
National Disability Policy: A Progress Report



National Council on Disability
March 31, 2009

National Council on Disability
1331 F Street, NW, Suite 850
Washington, DC 20004

National Disability Policy: A Progress Report

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National Council on Disability

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

Letter of Transmittal

March 31, 2009
The President
The White House
Washington, DC 20500

Dear Mr. President:

The National Council on Disability (NCD) is required by Section 401(b) of the Rehabilitation Act of 1973, as amended, to submit annually to the President and Congress a report assessing the status of the nation in achieving policies that guarantee equal opportunity for all individuals with disabilities and that empower individuals with disabilities to achieve economic self-sufficiency, independent living, and inclusion and integration into all aspects of society.

To that end, and on behalf of the Council's 15 members, I am pleased to submit the enclosed report, "National Disability Policy: A Progress Report." This report focuses on the current quality of life of people with disabilities in America and the emerging trends that should be factored into both the design and evaluation of the Federal Government's disability policies and programs in the coming years.

In preparing this report and developing our recommendations, NCD solicited and received input from hundreds of disability community stakeholder organizations and persons with disabilities from across the country. In addition, we analyzed several national disability-related data sources and also drew from NCD's current research and the studies of other government agencies. Based on our findings, this report provides 17 specific recommendations to address many of the disability community's most pressing concerns, as well as areas of disparity in the treatment of people with disabilities. Following those recommendations are several principles for reviewing and modernizing government programs to better serve people with disabilities and for promoting a more integrated, inclusive, and cost-effective approach to Federal disability policy.

In addition to the more than 50 million Americans with disabilities, the United States faces a rapidly approaching demographic shift to an older population, with an attendant increase in the incidence of disability. Given this impending increase, as well as the significant impact of the current economic crisis on people with disabilities, who even in the best of times experience significant socioeconomic disparities, now is the time to develop a bold, coherent, comprehensive approach to disability policy within the Federal Government. In past economic recessions, government programs aimed at ensuring the full inclusion of people with disabilities into society have fared poorly. Your recent and future efforts to stimulate the economy offer us a great opportunity to ensure that all

government initiatives thoughtfully incorporate the needs of people with disabilities and their families.

NCD continues to stand ready to assist the Administration and Congress in identifying opportunities to improve our nation's disability policy, and to enhance the quality of life, independence, and full inclusion of people with disabilities into all aspects of society.

Sincerely,

A handwritten signature in black ink, appearing to read "John R. Vaughn", with a stylized flourish at the end.

John R. Vaughn
Chairperson

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

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Acknowledgments

NCD expresses its appreciation for the contributions of the many people with disabilities, their families, and service providers around the country who provided input for this report. Their time and effort greatly enriched our understanding of the issues facing people with disabilities and will help to advance U.S. disability policy.

Table of Contents

EXECUTIVE SUMMARY	7
Recommendations	9
CHAPTER 1: INTRODUCTION	17
CHAPTER 2: EMERGING TRENDS AND CHALLENGES	21
Emergency Preparedness and Homeland Security.....	23
International Convention on the Rights of Persons with Disabilities	25
Health Care	26
Home- and Community-Based Services	29
Mental Health	32
Mental Health Services for Veterans and Service Members	34
Housing	36
Employment	39
Transportation	45
Education	48
Technology.....	52
Coordination.....	55
CHAPTER 3: FULL CITIZENSHIP—EMERGING ISSUES AND THE ROLE OF FEDERAL GOVERNMENT.....	57
The Current Economic Crisis	57
Future Policy Directions	59
CHAPTER 4: CONCLUSION.....	65
APPENDIX 1: MISSION OF THE NATIONAL COUNCIL ON DISABILITY.....	69
Overview and Purpose	69
Specific Duties	69
Statutory History.....	71
APPENDIX 2: STATISTICAL SOCIAL INDICATORS.....	73
APPENDIX 3: LIVABLE COMMUNITY DISCUSSION AND EXAMPLES.....	77
From “Livable Communities for Adults with Disabilities” (2004)	78
From “Creating Livable Communities” (2006)	78

From “Inclusive Livable Communities for People with Psychiatric Disabilities” (2008) .. 79

APPENDIX 4: THE ROLE OF GOVERNMENT IN THE PERVASIVE POVERTY OF PEOPLE WITH DISABILITIES 83

APPENDIX 5: PRIVATE INITIATIVES..... 85

Corporate Culture 85

Recruitment and Retention..... 86

Reasonable Accommodations..... 87

Education 87

APPENDIX 6: INTERGOVERNMENTAL REVIEW AND EXAMPLES 89

Emergency Response 89

Intergovernmental Programs Serving Low-Income People 89

Overlapping, Intergovernmental Programs..... 89

ENDNOTES 91

Executive Summary

In recent years, the National Council on Disability (NCD) Progress Report has been a retrospective review and analysis of Federal programs for people with disabilities. For this Progress Report, NCD members have chosen to depart from a retrospective approach, and, instead, will focus on the current status of the quality of life of people with disabilities, and the emerging trends that warrant changes in the Federal Government's disability policies and programs. The worldwide economic recession, the unprecedented changing demographics in America, and the advent of a new Administration and Congress taking bold new directions in fiscal policy, offer an opportunity for a proactive report on the state of affairs in the disability arena. This report suggests ways to address identified issues that are consistent with a fiscal policy aimed at unlocking the potential of America and thereby improving the quality of life and opportunities for the American people. It is our hope that these recommendations will ensure that the identified needs of people with disabilities and their families are not overlooked, as so often has happened in previous periods of economic recovery. Therefore, this report emphasizes opportunities to improve the quality of life of the growing number of citizens with disabilities, the emerging trends warranting changes in the government's response, and recommendations for reviewing and modernizing the way the Federal Government approaches disability policy.

In preparing this report, NCD solicited input from disability community stakeholders from across the country, analyzed national data sources, and drew from NCD's current reports and the studies of other government agencies in an attempt to paint a picture of the current status of people with disabilities in America. This report describes many of the personal challenges of living with a disability, emerging issues and trends concerning people with disabilities, how well government programs address the emerging needs of people with disabilities, and how funding resources could be better spent to address those needs. Only recently has national data begun to provide the information needed to develop an understanding of the status of the quality of life of people with disabilities in America, and many gaps in the data remain. Drawing on a

variety of sources of information, it is possible to glean that, as our society becomes more accessible, some people with disabilities are participating more in all aspects of community life. Strides have been made in access to transportation, education, communications, technology, and employment. Other factors, important to quality of life, however, impede progress toward full citizenship, such as the lack of affordable, accessible housing, difficulty breaking into the job market, poor access to health care, the institutional bias in Medicaid, access barriers to technology, and negative public attitudes about people with disabilities.

In many instances, improvements in quality of life for people with disabilities can be attributed to government programs, particularly those involving intergovernmental partnerships as well as partnerships with the private and volunteer sectors. Examples from the livable communities' model demonstrate the potential for such partnerships to improve life for all citizens—people with disabilities and aging baby boomers, in particular.

Conversely, many of the intractable problems for people with disabilities can be attributed to government programs and policies. Research reveals program fragmentation, lack of coordination, government policies that conflict with one another, and counterproductive eligibility and benefits restrictions. Certain government policies actually have the effect of forcing people to live in institutions, prevent people from working, and impede achievement of the overarching goals of the Americans with Disabilities Act (ADA), including equality of opportunity, full participation, independent living, and economic self-sufficiency.

Given the rapidly approaching demographic shift to an older population, the increase in the incidence of disabilities that will ensue, and the impact of the current economic crisis on people with disabilities, the time is now for Federal agencies and policymakers to establish the policy directions to respond to the broad-ranging implications of this increase in disability for individuals and for society. This report provides 17 specific recommendations to address today's most pressing problems for people with disabilities. These recommendations are followed by a set of principles for reviewing

and modernizing government programs to better serve people with disabilities, become more cost-effective, and promote a more integrated and inclusive society that is prepared for the changes ahead.

Recommendations

The National Council on Disability recommends the following:

1. The U.S. Department of Homeland Security (DHS) should establish and appropriately staff a department-wide Office on Disability that is responsible for: training all DHS employees about including and serving people with disabilities; integrating disability issues throughout the Department; enforcing compliance with the Americans with Disabilities Act (ADA) by local and state governments; and increasing collaboration between regional DHS staff and disability organizations.
2. The President should sign the United Nations Convention on the Rights of Persons with Disabilities (CRPD).
3. The President should establish a commission to identify the gaps in health care financing for people with disabilities over the life span, which include gaps that baby boomers will encounter as they age and acquire chronic health conditions and disabilities. The commission should develop recommendations for a more comprehensive, cost-effective health care financing system that better meets the health care needs of an aging society, and that is based on the following principles:
 - People with disabilities or chronic health conditions should have access to health coverage throughout the life span;
 - People with disabilities or chronic health conditions should have access to health wellness and prevention services to maintain good health and avoid acquiring secondary health conditions;

- People with disabilities or chronic health conditions should have access to home- and community-based health services and supports that prolong health and active, independent living; and
 - People with disabilities or chronic health conditions should have equal access to health care providers of their choice.
4. Congress should pass, and the President should sign, the Community Choice Act and make the Money Follows the Person program available in all states. Furthermore, the Secretary of the U.S. Department of Health and Human Services should convene a high-level task force to review all aspects of the Federal and state responses to the *Olmstead* decision and develop recommendations to eliminate the barriers preventing the transition of funding to home- and community-based services.
5. An evidence-based approach to integrated care should be the standard of practice in primary care through the following specific actions:
- The President should instruct all Federal agencies to identify and eliminate all barriers to the appropriate payment for interventions that support evidence-based, integrated care provided by teams of appropriate clinicians. For example, current Medicaid auditing procedures in the Centers for Medicare and Medicaid Services (CMS) regional offices that deny payment for a primary care visit and a mental health visit on the same day should be eliminated.
 - Congress should instruct CMS to reverse its current efforts to narrow the definition of “case management” activities in connection with evidence-based models of integrated care. Instead, CMS should broaden its definition specifically to recognize the key role that evidence shows case management and care coordination play in the coordinated, team-based delivery of integrated mental health, substance abuse, and primary care.

- The Substance Abuse and Mental Health Services Administration and the Health Resources and Services Administration should require that all of their grantees (both block grant and discretionary programs) demonstrate that they are adopting evidence-based approaches to integrated care throughout their federally funded initiatives. Criteria derived from successful integrated models of care should be embedded in the Federal oversight of these grant programs and should support both ongoing quality improvement and implementation science in their development and application.
6. The Department of Defense and the Veterans Administration should develop a plan to ensure continuous availability of mental health services for all service members and veterans. The plan must ensure that service members with post-traumatic stress disorder and traumatic brain injury, which may manifest after separation from the military, have continuous access to mental health services both before and after they separate from the military.
 7. Congress should enact legislation requiring lending institutions to mandate compliance with the accessibility provisions of the Fair Housing Act and the ADA, including its accessibility guidelines, in all real estate and commercial loans, including loans for construction of multifamily housing. Such legislation should require the U.S. Department of Housing and Urban Development to produce an annual report of the quantity and quality of affordable housing (including Low-Income Housing Tax Credit properties) accessible to persons with disabilities, including occupancy rates by persons with disabilities.
 8. Congress should fund a series of antistigma demonstration projects targeted to:
 - the general public, designed to address the lack of knowledge about challenges to employment for persons with disabilities;
 - employers and persons with disabilities, aimed at achieving a better match of job seekers to employers; and

- transition-age youth, designed to encourage them to consider careers in the areas of science, technology, engineering, and mathematics, and to expose such youth to the careers and opportunities these and other high-growth, high-income disciplines entail.
9. The President should issue an Executive Order requiring all Federal agencies to educate hiring managers and human resource personnel about the benefits of hiring people with disabilities, and to also educate them about the recently revised Schedule A civil service hiring authority, which makes it easier for Federal agencies to hire individuals with significant disabilities. The Executive Order should urge all Federal agencies to hire and advance more individuals with disabilities across the Federal workforce, including in the Senior Executive Service, with the goal of reaching the Equal Employment Opportunity Commission's aim of ensuring that 2 percent of the Federal workforce include employees with disabilities by the year 2010.

Additionally, to better monitor the progress of these efforts, NCD recommends that Congress require the Office of Personnel Management to include statistics about employees with disabilities in its annual report to Congress on the Federal Equal Opportunity Recruitment Program.

10. The Centers for Medicare and Medicaid Services and the Social Security Administration should work together closely to: (1) modify existing program regulations to uncouple Medicare and Medicaid coverage from Supplemental Security Insurance/Social Security Disability Insurance cash payments; (2) identify and eliminate the many employment disincentives currently built into the Medicaid waiver, Medicaid buy-in, and Health Insurance Premium Payment programs; (3) expand benefits counseling services to include the full range of financial education and advisement services, and to clarify that helping people to retain benefits while working is not in any way antagonistic to the goals of facilitating employment; and (4) work collaboratively with public and private insurance providers and business representatives to design public-private

insurance partnerships that will expand access to health care from sources other than Medicaid or Medicare for individuals with disabilities.

11. Congress should proceed with reauthorization of the Workforce Investment Act, maintaining the Rehabilitation Act as a separate section with a separate funding stream. This reauthorization should: (a) include dedicated funding for the infrastructure of the One-Stop Career Centers; (b) continue expansion of the Disability Navigator and Customized Employment demonstration projects; (c) require the development of performance standards that measure the number of persons with disabilities who are served in the One-Stop system and their ability to access and benefit from One-Stop services, which would include access to assistive technology and rehabilitation engineering services; and (d) require in the Rehabilitation Act (section IV) that Vocational Rehabilitation services be made available to eligible youth no later than three years before an adolescent or young adult exits from secondary education.
12. The Department of Transportation should: evaluate the effectiveness of the new pilot transportation initiatives for people with disabilities; develop permanent funding mechanisms to expand effective approaches across the country; and propose to Congress ongoing funding mechanisms to increase transportation options for the growing population of people who do not drive because of disabilities.
13. Congress should pass legislation requiring vehicles, including hybrid vehicles, to meet a minimum sound standard so that pedestrians who are blind and who rely on listening for safe travel can maintain mobility and independence. The legislation should direct the Secretary of Transportation to, within one year of passage, promulgate standards for the minimum sound level required to enable blind pedestrians to determine the speed, distance, and direction of travel of motor vehicles.

14. Congress should mandate that the Department of Education's Office of Special Education and Rehabilitative Services, the National Institute on Disability and Rehabilitation Research, and state education and state Vocational Rehabilitation agencies conduct rigorous school-to-work transition evaluation studies. The studies should identify the transition program components that directly correlate with improved employment and postsecondary education outcomes for transition-age youth.
15. Congress should:
 - Expediently reauthorize and fully fund the No Child Left Behind Act (NCLBA) to maintain academic accountability requirements and high expectations for students with disabilities, provide supports and incentives for teachers to offer differential instruction of rigorous content, begin to align the data elements and definitions of NCLBA and the Individuals with Disabilities Education Improvement Act (IDEIA), and expand the age for provision of transition services; and
 - Fund the Advisory Commission on Accessible Instructional Materials in Postsecondary Education for Students with Disabilities, as established in the Higher Education Opportunity Act of 2008, which authorizes grants to increase accessibility of college textbooks and Web site and distance learning information.
16. The Assistant Secretary of Education for Special Education and Rehabilitative Services should conduct an extensive dialogue with all state and territorial Vocational Rehabilitation agencies and state education agencies to determine in detail how and when they provide assistive technology, how they assess the implications of current and evolving technology for client or student assessment and goal-setting, and how they ensure that key personnel keep abreast of developments in assistive technology. Depending on the results of this assessment, the Assistant Secretary should determine whether the existing regulations implementing the statutory authorities for the use of AT adequately

reflect its importance, and if not, should propose appropriate amendments when Congress considers reauthorizing the Vocational Rehabilitation Act, the Assistive Technology Act, and the Individuals with Disabilities Education Act.

Congress should pass legislation that requires access to telephone and television-type equipment and services available through the Internet; decoder circuitry in all video programming devices; captioning of Internet-based television; audio description of television; and access to emergency broadcasts. The U.S. Access Board should adopt updated electronic and information technology and telephone guidelines to ensure increased accessibility of this technology to people with disabilities. The Federal Communications Commission should adopt regulations for ensuring that high-definition television will be fully accessible to persons with visual and hearing disabilities.

17. The President should establish, through Executive Order, an Interagency Disability Coordinating Council (Interagency Council), with a designated executive agency chair and required participation of all Federal agencies serving people with disabilities. The Interagency Council should be charged with submitting an annual report identifying instances of policy conflict or Federal disability-related program inconsistencies that interfere with the achievement of the overarching goals of the ADA, including equality of opportunity, full participation, independent living, and economic self-sufficiency. The Council should be charged with developing recommendations for the elimination of the conflict or inconsistency in all cases in which it substantially affects the lives of citizens with disabilities.

CHAPTER 1: Introduction

It has been nearly two decades since the Americans with Disabilities Act (ADA) prohibited disability discrimination in employment, access to government goods and services, and access to places of public accommodations. It has been 10 years since amendments to the Rehabilitation Act required equal access to government electronic and information technology. It has been 12 years since amendments to the Communications Act required access to telecommunications products and services. People with disabilities report improvements in access to commercial goods and services, public transportation, and telecommunications,¹ particularly access as a result of telephone relay services. Among some categories, the education gap between people with disabilities and people without disabilities is narrowing, and people with disabilities are attending postsecondary institutions in greater numbers.² Education supports and services for students with disabilities are now available at most of the nation's postsecondary institutions. People with disabilities report finding it easier to obtain reasonable accommodations if they are employed.

However, challenges and barriers remain that must be resolved. People with disabilities still find it difficult to break into the job market, and report that employment discrimination generally occurs during the hiring process.³ People with disabilities are more likely to be in poor health, and report going without needed medical care more often than people without disabilities.⁴ People with disabilities are nearly three times as likely as people without disabilities to live in poverty—the same ratio as before passage of the ADA.⁵

There is a surprising absence of ongoing, systematic data collection about the quality of life of people with disabilities. This lack of data has led to significant knowledge gaps about the impact of the civil rights laws and government programs designed to improve opportunities for people with disabilities. Even less is known about the well-being of people with disabilities as compared to people without disabilities. Social indicator systems, currently used to gather information about the American population, either underemphasize or do not include people with disabilities.⁶ Although most national data

collections over the past few decades have been sensitive to variations by race and gender, the same has not been true for disability.

In light of the absence of critical disability data, the National Council on Disability (NCD) undertook a year-long study to identify valid Federal data and to describe the status of the U.S. population of Americans with disabilities. In April 2008, NCD released “Keeping Track: National Disability Status and Program Performance Indicators” (hereinafter “Keeping Track”), which provides a set of statistical social indicators that can measure the progress of people with disabilities in important areas of life over time.⁷ The report identifies 18 indicators, spanning seven domains of importance to people with disabilities (e.g., employment, education, health status and health care, financial status and security, leisure and recreation, personal relationships, and crime and safety. See Appendix 2, Table A2.1). The selected indicators meet the following criteria:

- Data can be obtained relatively easily from existing government sources;
- The indicator is measured relatively frequently (annually or biannually);
- The survey has an adequate sample size to be statistically reliable;
- Comparison data for people with and without disabilities are available; and
- The identifier for people with disabilities is not based solely on “work limitation” questions, which tend to confound data about people with disabilities who work.

For future NCD Progress Reports, data for the set of topical indicators proposed in “Keeping Track” will be updated. These data will enable policymakers to measure the progress of people with disabilities in important life domains over time.

In preparation for this “National Disability Policy: A Progress Report,” and building on “Keeping Track,” through a nationally distributed Emerging Trends Public Consultation,⁸ NCD solicited specific input from people with disabilities. People were asked to comment on the personal challenges of living with a disability, the impact of attitudinal barriers on opportunities, how well government programs address the emerging needs of people with disabilities, and how funding resources could be better spent to address

those needs. In response, NCD received more than 400 submissions, including comments from parents, students, workers, advocates, service providers, individuals, and organizations. Nearly all of the quality-of-life domains, identified as important by stakeholders during “Keeping Track,” surfaced again as being important to people with disabilities who responded to the public consultation.

The purpose of this Progress Report is to:

- Provide an overview of the status of the quality of life for people with disabilities in the United States based on the voice of people with disabilities and the most current existing data;
- Identify emerging trends, systemic barriers, and challenges facing people with disabilities;
- Identify government programs and services that are effective in contributing to improved quality of life for people with disabilities, assess the potential of existing programs and services to meet the needs of people with disabilities in light of emerging trends; and
- Identify barriers that prevent access for people with disabilities or that result in failures to meet the needs of people with disabilities.

The report will offer principles and program policy approaches for reviewing Federal programs to incorporate successful practices into the government’s use of resources for improving quality of life for people with disabilities, and will set forth specific recommendations for the Administration and Congress to address many of the most pressing issues of concern to Americans with disabilities.

The recommendations in this report are based on the premise that the relationship between disability and disadvantage is not inevitable, nor is it a consequence of disability itself. Rather, the disadvantages that result from disability stem from long-held stereotypes, attitudinal barriers, conflicting government programs, and environmental barriers that can, and should be, broken down. Coming as it does at a turning point in

public policy, as a new Administration takes office, and as the current economic crisis demands new solutions to old and new problems, this report synthesizes key data, trends, and public input, and sets forth recommendations to help our nation chart a course toward achieving the goals of equality and full participation that we all share.

CHAPTER 2: Emerging Trends and Challenges

This section is based on NCD's public consultation on emerging trends, public input at NCD meetings, and recent NCD reports, and addresses two questions: (1) What did we learn and what can we say about the status of people's quality of life regarding personal challenges of living with a disability; individual barriers to full participation; attitudinal challenges that still exist; and systemic challenges in many quality of life areas? and (2) What are the most pressing issues and challenges facing people with disabilities, particularly in relation to their quality of life? While many of the issues discussed by people with disabilities overlap and are interrelated, the following subsections are presented by topic. Each subsection begins with salient comments by stakeholders, and follows with the most current information available on each topic, and NCD's specific recommendations.

"[We] have a hard time because of society's barriers and not our disabilities."

"[T]he most negative impacting issue people face is stigma; people meet the disability before they meet you."

"Until programs are designed [and] based upon what each individual with a disability needs, the system will continue to fail—by design."
(Public Comments)⁹

NCD's compilation and review of information revealed anecdotal accounts that included ongoing challenges, disappointments, obstacles, and some policies and practices that seem to be working. Overall, the comments received suggested overlaps and linkages among individual and community dimensions affecting quality-of-life and content topics that people with disabilities consider important. The commenters¹⁰ exposed unmet needs attributed, at least in part, to fragmented systems of Federal programs and services. Commenters also called attention to the limited use of, and the lack of,

meaningful opportunities to provide input regarding policies and practices that affect their lives.

After a tally of topic frequency, NCD identified key topics that commenters discussed most often—attitudes, health care and insurance, housing, employment, transportation, and education.¹¹ Other topics of importance to people with disabilities, which were identified through public comments and presentations at NCD public meetings, included emergency preparedness and homeland security, international issues, home- and community-based services and supports, mental health services for veterans and service members, and access to technology. The identified topics were consistent with the “Keeping Track” study and more than a decade of NCD’s work priorities.

“There is need to change the American culture of ‘me-me’ to a ‘connectedness culture’ of us all together.”

“Many people think that just because I’m using a cane that I’m worthless.”

“We must be free of the Homebound Rule/Home Care to function within our communities of choice as we wish.”

“Programs need to be designed no longer to deny services with the focus being institutionalization or based on society’s concept that people with disabilities have no value and are a drain on society.”
(Public Comments)

The most common thread involved encounters with an array of attitudinal barriers. Negative public attitudes were a factor in nearly all issues discussed. Across various topics, commenters told NCD about indifference, rudeness, and unfavorable attitudes toward people with disabilities.

Many commenters indicated difficulty in separating various topics they deemed important. For example, numerous commenters linked health care challenges with topics of insurance and employment. They also related those topics to the dimension of choice, and the pressing economic issue of health care coverage for all Americans. Other people identified overlaps in barriers to transportation, employment, housing (for rental or purchase), achieving individual aspirations, financial means, spontaneity, community inclusion, and integration, including consideration in emergency situations.

Emergency Preparedness and Homeland Security

“It is inexcusable to think that in an emergency situation, [people across disability types] will be left to try to figure out what is happening.”

“The first step is to realize that disabled people need to evacuate in the first wave. They can’t wait and they [also] must take greater responsibility for preparedness.” (Public Comments)

Scientists report an increase in the number of natural disasters, such as droughts, tsunamis, hurricanes, typhoons, and floods, over the past 25 years.¹² In 1980, only about 100 such disasters were reported per year, but that number has risen to more than 300 a year since 2000. The increase is expected to continue, and storm-related disasters are predicted to increase in intensity.¹³

Improving emergency preparedness, response, and recovery for people with disabilities has been a major priority for NCD for several years.¹⁴ As a result of its earlier work, Congress appropriated additional funding for NCD to carry out specific activities that will enhance the ability of the emergency preparedness and response network to meet the needs of people with disabilities in future disasters.¹⁵ To assist in meeting these responsibilities, NCD conducts extensive, ongoing information-gathering from stakeholders. People with disabilities continue to report to NCD about the ongoing challenges associated with both natural and manmade disasters and subsequent

recovery efforts, and the need for the Federal Government's continued involvement in homeland security planning and policymaking.

Homeland security has become a significant component of citizen safety, which was one of the important quality-of-life indicators identified by people with disabilities during NCD's "Keeping Track" research. Safety is typically associated with freedom from crime or abuse, but people with disabilities are increasingly concerned about surviving and recovering from manmade and natural disasters.

Through the inclusion of people with disabilities in stakeholder planning and simulations of disaster efforts, NCD has identified gaps in civil defense and public health arrangements. The resources have been identified that are needed to make facilities and information fully accessible in emergencies at local, regional, and national levels.¹⁶ NCD has identified gaps such as an inadequate number of emergency shelters that can accommodate people with disabilities, a shortage of accessible vehicles during evacuations, a lack of accessible temporary housing, and broadcast information that is not accessible to all people with disabilities. Other gaps in homeland security arrangements include ways to obtain replacement durable medical supplies and assistive technology, medications, medical care, and personal assistance during periods of evacuations. These are just some of the issues that must be addressed by DHS as it establishes department-wide general procedures and consistent standards for recognizing and addressing disability-related issues. This requires professional staff with disability expertise, as well as familiarity with the complexities of DHS, including Federal Emergency Management Administration operations across the various levels of government.

RECOMMENDATION 1

The U.S. Department of Homeland Security (DHS) should establish and appropriately staff a department-wide Office on Disability that is responsible for: training all DHS employees about including and serving people with disabilities; integrating disability issues throughout the Department; enforcing compliance with the Americans with

Disabilities Act (ADA) by local and state governments; and increasing collaboration between regional DHS staff and disability organizations.

International Convention on the Rights of Persons with Disabilities

“[We] ask that the United States ratify the United Nations Convention on the Rights of People with Disabilities for all the work undertaken for the support of the disabled, it is important that we begin to join with the world in recognizing the Convention for people with disabilities.”

“[W]e must demonstrate our leadership and commitment to providing access in the global community.” (Public Comments)

In December 2006, at its 61st Session, the General Assembly of the United Nations (UN) adopted the International Convention on the Rights of Persons with Disabilities, which marked the end of a five-year-long negotiation process that was unprecedented in its inclusion of nongovernmental organizations made up of people with disabilities.¹⁷

On May 3, 2008, the Convention on the Rights of Persons with Disabilities (CRPD) became legally binding on States Parties to the treaty. Many Americans with disabilities remain concerned that the United States has not signed the Convention.¹⁸ Given developments in U.S. and international policy regarding foreign assistance, human rights treaties, and disability over the last several years, signing the treaty would provide clear support for the principles of this landmark convention and continue the country's tradition as a world leader for people with disabilities.

It is anticipated that U.S. foreign assistance will continue to support the growth and development of disabled people's organizations in the developing world through the support of civil society capacity building initiatives, as well as support for the development of domestic disability legislation in line with the CRPD and the ADA principles of inclusion, nondiscrimination, and equality of opportunity. The Federal Government should continue to support the development of disability legislation in other

countries and to provide technical expertise in these endeavors, especially in the developing world, based on the U.S. experience.

Furthermore, in this global economy, millions of people with disabilities from the United States are now traveling abroad for pleasure, education, and employment, as well as for business and commerce. It is imperative that this new world economy be fully accessible to all people, including those with disabilities.

RECOMMENDATION 2

The President should sign the United Nations Convention on the Rights of Persons with Disabilities (CRPD).

Health Care

“[U]ntil we can change the provision of health care from a profit making business to one of universal coverage and access, we won’t have true health care for everyone.”

“Medicaid providers are the worst when implementing services because they are still looking at the reimbursement hours and not at the patient needs.”

“When our son with a disability ages out of our [private] health insurance policy we are uncertain what happens.”

“Many [people with disabilities] can’t afford to work if they lose health care coverage. (Public Comments)

People with disabilities tend to be in poorer health and to use health care at a significantly higher rate than people who do not have disabilities.¹⁹ They also experience a higher prevalence of secondary conditions and use preventive services at a lower rate than others.²⁰ People with disabilities experience more problems accessing

health care than other groups, and these difficulties increase for those with the most significant disabilities who are in the poorest health. Lack of access to health care has been associated with increased risk for secondary conditions for people with significant disabilities.²¹ People with disabilities are significantly less likely than people without disabilities to be satisfied with the quality of health care they receive.²²

People with disabilities are also affected disproportionately by barriers to care, including:

- health care provider misinformation, stereotypes about disability, and lack of appropriate provider training;
- limited medical facility accessibility and lack of examination equipment that can be used by people with disabilities;
- lack of accessible information; and
- lack of individualized accommodations.²³

Many people with disabilities report gaps in health care insurance coverage that limit or prevent access to needed prescription drugs, durable medical equipment, specialist care, postacute services, physical and vision rehabilitative services, and care coordination, all of which are critical for health, independence, and self-determination.²⁴ Additionally, inadequate transportation, limited personal assistance services, and patchwork financial assistance for people of low income compound health problems and affect the overall health status of people with disabilities.²⁵

Many people with disabilities are unable to obtain any health coverage because they are not poor enough to qualify for public programs, but are excluded from private insurance because of preexisting conditions.²⁶ According to the National Academies, one out of five adults with disabilities has no health insurance and does not qualify for Medicare or Medicaid. This limits these individuals to providers who will treat patients without insurance, usually requiring full payment upfront,²⁷ at a cost much higher than would be charged if the patient had health coverage.²⁸ Most uninsured go without

health care instead.²⁹ Provider choice is also limited for people with Medicaid because many providers will not accept Medicaid's low reimbursement rates.³⁰

Rates of disability increase with age.³¹ The numbers of older people are expected to grow substantially during the next several decades.³² Peak increases are projected through the year 2050.³³ Despite this rapidly approaching demographic shift, and the increase in incidence of chronic conditions and health care costs that will accompany it, the Institute of Medicine (IOM) warns that Federal agencies, policymakers, and health care systems have not yet mobilized their resources to respond to the broad-ranging implications of this increase in disability for individuals and for society.³⁴ Other national experts warn that severe shortages in the allied health professions will exacerbate the health care crisis for people with disabilities and chronic health conditions.³⁵ The acute care bias in the health care financing system not only fails to value maintaining good health, but it may actually contribute significantly to the overall costs of health care for people who are aging. The current system fails to provide coverage for the very supports and services that will maintain independent functioning and avoid the extraordinary expense of institutionalization or dependent care.

RECOMMENDATION 3

The President should establish a commission to identify the gaps in health care financing for people with disabilities over the life span, which include gaps that baby boomers will encounter as they age and acquire chronic health conditions and disabilities. The commission should develop recommendations for a more comprehensive, cost-effective health care financing system that better meets the health care needs of an aging society, and that is based on the following principles:

- People with disabilities or chronic health conditions should have access to health coverage throughout their life span;
- People with disabilities or chronic health conditions should have access to health wellness and prevention services to maintain good health and avoid acquiring secondary health conditions;

- People with disabilities or chronic health conditions should have access to home- and community-based health services and supports that prolong health and active, independent living; and
- People with disabilities or chronic health conditions should have equal access to health care providers of their choice.

Home- and Community-Based Services

“It seems that each time there are budget cuts to be made, Medicaid is one of the first targets, which impacts people with disabilities and others who are the most vulnerable of the population because they are viewed as not important and often the least able to defend themselves which makes them an easy target.”

“Though studies show that caring for someone in their home saves our states millions of dollars, we still choose to lock people with disabilities and seniors away in institutions.”

“The government is biased towards institutional care . . . [it] maintain[s] nursing homes [rather than] . . . building the infrastructure for people to age in place or remain/return to their communities.”
(Public Comments)

For many people with disabilities whose medical needs involve specialized services, recent cuts in state matching funds have led to reductions in home- and community-based services around the country. This exacerbates one of the most pressing public policy problems of the day—that Medicaid’s funding structure forces people out of their homes in the community and into nursing homes and other institutional settings to access services.

The current system for the provision of long-term care hails to the early 1960s, when the Medicaid and Medicare programs were first established. In 2007, Andrew J. Imparato,

President and Chief Executive Officer of the American Association of People with Disabilities, testified regarding the high human cost of the current system before the Senate Health, Education, Labor, and Pensions Committee, stating that:

Not surprisingly, given the origins of these programs, the system continues to exemplify the historically low expectations society has had for people with disabilities for decades. With the expectations for us so low, the mission of the old system was and remains to this day focused on simply maintaining people with disabilities in nursing homes, other institutions, and back rooms, outside of view and away from mainstream. In 1965, people with disabilities were largely out of sight, because society was inaccessible, both literally and attitudinally . . . Curb cuts were few and far between. There was no Americans with Disabilities Act. It is 42 years later, and it is an abomination that hundreds of thousands of people with disabilities remain trapped in a broken system that steals lives . . .³⁶

The home- and community-based services that most people with disabilities want and need are optional, meaning that Federal law does not require states to provide them, although it does make the provision of nursing home services mandatory.³⁷ Community-based services are provided under waiver programs, which receive far more limited and far more tenuous funding, making them an easy target for state budget cuts during economic downturns. Few assaults on individual dignity and self-determination are harsher than being forced to leave one's home and community to live in a segregated environment for these reasons.

Federal Medicaid funds, including funds for the provision of long-term services and supports, are allocated at the discretion of each state toward institutional and home- and community-based services.³⁸ Were the institutional bias eliminated, states would be more likely to provide fiscally responsible, consumer-desired services that are consistent with the principles of the ADA. This would create a starting point from which individuals with disabilities could more readily access opportunities that contribute to an

improved quality of life,³⁹ including employment, education, financial means, leisure and recreation, personal relationships, and so on—opportunities sorely absent in institutional, segregated environments.

Pursuant to *Olmstead*, the 1999 Supreme Court decision that ruled that undue institutionalization constitutes discrimination under the ADA,⁴⁰ the Federal Government has initiated a number of efforts to enhance the planning and coordination processes surrounding the implementation of home- and community-based services under Medicaid. Additionally, the Federal Government has established a number of financial incentive programs, most notably Money Follows the Person,⁴¹ to assist the states in this regard. The rate at which Medicaid dollars are being transferred from institutional to home- and community-based care is too slow,⁴² however, and funds for home- and community-based services are being reduced as a result of state budget cuts. At a time when Medicaid cost containment and rising demand for services combine to create a looming crisis, the comparative cost implications of nursing home versus community-based care should alone suffice to instigate dramatic policy reform.

Legislation to address the “institutional bias” in Medicaid has been introduced in slightly altered forms for more than 11 years. The first version of the legislation, the Medicaid Community-Based Attendant Services Act, was introduced in the House by former House Speaker Newt Gingrich in 1997. The most recent version of the legislation, now known as the Community Choice Act, has yet to be introduced in the current Congress, although its reintroduction is anticipated by advocates working closely with the legislation's bipartisan congressional champions. The legislation reforms Title XIX of the Social Security Act, which pertains to Medicaid, by allowing individuals who are eligible for Nursing Facility Services or Intermediate Care Facility Services for the Mentally Retarded⁴³ the option of choosing community-based attendant services and supports. The legislation calls for an enhanced state match and grants for the first few years to financially assist states in reforming their long-term services and supports systems before the benefit becomes permanent. The Community Choice Act⁴⁴ brings the principles of self-determination and independent living into the provision of this critical

Medicaid benefit, much like the Money Follows the Person state demonstrations have done, by eliminating the institutional bias and providing Medicaid recipients who need long-term services and supports the option of living in the community while receiving those services. Money Follows the Person has focused on helping people who want to live in the community to leave nursing homes while continuing to receive services and supports. The Community Choice Act would help to prevent people with disabilities from having to enter them in the first place.

RECOMMENDATION 4

Congress should pass, and the President should sign, the Community Choice Act and make the Money Follows the Person program available in all states.⁴⁵ Furthermore, the Secretary of the U.S. Department of Health and Human Services should convene a high-level task force to review all aspects of the Federal and state responses to the *Olmstead* decision and develop recommendations to eliminate the barriers preventing the transition of funding to home- and community-based services.

Mental Health

“I have bipolar disorder and also have worked in the mental health field for 7 years. I endured extreme trauma this past year but had no way to access a hospital short stay.”

“[T]here continue to be significant difficulties for individuals with mental health disabilities who feel overwhelmed in trying to navigate a system of health care, which is built on voice mails and where it is difficult to speak to a person.”

“[With] more opportunities for consumers to be involved in developing and evaluating services being delivered, there needs to be increasing funds allocated in the area of prevention of crisis through recovery-planning programs.” (Public Consultation)

Each year, one in 10 Americans will experience a mental disorder.⁴⁶ As a result of the development of an array of effective treatments, people with mental illnesses can often experience recovery and lead productive, satisfying lives.⁴⁷ Despite effective treatments, there are long delays—sometimes decades—between the onset of symptoms and treatment,⁴⁸ and a host of barriers to treatment resulting from reimbursement restrictions.⁴⁹ This contributes to some people living with disabilities unnecessarily.

The Institute of Medicine (IOM) has issued a call to action. To improve our health care system, the IOM advises that we must pay adequate attention to mental and substance use disorders.⁵⁰ One of the IOM's key recommendations is the integration of mental health care into general medical care. To realize this goal, evidence-based models of integrated mental health and primary care should become the standard practice for primary care in this country. This position is guided by the following principles:

- Any changes to current standards of practice must be based on a belief that our health care system should focus not just on illness but also on wellness and health.
- Incentives within the transformed health care system should be balanced across preventive care, acute care, and chronic care. This balance can be accomplished by realigning financing mechanisms to fund quality and coordination of care.

The institution, not the individual provider, bears responsibility for implementation of evidence-based care. Infrastructure to coordinate, measure, and track improvements should be provided in a standardized fashion to facilitate comparison and sustainability.

RECOMMENDATION 5

An evidence-based approach to integrated care should be the standard of practice in primary care through the following specific actions:

- The President should instruct all Federal agencies to identify and eliminate all barriers to the appropriate payment for interventions that support evidence-based, integrated care provided by teams of appropriate clinicians. For example, current Medicaid auditing procedures in the Centers for Medicare and Medicaid Services (CMS) regional offices that deny payment for a primary care visit and a mental health visit on the same day should be eliminated.
- Congress should instruct CMS to reverse its current efforts to narrow the definition of “case management” activities in connection with evidence-based models of integrated care. Instead, CMS should broaden its definition to specifically recognize the key role that evidence shows case management and care coordination play in the coordinated, team-based delivery of integrated mental health, substance abuse, and primary care.
- The Substance Abuse and Mental Health Services Administration and the Health Resources and Services Administration should require that all of their grantees (both block grant and discretionary programs) demonstrate that they are adopting evidence-based approaches to integrated care throughout their federally funded initiatives. Criteria derived from successful integrated models of care should be embedded in the Federal oversight of these grant programs and should support both ongoing quality improvement and implementation science in their development and application.

Mental Health Services for Veterans and Service Members

“[Veterans] have learned that the disability process can be a hard one. We need help at the highest level to break down the systemic barriers for veterans so they can get through rehabilitation.”

“I am a disabled veteran with a psychiatric disability, including a traumatic brain injury. I encountered numerous barriers that were blockers to my treatment . . . and a lot of veterans go through the same process. Most veterans coming for [mental health] treatment are

trying to get their veterans benefits, . . . trying to stay in treatment, but while they are waiting for benefits, end up homeless and have nowhere to go.” (Public Comments)

NCD has conducted research, including outreach to veterans returning from the current conflicts, about the programs available to assist them as they transition to life with a disability, and whether those programs are meeting their needs. During this research and outreach, NCD learned that there is a particular need to ensure that service members and veterans receive prompt, effective psychological screenings and services.

More than 1.6 million American service members have deployed to Iraq and Afghanistan in Operation Iraqi Freedom and Operation Enduring Freedom. As of December 2008, more than 4,000 troops have been killed and more than 30,000 have returned from a combat zone with visible wounds and a range of permanent disabilities. In addition, an estimated 25-40 percent have less visible wounds—psychological and neurological injuries associated with post-traumatic stress disorder (PTSD) or traumatic brain injury (TBI). Although the Department of Defense (DoD) and Veterans Affairs (VA) have dedicated unprecedented attention and resources to address PTSD and TBI in recent years, and despite evidence that suggests that these policies and strategies have had a positive impact, more work needs to be done.

Repeated deployments of mental health providers to support operations have revealed and exacerbated preexisting staffing inadequacies for providing services to military members and their families at home. The need for new strategies to effectively provide services to members of the Reserve Components requires particular attention. A DoD Mental Health Task Force reports that insufficient attention has been paid to the vital tasks of prevention and early intervention. PTSD and TBI can be quite debilitating, but the effects can be mitigated by early intervention and prompt effective treatment. According to current estimates, between 10 and 30 percent of service members will develop PTSD within a year of leaving combat. Evidence suggests that identifying PTSD and TBI early, and quickly referring people to treatment, can shorten suffering and lessen the severity of functional impairment. Several types of rehabilitative and

cognitive therapies, counseling, and medications have shown promise in treating both injuries. However, some service members continue to face barriers to care, including stigma and limited access to services. Veterans organizations report that long waiting lists, lack of information about where to find treatment, long distances to providers, and limited clinic hours create barriers to getting care. When care is not readily available, the “window of opportunity” may be lost.

RECOMMENDATION 6

The Department of Defense and the Veterans Administration should develop a plan to ensure continuous availability of mental health services for all service members and veterans. The plan must ensure that service members with post-traumatic stress disorder and traumatic brain injury, which may manifest after separation from the military, have continuous access to mental health services both before and after they separate from the military.

Housing

“People [without decent job benefits] cannot afford a \$700 a month rent when Social Security checks are only \$740.”

“The complexity and cost of special needs’ trusts prohibit many families from providing future plans for support; [we] need mechanisms to work with families in legal planning for a lifetime.”

“Waiting lists for affordable accessible housing keep people in nursing facilities or limit their full [community] integration.” (Public Comments)

Housing presents the best evidence for the proposition that disability is a function of the interaction between the individual and the environment. If an individual needs housing that accommodates wheelchair use, then it is the availability or unavailability of that housing, not the use of the wheelchair, which causes the individual's housing-related

disability. If Federal financial assistance programs effectively bar people from saving to buy a home, then it is these programs that are contributing to the affordable housing shortage.

NCD has undertaken a major study (slated for completion in 2009) into the current status of housing for people with disabilities and into the policy issues and historical background underlying housing.⁵¹ The study has three objectives: (1) to evaluate public laws, policies, and programs affecting the housing opportunities available to Americans with disabilities and others who need accessible housing needs as a result of aging or a temporary disability; (2) to analyze what is available in terms of housing, supports, and other benefits provided through the public and nonprofit or private sectors; and (3) to provide recommendations that can improve housing opportunities available in the U.S. to people with disabilities. The economics of housing are undergoing rapid change. At the same time, renewed concerns over energy, pollution, and urban sprawl are coming to play a larger role in the design and siting of housing. Each of these issues will have profound implications for people with disabilities, both as members of the general public and as people with specific accessibility and affordability concerns.

America enters this new era already facing a number of serious housing problems for its citizens with disabilities. These problems include: the disproportionate use of Medicaid's long-term care services to support institutionalization instead of supporting home and community services; the implementation of the Section 811 program to build or rehabilitate disability-specific, largely segregated housing; the reduction of support for housing vouchers under the Section 8 program that support integrated housing in the community; and the failure to require that housing built or financed through at least three major tax subsidies be accessible and available on a nondiscriminatory basis.⁵²

Even before the recent crisis, housing affordability was a problem for many, including many people with disabilities.⁵³ When these homes are rehabilitated so that they can be reoccupied by new or former owners or by rental tenants, the revitalization effort should keep affordability, accessibility, and visitability in mind. The scope and urgency of the

effort is an argument for, not against, the vigorous application and enforcement of housing discrimination and accessibility laws.

The implications of a rehabilitated housing stock go far beyond housing. If integrated planning and effective coordination between the housing and health care systems could be achieved, this could create affordable, quality housing for people presently confined to nursing homes, which could in turn result in long-term savings in public expenditure that outweigh any added costs associated with the commitment to accessibility. Developing effective means of integrating the planning, siting, and financing of housing and transportation could contribute significantly to the nation's energy goals, including to the national security goal of reducing dependency on imported oil.

Deliberations about ways to maximize homeownership should include considerations of the economic situations facing Americans with disabilities, along with those of other lower-income citizens. We must integrate accessibility concerns not just for a small percentage of units, but for all housing. We must also promote measures for incentivizing the creation and preservation of livable communities (e.g., communities with accessible mass transit, opportunities for colocation of needed services and facilities, nearby grocery shopping and other local stores, and other key infrastructure). For a more complete discussion of lessons learned from NCD's study of a livable communities framework, see Appendix 3.

For people with disabilities, an inclusive homeownership policy means a number of specific things. It means that disincentives to savings and earnings that have impeded homeownership in the past must be eliminated. This can be achieved in a number of ways, including expanding the range of people eligible to save for homeownership through individual development accounts (IDAs) or similar mechanisms.⁵⁴ (See Appendix 4 for a discussion of how several states have addressed this problem). An inclusive homeownership policy also means realigning the tax incentives for homeownership so that:

- the benefits of mortgage interest deductibility do not flow only to those who have already amassed enough money to buy a house;

- the availability of the Low-Income Housing Tax Credit is tied to accessible design; and
- the use of tax exempt bonds to finance housing and related community development is predicated on designs that contribute to the creation of livable communities.⁵⁵

Traditional reliance was on the private sector for the building and operation of the bulk of housing. However, through financing and regulation, government will have an expanded role for the foreseeable future. Public funds should not be used to build, rehabilitate, or finance any inaccessible housing, nor should the credit system being backed by Federal agencies be permitted to buy or insure loans that do not make accountable commitments to nondiscrimination. Furthermore, the considerable leverage of the tax system should be used in the interests of affordability.⁵⁶

RECOMMENDATION 7

Congress should enact legislation requiring lending institutions to mandate compliance with the accessibility provisions of the Fair Housing Act and the ADA, including its accessibility guidelines, in all real estate and commercial loans, including loans for construction of multifamily housing. Such legislation should require the U.S. Department of Housing and Urban Development to produce an annual report of the quantity and quality of affordable housing (including Low-Income Housing Tax Credit properties) accessible to persons with disabilities, including occupancy rates by persons with disabilities.

Employment

“Until employers want and have monetary incentives to hire people with disabilities, the government programs will not be successful.”

“Government should help pay for workplace accommodations.”

“Many people fear loss of basic health and nutrition benefits, if they become employed: I no longer receive raises (including cost of living) at work [because] that will put me over the poverty level and I will lose my insurance and food stamps.”

“Where there is no support . . . for a young adult with a disability to learn new skills [on the job training], how is he to engage in meaningful work after the school years are over?” (Public Comments)

Employment Barriers. The employment rate of people with disabilities is an important measure of the nation’s progress in meeting the goals of full opportunity and inclusion embodied in key disability legislation and policy. The employment rate of working-age people with disabilities in 2005 was 38 percent, compared to the employment rate of working-age people without disabilities, which was 78 percent (see Appendix 2). In October 2007, NCD published “Empowerment for Americans with Disabilities: Breaking Barriers to Careers and Full Employment,”⁵⁷ which includes significant summaries of data and experiences, detailed analyses of underlying issues, and comprehensive recommendations for actions by employers and government. (See Appendix 5 for a discussion of private initiatives that are improving employment opportunities for people with disabilities).

At the time of NCD’s employment study, looming labor shortages stemming from baby-boomer retirement were cited as a powerful argument for utilizing all the skill and potential the American workforce could offer, including the untapped resource of people with disabilities. Today, however, with the ranks of the unemployed growing by hundreds of thousands per month, some may say that unemployment among people with disabilities cannot be a major issue in an environment in which jobs are becoming scarcer for everyone. Such expressions reinforce many of the very stereotypes that explain why, even in periods of rapid economic growth, people with disabilities have not shared in the fruits of the economy. People with disabilities have endured, in good times as well as bad, unemployment rates that would be considered a national crisis if experienced by other groups.

National surveys of private employers find that about 20 percent say the greatest barrier to people with disabilities finding employment is discrimination, prejudice, or employer reluctance to hire them, and that attitudes and stereotypes are a barrier to employment of people with disabilities in their own firms.⁵⁸ (These figures are probably understated because of the “social desirability” bias in surveys that leads respondents to avoid acknowledging prejudicial attitudes.) In addition, a recent review of more than a dozen empirical studies of wage differentials concluded that “a substantial part of the wage differential” can be attributed to disability-related discrimination.⁵⁹

As documented in NCD's 2007 report “Implementation of the Americans with Disabilities Act: Challenges, Best Practices, and New Opportunities for Success”,⁶⁰ negative media stories about the ADA that perpetuate misperceptions about people with disabilities pervade print, television, the Internet, and other media. Clearly, such entrenched attitudes will undermine any attempts to increase employment opportunities for people with disabilities. A large-scale public awareness campaign is needed to begin to erase such uninformed beliefs and outdated stereotypes.

RECOMMENDATION 8

Congress should fund a series of antistigma demonstration projects targeted to:

- the general public, designed to address the lack of knowledge about challenges to employment for persons with disabilities;
- employers and persons with disabilities, aimed at achieving a better match of job seekers to employers; and
- transition-age youth, designed to encourage them to consider careers in the areas of science, technology, engineering, and mathematics, and to expose such youth to the careers and opportunities these and other high-growth, high-income disciplines entail.

Efforts to stimulate job growth should ensure that people with disabilities are an integral part of the available labor force of this country, and should be accompanied by mechanisms to ensure that nondiscrimination and equal opportunity rights are observed, that reasonable accommodations are provided according to law, and that recruitment, training, and outreach efforts include people with disabilities and the organizations serving and representing them.

Federal Employment. In no area of employment is the role of the Federal Government more central than that of its own personnel practices. Advocates and observers were shocked to learn from a January 2008 Equal Employment Opportunity Commission (EEOC) report that the percentage of workers with disabilities in the Federal workforce had declined steadily since 1994 and is at its lowest level in more than 20 years.⁶¹ EEOC issued 10 recommendations to improve the situation. However, for long-term improvement to occur, a full understanding of the causes for the decline is necessary. NCD is currently studying this issue and plans to release a paper on the employment of people with disabilities in the Federal Government this year.

RECOMMENDATION 9

The President should issue an Executive Order requiring all Federal agencies to educate hiring managers and human resource personnel about the benefits of hiring people with disabilities, and to also educate them about the recently revised Schedule A civil service hiring authority, which makes it easier for Federal agencies to hire individuals with significant disabilities. The Executive Order should urge all Federal agencies to hire and advance more individuals with disabilities across the Federal workforce, including in the Senior Executive Service, with the goal of reaching the Equal Employment Opportunity Commission's aim of ensuring that 2 percent of the Federal workforce include employees with disabilities by the year 2010.

Additionally, to better monitor the progress of these efforts, NCD recommends that Congress require the Office of Personnel Management to include statistics about

employees with disabilities in its annual report to Congress on the Federal Equal Opportunity Recruitment Program.

Work Disincentives. In recent years, interest among antipoverty scholars and advocates has begun to focus on asset reform. Numerous proposals have been introduced in Congress to ease the asset limitations applicable to senior citizens seeking Medicaid help for long-term care costs.⁶² The work disincentives that confront people with disabilities are far more complex and difficult to understand, and they involve a larger number of intertwined agencies and service systems than one can encounter in any other means-testing or needs-based program setting. Even in a robust job market, the effects of these disincentives are so powerful that they not only significantly offset the natural opportunities created in a good economy, but also diminish the value of Federal expenditures in a variety of employment-oriented programs.

Through a series of measures, including work incentive provisions in the Social Security Act,⁶³ in the Ticket to Work Act,⁶⁴ and through the creation of benefits counseling resources,⁶⁵ Congress has attempted to deal with the work disincentives problem. What has resulted is an impenetrable web of confusion and complexity that has led to the widespread belief among Supplemental Security Income (SSI) and Social Security Disability Income (SSDI) recipients with disabilities that employment or savings will cause the cessation of their benefits. The loss of health insurance is an even greater fear of beneficiaries, particularly under circumstances in which no private sector alternative is available.

Understanding the interlocking Social Security Administration (SSA), Centers for Medicare and Medicaid Services (CMS), and state Medicaid waiver and buy-in program regulations and policies is beyond the ability of even the savviest consumers. Even with the help of experts, it can be impossible to find answers to questions such as: which types of property are “countable” or not, how long certain revenues like earned income tax credit payments can be held before they become “countable resources,” which types of student income are treated differently than other wages for SSI earnings limit

purposes, which months count and for how long they count toward the application of the “trial work period” rules, what happens in months when earnings fluctuate because people are paid weekly or biweekly, which payroll deductions are “excludable” from income and which are not, how many separate accounts must be maintained to track permissible, sheltered savings goals, which types of retirement accounts are permitted under which programs and which are not, and so forth.⁶⁶ If the answers exist at all, understanding them often requires knowledge of the regulations and rulings of myriad Federal and state agencies.

Strategies to reduce these disincentives have included: creating new types of specialized, sheltered accounts; raising applicable limits and thresholds; and attempting to make benefit reductions gradual. These strategies have only resulted in further complexity. Only through the elimination of disincentives can people who want to work do so without jeopardizing needed supports. In the final analysis, what people with disabilities want and need are services and supports that enable them to work—not benefits and services at the expense of work.

RECOMMENDATION 10

The Centers for Medicare and Medicaid Services and the Social Security Administration should work together closely to: (1) modify existing program regulations to uncouple Medicare and Medicaid coverage from Supplemental Security Insurance/Social Security Disability Insurance cash payments; (2) identify and eliminate the many employment disincentives currently built into the Medicaid waiver, Medicaid buy-in, and Health Insurance Premium Payment programs; (3) expand benefits counseling services to include the full range of financial education and advisement services, and to clarify that helping people to retain benefits while working is not in any way antagonistic to the goals of facilitating employment; and (4) work collaboratively with public and private insurance providers and business representatives to design public-private insurance partnerships that will expand access to health care from sources other than Medicaid or Medicare for individuals with disabilities.

Reauthorization of the Workforce Investment Act. The forthcoming reauthorization of the Workforce Investment Act⁶⁷ offers another opportunity to further the process of eliminating work disincentives and replacing them with work incentives, as well as the opportunity to modernize the Vocational Rehabilitation (VR) system in other ways. More than 80 percent of the state One-Stop Career Center plans include people with disabilities or representatives of public and private agencies, such as VR programs, that serve people with disabilities in the state plan development process. Many Disability Program Navigators and SSA Community Work Incentive Coordinators agree that policy barriers exist for people with disabilities within the eligibility criteria for employment training programs offered through the One-Stop Career Centers. People with disabilities have often reported encountering access barriers to One-Stop Career Center facilities and services.

RECOMMENDATION 11

Congress should proceed with reauthorization of the Workforce Investment Act, maintaining the Rehabilitation Act as a separate section with a separate funding stream. This reauthorization should: (a) include dedicated funding for the infrastructure of the One-Stop Career Centers; (b) continue expansion of the Disability Navigator and Customized Employment demonstration projects; (c) require the development of performance standards that measure the number of persons with disabilities who are served in the One-Stop system and their ability to access and benefit from One-Stop services, which would include access to assistive technology and rehabilitation engineering services; and (d) require in the Rehabilitation Act (section IV) that Vocational Rehabilitation services be made available to eligible youth no later than three years before an adolescent or young adult exits from secondary education.

Transportation

“Transportation is a major stumbling block to jobs, housing, doctor’s visits, etc. . . the bus [for people with disabilities] ends 3 miles from me

but I would have to pay \$40 each way to get it [and] this is impossible on a limited income.”

“[N]ow 20 years old, I had transportation to doctors and physical therapy, but Medicaid won’t pay except from nursing homes rather than actual homes; aging parents drive me 4-5 days a week, but they are starting to experience their own health needs.”

“[U]rban and rural area transportation systems unavailable and inaccessible for people with disabilities [add to] all other problems/challenges.” (Public Comments)

New Freedom Initiatives. People with disabilities report that a lack of transportation restricts their ability to fully participate in all aspects of community life.⁶⁸ The lack of transportation for people with disabilities, particularly in rural areas, has a great human cost—sometimes even resulting in unnecessary institutionalization. While great strides have been made in the accessibility of public transportation in this country since the passage of the ADA, significant gaps remain for many sectors of the disability community. The ADA requires only that, where public transportation is provided, it must be accessible for people with disabilities. The underfunding of public transportation in general has directly limited the mobility of large sections of the disability community who are unable to use a car or access the pedestrian environment. The transportation problem will not be fully addressed without a fundamental shift in funding priorities to greatly improve public transportation, including the pedestrian environment, as a whole.

In 2006, Congress authorized funding for New Freedom formula grant programs designed to reduce barriers to transportation services and expand the transportation mobility options available to people with disabilities beyond the requirements of the ADA.⁶⁹ The New Freedom program is intended to fill the gaps between human service and public transportation services previously available and to facilitate the integration of individuals with disabilities into the workforce and their full participation in the community. Congress has authorized a total of \$339 million for these projects.⁷⁰ To

date, grants totaling \$110,463,597 have been awarded.⁷¹ No evaluation of the programs accessing funding from the New Freedom transportation initiative has yet been completed.

RECOMMENDATION 12

The Department of Transportation should: evaluate the effectiveness of the new pilot transportation initiatives for people with disabilities; develop permanent funding mechanisms to expand effective approaches across the country; and propose to Congress ongoing funding mechanisms to increase transportation options for the growing population of people who do not drive because of disabilities.

Pedestrian Safety. For many people with disabilities, the pedestrian environment serves as their connection to public transportation or as their primary means of mobility. The emergence of hybrid and electric cars, so-called “quiet cars,” threatens the safety of people who are blind, because their mode of safe travel includes listening to motor vehicles for cues about vehicle distance, direction, and speed. Not being able to hear vehicles when crossing streets, passing driveways, or navigating parking lots would make it extremely difficult for people who are blind to travel safely and independently.

Congressmen Towns (D-NY) and Congressman Stearns (R-FL) recently introduced The Pedestrian Safety Enhancement Act of 2009 (H.R. 734),⁷² which mirrors legislation introduced in the 110th Congress. The Pedestrian Safety Enhancement Act would require the Department of Transportation to research and ultimately set forth a minimum sound standard that must be met by hybrid and electric vehicles so that blind and other pedestrians may travel safely and independently in urban, rural, and residential environments.

RECOMMENDATION 13

Congress should pass legislation requiring vehicles, including hybrid vehicles, to meet a minimum sound standard so that pedestrians who are blind and who rely on listening for

safe travel can maintain mobility and independence. The legislation should direct the Secretary of Transportation to, within one year of passage, promulgate standards for the minimum sound level required to enable blind pedestrians to determine the speed, distance, and direction of travel of motor vehicles.

Education

“[Congress needs to] ensure that the College Loan Reduction and Access Act and other programs serve students with disabilities among the total student population . . . [and] address problems in trying to find full employment for people with significant disabilities.”

“[C]ommunity colleges, created to give everyone a shot at college, lack the supports and services crucial to the success of students with special needs, who often drop out.”

“[H]aving access to high cost equipment once I leave college is a concern.” (Public Comments)

Youth Transition. When Congress reauthorizes the No Child Left Behind Act (NCLBA), issues surrounding the relationship of that law to the Individuals with Disabilities Education Improvement Act (IDEIA) will receive heightened attention. The resources and procedures involved in special education and related services, and the relationship between general and special education must be addressed.

Many have strong opinions regarding the resources devoted to, and the requirements imposed by, special education, including fear over the presence of students with disabilities in mainstream classrooms and resentment about the alleged diversion of funds resulting from Federal mandates. At a time of shrinking resources, as declining local property tax revenues cause deep cuts in public school spending, it is probable that such expressions of resentment will only increase. Great strides have been made in bringing students with disabilities into mainstream education, and in narrowing the gaps

in education achievement between students with and without disabilities. Vigilance is required to ensure that resources devoted to schools in the forthcoming national infrastructure projects are allocated in ways that benefit all students and prevent the regression of the progress made to date.

In education, the need for data is especially great, but evaluation of the success of efforts to equalize education opportunities and outcomes for students with disabilities have been complicated by a lack of clarity and cross-referencing in the data elements and definitions required under NCLBA and IDEIA. The reauthorization of NCLBA provides an opportunity to begin aligning the data elements and definitions in the two governing statutes required for them to work effectively together. This effort at definition and alignment should prove valuable in focusing attention on our nation's expectations for students with disabilities and for the education system as a whole.

In view of the funding crisis gripping state and local governments, the level of Federal financial participation in federally mandated special education programs takes on heightened importance. If the nation is to make a renewed commitment to the future through education, it must not overlook the need to include all students.

A recent NCD study⁷³ was commissioned to assist policymakers and stakeholders in assessing the impact of NCLBA and IDEIA on schools, including on student outcomes. The evaluation produced mixed findings. Overall state math and English test scores for elementary students with disabilities showed improved academic achievement, but there was little improvement in test scores of high school students with disabilities. Yet, an important result of NCLBA and IDEIA appears to be that students with disabilities are no longer ignored. Study participants also cautioned that an increase in test scores was not necessarily attributed to NCLBA or IDEIA alone. Several problems still need to be addressed, including: overlapping reporting requirements, the need for increased collaboration at the Federal level regarding data collection, and the negative consequences that may result from inflexible policies (e.g., policies that restrict who is considered a high school graduate to only those students who received diplomas in a standard number of years.)

For young people exiting high school, only with effective transition services, planning, and supports can the efforts of either the education or the adult service systems be realized fully. Gaps in, or sudden cessation of, transition services are detrimental to transition-age youth with disabilities. Yet there is a lack of accountability for outcomes when the delivery of services falls between the cracks. NCD's 2008 report, "The Rehabilitation Act: Outcomes for Transition Age Youth,"⁷⁴ found that VR is serving only a small percentage of youth who could potentially benefit from transition services, and that relatively little is known about the extent and effectiveness of VR transition services.

RECOMMENDATION 14

Congress should mandate that the Department of Education's Office of Special Education and Rehabilitative Services, the National Institute on Disability and Rehabilitation Research, and state education and state Vocational Rehabilitation agencies conduct rigorous school-to-work transition evaluation studies. The studies should identify the transition program components that directly correlate with improved employment and postsecondary education outcomes for transition-age youth.

Education Standards and Information Access. Accessible technology has taken on new importance in the education arena. With the growth of technology have come dramatic changes in how and where education takes place. With distance learning on the increase, issues of accessibility are becoming more critical. According to the American Foundation for the Blind (AFB), schools, colleges, and universities are increasingly using online education tools that students must access to obtain course syllabi, retrieve lectures and associated material, participate in class discussions, read course material, and receive grades and feedback from instructors.⁷⁵ Findings from AFB's recent distance learning survey indicated that the most important and necessary features of online education tools presented significant problems for those using assistive technology such as screen reading or screen magnification software.⁷⁶ AFB concluded that access issues in distance learning are a matter of accessible design and provided a variety of recommendations to ensure accessible distance learning experiences for students and instructors using assistive technology.

Another area of concern is textbook accessibility. Because publishers have been reluctant to make textbooks available in electronic formats, and the textbooks must, therefore, be recorded on tape, it is not unusual for students who are blind or visually impaired to receive their textbooks long after their sighted peers. Recent efforts to ensure the accessibility of primary and secondary school textbooks have met with success as a result of new provisions in IDEIA that require publishers to make their textbooks available in standardized electronic formats. To facilitate comparable accessibility at the college level and in vocational training settings, Congress included provisions in the 2008 reauthorization of the Higher Education Opportunity Act⁷⁷ to establish an Advisory Commission on Accessible Instructional Materials in Postsecondary Education for Students with Disabilities. NCD is named as a member of this Commission in the statute. However, no funds were appropriated for this Commission, and it has not been formed.

RECOMMENDATION 15

Congress should:

- Expediently reauthorize and fully fund the No Child Left Behind Act (NCLBA) to maintain academic accountability requirements and high expectations for students with disabilities, provide supports and incentives for teachers to offer differential instruction of rigorous content, begin to align the data elements and definitions of NCLBA and the Individuals with Disabilities Education Improvement Act (IDEIA), and expand the age for provision of transition services; and
- Fund the Advisory Commission on Accessible Instructional Materials in Postsecondary Education for Students with Disabilities, as established in the Higher Education Opportunity Act of 2008, which authorizes grants to increase accessibility of college textbooks and Web site and distance learning information.

Technology

“Many of the adaptive technologies are unaffordable to those who need them.”

“[There is] difficulty in finding public videophones to make phone calls. TTYs are 30 years old. . . . In this age of computers, there are still many gaps in accessibility to certain websites . . . 95% of news, entertainment videos on the Internet are not captioned, please do not shut the deaf out.”

“Producing emergency preparedness information for the print disabled population is considered to be a best practice for training. . . . I believe that the publishing industry has a responsibility to truly ‘publish’ their information and not merely ‘print’ their materials. Today, to publish must mean to publish digitally in a format that all people can use effectively. . . . Communication and technical assistance need to be highly funded.” (Public Comments)

Access to the Internet. Use of the Internet is an inherent part of life today. For people with disabilities, however, access is not guaranteed. Because the ADA was passed before the Internet became pervasive, and the Department of Justice (DOJ) regulations do not address Internet access specifically, many Web sites still are not designed to be accessible by people with certain disabilities. As a result, people with disabilities have had to struggle to gain access to public and commercial Web sites. Some people have even had to resort to litigation.

Implementation of the Section 508 Web Accessibility standards in the Federal sector, as well as the global impact of the World Wide Web Consortium’s Web accessibility standards, demonstrate that the means for making Web sites accessible are well-established, and a Federal requirement for full accessibility of public Web sites is long overdue.

Assistive Technology. Assistive technology (AT) is technology that enables people with disabilities to maintain or improve their ability to function. AT includes the tools, resources, and technology to help increase independence, improve personal productivity, and enhance the quality of life for people with disabilities. Frequently, for people with functional limitations, the availability of AT makes it possible to participate in education, employment, recreation, government services, and commerce, particularly on the Internet.

The range of hardware and software comprising the AT sector is growing rapidly, creating new and exciting functional capabilities almost daily. However, data are lacking on whether these opportunities are fully understood and utilized by the service providers in the VR and special education systems. Data indicate that many people with disabilities who could benefit from AT are not aware of its existence or cannot afford it. Given the growing centrality of technology in every aspect of life, it is vital to gain better knowledge about how effectively the service systems are using their authority to provide appropriate AT devices and AT services, particularly in the important realm of education and vocational rehabilitation, where access to AT can determine success or failure for a person with a disability.

Digital Technology. The advent of digital media offers the potential for enhanced access, as well as challenges, to Americans with disabilities. Digital television, for example, offers opportunities and challenges regarding captioning. Unlike analog closed captions, digital caption capability provides tremendous flexibility and a new level of user control over caption display, including font style, text size and color, and backgrounds. However, set design, remote control design, and transmission within cable systems are all critical factors that can determine whether captioning can be used at all.

Similar issues exist regarding video description. The system for transmission must be implemented, and viewers must learn to access it. Viewer education and broadcaster instruction and implementation are both necessary for digital television to be available to people with disabilities.

Digital radio also offers opportunities and challenges for Americans with disabilities. For people who are deaf or hard of hearing, digital radio offers perhaps the first opportunity to receive radio information in an accessible manner via captioning. Additionally, persons who are blind or visually impaired may find new ways to enjoy radio reading services that are delivered at the listener's time preference rather than at the station's broadcast times. As with digital television, however, product design, consumer education, and broadcaster development and implementation are critical aspects of achieving the increased access available via this new medium.

RECOMMENDATION 16

The Assistant Secretary of Education for Special Education and Rehabilitative Services should conduct an extensive dialog with all state and territorial Vocational Rehabilitation agencies and state education agencies to determine in detail how and when they provide assistive technology, how they assess the implications of current and evolving technology for client or student assessment and goal-setting, and how they ensure that key personnel keep abreast of developments in assistive technology. Depending on the results of this assessment, the Assistant Secretary should determine whether the existing regulations implementing the statutory authorities for the use of AT adequately reflect its importance, and if not, should propose appropriate amendments when Congress considers reauthorizing the Vocational Rehabilitation Act, the Assistive Technology Act, and the Individuals with Disabilities Education Act.

Congress should pass legislation that requires access to telephone and television-type equipment and services available through the Internet; decoder circuitry in all video programming devices; captioning of Internet-based television; audio description of television; and access to emergency broadcasts. The U.S. Access Board should adopt updated electronic and information technology and telephone guidelines to ensure increased accessibility of this technology to people with disabilities. The Federal Communications Commission should adopt regulations for ensuring that high-definition television will be fully accessible to persons with visual and hearing disabilities.

Coordination

“There must be one entry system for adult state and federally funded supports. People who need the most help to be contributing members (i.e., have a job) have to contend with a myriad of confusing duplicate applications for each agency which is costly and incredibly inefficient.”

“I am currently looking at possible eviction as I don’t have enough money to pay all my rent let alone other bills. I am now in appeal for disability after being turned down twice and am told the process will take 19 months (which puts me into Fall of 2009).”

“Resources have not been made available that would enable disability related programs to be truly culturally competent both in their outreach and in their provision of services.”

“[Even] with a wonderful government program for people with disabilities, the process, the red tape involved is extremely time consuming and often too complex.” (Public Consultation)

The landscape of American government has grown rich with disability policies and programs over the past 50 years. However, as government policies and programs have emerged, sometimes in piecemeal fashion, to respond to specific needs as they arise, the result has been a complex, impenetrable web of government programs that often conflict with one another (see examples in Appendix 6). NCD and the Government Accountability Office (GAO) have repeatedly called for better interagency coordination of disability programs. Although a challenge, improved coordination across government programs offers the potential for significant improvements in outcomes for people with disabilities, as well as for substantial cost savings.

In 1992, Congress attempted to improve the coordination of Federal Government programs and services for individuals with disabilities; however, coordination remains

elusive. Congress authorized the Interagency Disability Coordinating Council (IDCC) to coordinate Federal activities to promote independence and productivity of individuals with disabilities.⁷⁸ However, IDCC has never met or reported to Congress, as required by law, and no other interagency body exists to perform this function. Although the IDCC was given the statutory authority to coordinate Federal activities and policies, no leadership authority was established, membership roles were not clearly defined, and outcomes were not prescribed. Consequently, no mechanism exists to ensure that multiple Federal agencies serving individuals with disabilities are communicating, coordinating, or working to resolve conflicts.

RECOMMENDATION 17

The President should establish, through Executive Order, an Interagency Disability Coordinating Council (Interagency Council), with a designated executive agency chair and required participation of all Federal agencies serving people with disabilities. The Interagency Council should be charged with submitting an annual report identifying instances of policy conflict or Federal disability-related program inconsistencies that interfere with the achievement of the overarching goals of the ADA, including equality of opportunity, full participation, independent living, and economic self-sufficiency. The Council should be charged with developing recommendations for the elimination of the conflict or inconsistency in all cases in which it substantially affects the lives of citizens with disabilities.

CHAPTER 3: Full Citizenship—Emerging Issues and the Role of Federal Government

This section addresses the role Federal Government programs and services should play to improve the quality of life for people with disabilities. The first subsection describes the economic climate at the time of the writing of this report, discusses the impact of the current economic climate on people with disabilities, and describes a few recent examples of public-private partnerships that are meeting immediate needs of people with disabilities. The second subsection addresses a more long-term role for Federal Government to play in improving the quality of life for people with disabilities. It offers a set of principles that can help to design a twenty-first-century government-wide disability policy.

The Current Economic Crisis

The role of the Federal Government in protecting the quality of life of people with disabilities is never more crucial than during economic hard times such as the present. Recent and ongoing fiscal problems have forced at least 40 states to propose or enact reduced services to families and individuals with disabilities.⁷⁹ At least 22 states plus the District of Columbia are cutting, or proposing cuts to, medical, rehabilitative, home care, or other services needed by people who have disabilities, including those who have low incomes.⁸⁰ For example, Arizona eliminated temporary health insurance for people with disabilities coping with serious medical problems. In Minnesota, policymakers capped enrollment at current levels for a program that provides expanded health services and care coordination for people with disabilities. Tennessee has reduced community-based services for people with intellectual disabilities and cut nursing services for some adults with serious disabilities. Illinois has reduced funding for child welfare, mental health, and youth services.

Proposed budget cuts at postsecondary institutions will also affect people with disabilities. At least 32 states have implemented or proposed cuts to public colleges and

universities. Florida has announced that it will eliminate 430 faculty and staff positions and decrease funding for disability services.

People with disabilities are most vulnerable during economic downturns. Medicaid, home- and community-based services, mental health services, and services for people with developmental disabilities are often the first programs to be cut by states in fiscal crisis. Social services caseloads swell just as personnel and services are reduced. The Federal Government has a critical role to play to prevent the current economic crisis from eliminating many of the gains that people with disabilities have achieved over the past 20 years. Many of the recommendations offered in this report, were they implemented, could mitigate some of the effects of the economic downturn and state budget cuts.

In the meantime, however, immediate, stop-gap measures may be necessary to protect people with disabilities who are at risk of dire consequences, and the Federal Government may need to explore more partnership opportunities. One possibility for new partnerships exists in the community and volunteer sectors. Because the present economic circumstances have left many individuals in shaky circumstances and many communities without funds for the upkeep or expansion of important programs and services, needs are mounting and, increasingly, customary labor and funding streams are drying up. Volunteerism and community involvement are more important now than ever in filling existing gaps. President Obama's Council for Faith-Based and Neighborhood Partnerships (Council) is one venue for organizing community response to specific concerns of people with disabilities. The Council is tasked with directing Federal social service dollars to faith-based charities and increasing charities' involvement in antipoverty initiatives.⁸¹

In addition to the potential for increased faith-based interest in disability concerns, grassroots-directed service projects hold extraordinary potential to increase awareness of and interest in the issues that affect people with disabilities. On January 19, 2009, a National Day of Service, members of communities organized more than 13,000 service

projects in all 50 states.⁸² Among these numbers were service projects organized by Independent Living Centers across the nation.

The Freedom Resource Center for Independent Living in Fargo, North Dakota, issued a call for volunteers to shovel snow to clear walkways for increased wheelchair access in the city, which was under heavy snow.⁸³ More than 50 individuals showed up to dig out problem areas. The Independent Living Center of Southern California in Van Nuys, California, organized an emergency food drive for its homeless clients.⁸⁴

Volunteer Florida has received several awards for its innovative 6 Days 6 Ramps project, which actively recruits volunteers with disabilities to help build wheelchair ramps for people in need.⁸⁵ 6 Days 6 Ramps started in 2000 as a joint project between Volunteer Florida and AmeriCorps Florida State Parks as a single-event, single-site community service project. Since that time, it has grown into a six-day, multi-site community-strengthening event involving more than 1,000 volunteers—many with disabilities.

In 2008, 6 Days 6 Ramps engaged 409 volunteers to build 42 ramps in seven cities. These are exciting and laudable outcomes, and ones that, if replicated and sustained, could address both the acute and chronic service needs of people with disabilities across the country, as well as provide opportunities for volunteers with disabilities to give back to their communities. Such initiatives could spur strides in improving society's attitudes toward people with disabilities in their communities.

Future Policy Directions

Through our research and our enhanced efforts to gather input from stakeholders across the country, NCD has learned many lessons that can assist in modernizing programs and services to reflect the changed and changing needs of people with disabilities in our communities. While a program-by-program evaluation is beyond the scope of this report, NCD offers the following principles to guide the review of existing government programs, as well as to serve as a road map for the design of new

government programs. We believe that adherence to these principles can result in a responsible and responsive use of government resources that will benefit people with disabilities as well as the nation as a whole.

- 1. Ensure that Federal Government programs and services for people with disabilities are consistent with the overarching goals of the ADA—promoting equality of opportunity, full participation, independent living, and economic self-sufficiency.**

Federal programs and services should be reviewed to identify and eliminate eligibility criteria, benefit limits, or rules or practices that conflict with these goals. Having a disability and being eligible for supports and services should not require giving up a job, limiting one's earnings or savings, leaving one's home, having to choose between health care and housing, forgoing having a family, or giving up one's independence. Too often, programs providing the basic necessities of life require people with disabilities to live in poverty and forgo basic freedoms. Requiring states to provide care in nursing homes, while making home- and community-based care optional, is inconsistent with the goals of the ADA, costs more overall, and forces people with disabilities to live in institutions when they would rather live at home.

- 2. Project the cost-benefits of government programs or policies for people with disabilities based on long-term, human costs and benefits.**

Decisions about disability policies and programs are often made based on costs to one program rather than by analyzing the decisions' effects on the quality of individuals' lives or the decisions' overall cost to society. This approach may merely shift costs from one program to another. This approach may also result in a lapse in vital services for people with disabilities, leading to a greater long-term cost to society. For example, having a two-year waiting period for Medicare benefits for people who must retire early because of disability⁸⁶ may create a savings for Medicare, but leaving people without health coverage, just when they

need it most, financially devastates people with disabilities and their families. This forces otherwise self-sufficient people to resort to public safety nets.

3. Build program bridges.

This report cites many examples of gaps between government programs where there should be bridges. Whether a person with a disability is transitioning from high school to college, from school to work, from work to SSDI, from SSDI to work, from DoD to the VA, or from a nursing home to the community, a fall between the cracks can mean a permanent fall for someone with a disability. Lengthy application processes, eligibility determinations, and waiting periods are often cited as the reason someone with a disability is without income, health coverage, personal assistant services, or access to housing or transportation. Surely, the human cost and the cost to society when someone with a disability falls through one of these cracks is significantly greater than the cost of the bridges that could facilitate a seamless transition. Programs for people with disabilities should include bridges from one service to another when someone is entering the system, so that needed services from one program do not end before another program begins. Government agencies should be required to work together to create seamless transitions into and out of their programs, for example, by establishing presumptive eligibility, transferring application records, and eliminating arbitrary waiting periods.

4. Design for inclusion.

If universal design principles had been used whenever tax dollars financed the building of facilities, housing, public rights-of-way, and other investments in public infrastructure, what an accessible America it would be. Universal design principles ensure that construction is inclusive, accessible, and usable by everyone, including people with disabilities. This report cites many reports from people with disabilities about how environmental barriers restrict their full participation in all aspects of community life.

Regrettably, much of our existing taxpayer-funded infrastructure will remain inaccessible for generations to come. However, we should immediately begin incorporating universal design principles in all future government-funded projects. As we begin implementing an economic stimulus package and make an unprecedented investment in public infrastructure, we have the opportunity to ensure that all new construction is designed for inclusion and that tax dollars are not used to perpetuate environmental barriers for people with disabilities.

Universal design principles are equally important for technology access. Access to mainstream technologies has improved substantially for people with disabilities in recent years. This is attributable, in part, to Federal laws requiring disability access, e.g. Section 508 of the Rehabilitation Act and Section 255 of the Telecommunications Act. To ensure continued access for people with disabilities, these laws must be continually updated and enforced. In addition, all Internet technologies, consumer electronics, and telecommunication devices must be developed using universal design principles to ensure equal access. Accessible technology is increasingly important to ensure that people with disabilities have access to employment, health care, education, commerce, and social communications.

5. Commit the full force of the Federal Government to enforcing and upholding the civil rights of people with disabilities.

The civil rights of people with disabilities are in their infancy and require special attention by the Federal agencies charged with their enforcement. Implementation of the ADA, for example, is far from complete.⁸⁷ ADA implementation is impeded by negative attitudes and stereotypes, a lack of access to appropriate durable medical equipment and assistive technology, and government practices and funding priorities that continue to neglect, and even segregate, people with disabilities.

Nineteen years after the passage of the ADA, regulations for public rights-of-way have not been issued—contributing to significant barriers to full participation of people with disabilities in all aspects of community life. Certain sectors of the business community remain largely out of ADA compliance, and while extremely effective, enforcement by the U.S. Department of Justice is neither mandatory nor common.⁸⁸

Private enforcement of the ADA by individuals is not financially or practically feasible, as the provisions requiring access to public places and commercial facilities do not permit monetary damage claims,⁸⁹ and a Supreme Court ruling now makes it difficult to obtain attorneys' fees in civil rights cases.⁹⁰ Thus, Federal enforcement of civil rights for people with disabilities is of paramount importance.

Tragically, according to the U.S. Commission on Civil Rights, budget cutbacks for Federal enforcement of all civil rights laws have resulted in fewer compliance reviews, abbreviated investigations, less policy development, and less defense of civil rights laws in court.⁹¹ It concluded that “[u]ntil the President and Congress remedy this situation, millions of individuals will be deprived of adequate means to seek justice and equal opportunity.”

6. Promote a culture of integration of people with disabilities into all Federal programs, policies, practices, and research.

This report contains many examples of barriers to Federal programs that have the consequence of subjecting persons with disabilities to dependency, segregation, exclusion, and paternalistic treatment. Some barriers are caused by the Federal programs themselves. Barriers are attitudinal (such as fear, ignorance, prejudice, and stereotypes), physical (such as architecture, transportation, and communication), and institutional (such as policies, practices, and procedures). Sometimes these barriers are intentional and are the result of deep-seated prejudice. More often, however, they are the result of

thoughtlessness, indifference, a lack of understanding, or the result of a history of separate programs. For people with disabilities, however, the effect is the same—exclusion, isolation, and unequal treatment. Whether it is data collection that does not count people with disabilities, eligibility criteria that have the effect of screening out people with disabilities from program participation, diversity initiatives that fail to recognize people with disabilities, or Federal funding for facilities that are not physically or programmatically accessible, it is clear that the Federal Government has yet to integrate people with disabilities into its generic, mainstream programs, policies, practices, and research. Disability is a normal part of the human condition, and the Federal Government would be enhanced by a broader conceptualization of disability that calls for inclusion, integration, and equality throughout the government.

CHAPTER 4: Conclusion

In studying the quality of life of people with disabilities and the emerging trends concerning them, the positive and negative impacts of government programs on the lives of people with disabilities were evident at every turn. Consistency and coordination across government programs is lacking and some programs actually conflict with one another. This report presents some approaches that appear to be successful in improving the quality of life for people with disabilities, identifies the remaining gaps, and discusses the emerging trends that warrant the focus of government agencies and policymakers. Many successful programs have resulted from building working partnerships with state and local governments, as well as with the private and volunteer sectors.

Issues of central importance to people with disabilities included attitudes, employment, emergency preparedness and homeland security, health care, housing, transportation, social security, education, technology, and foreign policy. NCD included recommendations on each of these topics of importance to people with disabilities. These recommendations are designed to ensure that the quality of life for people with disabilities continues to improve, and to eliminate potential barriers, both physical and attitudinal, that detract from their quality of life. Also included are a set of principles to guide the evaluation of existing government programs, as well as to facilitate the development of a more coherent, comprehensive approach to disability policy within the Federal Government that will enhance the employability, independence, and full inclusion of all people with disabilities.

Appendices

APPENDIX 1: **Mission of the National Council on Disability**

Overview and Purpose

The National Council on Disability (NCD) is an independent Federal agency with 15 members appointed by the President of the United States and confirmed by the U.S. Senate. The purpose of NCD is to promote policies, programs, practices, and procedures that guarantee equal opportunity for all individuals with disabilities, regardless of the nature or significance of the disability, and to empower individuals with disabilities to achieve economic self-sufficiency, independent living, and inclusion and integration into all aspects of society.

Specific Duties

The current statutory mandate of NCD includes the following:

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

disabilities, access to health care, and policies that act as disincentives for individuals to seek and retain employment;

- Making recommendations to the President, Congress, the Secretary of Education, the Director of the National Institute on Disability and Rehabilitation Research, and other officials of Federal agencies about ways to better promote equal opportunity, economic self-sufficiency, independent living, and inclusion and integration into all aspects of society for Americans with disabilities;
- Providing Congress, on a continuing basis, with advice, recommendations, legislative proposals, and any additional information that NCD or Congress deems appropriate;
- Gathering information about the implementation, effectiveness, and impact of the Americans with Disabilities Act of 1990 (ADA) (42 U.S.C. § 12101 et seq.);
- Advising the President, Congress, the Commissioner of the Rehabilitation Services Administration, the Assistant Secretary for Special Education and Rehabilitative Services within the Department of Education, and the Director of the National Institute on Disability and Rehabilitation Research on the development of the programs to be carried out under the Rehabilitation Act of 1973, as amended;
- Providing advice to the Commissioner of the Rehabilitation Services Administration with respect to the policies and conduct of the Administration;
- Making recommendations to the Director of the National Institute on Disability and Rehabilitation Research on ways to improve research, service, administration, and the collection, dissemination, and implementation of research findings affecting people with disabilities;
- Providing advice regarding priorities for the activities of the Interagency Disability Coordinating Council and reviewing the recommendations of this council for legislative and administrative changes to ensure that such recommendations are consistent with NCD's purpose of promoting the full integration, independence, and productivity of individuals with disabilities; and

- Preparing and submitting to the President and Congress an annual report titled “National Disability Policy: A Progress Report.”

Statutory History

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

APPENDIX 2: Statistical Social Indicators

TABLE A2.1

Statistical Social Indicators

Indicator Measures	People with a Disability	People with No Disability
Employment		
Employment rate	38%	78%
Employment rate by educational attainment		
• less than high school graduate	25%	66%
• high school graduate	36%	76%
• some college or Associate degree	44%	80%
• Bachelor's degree or higher	55%	83%
Median annual labor earnings for full-time/full-year workers	\$30,000	\$36,000
Median annual labor earnings for full-time/full-year workers by educational attainment		
• less than high school graduate	\$22,000	\$22,000
• high school graduate	\$27,000	\$30,000
• some college or Associate degree	\$32,000	\$35,000
• Bachelor's degree or higher	\$47,000	\$54,000
Education		
% of working-age people with less than a high school diploma	25%	12%
% of working-age people with at least a college degree	13%	30%

Continued next page

Table A2.1 Statistical Social Indicators (cont'd)

Indicator Measures	People with a Disability	People with No Disability
Health Status and Health Care		
Obesity among working-age people	38%	23%
% of working-age people who smoke tobacco daily	23%	16%
Health insurance status of working-age people		
• Private	46%	74%
• Medicare or Medicaid	33%	4%
• Other	5%	3%
• Uninsured	17%	19%
Failure to get needed care because of cost, by poverty status		
• Below poverty	29%	14%
• Above poverty	17%	5%
% of working-age patients who report that doctors or other health providers always show respect for what the patient has to say	57%	63%
Financial Status and Security		
Median income of working-age people	\$35,000	\$61,500
Poverty rate among working-age people	25%	9%
Leisure and Recreation		
% of working-age people who participate in leisure time physical activity	44%	65%

Continued next page

Table A2.1 Statistical Social Indicators (cont'd)

Indicator Measures	People with a Disability	People with No Disability
Personal Relationships		
% of working-age people who report that they always or usually get the social and emotional support always available	66%	77%
Marital status of working-age adults		
• Married	49%	61%
• Separated/divorced/ widowed	28%	15%
• Never married	23%	24%
Crime and Safety		
Violent crimes per 1,000 people	Data not published as of report printing	Data not published as of report printing
Property crimes per 1,000 people	Data not published as of report printing	Data not published as of report printing

Source: National Council on Disability, "Keeping Track: National Disability Status and Program Performance Indicators" (Washington, DC: NCD, April 2008), Exhibit 5.2.92

Data apply to the working-age population of people with disabilities (21-65 years old).

APPENDIX 3: **Livable Community Discussion and Examples**

Communities are vital in shaping people's opportunities and capabilities. 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 people with disabilities and the growing population of seniors. People are living longer lives today than ever before and the population of people age 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 age 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 seniors grows, the number of people age 65 and older with disabilities will also grow, particularly those 75 years of age and older.

One of the most practical public sector strategies to ensure that all communities are in the best possible position to support people throughout their lives is to empower local people and communities to develop tailored and locally owned solutions to the problems they face. Over the past several years, NCD has engaged in a series of investigations into how communities are becoming more accessible, affordable, and available for people with disabilities.

In 2004, NCD issued a comprehensive report, "Livable Communities for Adults with Disabilities,"⁹³ which contained a number of specific recommendations to promote the full integration of people with disabilities. In the follow-up report in 2006 entitled "Creating Livable Communities,"⁹⁴ NCD identified six elements that are integral to improving the quality of life for all citizens with disabilities of all ages:

- Providing affordable, appropriate, accessible housing;
- Ensuring accessible, affordable, reliable, safe transportation;
- Adjusting the physical environment for inclusiveness and accessibility;
- Providing work, volunteer, and education opportunities;

- Ensuring access to key health and support services; and
- Encouraging participation in civic, cultural, social, and recreational activities.

In March 2008, NCD expanded the livable communities framework to include people with psychiatric disabilities. The paper describes a number of existing programs that can serve as models of successful integration of recovery into practice, delivering services that enable people diagnosed with serious mental illnesses to live integrated lives in the community.

Some examples of livable communities from NCD reports and papers follow.

From “Livable Communities for Adults with Disabilities” (2004)⁹⁵

The Wisconsin Partnership Program is a comprehensive program of services for older adults and people with physical disabilities that integrates health and long-term support services, including home- and community-based services, physician services, and all other health care services. The Department of Health and Family Services contracts with community-based organizations to implement the Partnership Program. These organizations, in turn, subcontract with hospitals, clinics, home health agencies, residential providers, nontraditional service providers, pharmacies, and other providers to ensure a comprehensive network of acute and long-term care. The Wisconsin Partnership Program combines the benefits of the Medicaid/Medicare systems into one program through an 1115/222 dual waiver, which helps avoid fragmentation and duplication of services. It provides high-quality, flexible, consumer-centered, comprehensive, and continuous care across settings and providers. It uses a model of service delivery based on collaborative, interdisciplinary teams that work with enrollees to develop care plans that coordinate all service delivery.

From “Creating Livable Communities” (2006)⁹⁶

The Aging and Disability Resource Center (ADRC) grant program was established to pilot new approaches to interagency coordination that improve access and the

availability of information to meet the needs of target populations. States must target ADRC services to the elderly population and at least one additional population (i.e., individuals with physical disabilities, serious mental illnesses, or intellectual/developmental disabilities) with the goal of overcoming barriers to community living for people with disabilities of all ages. The ADRC program is the collaborative effort of the U.S. Department of Health and Human Services Administration on Aging and the Centers for Medicare and Medicaid Services. Ready access to consolidated information and referral services helps make communities more livable for residents of all ages and abilities. ADRC programs provide information and assistance to both public and private pay individuals and serve as the entry point to publicly administered long-term supports, including those funded under Medicaid, the Older Americans Act, and state revenue programs.

From “Inclusive Livable Communities for People with Psychiatric Disabilities” (2008)⁹⁷

Oregon is an example of a state that has made personal assistant services (PAS) widely available to people with psychiatric disabilities. Currently, more than 600 mental health consumers are being served in the PAS program, which is funded by Medicaid. Many of the personal care attendants are themselves people diagnosed with a mental illness, who are further along in their own recovery than the people they are assisting. In an interview, Michael Moore, adult services coordinator for the Oregon Department of Human Services, describes how working as a personal care attendant assists his recovery:

“When people go to work, the symptoms of their mental illness[es] actually go down quite a bit, and that makes sense to me, intuitive sense. If you’re sitting at home not doing much, you’re probably gonna dwell a little bit on yourself. It’s probably not too great on the brain.”

An Oregon public radio story describing the program interviewed a woman whose severe agoraphobia had kept her housebound until she acquired a personal care attendant. The attendant, herself a person in the process of recovery, receives a salary of \$9 an hour to provide 20 hours a month of PAS, such as assisting with shopping and housekeeping. Moore developed the program based on similar programs that serve people with general medical disabilities, and he believes that it both saves the state money and assists people toward independence. Moore plans to increase the size of the program to serve a thousand recipients by 2008.

In addition to providing practices and models of livable communities in action, these NCD reports and papers propose necessary changes in public policy. The intention of such change is twofold: (1) to ensure that communities are designed to be affordable, available, and accessible; and (2) to support people with disabilities so that they will have access to all the opportunities and choices that are available to people without disabilities.

Government has a central role in supporting people to develop the skills and capabilities needed to succeed in the modern world. Children and youth need support during their early years so that they can develop the skills and abilities that lead to their ability to secure good jobs. Young people need support as they develop and make the transition from school to work, through further education and training to higher education. Adults need support to acquire or continue developing their skills in a changing labor market. Families and communities need support in a complex and often challenging world to ensure that necessary resources reach the people who need them. Government at all levels must support these efforts by ensuring that: (1) public services and supports are excellent, personalized, and responsive to users; (2) the tax and benefits system is fair, creating the right financial incentives, and supporting people when they need it; and (3) by ensuring a goodness-of-fit between the public infrastructure and individual and family expectations and needs. There is much to do to enable people with disabilities to fulfill their potential. But with the right policies, this country can improve educational attainment levels, raise the overall rate of labor participation, increase incomes and the

number of good jobs, and enhance individuals' health and wellness. At the same time, these policies can assist the nation's effort toward building more livable communities and creating a fair society for all.

APPENDIX 4: The Role of Government in the Pervasive Poverty of People with Disabilities

Historically, families with members who have a disability are often at a disadvantage. According to a 2005 U.S. Census Bureau research brief, Census 2000 counted a total of 72.3 million families, and found that nearly 28.9 percent of them (about two in every seven families) reported having at least one member with a disability. Families with members with a disability were less likely than other families to have earnings and more likely to receive income from Social Security and public assistance. Family householders with disabilities were less likely to be employed and less likely to be in the labor force than other family householders.⁹⁸ The Federal poverty level used in the United States is an absolute income measure. As such, the Federal poverty level does not account for actual consumption, elevated health care needs, or receipt of noncash benefits. It must be noted, then, that families with members with disabilities who are in poverty typically experience greater hardship than do other families.

As disability policy stands today, a child with significant disabilities born in the United States has little chance of gaining access to assets and escaping poverty, despite advances in health care and technology. In part, this is due to the continued all-or-nothing dichotomy of public policy that views disability as the inability to work and that provides needed public assistance only if one remains poor and completely dependent on government help.

How can the United States affect this vexing policy problem? What strategies are most effective in tackling the vexing quality-of-life problems families face in their communities? In 2008, NCD issued “The State of 21st Century Financial Incentives for Americans with Disabilities.”⁹⁹ The report describes financial incentives affecting people with disabilities and presents research findings in key areas of people’s lives. The report highlights Federal and state programs that offer direct, indirect, or community financial incentives and support that can help to address some of the challenges.

In the past 10 years, states have become important originators of social policy reforms that respond to challenges related to affordable housing, welfare and work, access to health care, and transportation. The six states with innovations affecting asset development and wealth accumulation are: Kentucky, Louisiana, Maryland, Missouri, Washington, and Wisconsin. Table A4.1 presents each state's program area and focus.

TABLE A4.1
**States with Innovations Affecting
Asset Development and Wealth Accumulation**

State	Program Area and Focus
Kentucky	<ul style="list-style-type: none"> • Housing • Universal Design Program
Louisiana	<ul style="list-style-type: none"> • Education • Student Tuition Assistance and Revenue Trust (START) Savings Program
Maryland	<ul style="list-style-type: none"> • Transportation • Statewide Special Transportation Assistance Program (SSTAP)
Missouri	<ul style="list-style-type: none"> • Long-Term Services and Supports • Assistive Technology Program
Washington	<ul style="list-style-type: none"> • Asset Development • Individual Development Accounts
Wisconsin	<ul style="list-style-type: none"> • Employment • Medicaid Buy-In Program (also called Medicaid Purchase Plan)

APPENDIX 5: **Private Initiatives**

All sectors—business, labor, community agencies, and persons with disabilities and their advocates—have a role to play in improving the employment situation of persons with disabilities. NCD explored these roles in its 2007 report “Empowerment for Americans with Disabilities: Breaking Barriers to Careers and Full Employment.”¹⁰⁰ The practices below demonstrate the important role the private sector can play in improving employment and education opportunities for people with disabilities, and demonstrate the value of public-private partnerships in achieving the government's goals for citizens with disabilities. These practices also highlight the role frontline service providers and community organizations play in working with persons with disabilities, employers, and government agencies to identify opportunities and facilitate workplace accommodation.

Corporate Culture

At SunTrust Bank, “Initially, disability etiquette training [at SunTrust] was developed and provided to recruiters and staffing managers in order to prevent many misunderstandings that could occur when the management employees are not aware of the laws and situations associated with hiring people with disabilities. One large phone campaign required approximately 600 temporary employees, and several people with disabilities were hired, due to the proactive stance of the hiring manager for the project. When that project proved successful, other managers in the bank wanted to know her ‘secret,’ and she was identified as an internal champion for the hiring of people with disabilities. This bottom-up approach to promoting the hiring and retention of people with disabilities has proven effective in reducing resistance to change throughout the company.”

Nike’s Disabled Employees and Friends Network (DEN) has a “mission to add value and enrich Nike and the community in which it operates for more inclusion and full utilization of employees with disabilities. . . . DEN is truly unique in as much as this vibrant group involvement is solely based on the interest of employees and the awareness activities, such as the campus-wide wheelchair race for individuals without disabilities, and is on the cutting edge in terms of disability awareness programs. It also

provides a supportive employee base for larger outreach and innovation activities in the local community on the part of corporate management.”

Recruitment and Retention

The Giant Eagle grocery chain sponsors disability awareness training for its human resource managers every two years, which is held offsite at a YMCA camp with participation from several public and private disability agencies. During the training, “[h]alf of the day is spent learning about the ADA and interviewing skills, while the remaining half of the day the human resource managers spent actually experiencing disabilities. Stations are manned by job coaches who simulate for the human resource managers what it is like for someone with a disability. For example, a wheelchair exercise allows the human resource managers to perform everyday activities, such as using a drinking fountain, maneuvering through doors and up and down ramps, and reaching for something on a shelf.”

At Hewlett Packard, “front line supervisors, sometimes challenged with worker shortages, have been trained to expand their applicant pool, often going to a university they know and interacting with faculty to identify persons with disabilities who also have the necessary technical skills needed for a particular position. [In addition,] HP makes a point of working with employment agencies that are noted for their training of people with disabilities.”

IBM’s Entry Point program is a collaboration with the American Association for the Advancement of Science (AAAS) and NASA. Its mission is to place students with disabilities in business and government and prepare them for corporate and community leadership. Since 1997, IBM has had 191 student placements in summer internships and hired 44 students into regular employment.

Reasonable Accommodations

“In addition to a centralized accommodation budget, Microsoft has an ADA Accommodations committee. This committee meets monthly and is given the responsibility of coordinating accommodations throughout the company, discussing the potential impact of new technologies, and evaluating current accommodation programs. Moreover Microsoft has an Assistive Technologies Team that makes approximately twenty evaluations a month, and an Ergonomics Team that makes approximately 180 one-on-one evaluations a month, spending six to eight hours with each employee evaluated.”

Marriott teaches its managers to be accommodating to all employees. “Thus the issue of perceived fairness of various accommodations seems to be lessened when managers are trained to be accommodating across the board—no employee can predict when a temporary illness or a need to care for a family member will arise and mean they need flexibility or accommodation from their employer as well.”

Education

Pitney Bowes has “made a commitment to mentor high school students with disabilities. They have provided internships to the students with disabilities from Goodwill’s High School/High Tech program.”

IBM’s Entry Point program, as noted in the “Recruitment and Retention” section above, places students with disabilities into summer internships that often lead to regular employment. In addition to the internships, the program has STEM (Science, Technology, Engineering, Math) Entry Point Camps focused on providing training for boys and girls with disabilities in middle and high school.

APPENDIX 6: Intergovernmental Review and Examples

Emergency Response

One of the more recent examples of intergovernmental policies and programs that significantly affects the lives of people with disabilities is the government's response during emergencies and disasters. Since September 2005, when people with disabilities in the Gulf Coast areas of Alabama, Mississippi, and Louisiana experienced tremendous loss of life and devastation caused by Hurricane Katrina, the Federal Government has monitored government progress in emergency preparation. This monitoring has involved frequent congressional oversight of ongoing intergovernmental problems involving unhealthy and inaccessible housing, unavailable and inaccessible transportation, and insufficient public and private sector collaboration.¹⁰¹ Given that there are more natural disasters now than in the past, and that these disasters are more severe, improvements to emergency preparation and management is a national imperative.

Intergovernmental Programs Serving Low-Income People

In 2005, the Government Accountability Office (GAO) identified a number of Federal programs wholly devoted to serving mostly low-income individuals with disabilities and conservatively calculated the cost, when combined with costs of Medicare and Medicaid, at more than \$240 billion.¹⁰² The GAO surveyed 20 different Federal agencies that administer more than 200 disability programs (many of which are defined as financial incentives) and found that 59 percent of the programs provided indirect support to people with disabilities through state grants, while the balance provided direct support to 34 million beneficiaries or clients.

Overlapping, Intergovernmental Programs

Another GAO report in 2007 indicated that multiple agencies run programs that provide similar types of assistance, and these programs often serve different populations of persons with disabilities because of varying eligibility criteria.¹⁰³ Participants at a 2007

GAO forum noted that many Federal departments achieve good outcomes, yet they also acknowledged fragmentation, duplication, and a need for greater coordination.

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¹⁰ Commenters represent people living with disabilities, families, other advocates, and service providers.

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