recreation, training, prevention, early intervention, and education. The report shall include recommendations for policy change.

(3) In determining the issues to focus on and the findings, conclusions, and recommendations to include in the report, the National Council shall seek input from the public, particularly individuals with disabilities, representatives of organizations representing a broad range of individuals with disabilities, and organizations and agencies interested in individuals with disabilities.

## **Compensation of National Council Members**

- **Sec. 402.** (a) Members of the National Council shall be entitled to receive compensation at a rate equal to the rate of pay for level 4 of the Senior Executive Service Schedule under section 5382 of title 5, United States Code, including travel time, for each day they are engaged in the performance of their duties as members of the National Council.
- (b) Members of the National Council who are full-time officers or employees of the United States shall receive no additional pay on account of their service on the National Council except for compensation for travel expenses as provided under subsection (c) of this section.
- (c) While away from their homes or regular places of business in the performance of services for the National Council, members of the National Council shall be allowed travel expenses, including per diem in lieu of subsistence, in the same manner as persons employed intermittently in the Government service are allowed expenses under section 5703 of title 5, United States Code.

#### **Staff of National Council**

- **Sec. 403.** (a)(1) The Chairperson of the National Council may appoint and remove, without regard to the provisions of title 5, United States Code, governing appointments, the provisions of chapter 75 of such title (relating to adverse actions), the provisions of chapter 77 of such title (relating to appeals), or the provisions of chapter 51 and subchapter III of chapter 53 of such title (relating to classification and General Schedule pay rates), an Executive Director to assist the National Council to carry out its duties. The Executive Director shall be appointed from among individuals who are experienced in the planning or operation of programs for individuals with disabilities.
- (2) The Executive Director is authorized to hire technical and professional employees to assist the National Council to carry out its duties.
- (b)(1) The National Council may procure temporary and intermittent services to the same extent as is authorized by section 3109(b) of title 5, United States Code (but at rates for individuals not to exceed the daily equivalent of the rate of pay for level 4 of the Senior Executive Service Schedule under section 5382 of title 5, United States Code).

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- (A) accept voluntary and uncompensated services, notwithstanding the provisions of section 1342 of title 31, United States Code;
- (B) in the name of the Council, solicit, accept, employ, and dispose of, in furtherance of this Act, any money or property, real or personal, or mixed, tangible or nontangible, received by gift, devise, bequest, or otherwise; and
- (C) enter into contracts and cooperative agreements with Federal and State agencies, private firms, institutions, and individuals for the conduct of research and surveys, preparation of reports and other activities necessary to the discharge of the Council's duties and responsibilities.
- (3) Not more than 10 per centum of the total amounts available to the National Council in each fiscal year may be used for official representation and reception.
- (c) The Administrator of General Services shall provide to the National Council on a reimbursable basis such administrative support services as the Council may request.
- (d)(1) It shall be the duty of the Secretary of the Treasury to invest such portion of the amounts made available under subsection (a)(2)(B) as is not, in the Secretary's judgment, required to meet current withdrawals. Such investments may be made only in interest-bearing obligations of the United States or in obligations guaranteed as to both principal and interest by the United States.
- (2) The amounts described in paragraph (1), and the interest on, and the proceeds from the sale or redemption of, the obligations described in paragraph (1) shall be available to the National Council to carry out this title.

#### **Administrative Powers of National Council**

- **Sec. 404.** (a) The National Council may prescribe such bylaws and rules as may be necessary to carry out its duties under this title.
- (b) The National Council may hold such hearings, sit and act at such times and places, take such testimony, and receive such evidence as it deems advisable.
- (c) The National Council may appoint advisory committees to assist the National Council in carrying out its duties. The members thereof shall serve without compensation.
- (d) The National Council may use the United States mails in the same manner and upon the same conditions as other departments and agencies of the United States.
- (e) The National Council may use, with the consent of the agencies represented on the Interagency Disability Coordinating Council, and as authorized in title V, such services,

personnel, information, and facilities as may be needed to carry out its duties under this title, with or without reimbursement to such agencies.

## **Authorization of Appropriations**

## Sec. 405.

There are authorized to be appropriated to carry out this title such sums as may be necessary for each of the fiscal years 1999 through 2003.

## Strategic Plan

#### Vision

The United States of America will be a stronger country when its 54 million citizens with disabilities are fully integrated into all aspects of American life. The United States has made significant progress in recent years in furthering opportunities for education, employment and independent living for people with disabilities through a broad range of programs that protect the rights of individuals with disabilities from discrimination in education, employment, housing and transportation. Yet significant barriers to achieving the goals of independence, inclusion and empowerment for all persons with disabilities still remain. Conflicting, poorly designed or outdated government programs and policies combine with service gaps and continued negative attitudes toward people with disabilities to marginalize the 54 million Americans with disabilities.

The effects of these barriers on both people with disabilities and society are enormous. Physical and spiritual isolation rob individuals of energy, creativity and productivity. Society loses by not enjoying the benefits of their talents and by incurring large costs to support them.

Through collaboration with its stakeholders, the National Council on Disability (NCD) will pursue a focused agenda that will promote government programs and policies in support of full inclusion of all people with disabilities into the educational, economic and social fabric of the American community. NCD will use the expertise of its diverse membership and well-trained and well-managed staff to identify barriers to inclusion and independence and to develop solutions. NCD will listen to people with disabilities across the country to identify emerging issues that need a response.

As the only agency in the Federal Government that addresses the issues of all people with disabilities, regardless of type or severity, NCD will be aggressive and resolute until the day arrives when people with disabilities in every corner of the land no longer are distinguished by a disability label, but are known as students, workers, parents, neighbors and friends.

#### **Mission Statement**

NCD's mission is to promote the full inclusion, independent living and economic self-sufficiency of people with disabilities of all ages and backgrounds by providing advice, analysis, and recommendations on disability policy to the President, Congress, and other federal entities.

## Strategic Goals, Objectives, and Results

I. Make evidence-based public policy recommendations that can enhance the lives of people with disabilities of all ages and backgrounds.

#### **Objectives:**

- 1.1 Develop and refine policy recommendations at least annually.
- 1.2 Gather and record information on policy matters affecting people with disabilities through the use of forums, hearings, teleconferences, the Internet, independent studies, and interagency information sharing.
- 1.3 Monitor the effectiveness of the implementation of the Americans with Disabilities Act and other civil rights laws.

#### **Results:**

- 1.1 NCD reviewed and evaluated new and emerging policy issues affecting people with disabilities at the federal, state, and local levels, and in the private sector, and developed policy recommendations where needed. During FY 2005, NCD produced 20 publications and a series of papers containing specific policy recommendations. They include: Consumer-Directed Health Care: How Well Does It Work?; Design for Inclusion: Creating a New Marketplace; Creating a New Marketplace—Industry White Paper; Update on the UN Convention on the Rights of People with Disabilities; Righting the ADA; Livable Communities for Adults with Disabilities; National Disability Policy: A Progress Report; Spector v. Norwegian Cruise Line, Ltd.—Background, Legal Issues, and Implications for Persons with Disabilities; Update on the Fifth Session UN Convention on the Rights of People with Disabilities; NCD Recommendations on Workforce Investment Act Reauthorization; Saving Lives: Including People with Disabilities in Emergency Planning; Questions and Answers for Parties to Mediation: *Mediation and the Americans with Disabilities Act; Same Struggle, Different Difference:* Civil Rights Policy Forum Summary Paper; Reissuance of the NCD Statement Opposing Legislation of Assisted Suicide; The Current State of Transportation for People with Disabilities; Hearing on Voter Verification in the Federal Elections Process; NCD and the Americans with Disabilities Act: 15 Years of Progress; Topical Overview for Delegates to the United Nations 6th Ad Hoc Committee on the Protection and Promotion of the Human Rights of People with Disabilities; The Civil Rights of Institutionalized Persons Act; Has It Fulfilled Its Promise?; Individuals with Disabilities Education Act Burden of Proof: On Parents or Schools?; National Council on Disability on Hurricane Katrina Affected Areas; and, Update on the UN Convention on the Rights of People with Disabilities.
- 1.2 NCD gathered information and identified the overall needs and concerns of people with disabilities in a variety of ways that included hearings and conferences, and by responding to literally thousands of telephone calls, e-mail messages, and written inquiries.

#### **ADA Monitoring**

In keeping with its mandate to monitor the effectiveness and implementation of the ADA, NCD completed its two-year project to analyze the Supreme Court decisions interpreting the ADA. This project involved publication of 19 policy briefs, available at <a href="http://www.ncd.gov/newsroom/publications/2003/policybrief.htm">http://www.ncd.gov/newsroom/publications/2003/policybrief.htm</a>.

The project culminated in a comprehensive final report, *Righting the ADA* (http://www.ncd.gov/newsroom/publications/2004/righting\_ada.htm), which includes NCD's legislative proposal, entitled "ADA Restoration Act," intended to restore the protections of the ADA that have been restricted by the U.S. Supreme Court decisions over the past few years.

#### **ADA Impact Project**

NCD awarded a contract for \$180,000 to Lockheed Martin Information Technology of Seabrook, Maryland, to evaluate the impact of the Americans with Disabilities Act (ADA) and the effects of U.S. Supreme Court cases interpreting ADA. The contractor will gather input from ADA stakeholders about the impact of ADA, gather testimony and documentation regarding the impact of the Supreme Court's decisions on people with disabilities, assemble all information gathered, organize all testimony and incidents reported into a consistent format within each of the issue areas, and summarize the findings.

#### **Mediation Technical Assistance**

NCD collaborated with the U.S. Equal Employment Opportunity Commission (EEOC) and the U.S. Department of Justice on a Mediation Technical Assistance Project to enhance the use of mediation by people with disabilities to resolve employment disputes and highlight the importance of reasonable accommodation in the alternative dispute resolution process. EEOC has dealt with these issues in its highly regarded mediation program for resolving employment discrimination claims. NCD examined mediation issues in its 2000 ADA report *Promises to Keep* and has worked with mediators on accessibility issues. EEOC and NCD combined their experience and expertise to provide technical assistance on disability issues in the mediation of employment discrimination disputes.

Two technical assistance documents were produced—one for mediators and one for consumers.

#### **Long-Term Services and Supports**

Through its contractor, National Cooperative Bank Development Corporation, National Disability Institute, NCD completed its research study examining critical issues surrounding the configuration, financing, and delivery of long-term services and supports financing and systems reform. Current financing mechanisms will become unsustainable in the near future. Without significant reform, tens of millions of Americans with

disabilities will be unable to find the wide array of affordable and high-quality long-term services and supports options we all expect and deserve.

This research focuses on the following areas: (1) current level(s) and type(s) of involvement by the Federal Government in a range of long-term services and supports systems and financing; (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 long-term services and supports financing and systems reforms; (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 cohesive and comprehensive long-term services and supports financing and systems reform; 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. The report was released on December 15, 2005.

#### **Design for Inclusion**

On October 28, NCD released a report entitled *Design for Inclusion: Creating a New Marketplace* (http://www.ncd.gov/newsroom/publications/2004/newmarketplace.htm) at a news conference at the National Press Club in Washington, DC. The report seeks to educate designers and manufacturers about how electronic and information technology (E&IT) intersects with the needs of individuals with disabilities, and how designing with access in mind can significantly increase the size of targeted markets for E&IT.

News conference participants included Joel I. Kahn, Ph.D., Member, NCD; Benjamin H. Wu, Assistant Secretary Nominee for Technology Policy, U.S. Department of Commerce; P.J. Edington, Governmental Programs Executive, Accessibility, IBM; Jamal Mazrui, Technology Specialist, Federal Communications Commission; Brad Fain, Ph.D., Senior Research Scientist, Georgia Tech Applied Research Institute; Laura Ruby, Manager, Regulatory and Industry Affairs, Microsoft; Ken Salaets, Director, Government Relations, Information Technology Industry Council; Kelly Pierce, Cofounder, Digit-Eyes; and John Yeh, President, Viable Technologies.

This event is available as an archived Web cast at <a href="http://www.connectlive.com/events/ncd">http://www.connectlive.com/events/ncd</a>. It will also be available at <a href="http://www.ncd.gov">www.ncd.gov</a> in November.

#### **Consumer-Directed Health Care**

On October 26, NCD released a report entitled *Consumer-Directed Health Care: How Well Does It Work?* 

(http://www.ncd.gov/newsroom/publications/2004/consumerdirected.htm) at a news conference and public dialogue at the National Press Club in Washington, DC.

The report evaluates the evidence base for the nation's consumer-directed health care efforts. It also offers a clear picture of the strengths and weaknesses of the Federal Government's current research agenda for consumer-directed health care for Americans with disabilities. The report sheds light on the relationship between consumer-directed health care and practice. It provides a basis for policymakers who use health research evidence to inform their policy decisions (e.g., about MiCASSA, Money Follows the Person, *Olmstead*, and Real Choice Systems Change Grants) in keeping with the intent of the New Freedom Initiative.

News conference participants included Carol Novak, Member, NCD; Dennis G. Smith, Director, Center for Medicaid and State Operations; Jonathan Hughes, Consumer, Tampa, Florida; Carol Tobias, Assistant Professor, Boston University, School of Public Health; Bob Kafka, National Organizer, ADAPT (American Disabled For Attendant Programs Today); and Linda Horton St. Hubert, Director of Consumer and Community Education, AIDS Alliance.

#### Righting the ADA

On December 1, NCD called on the Administration and Congress to support legislation that will "right" the course of the Americans with Disabilities Act (ADA) and protect the civil rights of people with disabilities.

Over the past two years, NCD conducted an in-depth analysis of the Supreme Court's interpretations of the ADA. NCD has determined that, while some of the Court's decisions have clearly liberated people with disabilities, e.g., *Tennessee v. Lane, Martin v. PGA Tours*, and *Olmstead v. L.C.*, several of the Court's rulings involving the ADA depart from the core principles and objectives of the ADA. NCD's report *Righting the ADA* (<a href="http://www.ncd.gov/newsroom/publications/2004/righting\_ada.htm">http://www.ncd.gov/newsroom/publications/2004/righting\_ada.htm</a>) provides an analysis of the problematic rulings, describes the resulting impact on people with disabilities, and offers legislative proposals designed to restore the ADA to its original intent.

The purpose of the ADA was "to provide a clear and comprehensive national mandate for the elimination of discrimination against individuals with disabilities." The provisions of the ADA addressing architectural, transportation, and communication accessibility have changed the face of American society in numerous concrete ways, enhancing the independence, full participation, inclusion, and equality of opportunity for Americans with disabilities. However, the provisions of the ADA that have been narrowed by Court rulings currently do not provide the same scope of opportunities and protections expressed by those involved in the creation and passage of the ADA. Legislation is urgently needed to restore the ADA to "assure equality of opportunity, full participation, independent living, and economic self-sufficiency" for Americans with disabilities.

NCD is charged with gathering information about the implementation, effectiveness, and impact of the ADA.

#### **Livable Communities**

On December 2, NCD called on the Administration and Congress to develop a cohesive public policy agenda for livable communities for adults with disabilities.

The advances in America's policy and programs on behalf of citizens with disabilities have been inspiring. Notwithstanding the individual social policy and legislative achievements of the past 50 years, however, we need to establish a cohesive public policy agenda in the coming years. We need a common vision, with clear objectives, that speaks to the strength of our commitment to our citizens and the quality of their lives, and one that addresses the challenges facing us in the years ahead.

Communities in the United States are faced with increasingly difficult choices and decisions about how to grow, plan for change, and improve the quality of life for adults with disabilities as well as elders who may develop disabilities. People are living longer today than ever before and the population of people aged 65 and older is growing rapidly. One in five people in the United States will be over the age of 65 by 2030. Currently, more than 4.7 million Americans aged 65 years or older have a sensory disability involving sight or hearing, and more than 6.7 million have difficulty going outside the home. As the population of elders grows, it is possible that the number of people aged 65 and older with disabilities will also grow, particularly those 75 years of age and older.

Livable Communities for Adults with Disabilities (http://www.ncd.gov/newsroom/publications/2004/LivableCommunities.htm) offers a compelling vision for our nation. It articulates the elements of a livable community, highlights existing examples of livable communities in the United States, which can serve as models for others, and describes how communities can develop and sustain their livability features. The report was developed with the advice of a national consumer advisory committee.

NCD's recommendations are in line with President Bush's emphasis in the New Freedom Initiative on community integration, participation, and enhancement of the independence of people with disabilities at home, at work, and throughout the course of their daily lives.

#### **Progress Report**

On December 9, NCD released its annual report, *National Disability Policy: A Progress Report* (<a href="http://www.ncd.gov/newsroom/publications/2004/ProgressReport2004.htm">http://www.ncd.gov/newsroom/publications/2004/ProgressReport2004.htm</a>), noting progress has been made, but gaps remain.

The report covers the period from December 2002 through December 2003. It reviews federal policy activities by issue areas, notes input by other federal agencies on their progress where it has occurred, and makes further recommendations where necessary, primarily to the executive and legislative branches of the Federal Government.

NCD has observed examples of progress in disability policy and in the broader policy arena. Among these are the findings and recommendations of the President's New Freedom Commission on Mental Health in its report on recovery from mental illnesses and a proposed transformation of the nation's approach to mental health care; the Department of Health and Human Services' funding of several model projects (e.g., Demonstration to Improve the Direct Service Community Workforce) designed to develop and implement programs that recruit and retain personal assistance workers for people with disabilities and people who are aging; and critical attention to the needs and inclusion of people with disabilities in preparation for emergency situations, such as the Department of Homeland Security's work and coordination with other agencies.

Examination of the status of disability policy reveals that incremental progress made in some areas is clouded by other major barriers and challenges that continue to block paths available to the general population. Gaps in necessary services and supports remain to the extent that, as stated in NCD's 2002 report on progress, far too many Americans with disabilities are undereducated and unemployed

NCD encourages all government agencies and Congress to use NCD's work as a reference point and source of data for recommendations and in future investigations of disability policy issues.

#### **NCD Holds Social Security Consensus Meeting**

On January 26, Virginia Commonwealth University organized an NCD Consensus Building Conference on Social Security at the National Press Club. The meeting brought together approximately 100 stakeholders to review seven topic papers examining the evidence-based practices that support the return (and transition) to work for social security beneficiaries. Specifically, the papers cover 1) public and private health coverage for social security disability beneficiaries who work; 2) post-eligibility policies and procedures: eliminating disincentives to employment in the Social Security Administration (SSA) benefits programs; 3) SSA's efforts to implement the Ticket to Work and Work Incentives Improvement Act; 4) lessons from the foreign experience: how some other countries deal with barriers to employment of people with disabilities; 5) beneficiary experiences, entitlement, and return to work for Social Security Disability Insurance and Supplemental Security Income beneficiaries; 6) early intervention and diversion strategies for stemming the growth in social security disability programs; and 7) evidence-based practices that promote employment of people with disabilities.

The conference was aimed at achieving consensus on a prioritized list of recommendations for social security policy change.

#### **Employment Study RFP**

On January 10, NCD published a presolicitation notice on the Federal Business Opportunities Web site (http://www.fedbizopps.gov/) for an employment study.

NCD has begun an assertive and systematic review of both public and private policies and initiatives aimed at improving the employment of people with disabilities. A primary building block in the sequential but complementary studies on employment is NCD's Social Security/Transitioning to Work Study, which is examining the evidence-based practices that promote the return to work (and transition to work) of Social Security Disability Insurance and Supplemental Security Income program beneficiaries.

The next building block will be this employment study, which will include the following major components: a) a thorough, systematic examination or environmental scan of the nexus between employment and the following areas: transportation; housing; reasonable accommodations; education; health care; assistive technology; telecommunications; longterm services and supports; and telecommuting, among other topics; b) a business advisory committee and public forums to solicit information and input on employment issues and practices; c) informational issue briefs that examine the status and impact of existing employment strategies at the federal, state, and local levels, such as customized employment, entrepreneurship, telework, supported employment, microbusiness, e-commerce, and competitive employment; and d) a cohesive final report with information drawn from the first three components along with recommendations aimed at improving the employment status of people with disabilities. Concurrent with the employment study, NCD will undertake a complementary research initiative on financial incentives available to enhance the ability of people with disabilities to live and work independently and in the community of their choice. The estimated contract period is 12 months. NCD will distribute its Employment Study Request for Proposals (RFP) on February 4, 2005. Interested parties must submit their responses by March 22, 2005.

#### **NCD Provides Disaster Guidance to State Department**

On January 11, NCD provided guidance to the Secretary of State on U.S. assistance with the relief and reconstruction efforts in the wake of the tsunami devastation in Asia. The United States has an opportunity to improve the lives of the many citizens with disabilities in the affected countries, and those who acquire a disability as a result of the disaster.

It is hard to imagine how anything positive can come out of a tragedy of this magnitude, but in rebuilding homes, businesses, and public facilities, there will be an unprecedented opportunity to make them accessible to people with disabilities, thus empowering many people to improve their lives by gaining access to schools, hospitals, and government buildings.

This is not just a laudable goal. The United States has a responsibility to ensure that the rights of people with disabilities are addressed in its foreign assistance efforts. The Consolidated Appropriations Act, 2005, Part D (Foreign Operations), Sec. 579 (d) specifies that, "The Secretary of State, the Secretary of the Treasury, and the U.S. Agency for International Development (USAID) Administrator shall seek to ensure that

the needs of people with disabilities are addressed, where appropriate, in democracy, human rights, and rule of law programs, projects and activities supported by the Department of State, Department of the Treasury, and USAID." Furthermore, Section 579 (e), specifies that USAID "shall implement procedures to require that prospective grantees seeking funding from USAID specify, when relevant, how the proposed program, project or activity for which funding is being requested will include protecting the rights and addressing the needs of persons with disabilities."

With its inclusive foreign assistance laws, the United States is well positioned to lead the world in rebuilding the tsunami-affected countries and demonstrate how to build on the tremendous human potential of the more than 600 million people worldwide who have disabilities.

#### **NCD Makes Emergency Planning Recommendations**

On April 15, NCD released its report Saving Lives: Including People with Disabilities in Emergency Planning

(<u>http://www.ncd.gov/newsroom/publications/2005/saving\_lives.htm</u>), recommending immediate federal changes in emergency planning for people with disabilities.

Saving Lives provides an overview of steps the Federal Government should take to build a solid and resilient infrastructure that will enable the government to include the diverse populations of people with disabilities in emergency preparedness, disaster relief, and homeland security programs. This infrastructure would incorporate access to technology, physical plants, programs, and communications. It also would include procurement and emergency programs and services.

NCD commends the Administration and those in leadership positions for the issuance of the July 22, 2004, Executive Order on people with disabilities and emergency preparedness. In addition, NCD acknowledges the work of the Department of Homeland Security (DHS) and the Federal Communications Commission (FCC) in their efforts to ensure that Americans with disabilities are included in the developing infrastructure.

#### **Joint Mediation Document Released**

On May 10, the U.S. Equal Employment Opportunity Commission (EEOC), NCD, and the U.S. Department of Justice (DOJ) jointly released two new publications addressing how to ensure that mediation of equal employment opportunity disputes is accessible to people with disabilities. The publications are available on all three agencies' Web sites at www.eeoc.gov, www.ncd.gov, and www.ada.gov.

The documents, titled *Questions and Answers for Mediation Providers: Mediation and the Americans with Disabilities Act* and *Questions and Answers for Parties to Mediation: Mediation and the Americans with Disabilities Act*, address the obligations of all private and public sector mediation providers, including employers who offer their employees

mediation as a benefit of employment. The documents are written in a question-and-answer format and discuss topics such as the following:

- types of reasonable accommodations that may be necessary to make mediation accessible to people with disabilities;
- best practices for ensuring that mediation is accessible;
- the confidentiality of medical information disclosed during mediation; and,
- recommended types of ADA training for mediators.

#### **NCD Reissues Assisted Suicide Paper**

On June 9, NCD reissued its statement opposing the legalization of assisted suicide.

In 1997, NCD issued *Assisted Suicide: A Disability Perspective* (<a href="http://www.ncd.gov/newsroom/publications/1997/suicide.htm">http://www.ncd.gov/newsroom/publications/1997/suicide.htm</a>), as part of its role as the principal agency within the Federal Government charged with the responsibility of providing cross-disability policy analysis and recommendations regarding government programs and policies that affect people with disabilities. At the time the position paper was issued, the U.S. Supreme Court was preparing to rule on appeals from the Second and Ninth Circuit Courts, each of which had declared assisted suicide a constitutional right.

After a thorough review of the forms of discrimination people with disabilities experience in American society, the Council decided to oppose legalization of assisted suicide, concluding that:

Current evidence indicates clearly that the interests of the few people who would benefit from legalizing physician-assisted suicide are heavily outweighed by the probability that any law, procedures, and standards that can be imposed to regulate physician-assisted suicide will be misapplied to unnecessarily end the lives of people with disabilities . . . . At least until such time as our society provides a comprehensive, fully-funded, and operational system of assistive living services for people with disabilities, this is the only position that the National Council on Disability can, in good conscience, support.

#### **NCD Releases Transportation Report**

On June 13, NCD released its report *The Current State of Transportation for People with Disabilities* (<a href="http://www.ncd.gov/newsroom/publications/2005/current\_state.doc">http://www.ncd.gov/newsroom/publications/2005/current\_state.doc</a>), stating that improvements have been made in transportation for people with disabilities, but more remains to be done.

The report was developed with the input of individuals with disabilities and transportation professionals from around the country. The purpose of this project was to develop a better understanding of access to transportation and mobility for people with

disabilities, including access to traditional public transportation systems, private transportation services, alternative transportation initiatives, and the pedestrian environment; to identify transportation barriers as well as promising practices and models; and to develop recommendations in keeping with the goals of President Bush's New Freedom Initiative to "expand transportation opportunities for people with disabilities."

There have been many advances in America's transportation systems and services for citizens with disabilities, particularly since the passage of the Americans with Disabilities Act of 1990. The U.S. Department of Transportation and the nation's public transportation industry are to be applauded for their part in bringing about this progress. However, research reveals that many barriers to transportation continue to exist, and prevent the full inclusion and full participation of people with disabilities in society.

The report highlights industry best practices and successful initiatives that can serve as models for communities for enhancing transportation and mobility for people with disabilities. This report also sets forth a variety of recommendations for service improvements and for additional research that will lead to greater options for the 6 million Americans with disabilities who have difficulties obtaining the transportation they need to live independent and productive lives.

Panelists included: Graham Hill, Member, NCD; David Wenzel, Member, NCD; Michael A. Winter, Director, Office of Civil Rights, Federal Transit Administration, U.S. Department of Transportation; William Millar, President and CEO, American Public Transportation Association; Maureen McCloskey, National Advocacy Director, Paralyzed Veterans of America; Robert Coward, President, Washington, DC ADAPT; and Julie Carroll, Senior Attorney Advisor, NCD. Remarks can be found at <a href="http://www.ncd.gov/newsroom/testimony/05testimony.htm">http://www.ncd.gov/newsroom/testimony/05testimony.htm</a>.

The Associated Press ran a story on the NCD transportation report that was carried in more than 400 news outlets around the world. This coverage also sparked a CNN interview with NCD chairperson Lex Frieden.

#### **ADA 15th Anniversary**

On July 25 and 26, NCD and its federal partners observed the 15th ADA anniversary with two events. More than 700 people attended an invitation-only reception at the John F. Kennedy Center for the Performing Arts in Washington, D.C., where former President George H. W. Bush was the keynote speaker. Also speaking were Health and Human Services Secretary Michael O. Leavitt, Labor Secretary Elaine L. Chao, Housing and Urban Development Secretary Alphonso Jackson, Transportation Secretary Norman Y. Mineta; Tom Harkin, U.S. Senator (D-IA), and Steny Hoyer, U. S. Representative (D-MD); Lex Frieden, NCD chairperson; and Janice M. Tuck, Chair, U.S. Access Board.

The program for the reception can be found at <a href="http://www.ncd.gov/newsroom/publications/2005/anniversary\_event1.htm">http://www.ncd.gov/newsroom/publications/2005/anniversary\_event1.htm</a>.

During the program President George H. W. Bush awarded the George Bush Medal for the Empowerment of People with Disabilities to Allan Reich, president emeritus, National Organization on Disability; Dr. I. King Jordan, president, Gallaudet University; and Representative Steny Hoyer (D-MD).

The medal is intended to reinforce the nation's commitment to keeping the promise of the ADA to all Americans and to encourage the spirit of ADA throughout the world.

Past recipients include: Senator Tom Harkin (1994); Ed Roberts and Bengt Lindqvist (1996); and Elizabeth Boggs, Justin Dart, Jr., Evan J. Kemp, Jr., Joshua Teke Malinga, Dick Thornburgh, and Patrisha A. Wright (2000).

The second event was an ADA seminar that took place on July 26 at the Marriott at Metro Center in Washington, D.C. More than 300 people participated in the seminar, which included an opening plenary session, six ADA-related workshops, and a closing plenary session. Speakers included Homeland Security Secretary Michael Chertoff, Transportation Secretary Norman Y. Mineta, Equal Employment Opportunity Commission Chair Cari M. Dominguez, and Social Security Administration Commissioner Jo Anne Barnhart. The seminar agenda can be found at <a href="http://www.ncd.gov/newsroom/publications/2005/anniversary\_event2.htm">http://www.ncd.gov/newsroom/publications/2005/anniversary\_event2.htm</a>.

#### **ADA Paper**

On July 26, NCD released its latest paper *NCD* and the Americans with Disabilities Act: 15 Years of Progress, which describes NCD's role in the passage of the ADA and the continuing efforts of the Council in evaluating the implementation, effectiveness and impact of the ADA. The paper can be found at <a href="http://www.ncd.gov/newsroom/publications/2005/15yearprogress.htm">http://www.ncd.gov/newsroom/publications/2005/15yearprogress.htm</a>.

NCD Calls for Federal Disability Recovery Plan in Response to Hurricane Katrina NCD expresses its deep concern for the tremendous loss of life and devastation caused in the southern part of the United States by Hurricane Katrina and urges the Federal Government to craft a strong coordinated Federal Disability Recovery Plan for the victims and survivors of the hurricane.

Current data indicates that people with disabilities are now most at risk in this situation—and will need recovery assistance for months or years. A disproportionate number of the hurricane survivors are people with disabilities whose needs for basic necessities are compounded by chronic health conditions and functional impairments. Relief agencies

must prioritize efforts and take special steps to address the unique and complex needs of this population.

NCD's 2005 report titled *Saving Lives: Including People with Disabilities in Emergency Planning* (<a href="http://www.ncd.gov/newsroom/publications/2005/publications.htm">http://www.ncd.gov/newsroom/publications/2005/publications.htm</a>) recommends immediate federal changes in emergency planning for people with disabilities. NCD encourages Hurricane Katrina responders to follow the findings and recommendations in this timely report.

Saving Lives: Including People with Disabilities in Emergency Planning, NCD's 2005 report, provides an overview of steps the Federal Government should take to build a solid and resilient infrastructure that will enable the government to include the diverse populations of people with disabilities in emergency preparedness, disaster relief, and homeland security programs. This infrastructure would incorporate access to technology, physical plants, programs, and communications. It also would include procurement and emergency programs and services.

NCD commends the Administration and those in leadership positions for the issuance of the July 22, 2004, Executive Order on people with disabilities and emergency preparedness. In addition, NCD acknowledges the work of the Department of Homeland Security and the Federal Communications Commission in their efforts to ensure that Americans with disabilities are included in the developing infrastructure.

All too often in emergency situations the legitimate concerns of people with disabilities are overlooked or swept aside. In areas ranging from the accessibility of emergency information to the evacuation plans for high-rise buildings, great urgency surrounds the need for responding to the concerns of people with disabilities in all planning, preparedness, response, recovery, and mitigation activities. The homeland security terrorist event of September 11, 2001, as well as the recent energy blackouts in the U.S. Northeast and Midwest and, more recently, the natural disaster hurricane events in Florida, the tsunami event of 2004, and this most recent event, Hurricane Katrina, underscore the need to pay attention to the concerns raised in this report.

The decisions the Federal Government makes, the priority it accords to civil rights, and the methods it adopts to ensure uniformity in the ways agencies handle their disability-related responsibilities are likely to be established in the early days of an emergency and be difficult to change if not set on the right course at the outset. Through this report, NCD offers advice to assist the Federal Government in establishing policies and practices in these areas. This report provides examples of community efforts with respect to people with disabilities, but by no means is it a comprehensive treatment of the emergency preparedness, disaster relief, or homeland security program efforts by state and local governments.

Please visit <a href="https://disasterhelp.gov/portal/jhtml/index.jhtml">https://disasterhelp.gov/portal/jhtml/index.jhtml</a>, the Federal Government's Web portal for disaster information and help.

#### **IDEA Burden of Proof**

On August 9, NCD released *Individuals with Disabilities Education Act Burden of Proof:* On Parents or Schools? a position statement on Schaffer v. Weast, which is pending in the Supreme Court of the United States

(http://www.ncd.gov/newsroom/publications/2005/burdenofproof.htm).

The Individuals with Disabilities Education Act does not specify whether parents or school districts have the burden of proof in special education litigation. It is NCD's position that school districts, not parents, should have the burden of proof in issues about IEPs, placement, eligibility, and other matters related to appropriate education.

In *Schaffer v. Weast*, the United States Court of Appeals for the Fourth Circuit held that "parents who challenge an IEP . . . have the burden of proof in the administrative hearing." The court noted that the ". . . circuits are split—and splintered in reasoning—on this question." The split revolves around the Tatro / Alamo Heights line of cases contrasted with the Lascari / Oberti line of cases. Five circuits have assigned the burden of proof, the Tatro / Alamo Heights rule, to parents. Five other circuits, following the Lascari / Oberti rule, assign the burden to schools. The United States Supreme Court agreed to resolve the split between the Circuits. Oral argument is scheduled for October 5, 2005.

If a parent disputes an IEP, the courts agree that it is the parent's burden to "place in issue the appropriateness of the IEP." The next issue is whether the parent has the burden of proving that the IEP is not appropriate or whether the school district has the burden of proving that the IEP is appropriate.

There are several competing principles. Should the party attacking the terms of an IEP bear the burden of showing why the IEP is not appropriate? Or should the party that prepared the IEP and has greater expertise and resources have the burden of proving that the IEP is appropriate?

If a statute is silent regarding which party has the burden of proof, the complainant usually has the burden of proof. The U. S. Supreme Court has issued several decisions about burden of proof in the absence of statutory guidance. In most cases, the Court, relying on the policy and history of the statute and concerns of fundamental fairness, has been consistent in assigning the burden of proof to the party more likely to have access to the information that explains its actions in order to arrive at a result that is "right" and "just."

This paper reviews the history of special education, special education law, the *Mills* case, which formed the backbone of the procedural safeguards in the Individuals with

Disabilities Education Act, special education burden of proof cases, and U. S. Supreme Court cases.

Brian Schaffer, Peter Mills and Bill Dunstan are children with disabilities whose cases were decided by different courts. Their own educational and legal processes are typical of the circumstances when parents and schools disagree. Because the burden of proof was assigned to Bill Dunstan, the outcome in his case was not fair or right; it was unjust.

The release of the NCD position statement caused one of the counsels for the respondents, to petition the Court to dislodge the NCD position statement and other material from the Court's view. On August 25, the Court granted the plaintiff's motion to lodge these documents, including NCD's position statement, for the record.

#### **CRIPA**

On August 8, NCD released its long-awaited report titled *The Civil Rights of Institutionalized Persons Act: Has It Fulfilled Its Promise?* (http://www.ncd.gov/newsroom/publications/2005/personsact.htm).

Congress enacted the Civil Rights of Institutionalized Persons Act (CRIPA) in 1980 to enable the Department of Justice (DOJ) to protect the rights of people residing in state institutions. The law authorizes the Attorney General to initiate or intervene in lawsuits in federal court to vindicate the rights of people in state-run or locally operated jails and prisons, juvenile correctional facilities, public nursing homes, mental health facilities, and institutions for people with intellectual disabilities.

Twenty-five years later, CRIPA remains critically important. The isolated nature of institutions and the vulnerability of their residents combine to create environments ripe for abuse. One and a half million Americans reside in 17,000 nursing homes, and 30 percent of those facilities have been cited for harming residents or placing them at risk of serious injury or death.

The actual incidence of abuse is far higher. Studies suggest that 80 percent to 85 percent of abuse in institutions goes unreported. Abuse typically occurs behind closed doors. Residents and family members are often reluctant to report abuse for fear of reprisal. In some cases, disabilities may interfere with residents' ability to ask for help or may lead caregivers to disregard what residents say.

This report examines how DOJ has used its congressional mandate. DOJ's enforcement of CRIPA has been excellent in some respects and lacking in others. DOJ's investigations of complaints are thorough and effective. Its letters of findings accurately reflect the results of its investigations and provide information about how states can remedy constitutional and statutory violations. CRIPA requires DOJ to attempt to persuade states to voluntarily comply with the law before initiating lawsuits, but DOJ has been too reluctant to use its authority to litigate, focusing too much time and energy on

conciliation as a means of achieving compliance. When DOJ does litigate, it does so skillfully; however, it undermines its advocacy by resolving some cases through private agreements rather than enforceable consent decrees.

#### NCD Makes Recommendations on Disability in America

On August 1, 2005, NCD staff attended an Institute of Medicine (IOM) invitational workshop titled "*Disability In America: A New Look.*" Based on NCD staff attendance at that workshop, including a review of the workshop materials and presentations, NCD offered the IOM Committee on Disability in America recommendations for its impending report on Disability in America.

The full text of the NCD's recommendations can be found at http://www.ncd.gov/newsroom/correspondence/2005/field 08-09-05.htm.

#### NCD Comments on NIDRR Long-Range Plan

On August 9, NCD submitted comments to the Office of Special Education and Rehabilitative Services in response to its July 27 *Federal Register* notice seeking comment on the National Institute on Disability and Rehabilitation Research's (NIDRR) Long-Range Plan for fiscal years 2005 through 2009.

The full text of the NCD letter is available at <a href="http://www.ncd.gov/newsroom/correspondence/2005/tingus\_08-09-05.htm">http://www.ncd.gov/newsroom/correspondence/2005/tingus\_08-09-05.htm</a>.

#### **Natural Disaster Recovery Recommendations**

On September 9, NCD published an op-ed piece on making improvements now to help people with disabilities recovering and rebuilding from hurricanes and other natural disasters (<a href="http://www.ncd.gov/newsroom/news/2004/op-ed04-459.htm">http://www.ncd.gov/newsroom/news/2004/op-ed04-459.htm</a>). NCD recommended that those involved in rebuilding the homes lost in the storms keep in mind the many benefits of basic universal accessibility, including ramps and doorways wide enough for wheelchairs and walkers.

#### NCD Calls for Urgent Action from the Department of Homeland Security

On September 19, NCD chairperson Lex Frieden wrote to Secretary of Homeland Security Michael Chertoff recommending urgent action by the Department in assisting people with disabilities who were affected by Hurricane Katrina.

NCD made the following short-term recommendations to be implemented in the next several months:

1. Establish a Point Person on Disability who reports directly to the Secretary and interacts directly with the Department of Homeland Security (DHS) senior leadership team and is vested with the responsibility, authority, and resources for providing day-to-day leadership, guidance, and coordination for emergency preparedness, disaster relief, and recovery operations of the Federal Government on behalf of Americans with

disabilities. The Point Person should be a qualified senior-level person, and should be in regular contact with other members of the DHS senior staff as well as members of the Interagency Coordinating Council on Emergency Preparedness for People with Disabilities, state and local authorities, and citizens, as necessary.

- 2. Develop and implement a coordinated Federal Disability Recovery Plan for Hurricane Katrina that focuses particularly on people with disabilities.
- 3. Establish a Hurricane Katrina Disability Access Advisory Group, made up of qualified people with disabilities and others with disability-specific disaster experience, who meet regularly with senior officials to help craft the Katrina recovery plan, share real-time information from the Gulf Coast region, and discuss events, challenges, and progress.
- 4. Use all available "on the ground" personnel to provide funds and target resources that specifically meet the identified critical needs of Katrina survivors with disabilities, including:
- assisting with the restoration of the organizations that serve them;
- identifying accessible temporary and permanent housing and addressing the specific requests of leaders in the devastated areas and those in areas to which people with disabilities are being evacuated;
- ensuring effective coordination with social services, health services, education services, and other human services providers and agencies throughout the recovery and restoration process;
- ensuring the use of accessible communications technology for people with disabilities during the region's recovery from this disaster to help assess damage, collect information, and deploy supplies; and
- ensuring that the response to and the recovery from Hurricane Katrina comply with federal law requiring nondiscrimination and accessibility, including the requirements of the Americans with Disabilities Act and the Rehabilitation Act.

#### NCD also made long-term recommendations:

- 1. Recovery, rebuilding, and resettlement operations must have the appropriate resources, medical equipment, supplies, and training to address the needs of people with disabilities. Many individuals with disabilities will require accessible housing, appropriate health services, and assistive technologies. At the outset and during all its phases, these operations should include people with disabilities with experience and expertise on these matters.
- 2. Recovery, rebuilding, and resettlement personnel must be educated and trained to support the independence and dignity of persons with disabilities in the months and years following Hurricane Katrina. People with disabilities should assist in the development of the response personnel and should be supported by the appropriate accommodations.

- 3. A universal design approach should be followed to meet the needs of people with disabilities affected by recovery, rebuilding, and resettlement efforts in the Gulf Coast region. The Federal Government should mandate universal design and full accessibility for all new construction in the region affected by Hurricane Katrina.
- 4. Disability organizations must participate in all Hurricane Katrina recovery, rebuilding, and resettlement government (and non-government) operations and be relied on for ongoing advice, guidance, and leadership.

The entire letter can be found at http://www.ncd.gov/newsroom/correspondence/2005/chertoff\_09-19-05.htm.

On September 23, Secretary Chertoff signed a memorandum stating his concern for the suffering of people with disabilities in the affected regions. He called attention to the large number of people with disabilities in these states—close to one million people, according to Census Bureau data.

Secretary Chertoff directed Federal Emergency Management Agency (FEMA) officials to add to their staffs specialists in issues affecting people with disabilities. These individuals would help with the complex issues we are so familiar with:

- ensuring the availability of durable medical equipment, such as mobility aids, adaptive accessories, and hearing aids;
- ensuring that there are adequate stocks of medicines needed by people with disabilities; ensuring that there is sufficient accessible housing; and dealing with issues that arise.

Secretary Chertoff also ordered that the needs of people with disabilities be fully incorporated in future emergency preparedness planning.

# NCD Seeking Information about the Experiences of People with Disabilities Affected by Hurricanes Katrina and Rita

On September 21, NCD issued a request for information on how Hurricanes Katrina and Rita affected people with disabilities and their relatives, friends, and neighbors, and how they affected organizations assisting people with disabilities. NCD is asking people with disabilities to share their experiences, using the questions that follow as guidance for their response.

On September 2, NCD called for a federal disability response and recovery plan (<a href="http://www.ncd.gov/newsroom/news/2005/r05-496.htm">http://www.ncd.gov/newsroom/news/2005/r05-496.htm</a>) and published two briefs on Hurricane Katrina-affected areas. The first brief,

(<a href="http://www.ncd.gov/newsroom/publications/2005/katrina2.htm">http://www.ncd.gov/newsroom/publications/2005/katrina2.htm</a>), was released September 2; the second, (<a href="http://www.ncd.gov/newsroom/publications/2005/katrina.htm">http://www.ncd.gov/newsroom/publications/2005/katrina.htm</a>),

September 7. Issues raised include the effects of Hurricane Katrina on people with disabilities, where help can be sought, the response of the government, additional help needed, subsequent actions that must be undertaken, and the response of the disability community to the hurricane.

The following questions can be used as guidance in responding to NCD's request for information.

- 1. How were people with disabilities provided with information about the severity of the emergency caused by the hurricanes, how to prepare for them, and how to evacuate?
- 2. Was individual assistance (such as personal attendants, sign language interpreters, readers, and service animals) available to people with disabilities during and after the emergency?
- 3. What assistive devices (such as wheelchairs, walkers, canes, crutches, speech-enabled or Braille notetakers, pagers, closed captioning, TTYs, hearing aids, and batteries) were people with disabilities able to keep with them during or after the hurricanes? What assistive devices were they not able to keep? How were these assistive devices replaced?
- 4. What accessible temporary housing or shelter was offered to people with disabilities?
- 5. What accessible transportation was provided to people with disabilities during evacuations, distribution of food and water, and relocation to temporary shelters or housing? Were people who use assistive devices able to keep them during such transport?
- 6. What medical and mental health treatment, such as emergency care, counseling, or medication, was offered to people with disabilities? What types of accessibility problems arose?
- 7. What schools offered accommodations to students with disabilities affected or dislocated as a result of the hurricanes?
- 8. What types of temporary or permanent employment opportunities were offered to people with disabilities?
- 9. What government services (such as Social Security, Medicare, Medicaid, subsidized housing, food vouchers, or any other government assistance) were, and continue to be, made available to people with disabilities?
- 10. Describe the immediate, short-term, and long-term aid provided by private, civic, faith-based, advocacy organizations or by other groups to people with disabilities.

# Civil Rights of Institutionalized Persons Act (CRIPA) and Hurricane Recovery Efforts

In the wake of ongoing hurricane recovery efforts, recommendations published in NCD's August 2005 report *The Civil Rights of Institutionalized Persons Act: Has It Fulfilled Its Promise?* (http://www.ncd.gov/newsroom/publications/2005/personsact.htm) underscore the urgency of recovery efforts for people residing in a variety of institutions.

The report examines the U.S. Department of Justice's (DOJ) enforcement of CRIPA, which was enacted by Congress in 1980 to protect the rights of people in state-run nursing homes, mental health facilities, institutions for people with intellectual and developmental disabilities, and correctional facilities for children and adults.

The isolated nature of institutions and the vulnerability of their residents combine to create environments ripe for abuse. Three and a half million Americans reside in institutions. One and a half million Americans reside in 17,000 nursing homes, and 30 percent of those facilities have been cited for harming residents or placing them at risk of serious injury or death.

The report makes recommendations for ways DOJ could better protect the rights of people in institutions, including adopting strategic and multifaceted enforcement, broadening the scope of investigations, resolving cases through enforceable consent decrees, increasing technical assistance to states to help them comply with federal laws, increasing federal agency coordination to support human and civil rights, making better use of the press, and including more and consistent data in its annual reports to Congress.

Based on recent news reports from the Gulf Coast regarding the treatment of people with disabilities residing in institutional settings, NCD CRIPA recommendations should be followed in the rebuilding of that devastated area.

#### **NCD Conducting ADA Impact Forums**

As a part of a year-long study, NCD is sponsoring five public forums around the country to gather testimony from people with disabilities, their families, and their advocates on the impact the Americans with Disabilities Act of 1990 (ADA) has had on their lives.

In addition to holding public forums, the NCD's ADA Study Team is conducting focus groups and interviews with individuals with disabilities, employers, service providers, business and trade association representatives, and other stakeholders who have been directly affected by ADA. Rounding out the research activities, the ADA Study Team is also conducting an environmental scan to collect data on such ADA impact statistics as number of curb cuts, number of telephone relay calls, number of reasonable accommodations provided by employers, and other indicators to determine whether the law has brought about significant change in the past 15 years.

The ADA Study Team is being advised by a blue ribbon panel of nationally and internationally recognized experts on disability policy.

#### NCD Completes Social Security Impact Study

NCD completed its research evaluating the effectiveness and direction of federal social security benefits programs that support people with disabilities. NCD examined in detail the impact of the Supplemental Security Income and Social Security Disability Insurance benefits programs on people with disabilities, particularly with respect to how these programs support transitioning or returning beneficiaries to work. The study incorporated the expertise of key stakeholders, including consumers, service providers, employers, and other community organizations. The study's recommendations and findings are slated for release in November 2005.

#### **Foreign Assistance Recommendations**

In its advisory capacity, NCD has had an influence on U.S. foreign assistance policy and legislation. In September of 2003, NCD released a report recommending the adoption of specialized new legislation to ensure the inclusion of people with disabilities in U.S. foreign assistance efforts. In the FY 2005 Omnibus Appropriations bill, (originally under Section 579 of the Foreign Operations Appropriations bill, which was folded into the Omnibus bill). The significant pieces of legislation included: (1) The creation of a fund in the amount of \$2.5 million that will be made available for programs and activities that address the needs, and protect the rights of people with disabilities in developing countries (these funds can also be made available for an international conference on the needs of people with disabilities, including disability rights, advocacy and access); (2) a requirement that the Secretary of State and USAID each designate a disability advisor in their respective agencies; (3) the requirement that the Secretary of State, Secretary of the Treasury, and the USAID Administrator shall seek to ensure that the needs of people with disabilities are met where appropriate in democracy, human rights, rule of law, programs and activities supported by the Department of State, Department of Treasury and USAID; and (4) the requirement that the USAID Administrator shall fully comply with its September 12 policy paper on disability which requires that USAID implement procedures to require prospective grantees seeking funding from USAID to specify, where relevant, how the proposed program will include protecting the rights and addressing the needs of people with disabilities.

#### As a result of this legislation:

1) An Advisory Committee on Persons with Disabilities was established under the general authority of Secretary of State Condoleezza Rice and the USAID Administrator. The Committee advises USAID and the US Department of State on the interests of people with disabilities as those interests pertain to the formulation and implementation of US foreign policy and foreign assistance programs. The first meeting was held on August 15, 2005.

- 2) USAID's Human Resources Department has developed an e-learning course that will target all USAID employees, especially managers, supervisors, and program team leaders. Course topics include inclusive development practices; creation of a mission disability plan; and barriers to inclusion.
- 3) The Administrator of USAID located the point of contact for disability-related activities within the Democracy, Conflict, and Humanitarian Assistance Bureaus.
- 4) Guidance has been developed on accessibility standards in USAID-financed construction. The guidance pertains to any new construction or renovation project fully or partially funded by USAID. An implementation directive has also been issued.
- 5) A directive has also been issued which requires a provision supporting USAID's disability policy in all solicitations and in the resulting awards for contracts, grants, and cooperative agreements.

In 2005, NCD cosponsored a symposium to bring stakeholders up to date on the status of current negotiations on monitoring taking place during deliberations on the United Nations Convention on the Rights of People with Disabilities. The symposium brought together human rights and disability experts to discuss innovative models for monitoring the implementation of the convention, as well as gave attention to national level components of monitoring. It resulted in a report being developed for distribution to interested stakeholders on potential monitoring models. Ideas from the report were clearly reflected in the Office of the High Commissioner For Human Rights report that came out on monitoring last year.

#### **Advisory Committees**

The NCD policy team liaisons to three committees formed under the Federal Advisory Committee Act (FACA) continued to provide ongoing guidance and facilitate communication with the committees. Under FACA, these liaisons are the Designated Federal Officials responsible for oversight and coordination of the committees. They assisted the committees in the development of committee purpose, function, and priority areas of focus, within the scope of NCD's statutory authority. The FACA officials consulted with the NCD Board Members assigned to each committee to assure that the needs of youth and young adults with disabilities, people from diverse cultures, and international issues are properly addressed within the scope of the responsibilities of each committee. These officials will carry out their responsibilities in compliance with all of the FACA requirements. The committees are: Cultural Diversity, International Watch, and Youth.

#### II. Educate the public and elected officials on disability issues.

#### **Objectives:**

- 2.1 Strengthen NCD's communication plan, drawing upon new technologies and reaching targeted underrepresented populations.
- 2.2 Disseminate newsletters and reports on disability policy issues.
- 2.3 Hold federal partners meetings with Cabinet secretaries, appointees, and other key individuals to review and promote NCD's disability policy recommendations.
- 2.4 Participate in interagency working groups with federal partners on priority issues.
- 2.5 Serve as the focal point for international activities around the dissemination of information on disability policy in the United States of America and throughout the world.

#### **Results:**

2.1 NCD's Web site (<a href="http://www.ncd.gov">http://www.ncd.gov</a>) is fully accessible to all people with disabilities. Approximately 12 million hits were recorded on the site in FY 2005. All NCD reports, papers, newsletters, and other NCD documents are available to the public on the NCD Web site.

NCD continued to refine its communications strategy, which promotes NCD's recommendations and provides greater opportunities for advancing public awareness of disability issues, especially for people from culturally diverse backgrounds. Through the standard use of a newspaper clipping service, NCD was able to track the number of minority-owned newspapers that ran stories relating to NCD and disability policy.

NCD continued to work with civil rights organizations, such as the Leadership Conference on Civil Rights, the National Urban League, and the National Council of La Raza to provide information to targeted culturally diverse populations and organizations serving people with underrepresented disabilities. Members of civil rights organizations appeared often at NCD events and news conferences, delivering messages of support for people with disabilities.

2.2 NCD gathered information from its board, staff, and other sources for inclusion in its monthly newsletter, *NCD Bulletin*(http://www.ncd.gov/newsroom/bulletins/2005/05bulletins.htm)(http://www.ncd.gov/newsroom/bulletins/2004/04bulletins.htm(http://www.ncd.gov/newsroom/bulletins.html. NCD disseminated the *Bulletin* to more than 9,000 people each month by U.S. Mail and another 3,000 copies through the NCD listserv. NCD's news releases and monthly newsletter also appear on U.S. Newswire, which disseminates this information electronically to thousands of news outlets across the country and to each Congressional office.

NCD reports and other publications

(http://www.ncd.gov/newsroom/publications/2005/publications.htm(http://www.ncd.gov/newsroom/publications/2004/publications.htm) were mailed to approximately 50,000 people. More importantly, more than 200,000 reports were downloaded from the NCD Web site during FY 2005. This is another NCD fiscal year record and fully supports the President's expanded electronic government management initiative to improve the government's ability to serve its citizens.

- 2.3 During FY 2005, NCD assisted the House Administration Committee with issues and advice regarding July 28, 2005, Hearing on Accessibility of the House Complex for Persons with Special Needs; issued NCD recommendations on Workforce Investment Act reauthorization including the Rehabilitation Act to House and Senate Committees; conducted numerous follow up meetings and information exchanges with House and Senate Members and personal and committee staff; worked with Members of the Senate and Staff on possible legislation to establish a preference under the Internal Revenue Service's debt collection contracting program to hire disabled veterans and other people with disabilities; worked with legislative staff inquiry and research regarding issues regarding lawsuits with state employees and discrimination against people with disabilities; assisted legislative staff with formulating questions for Members of Congress to ask during Committee Hearings and additional questionings on a variety of disability issues.
- 2.4 NCD continued its interagency policy liaison activities with the National Youth Leadership Network, the National Institute on Disability and Rehabilitation Research, President's Committee for People with Intellectual Disabilities, White House Initiative on Asian Americans and Pacific Islanders, Substance Abuse and Mental Health Administration, the Rehabilitation Services Administration, the Office for Special Education and Rehabilitative Services, the Office of Disability Employment Policy, the Centers for Disease Control and Prevention, the Department of Transportation Interagency Coordinating Committee, the Homeland Security Interagency Coordinating Committee, and the National Center for Medical Rehabilitation Research.
- 2.5 In 1995, NCD was designated by the Department of State to be the official contact point of the U.S. government for disability issues. Specifically, NCD interacted with the special rapporteur of the United Nations Commission for Social Development on disability matters. As the original author of the Americans with Disabilities Act, NCD continues to be the focal point for international activities around the dissemination of information on disability policy in the United States and throughout the world. To that end, NCD continued to serve as the official point of contact with the U.S. government for disability issues. NCD's International Team and International Watch advisory committee met on several occasions to discuss international disability policy.

NCD provided technical assistance upon request to many countries seeking to learn from the American experience about disability law and policy. Some of those countries included Pakistan, Iraq, the European Union, the United Kingdom, and Bulgaria. NCD also provided technical assistance to stakeholders during the negotiations on the United Nations Comprehensive and Integral International Convention on the Protection and Promotion of the Rights and Dignity of Persons with Disabilities via several topical papers on health, employment, education, transportation, political and public life, information technology, and living independently. At the conclusion of each Ad Hoc Committee meeting, NCD provided an update on the current status of deliberations.

III. Promote effective delivery of federal services and programs to all people with disabilities, particularly unserved and underserved populations, such as people from diverse cultures, rural residents, and youth.

#### **Objectives:**

- 3.1 Monitor federal agencies having civil rights responsibilities to evaluate their efforts to serve underserved populations such as people from culturally diverse backgrounds, rural residents, and youth with disabilities, and develop recommendations to enhance services to these populations.
- 3.2 Promote best practices programs of education and empowerment regarding disability rights for people from culturally diverse backgrounds, rural residents, and youth with disabilities.
- 3.3 Provide an opportunity for leadership development for youth with disabilities.
- 3.4 Establish relationships with national organizations serving these underrepresented populations.

#### **Results:**

3.1 NCD's Cultural Diversity Advisory Committee

(<a href="http://www.ncd.gov/newsroom/advisory/cultural/cultural.html">http://www.ncd.gov/newsroom/advisory/cultural/cultural.html</a>) continued to provide advice and recommendations to NCD on issues affecting people with disabilities from culturally diverse backgrounds. Specifically, the committee assisted in identifying issues, expanding outreach, infusing participation, and elevating the voices of underserved and unserved segments of this nation's population that help NCD develop federal policy that will address the needs and advance the civil and human rights of people from diverse cultures. This advisory committee is an on-going activity.

#### **Unserved and Underserved Groups**

As a follow-up activity to its August 2003 report and toolkit guide addressing issues related to American Indians and Alaska Natives with disabilities, NCD conducted its outreach to underserved and unserved groups.

NCD is also represented on the Interagency Working Group for the White House Initiative on Asian Americans and Pacific Islanders.

NCD coordinated and promoted efforts to focus attention on integration and inclusion of cultural diversity issues across all federal programs monitored by NCD and in NCD reports.

3.2 NCD promoted best practices programs of education and empowerment regarding disability rights for people from culturally diverse backgrounds, rural residents, and youth with disabilities by meeting with stakeholders and representatives of disability and traditional civil rights groups to discuss the unique issues faced by culturally diverse people with disabilities. NCD also facilitated dialogue opportunities for various racial and ethnic groups planning follow-up activities around NCD's report recommendations.

In addition to input from the FACA committees, an ad hoc group was also formed that provided specific advice on reaching families and people with disabilities in ways that respect cultural traditions. A group representing tribal communities guided NCD's dissemination of resource materials and responses to requests for knowledgeable people to participate in panels, conferences and other gatherings in Indian country.

### 3.3 NCD's Youth Advisory Committee

(http://www.ncd.gov/newsroom/advisory/youth/youth.html) met quarterly times, expanded its outreach to include a recommendation passed by NCD adding two new positions for high school students and provided advice to NCD on various issues, such as NCD's planning and priorities for the upcoming fiscal year. The committee targeted transition from school to employment and independent living as key areas of focus. NCD sought this type of input in order to make sure NCD's activities and policy recommendations respond to the needs of youth with disabilities. The committee also visited key committee staffers and Members of Congress to disseminate NCD's briefing material and shared personal stories that educated legislators about the impact of national public policy on lives of youth and young adults.

3.4 During FY 2005, NCD began to renew its relationships with national organizations serving underrepresented populations.

#### IV. Maintain NCD's status as a high performance organization.

#### **Objectives:**

- 4.1 Provide the necessary tools and training to achieve a highly skilled and high-performing work force.
- 4.2 Provide a physical environment that promotes the health and well-being of employees.
- 4.3 Prepare budget testimony.
- 4.4 Provide support to NCD teams.
- 4.5 Maintain accurate accounting of all NCD obligations and expenditures.
- 4.6 Arrange for NCD quarterly meetings.
- 4.7 Conduct personnel evaluations.
- 4.8 Produce weekly news clips.

#### **Results:**

- 4.1 In order for NCD staff to stay current with critical issues facing people with disabilities and for staff to improve their technical skills, participation in training programs is necessary. Specific training needs were identified for individual staff development plans. Staff attended training programs in one or more of the following areas: contract management, computer technology, financial management, supervision, management, and media relations.
  - NCD held monthly staff and team building sessions, which led to the development and promotion of new processes for administration.
- 4.2 NCD developed budget priorities and submitted its budget request to the Office of Management and Budget.

NCD is a leader in providing a physical environment that promotes the health and well-being of its employees. All accommodations that are necessary for employees with disabilities to perform at the highest levels are made. These accommodations include Braille printers, telecommunications devices for the deaf, sign language interpreters, special lighting, large screen computer monitors, ergonomic furniture, assistive technology such as screen readers and notetakers, computer aided real time transcription, etc. NCD is also located in a very accessible building in Washington, DC. Every effort is made to create a physical atmosphere that equates to productive employees.

- 4.3 NCD contacted Congressional subcommittee staff regarding its budget submission and submitted testimony for the record. NCD submitted its budget request in a timely fashion to Congress.
- 4.4 NCD staff provided administrative and policy support to NCD's teams, keeping team members abreast of new developments in their issue areas. NCD arranged meetings and teleconferences to facilitate team work.
- 4.5 NCD conducted its biannual financial audit and developed a management response to the audit findings. Financial procedures have been updated to conform to current accounting practices.
- 4.6 NCD coordinated and conducted four quarterly meetings and one teleconference meeting for the NCD board in FY 2005:

November 29–December 1, 2004, Washington, DC March 9–11, 2005, Honolulu, HI May 9, 2005, Washington, DC July 25–27, 2005, Washington, DC

- 4.7 NCD conducted staff evaluations for all employees and in some cases provided individualized development plans.
- 4.8 NCD also sent time-sensitive news accounts by e-mail, posting some of the more important articles to the NCD in the News page (<a href="http://www.ncd.gov/newsroom/inthenews/inthenews.htm">http://www.ncd.gov/newsroom/inthenews/inthenews.htm</a>) on the NCD Web site.

# Federal Managers' Financial Integrity Act Signed Assurance Statement

June 26, 2006

The Honorable Rob Portman, Director Office of Management and Budget Executive Office Building 17th Street and Pennsylvania Avenue, NW Washington, DC 20503

Dear Mr. Portman:

On the basis of the National Council on Disability's (NCD) management control process, I am pleased to certify with reasonable assurance that NCD's systems of accounting and internal controls are in compliance with the internal control objectives in OMB's Bulletin Number 01-02. I also believe these same systems of accounting and internal controls provide reasonable assurance that NCD is in compliance with the provisions of the Federal Managers' Financial Integrity Act.

The Federal Managers' Financial Integrity Act requires agencies to provide an annual statement of assurance regarding management controls and financial systems. NCD is pleased to report continued progress in strengthening management controls. The continuous improvement of program and operational management process is ongoing. Agency financial management controls and systems, taken as a whole, provide reasonable assurance that accounting systems comply with appropriate federal requirements. This conclusion is based on the review and consideration of internal analyses, reconciliations, reports, and other information.

Prior to the enactment of the Accountability of Tax Dollars Act, NCD had established a policy to conduct an audit biannually. NCD conducted an audit of its FY 2004 financial statement in accordance with the Accountability of Tax Dollars Act. NCD received a clean opinion.

If there are any questions or additional information is needed, please contact the NCD office at 202-272-2004.

Sincerely,

Ethel D. Briggs
Executive Director

# **Conclusion**

In conclusion, NCD continues to be a leader in the development and analysis of disability policy. The use of the *Annual Performance Report to the President and Congress Fiscal Year 2005*, as required by the Government Performance and Results Act, has greatly assisted NCD in carrying out its mission. The findings of this report clearly indicate that NCD has either met or exceeded the projected levels in its performance plan.