

# National Disability Policy: A Progress Report

December 2002–December 2003



National Council on Disability

December 9, 2004

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

**National Disability Policy: A Progress Report  
December 2002–December 2003**

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

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## NATIONAL COUNCIL ON DISABILITY

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*An independent federal agency working with the President and Congress to increase the inclusion, independence, and empowerment of all Americans with disabilities.*

December 9, 2004

The President  
The White House  
Washington, D.C. 20500

Dear Mr. President:

On behalf of the National Council on Disability (NCD), it is my duty and honor to submit NCD's *National Disability Policy: A Progress Report*, as required by Section 401(b)(1) of the Rehabilitation Act of 1973, as amended.

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

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

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

NCD encourages all government agencies and Congress to use our work as a reference point and source of data for recommendations and in future investigations of disability policy issues. NCD offers its readiness to work with the Administration, Congress, federal agency partners, and members of the public in ways that have a bearing on the lives of people with disabilities.

Sincerely,

A handwritten signature in cursive script that reads "Lex Frieden".

Lex Frieden  
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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## **Executive Summary**

This National Council on Disability (NCD) annual progress report to the President and Congress is prepared pursuant to NCD's statutory responsibility to make a full report of its activities, findings, and recommendations in key areas to the leaders of our nation. The report covers subjects on which NCD must report according to the law. It also addresses several additional subjects that NCD believes to be of importance to Americans with disabilities and to the nation.

This report's 13 chapters address disability statistics and research, civil rights, education, health care, long-term services and supports, youth, employment and the workforce development system, welfare reform, housing, transportation, assistive technology and telecommunications, international affairs, and homeland security. Each chapter recounts developments of importance from the previous year, describes the key issues likely to emerge or open for discussion in 2004, and addresses long-term trends and interconnections between subject areas that NCD believes must inform our analysis. Each chapter also contains detailed recommendations, addressed to specific agencies or decision makers. The chapters call for actions that NCD has concluded would contribute to improvement of the opportunities available in society for people with disabilities. For easy reference, these recommendations are numbered and grouped by targeted institutions—Congress, the Administration, implementing entities, and courts—at the end of each chapter. The final section of the report is a compilation of the recommendations into three sub-sections directed to Congress, the Administration, and specific federal agencies and courts.

NCD's 2003 *Progress Report* contains the following salient findings and recommendations.

### **Chapter One: Disability Statistics and Research**

*Findings*—Based on an examination of the methods and uses of disability research over recent years, problems with research techniques and inconsistencies among data sources have made reliable assessment of many issues difficult, including even such fundamental questions as the precise number of Americans with disabilities. Because of the difficulties associated with



obtaining adequate data, and because even good data does not necessarily point the way clearly toward the most effective solution, there may be a need to reassess the kinds of research being conducted and the purposes for which that research is done.

*Recommendations*—Congress should authorize research to supplement the accumulating baseline data and to conduct forward-looking experiments designed to create new statistics by observing and measuring the impacts of various innovations on people’s lives. Prospective designs that observe and measure the results—instead of relying on retrospective methods of trying to determine impact—would prove far more useful in creating meaningful statistics and clarifying policy options. Disability-related questions need to be retained and improved in the 2010 census. The Census Bureau should seek whatever authority is needed to make improvements.

## **Chapter Two: Civil Rights**

*Findings*—A succession of Supreme Court decisions narrowly interpreting the Americans with Disabilities Act (ADA) and ruling against individuals with disabilities have combined with other factors to create great unease among Americans with disabilities regarding the robustness of our nation’s commitment. Among other concerns are the failure of the federal courts to take voluntary actions, such as making more of their electronic documents accessible; the need for improved accountability in civil rights enforcement; growing concerns about genetic discrimination; and questions about accessibility issues linked to voting technology.

*Recommendations*—Pilot experimental implementation programs are suggested to the federal courts to provide them with the kind of experience that would lead to more informed and balanced adjudication of disability rights claims in the future. With the increasingly complex issues of our time, intergovernmental efforts are required to ensure that consistent and effective application of Section 504 is carried out to achieve greater civil rights. This recommendation coincides with the recommendations of NCD’s recent major report on Section 504 of the Rehabilitation Act (*Rehabilitating Section 504*). On accountability, NCD recommends that methods be developed for establishing the relative value of various approaches (e.g., agency

reporting of numerical data reflecting settlements, cases processed, technical assistance, or other dimensions of civil rights implementation), alone or in combination with civil rights enforcement. NCD also calls for the prompt enactment of pending legislation that would prohibit the use of genetic information to deny people employment, housing, insurance, or other basic opportunities. Finally, NCD advises that vote verification is important, but this must not be achieved at the cost of hard-won accessibility rights. Congress should ensure full implementation of the Help America Vote Act.

### **Chapter Three: Education**

*Findings*—Behind the debate over such hot-button issues as school discipline, full funding, and high-stakes testing, important decisions are due to be made by Congress that will affect the lives and futures of many school-age Americans with disabilities via reauthorization of major components of the Individuals with Disabilities Education Act (IDEA). Despite strides made in reconciling the operation and tenets of IDEA and the No Child Left Behind Act (NCLB), much work remains to be done in applying the philosophies of the two Acts seamlessly and in a manner that will be wholly respectful of each. Issues of paying for and obtaining appropriate supports, services, and accommodations for postsecondary or other continuing education still confront students with disabilities and institutions of higher education working with these students. Despite government efforts to address transition through more effective cooperation between educational, rehabilitation, and other adult service systems, smooth transition from secondary school to postschool pursuits for people with disabilities has remained elusive in all too many cases.

*Recommendations*—Because adequate data does not yet exist to justify curtailment of parental due-process rights in special education, Congress should undertake definitive research to provide empirical evidence on the impact of appeals and attorneys on special education before it further restricts family rights. Congress should also ensure that when disciplinary considerations require the removal of students with disabilities from the mainstream, integrated classroom, such students are ensured the right to uninterrupted educational and related services consistent with

their Individualized Education Program (IEP) and with evolving assessments and needs in the most appropriate educational settings. In this way, no child will be left behind. Building on approaches the Administration has taken to help resolve other persistent problems and to contribute to the ability of families to advance their children's education, NCD suggests new tax-based strategies that may help to improve the availability of transition resources.

## **Chapter Four: Health Care**

*Findings*—Changes in Medicaid (e.g., budgetary and structural), along with what is known as the institutional bias of the Medicaid program, have major implications for people with disabilities. Aspects of the recent Medicare reform legislation also have a distinct bearing on the lives of people with disabilities and need to be addressed. A related matter—medical device review—presents issues important to assistive technology (AT) users. The need for parity in insurance coverage for mental and physical health services continues. The report of the President's New Freedom Commission on Mental Health confirmed many of NCD's earlier reports of major shortcomings and coordination and systemic problems in current arrangements for the provision of mental health treatment and services, and made important, far-reaching recommendations for reform.

*Recommendations*—Congress should begin the process of facilitating expanded use of Medicaid buy-in programs, in light of their potential to reduce the number of uninsured Americans, by adopting the Family Opportunity Act and by enacting the Money Follows the Person legislation. Federal agency leadership in improving medical device review will need to give attention to low-incidence AT device users, coordination of device regulations, and review between the Food and Drug Administration and the Centers for Medicare and Medicaid Services. Congress needs to establish a national commission to study the question of how consumer participation and direction can be maximized throughout the federal health insurance programs, with a view to adding the findings and recommendations of this study to future Medicaid reform proposals. In view of the accumulating weight of findings and data that point to parity needs, NCD urges Congress to implement the major recommendations of the President's New Freedom

Commission on Mental Health and NCD reports. The Administration should publish detailed, point-by-point reactions to the findings and recommendations.

## **Chapter Five: Long-Term Services and Supports**

*Findings*—The nation could face a crisis as life expectancy increases, unless our nation finds some way to reallocate the growing costs of long-term care and provide the same attention to long-term services as health care or income support has received. NCD fully shares the vision of the President’s New Freedom Initiative (NFI) in support of home and community-based services (as alternatives to institutional settings) as a means to achieving greater equality and full participation in society for people with disabilities. NCD commends the Administration for sponsoring important research into a number of key related issues. However, in view of the variety of legal and economic forces operating to slow *Olmstead* implementation, strong and concerted measures are required at the national level to overcome barriers to community integration. NCD recognizes the role of private insurance in any comprehensive effort to reform our systems of long-term care. Accountability and cost-effectiveness continue a major theme throughout this report and require the development of means for assessing the efficacy of various public expenditure patterns.

*Recommendations*—The Department of Health and Human Services Centers for Medicare and Medicaid Services should require timely planning for and documented achievement of *Olmstead* goals as a condition for states to receive federal funds under the Medicaid program. NCD also recommends measures and research designed to tap the potential of the private sector in this area, with significant partnership and involvement of the nation’s insurance industry. Congress should hold hearings to fully explore the potential role of the insurance industry, the tax code, the employer community, and existing programs in fashioning experimental models of coverage that can be tested and studied.

## **Chapter Six: Youth**

*Findings*—NCD’s 2003 juvenile justice report paralleled the findings of major reports by the Government Accountability Office and the President’s New Freedom Commission on Mental Health. Children and young adults with disabilities continue to be overrepresented among incarcerated juveniles. There is a continuing need for knowledge about what constitutes effective programs that may prevent entry into the juvenile justice system, ways to address and provide clear governmental support for ongoing youth leadership programs, and efforts to increase the direct input of youth with disabilities in decision making.

*Recommendations*—The Administration should appoint a high-level national commission to make recommendations about juvenile justice systems and disability interconnections. A federal official should be designated with authority to speak for the Administration. The findings must be formally reviewed, adopted, rejected, or otherwise responded to by the appointed federal official as part of follow-up work on the commission’s advice. The Administration should instruct each federal agency that implements programs and services for youth with disabilities or their families to develop ways of obtaining and considering opinions, experiences, and recommendations of this constituency in future program planning.

## **Chapter Seven: Employment and the Workforce Development System**

*Findings*—Among the key findings are the need for antidiscrimination provisions in legislation, the development of program outcome measures as they relate to individuals with disabilities, and increased attention to the implications of the aging of the workforce for people with disabilities. The latter observation also portends a substantial increase in the proportion of people with disabilities in the workforce, given the strong correlation between disability and aging. The new role of the vocational rehabilitation (VR) system operating through One-Stop Centers raises questions that VR needs to address. Finally, the availability and feasibility of resources to support employment of people with disabilities will require addressing issues linked to various loan programs, employment tax incentives, and the Ticket to Work and Work Incentives Improvement Act (TWWIIA).

*Recommendations*—A critical proposal focuses on ensuring that evolving principles of accountability can be applied to enhance the ability of the workforce development system, in its mainstream and specialized components, to respond most effectively to the employment needs and aspirations of Americans with disabilities. The Department of Labor (DOL) needs vigorously monitor and enforce the law, as one key means for ensuring full participation in the workforce and employment development system by all job seekers. DOL should also develop outcome measures that take due account of all the relevant variables involved in working with job seekers with disabilities—including not only the potential costs of working with this population within a mainstream setting, but also the benefits to the taxpayers of commitment and success in such work. The Administration should establish a blue-ribbon task force for expedited study and recommendations to Congress on ways to strengthen the capacity of the economy to retain and benefit from the services and experience of older workers with adult-onset disabilities. Recommendations are also made for clarifying the objectives of loan programs, enhancing the reach of the Work Opportunity Tax Credit (currently awaiting reauthorization), and responding to key research findings on the adequacy of TWWIIA incentives and procedures to meet the needs of people with disabilities.

## **Chapter Eight: Welfare Reform**

*Findings*—Rigid application of recipient time and benefits limits and work requirements—central to the current Temporary Assistance for Needy Families (TANF) legislation and which seem likely to be retained in some form in the reauthorization—may not serve the goals of promoting independence and self-sufficiency. People with disabilities may have unique training and/or supports (including AT) needs in order to reach their goals of joining the workforce. Individual Development Accounts (IDAs) are a source of increased funds for goods and services needed for success in employment, but currently applicability to TANF recipients with disabilities is limited in ways that are easily correctable.

*Recommendations*—As Congress considers reauthorization of TANF, flexible interpretation and application of the law that provides for structured relationships between the welfare and

disability services sectors, including VR, are recommended to ensure that the goal of people with disabilities joining the workforce is served. Congress should broaden the definition of qualifying savings goals for TANF IDAs to include assistive or universally designed technology and modified vehicles or other specialized transportation services needed in order to work. Before sanctioning or curtailing benefits based on time and duration limits, states should ensure that any individual with a significant disability, a hidden disability, or whose service needs as primary caregivers for family members with disabilities have been offered a full medical-vocational assessment through the state's Office of Disability Determination and its VR agency.

## **Chapter Nine: Housing**

*Findings*—Problems are inherent in the lack of coordination among programs and agencies. Improvement is needed in evaluating the effectiveness of existing housing programs that have unique implications for people with disabilities or that were designed to specifically impact the lives of people with disabilities. Civil rights enforcement continues to play a key role in bringing about an increase in the supply of accessible and affordable housing. The marketplace needs incentives to build accessible housing and modify existing units to make them accessible.

*Recommendations*—Agencies need to ask basic questions in order to evaluate the effectiveness of housing programs. The Departments of Justice (DOJ) and Housing and Urban Development (HUD) should systematically address each of the housing accessibility and discrimination issues and jointly publish guidelines delineating the management of cases from HUD (or Fair Housing Assistance Program) complaint to DOJ or judicial disposition. Procedures and standards could be applied to ensure that antidiscrimination provisions are meaningfully implemented and that they contribute to the achievement of their objectives. The Administration should appoint a high-level national commission—composed of economists, housing and transportation experts, tax practitioners, legal analysts, architects, land-use planners, and individuals with disabilities—to map a long-term strategy for steadily increasing the proportion of the nation's housing stock that meets standards of accessibility. Pending the full demonstration and realization of the broad-based benefits of greater housing accessibility, interim recommended measures include stronger

federal encouragement of the visitability concept and the modernization of standards for what constitutes accessibility.

## **Chapter Ten: Transportation**

*Findings*—Without attention to transportation, important goals in employment, education, access to medical care, and even the ability to live in the community may all be put at risk. The Transportation Security Administration (TSA) can build on its successes in incorporating the rights of people with disabilities into the nation’s airport security screening system. The expected reauthorization of the Transportation Equity Act for the 21<sup>st</sup> Century raises issues such as authority for NFI transportation programs and other specialized transit demonstrations and programs of particular interest to people with disabilities. New challenges confront paratransit programs, such as the practice of determining trip eligibility on a trip-by-trip basis, as well as new needs created by changing residential and employment patterns.

*Recommendations*—TSA should build on its successes with disability rights by clarifying for consumers the distribution of authority for civil rights enforcement, and incorporating accessibility considerations into the design of new airport technologies. Coordination of transportation planning with state-based efforts to implement the *Olmstead* Supreme Court decision is also recommended. How the practice of determining trip eligibility on a trip-by-trip basis affects the users of the service should be investigated.

## **Chapter Eleven: Technology and Telecommunications**

*Findings*—The Assistive Technology Act is in danger of sunseting if not reauthorized. Key areas of Federal Communications Commission (FCC) jurisdiction have important bearing on the technological infrastructure regarding equal opportunities for people with disabilities. The DOJ is recognized for undertaking to survey federal agencies regarding various aspects of their implementation of Section 508 of the Rehabilitation Act.



*Recommendations*—Congress should move forward to reauthorize the Assistive Technology Act. The FCC needs to enforce Section 255 of the Federal Communications Act—the law vests the FCC with jurisdiction to enforce requirements for accessibility of telecommunications equipment and services—in the manner intended by Congress or necessary for achievement of the law’s objectives. The FCC should also ensure that schools and libraries receiving subsidized telecommunications services will make those services accessible to persons with disabilities. Further research is needed on agencies’ practices in areas such as how exemptions to Section 508 of the Rehabilitation Act requirements are granted.

## **Chapter Twelve: International Affairs**

*Findings*—U.S. foreign assistance programs can be made responsive to the rights and interests of persons with disabilities within the countries receiving aid. Civil rights protections afforded to Americans under such laws as Section 504 and the ADA can be brought to bear on behalf of Americans serving their nation abroad and even on behalf of the residents of other nations.

*Recommendations*—Successful efforts to incorporate human rights or other ethical concerns into the administration of foreign assistance should be used as examples of how to ensure U.S. foreign assistance programs are responsive to human rights and interest of people with disabilities. Strong Administration support for the treaty of the pending United Nations Convention on the Rights of People with Disabilities, including a commitment to ratification, is recommended.

## **Chapter Thirteen: Homeland Security**

*Findings*—The Department of Homeland Security (DHS) has taken steps to incorporate nondiscrimination into its programs. Models and technical assistance supporting dissemination and application of the models for including people with disabilities in emergency preparedness planning at all levels are vitally necessary. NCD commends efforts to address the issue on the federal interagency level.

*Recommendations*—NCD applauds DHS efforts on inclusion and offers its assistance in the agency’s continued application of nondiscriminatory policies and practices to a variety of situations and contexts. Emergency preparedness models should be extended to the private sector. DHS should study its contractors’ policies and practices and provide them with the technical assistance necessary to ensure that in the development of all technology and procedures, users with disabilities will be included in the testing process and otherwise be taken fully into account. Civil rights protections need to be extended to the variety of private sector entities doing product and systems development on behalf of homeland security.

As stated previously, a compilation of all specific recommendations to Congress, the Administration, federal agencies, courts, and other entities can be found at the end of the report.



# Chapter One

## Disability Statistics and Research

### Introduction

Statistics play a large role in all we do. From the role of population and relative wealth and poverty in determining the allocation of various federal funds among the states, to the use of trend data about various diseases that influences the allocation of medical research funds, statistics are a constant source of data for policy and decision making.

In the area of disability, the need for good baseline statistical data and the complexities encountered in collecting that data are considerable. This chapter reviews some established strategies and assumptions and suggests some new approaches that may help to break new ground in the gathering and effective use of statistical data.

The first section reviews some of the major assumptions that have gone into the collection of disability-related statistics over the years. The next section discusses limitations in our traditional approach. The third section addresses new approaches for defining and obtaining the statistical information we need.

### The Premise of Disability Statistics

No one is likely to dispute the premise that the more we can learn about the number of people with disabilities in this country, about the types of disabilities they have, and about the kinds of lives they live, the better informed decision making will become. Such evidenced-based data can inform public policy; give direction to the allocation of time and resources; and offer baseline data from which trends, improvements, or deterioration can be measured.

On this premise, we have concentrated considerable attention on the long form used by the Census Bureau for the decennial censuses of 1990 and 2000, the Census Bureau's American Community Survey (ACS) program, and research funded under the auspices of the Centers for

Disease Control and Prevention (CDC). Efforts were undertaken in collaboration with the National Institute on Disability and Rehabilitation Research (NIDRR) and other government agencies. Common to these efforts were objectives focused on (a) determining the number of people with disabilities; (b) establishing the levels of income, employment, and education of these citizens; and (c) comparing existence and experience data on people with and without disabilities in a variety of areas.<sup>1</sup>

By and large, this research has taken as its point of departure the notion of disability as a static, although often subjective, fact. When people are asked in self-reporting surveys whether they have a disability or condition that limits one or more major life activities, including a work disability, we assume that, although two people in very similar situations may answer the question differently, or the same person may even answer it differently at different times, the answer given reflects some assessment of factual data by the respondent at that moment.

One may characterize this research as one dimensional as it relates to employment, education, health care, or other intervention programs. That is to say, it seeks to develop direct correlations and draw conclusions based on the premise that the existence of a disability gives rise to certain consequences and predicts the need for and the utility of certain services and programs.

Because reliable and comprehensive data has proved difficult to collect, researchers and decision makers have found themselves without effective means to fully evaluate and validate the intervention strategies and program models we have used. While continuing to refine data collection techniques in traditional demographic areas, perhaps it is time to pursue new avenues of research as well. Further discussion in this regard is presented in the sub-section below on new directions in research.

### **Limitations in the Approach**

In its annual progress reports over the past several years, NCD has discussed in detail the limitations confronting the collection and use of current disability statistics and research data.<sup>2</sup>

We do not propose to repeat those findings here. Suffice it to say, a number of factors have combined with bureaucratic and interagency coordination issues to stymie the collection and use of current disability statistics and research data. Examples include varying definitions of disability from statute to statute and program to program, ambiguities in the wording of questions, and variations in the precise wording of questions among survey instruments. In addition, many respondents are unaware of the availability of assistive technology or other resources that could overcome functional limitations and legal restrictions on eligibility under various programs (which in effect force people to assume lesser roles in society).<sup>3</sup>

Nor is it even clear that more reliable statistics would have a definite impact on public policy. Debate persists over the number of Americans with disabilities, with estimates varying widely. But is there any ground for supposing that the competing approaches to improving participation levels and quality of life for people with disabilities would differ depending on if there were 40 or 60 million such persons? For example, answers to one of the six disability-related questions on the Census 2000 long form suggest significantly higher levels of employment than other data does. Can the people who follow one set of policies be readily distinguished from those who advocate another set of policies based on their belief as to the reliability of the answers to this census question? The answer is no. Everyone agrees that the unemployment number is still too high, and disputes over the kinds of programs to adopt are not fought on the basis of clearly differentiated positions on the trajectory of disability employment.

NCD strongly supports the continued collection and refinement of all possible data. To that end, NCD recommends that disability-related questions be retained and improved in the 2010 Census. If the Census Bureau believes that it lacks legislative authority to retain or enhance these questions, it should immediately seek the necessary legislative authority from Congress.

NCD further recommends that the U.S. Government's Interagency Committee on Disability Research (ICDR) be given all possible resources, status, and visibility by the Administration to

carry out the interagency research and coordination so vitally necessary to the collection and rationalization of disability statistics.

While these important efforts go forward, new directions in statistical research are urgently needed. These efforts will not only lead to clear answers to important questions, but by spotlighting new questions they can help to improve and modernize policy and law affecting people with disabilities in many areas of American life.

## **New Directions and Approaches**

### **The New Paradigm**

NCD believes, in concert with the growing body of opinion among people with disabilities and others, that a disability is not an objective or static fact or event. Consistent with the approach taken by the International Classification of Functioning, Disability and Health (ICF),<sup>4</sup> NCD believes that disability, too often confused with impairment, exists not in the individual, but in the inadequate interface between the individual and society.

We know that when buildings are made accessible, people with mobility disabilities can enter, learn, shop, and work there. We know that when information is provided in an accessible format, persons with sensory disabilities can obtain and use it in the same manner as anyone else. In a world in which technology and society reflect the fact that the interface between the individual and the environment is what determines function and possibilities, there is little point or meaning in asking people whether they have a substantial limitation in one or more major life activities due to a physical or mental impairment.<sup>5</sup> The source or measure of substantial limitation resides not within the individual, but rather in the absence of an elevator, a sign-language interpreter, or assistive technology resources.

There is nothing new in this paradigm. What may be new is to ask a perennial question in a different way: If we recognize and embrace the role of technology, convenience, and infrastructure in the lives of Americans at large, how can there still be debate over whether it is

the presence or absence of these, rather than any individualized limitations, that in aggregate terms defines the participation and function of America's nearly 60 million citizens with disabilities?

### **New Directions in Research**

From the limitations of existing data and from this new paradigm, it follows that new kinds of research are urgently needed. The growing awareness of the need for accountability in public expenditure and programs also points the way toward, and emphasizes the need for, new directions in investigation.

Broadly speaking, the need is for vastly more data on the effects of various societal decisions and arrangements on people with disabilities, and on the diverse costs and benefits to society of changes in those arrangements. For example, under most of our disability civil rights laws, what constitutes a reasonable accommodation under the Americans with Disabilities Act (ADA)<sup>6</sup> is conditioned on whether the necessary measure would represent an "undue burden" to the employer, state or local government, or public accommodation. Of course it is appropriate to make this determination and vital to avoid making demands on any sector of society that would be disproportionate, counterproductive, or unachievable. But the matter cannot end there.

Too often, as is increasingly the government's approach in Office of Management and Budget (OMB) or other assessments of proposed actions or regulations, inquiry and official interest focus on short-term financial impact on a small group of entities. This may be small businesses, large businesses, or units of government, depending on the circumstances. Again, it is just as important to avoid disproportionately burdening or harming definable sectors of society as it is to avoid doing such harm to individuals or single companies. But again, this cannot be the end of the discussion.



We must also pursue with equal vigor, and with equal methodological rigor, the related question of the effects on people with disabilities of the particular decision at issue. What will be the opportunity costs of exclusion, and what will be the benefits of fuller participation and access?

Today, we have few tools for reliably addressing these issues, particularly in connection with policy proposals that involve upfront expenditures but will yield their full economic return to society over a number of years. Statements such as “every dollar spent on rehabilitation returns \$7 in taxes and consumer demand” are gospel to some people, urban myth to others; but until we have reliable means for evaluating them, and for placing their results on a par with the interests and prospects of other groups in society, can we hope to develop or implement effective policy?

Throughout this report, we will encounter instances in which the existence and application of new analytical tools would, to a great degree, inform and clarify decision making. The process of developing these tools is by no means simple, but as competition for scarce resources intensifies and the need for accountability grows, what alternative do we have?

Accordingly, NCD recommends that Congress authorize research studies into the effectiveness of a number of leading programs and intervention strategies. The first step might be assessing key indicators—such as the employment and income status of persons with disabilities who have been employed following successful completion of vocational rehabilitation (VR) programs—and comparing the information obtained to the disability population generally and the working-age population as a whole. Additional avenues of study should look at the employment and income status of persons with disabilities who have graduated from college and/or those who are in a pilot experiment, ensured of full and uninterrupted access to comprehensive medical care after they enter employment. Other research should address the impact—again through a pilot experiment, if necessary—of the provision of adequate transportation in rural areas on nursing home admissions and care costs. Finally, the research could focus on the level of employment sustainability achievable in a sample of persons who are allowed to retain their Social Security

Income (SSI) cash benefits for two years after they enter work, subject to gradual phase out over a multiyear period.

Such studies will not resolve differences in approach and will not answer all questions as to what is fair or appropriate. But such studies will provide data on the basis of which such underlying philosophical and pragmatic disagreements can be more responsibly discussed and addressed. Until such data begins to become available across a broad range of programs and issues, we can have little confidence in the wisdom of current approaches or in the relative merits of alternative proposals.

Even more broadly, we need analytical tools for measuring the diverse effects—short- and long-term, direct and indirect—of current or prospective policy. While the law of unintended consequences may be the one law we can always be sure of, methods can be improved for assessing the knowable consequences of our acts, especially the indirect implications for one program, group of people, or action taken with particular reference to other programs or target populations. Accordingly, NCD recommends that the Administration appoint a high-level presidential task force that includes leaders in economics, demographics, health care, education, and law, and leaders from within the disability community. This task force should begin the task of identifying econometric, statistical, observational, forecasting, and other techniques and tools that may be available to bring greater accountability to disability policy. It should also identify the range of outcomes, consequences, implications, and relationships that must be taken into account in designing policy and assessing its effects. This presidential task force should be charged with developing methods for identifying long-term benefits that are as reliable and persuasive as those methods we now use for measuring short-term costs. It should assemble all data on the investment value of public expenditures and on the relative impact of various forms of subsidy and cross-subsidy arrangements, including those we now utilize. It should also develop and apply techniques for measuring opportunity costs and for measuring other hitherto conjectural, but nonetheless increasingly real and powerful, dimensions of our collective experience.

## **Conclusion**

This chapter has reviewed the assumptions and issues surrounding current and traditional disability statistics collection and research. It has suggested the strengths and weaknesses of such research, and it has indicated the reasons for believing that emerging new value systems call for new statistical approaches aimed at gathering and validating new categories of information. The chapter suggests some of the techniques that might be used and outcomes that might be foreseen. The chapter closes with the confidence and hope that better research techniques, resulting in the availability of better data, and dealing with the pressing issues of our time, cannot help but be useful, whatever strategy or approach they tend to support.

## **Recommendations Summary**

### **Recommendations to the Administration**

*Recommendation 1.1*—NCD recommends that the Administration give the Interagency Committee on Disability Research (ICDR) all possible resources, status, and visibility to carry out the interagency research and coordination so vitally necessary to the collection and rationalization of disability statistics.

*Recommendation 1.2*—NCD recommends that the Administration appoint a high-level presidential task force, including leaders in economics, demographics, health care, education, and law, and leaders from within the disability community, to begin the task of identifying econometric, statistical, observational, forecasting, and other techniques and tools to bring greater accountability to disability policy, and to identify the range of outcomes, consequences, implications, and relationships that must be taken into account in designing policy and assessing its effects.

### **Recommendation to Congress**

*Recommendation 1.3*—NCD recommends that Congress authorize research studies into the effectiveness of a number of leading programs and intervention strategies. The first step might be

assessing key indicators such as the employment and income status of persons with disabilities who have been employed following successful completion of vocational rehabilitation programs and comparing the information obtained to the disability population generally and the working-age population as a whole. Additional avenues of study should look at the employment and income status of persons with disabilities who have graduated from college and/or those who are in a pilot experiment, ensured of full and uninterrupted access to comprehensive medical care after entering employment. Other research should address the impact—again through a pilot experiment if necessary—of the provision of adequate transportation in rural areas on nursing home admissions and care costs. Finally, the research could focus on the level of employment sustainability achievable in a sample of persons who are allowed to retain their SSI cash benefits for two years after they enter work, subject to gradual phase out over a multiyear period.

#### **Recommendation to the Census Bureau**

*Recommendation 1.4*—NCD recommends that disability-related questions be retained and improved in the 2010 Census. If the Census Bureau believes that it lacks legislative authority to retain or enhance these questions, it should immediately seek the necessary legislative authority from Congress.



# Chapter Two

## Civil Rights

### Introduction

This chapter presents a number of threats to and opportunities in the area of civil rights. It also addresses issues that need to be discussed publicly in developing policies to maximize and ensure the fullest effectiveness of civil rights laws.

This chapter addresses the Americans with Disabilities Act, examines Section 504 of the Federal Rehabilitation Act, discusses accountability in civil rights enforcement, examines concerns about genetic discrimination, and considers voting rights.

### The ADA

#### Continued Erosion of Rights in the Courts

The year 2003 witnessed continuation of the trend of Supreme Court and lower federal court decisions narrowing the scope of the ADA and complicating reliance on its provisions. Supreme Court decisions of note this year included the *Clackamas* case, an employment discrimination case that narrowly defined the term “employee” for purposes of determining whether a medical facility had the minimum number of employees (15) required for coverage under Title I of the ADA.<sup>7</sup> In another major decision, the *Raytheon* case, the Supreme Court was called on to determine whether a firm’s refusal to rehire a rehabilitated substance abuser violated the law. The Court did not answer the question, but found instead that the lower court had applied an improper analysis and remanded the case for further proceedings. The Court acknowledged that discrimination claims based on disparate treatment (the intention to discriminate against an individual because of his disability) and cases based on disparate impact (facially neutral, but discriminatory in effect) are cognizable under the ADA. However, the Court stated that, in a claim of disparate treatment, if an employer applies a neutral, generally applicable no-hire policy in rejecting an employment application, the ADA is not violated.<sup>8</sup>

Perhaps as important as the cases that were addressed or resolved by the Supreme Court in 2003 are the issues that were not. Several cases presenting major issues were settled, withdrawn, or otherwise terminated short of Supreme Court adjudication. These cases raised issues such as how undue burden was to be measured when a city that had failed to comply with the ADA's requirements for sidewalks and curb cuts for more than a decade now claimed that requiring it to make up for lost time would be too financially burdensome.<sup>9</sup> Yet another case would have raised the issue of whether the ADA covers decisions by state boards regarding professional licenses.<sup>10</sup>

As 2003 ended, attention focused on a case that was argued before the Supreme Court on January 13, 2004. The much-publicized case of *Tennessee v. Lane*<sup>11</sup> squarely raised the question of whether Title II of the ADA can be used for lawsuits by private individuals for money damages against states, or whether, as with cases alleging employment discrimination under Title I, such suits are barred by the doctrine of sovereign immunity under the Eleventh Amendment to the Constitution.<sup>12</sup> The case has received as much attention as any disability rights case, or perhaps more.<sup>13</sup> One reason may be the compelling facts of the case: A citizen who uses a wheelchair, after first crawling up two flights of stairs to an inaccessible courtroom, refused to do so again and as a result was arrested for failure to appear. Or the attention may stem from the poignant fact that access, not merely to public services in the abstract, but specifically to the courts, is at issue; from the absolutist position taken by the state, which argued that its actual behavior is not at issue because the Constitution bars the suit;<sup>14</sup> or perhaps from the potentially large sums of money at stake, depending on whether or not citizens are permitted to sue states for damages under Title II.

NCD wishes to commend the Department of Justice (DOJ) and the solicitor general for the amicus brief supporting the constitutionality of the ADA filed with the Supreme Court in this case.<sup>15</sup> The recognition by an Administration, generally committed to states' rights, of the need for application of a federal statute in this case affirms the importance of the rights at stake in *Lane*.

NCD prepared a policy brief on the issues raised by the *Lane* case and recommended that the Court uphold the constitutionality of Title II as a whole.<sup>16</sup> Limiting the Title II remedy to recognized constitutional violations or to violations based on the Due Process Clause would impose arbitrary limitations on the reach of the remedy because it would exclude situations in which Congress was well within its power to legislate under Section 5 of the Fourteenth Amendment, and where the states have demonstrated a record of constitutional violations. However, it is likely that the *Lane* case will be decided in favor of a disabled individual's right to sue states for disability-based discrimination for failing to make judicial proceedings accessible, leaving unanswered questions about how the Supreme Court will interpret the constitutionality of Title II as applied in other state programs and services.

### **The Need for New Approaches to the Judicial Process**

To the degree that many Supreme Court decisions limiting the ADA involve constitutional issues, advocates have been at something of a loss to know how to respond to or reverse these decisions. Amending the Constitution would be difficult and dangerous, and would in any event take many years to accomplish. Short of such a drastic and impractical measure, efforts to educate judges, greater awareness as they see more cases, and perhaps even their own personal experiences as they and their family members grow older may, in time, result in some reassessment of their views, even of their constitutional philosophies; but these, too, are long-term and highly uncertain prospects.

To expedite the learning processes that we hope and believe will take place, NCD urges that the Judicial Conference of the United States, through the Administrative Office of the Courts, undertake a number of discretionary measures that may be helpful in better acquainting courts with the human suffering that discrimination entails and also with the usually simple strategies available for preventing its occurrence. First, NCD recommends that attorneys and judges with disabilities be invited to participate in seminars at institutes and meetings of and for federal judges held under various auspices during the year. Second, NCD recommends that, in several sample federal districts and circuit courts of appeals, the courts undertake a comprehensive ADA



self-assessment, including physical, programmatic, and communications barriers. We believe that such an assessment would serve three goals. First, it would familiarize judges and administrators with hitherto unexposed issues that are of concern to citizens, litigants, employees, journalists, and attorneys with disabilities. Second, it would demonstrate how relatively unobtrusive and nonburdensome elimination of most of these barriers can be. Third, once judges and court administrators realize the great benefits and the minimal disruption associated with nondiscrimination and barrier removal, they are likely to incorporate such new knowledge into their actions in the management of the courts and into the ways they approach cases coming before them.

One serious but easily remedied barrier to access to the federal courts is the inaccessibility of many electronic versions of court documents, including judicial decisions. Although this inaccessibility occasionally results from the design of the Web sites on which the materials are published, the major problem appears to be that they are created in a PDF format, which is not readily accessible to persons using screen-readers—people who are blind, who have low vision, and who have other disabilities that interfere with reading standard print.

It is not our purpose here to review the methods that other branches of the Federal Government have successfully used and smoothly adopted to make a wide variety of documents, including documents of record, available in formats accessible to citizens. Suffice it to say that, without compromising the independence or autonomy of the judicial branch in any way, resources and technical assistance for doing this are readily available within and outside the government.

Accordingly, NCD recommends that the Judicial Conference of the United States adopt the standards and protocols for Web site accessibility and document formatting and design embodied in Section 508 of the Rehabilitation Act; seek and provide the technical assistance resources that each court will need to implement these principles; establish realistic but meaningful timetables for completion of the work; and seek the input of persons with disabilities, including attorneys,

litigants and court employees, as well as jurists, to provide input and feedback as the process goes forward.

Even if these experimental measures do not effect trends in constitutional jurisprudence or judges' senses of where the balance between competing rights and principles should be struck, they can hardly fail to have a large impact on the growing array of critical cases where statutory interpretation rather than constitutional adjudication is involved.

The judicial branch should, at its discretion and under its sole management and control, undertake additional consciousness-raising efforts. Such efforts might include surveying federal judges about the number of law clerks with disabilities they have employed or interviewed. Similar research in the past, conducted within and outside the court system, has disclosed a significant lack of ethnic and cultural diversity in the ranks of high-level judicial personnel and has resulted in levels of awareness that one hopes are leading to remedial action and renewed outreach.<sup>17</sup>

Efforts to educate the federal judiciary must also proceed along the traditional lines of legal scholarship and argumentation. NCD has published a series of some 20 *Righting the ADA* policy briefs since late 2002, carefully and comprehensively analyzing the legal issues raised by the Supreme Court's ADA decisions.<sup>18</sup> These policy briefs offer a wealth of insights and data for those wishing to advance legal arguments on behalf of the rights of Americans with disabilities in a variety of settings or forums.

But these briefs also do something more, something for which, in this age of accountability, the judiciary needs to acknowledge and accept responsibility. They show that in many legal contexts, the Supreme Court has adopted shifting standards and result-oriented analytical principles, in ways that compel the conclusion that many of the decisions are preordained. This progress report is not the place to reiterate or summarize the inconsistencies and patterns in

question, but mention of a few of the most glaring examples may at least help to explain why the disability community may be growing apprehensive and mistrustful of our courts.

Three illustrations may be cited. First, gratuitous language in a number of the opinions reflects hostility to the civil rights claims of individuals with disabilities. Second, in many disability rights cases, normal and well-established maxims of statutory construction, such as the principle that civil rights statutes should be broadly construed to achieve the purposes of the law, are rejected, without explanation, in favor of narrow constructions—for example, the definition of “substantial limitation of a major life activity.” Third, in cases where reliance on the administrative interpretations of law made by federal oversight agencies such as the Equal Employment Opportunity Commission (EEOC) support a decision against the disability rights claim, the court embraces deference to agency expertise. But in cases where such reliance would support a finding in favor of the civil rights claim, agency interpretations of the law are dismissed, usually without explanation as to why they are being treated differently.<sup>19</sup> This pattern gives disparate impact a whole new meaning.

Citizens, of course, have no means of holding appointed, life-tenured judges accountable for their actions, nor would anyone advocate curtailment of the independence and autonomy of the courts. All that citizens and advocates can do is call on the conscience of the judicial and legal communities to search their law books and hearts to ensure that, whether the decisions come out for or against this or that interest or value system, they are made in accordance with neutral principles of law and without fear or prejudice.

### **New Federal Legislation**

The year 2003 witnessed reintroduction in Congress of the ADA Notification Act,<sup>20</sup> a bill that would require potential ADA litigants to give defendants 90 days’ notice of their intention to sue. While justified on grounds of giving defendants an opportunity to avoid litigation by remedying violations of the law, this proposal treats the threat of ADA litigation differently from that of lawsuits under any other federal statute; nowhere else in the law are potential defendants

given this benefit. To comprehensively provide for a warning period in the case of all civil suits under all federal statutes would be one thing; to single out the ADA this way, particularly when the ADA Notification Act would also restrict the availability of attorneys' fees, is something else, reflecting an agenda having little to do with balance or justice.

The proposed ADA Notification Act also would likely restrict the ability of individuals to obtain emergency injunctive relief to prevent imminent and irreversible harm. The proposal appears to make no exception to the notice requirement in such cases, and certainly nothing in the bill would prevent the courts from interpreting it to apply to suits for emergency injunctive relief as well as to conventional lawsuits brought under the ADA.

NCD is gratified by President Bush's opposition to this proposal.<sup>21</sup> If Congress wishes to consider waiting periods for all civil lawsuits, including suits by large and powerful entities against individuals, the disability community would hope to play a part in such deliberations.

While the yearly reintroduction of legislation such as the ADA Notification Act has naturally placed the focus of the disability community on forestalling ill-advised legislation, and while many have feared that opening the ADA to any amendment would be dangerous in the absence of the broad consensus that brought about its passage 14 years ago, the time may have come when the risks of new legislation are outweighed by the risks of inaction. Leaving aside the Supreme Court's constitutional decisions, court rulings interpreting and applying the ADA on statutory grounds have combined to render the law a virtual nullity in many of the settings to which it was widely expected and presumably intended to apply. In such areas as the meaning of "substantial limitation," the role of "mitigating measures," the definition of "regarded as" having a disability, the availability of damages, the procedures applicable to mediation, the role of seniority systems, the meaning of "place" in the concept of public accommodations, and numerous other areas where the courts have interpreted the statute adversely to the interests of individuals with disabilities, Congress has the authority and the responsibility for determining whether the existing judicial determinations are in accord with its intentions or with the goals of

full participation in society that President Bush's New Freedom Initiative (NFI) has so consistently and clearly espoused.

In connection with the ADA and in other areas as well, the Supreme Court's constitutional decisions over the past decade have dramatically altered the balance of power among the three branches of our government, depriving Congress of much of the authority that liberals and conservatives alike have assumed it possessed, whether wisely or unwisely exercised, over the past 70 years. What Congress can or should do to restore its prerogatives is beyond the scope of this report, but Congress can address the statutory dimensions of ADA implementation to a considerable and important degree.

Accordingly, NCD recommends that Congress enact an ADA Restoration Act, which will responsibly recalibrate the balance between fairness and individual dignity on the one hand, and institutional costs and convenience on the other, by addressing many of the interpretive and procedural issues noted above.

### **Section 504 of the Rehabilitation Act**

With so much attention focused on the ADA, it may not be surprising that another equally important federal civil rights statute has been pushed into the shadows. This is Section 504 of the Rehabilitation Act of 1973,<sup>22</sup> the first statute to declare discrimination against persons with disabilities by entities and programs utilizing federal funds to be illegal. Because of neglect in enforcing this law, and because of its continued legal and symbolic importance, NCD has sought to restore attention to Section 504 and to evaluate its implementation and its prospects in a major report, *Rehabilitating Section 504*, published in February 2003.<sup>23</sup>

The latest in NCD's series of major civil rights monitoring reports,<sup>24</sup> *Rehabilitating Section 504* examines the enforcement of the law by the five major federal agencies responsible for its implementation (namely, the Departments of State, Education [ED], Health and Human Services [HHS], Justice [DOJ], and Labor [DOL]). In findings that are systemic and of long standing, and

that implicate Administrations of all parties, NCD's careful review and assessment finds significant absences of leadership, resources commitment, and focus in connection with the exercise by these agencies of their responsibilities under the law. Though a number of agency initiatives—including HHS's Web site, ED's technical assistance guidance, and DOL's reasonable accommodations information—warrant praise and emulation, the report discloses large-scale indifference to Section 504 on the part of the Department of State. Significantly, with respect to DOJ, which has a preeminent responsibility and a unique opportunity through its coordinating role, the report finds that DOJ has largely failed to meet its obligations in this area.

Specifically, the report finds that the Interagency Disability Coordinating Committee (IDCC), the designated vehicle for Section 504 coordination across the range of involved federal agencies, is essentially defunct. The group has not accomplished what is needed to put any alternative mechanisms in place.

The report's findings offer a blueprint and a starting point for necessary and long-overdue reforms. Its appearance is particularly timely because, for a number of reasons, Section 504 may actually be as important legally as it has been at any time since the passage of the ADA—or more so. Section 504 and the ADA parallel each other in certain respects—for example, in the obligations they impose on state and municipal recipients of federal funds—but the two laws also differ in material respects—including what entities and activities are covered, who is protected, and what actions are barred or mandated by the law.<sup>25</sup> As ADA enforcement becomes more and more problematic, this parallel statute may become more and more important. Section 504 also has important applications, alongside but separate from those in the Individuals with Disabilities Education Act (IDEA), in the area of education of students with disabilities.<sup>26</sup>

This report cannot address in detail all the specific areas where Section 504 may uniquely apply or where it creates rights, responsibilities, and opportunities distinctive from those established under other laws. Suffice it to say that, in the absence of effective implementation, including,

especially, coordination of resources, planning, priorities, and procedures, the law's purposes and benefits cannot hope to be achieved.

Accordingly, NCD recommends that DOJ reactivate and support the work of the IDCC, with a view to developing, publicizing, and implementing a cross-agency plan for the implementation and administration of Section 504 that will ensure clarity, consistency, and predictability for both individuals with disabilities and entities receiving federal financial assistance.

Beyond making up for lost time, major new issues also confront the enforcement of Section 504. In order to avert potential litigation, there are issues that DOJ needs to address by regulation or other authoritative pronouncement. Especially noteworthy in this regard is the changing meaning of the concept of "federal financial assistance."

As the Federal Government utilizes more and new kinds of contractual relationships in its efforts to enlist partners in the delivery of public services and in the creation of new service-delivery models that emphasize competition and choice, the question of which of these contractual relationships are covered by Section 504 emerges with increasing urgency. Existing case law does not appear to offer clear guidance on the question of whether all or only certain contractual relationships involving the allocation of federal funds to private, nonprofit, faith-based, and state and local governmental entities constitute "federal financial assistance" within the meaning of the law. If, for example, the Medicare program pays or reimburses a managed care organization for the provision of prescription drugs or other health care coverage, does the transfer of federal funds to that HMO or other managed care entity constitute federal financial assistance? Would the answer to that question depend to any degree on whether the federal payment was regarded as reimbursement only, or whether it contained an additional component designed to incentivize the HMO's participation in the Medicare program? Would Section 504 come into play if a participating prescription-drug discount-card provider refused to include drugs needed by people with certain major disabilities in its formulary?

Similarly, if a faith-based organization providing services under contract with the Federal Government declines or is unable, for reasons of conscience or doctrine, to comply with the requirements of Section 504 in some respect, does that organization fail to meet the obligations required of an entity receiving federal financial assistance? If it does, can a First Amendment religious freedom argument be interposed to block the application of Section 504?

Faced with these and other new issues, NCD urges DOJ to initiate rulemaking or other processes, based on extensive input from the public, to identify and resolve all current and potential ambiguities in the application of the law. Only in this way can the legitimate interests of people with disabilities and of funds recipients be served with certainty and predictability. Likewise, if DOJ's effort reveals the need for new or clarifying legislation, the Administration and Congress can work together to fashion the necessary new measures. For those people, from either end of the political spectrum, who worry about the undue involvement of the courts, such prophylactic measures are likely to prove of great value.

### **Accountability in Civil Rights Enforcement**

Beyond the specifics of ADA or Section 504 philosophy and implementation, our nation today faces unique demands for effective administration of the law, persistent budgetary pressures that mandate the most efficient possible deployment of resources, and, above all, strong and long-overdue demands for accountability in the administration of all laws and programs. Because these relate to civil rights, they suggest the need for an inclusive national dialogue on the priorities and assumptions underlying current approaches to the enhancement of civil rights and on the means available for determining what approaches are most successful.

For example, testifying in February 2003 before the House Judiciary Subcommittee on the Constitution, the assistant attorney general for civil rights spoke proudly of the Administration's increased rate of settlements of civil rights complaints.<sup>27</sup> Needless to say, reducing backlogs and avoiding costly or protracted litigation are in the best interests of everyone. But as with the buying or selling of houses, you can always make a deal if you are willing to raise or lower the



price enough. For all those affected by the civil rights enforcement process, the key questions to ask relate to the nature of these settlements, to how the commitments and undertakings made by parties to these settlements are tracked and monitored, and to how effective current settlement policies prove to be in bringing about compliant behavior and positive long-term change among complainants and defendants alike.

It is not the place of this report to guess whether settlement policies are too lenient or too harsh, or whether they foster long-term compliance or contribute to an atmosphere of gamesmanship and hair-splitting. What it is appropriate for this report to do is suggest that the criteria for settling cases, and the goals sought by current settlement policies, be a matter of public record and open to input from the disability, business, and other relevant communities.

This question is not unique to DOJ, as we will see in our discussion of the enforcement of the Air Carrier Access Act in Chapter Ten.

Two broader issues are raised by an inquiry into settlement practices and standards. These critical but relatively unexplored issues lead directly back to the question of accountability. The first question is how and whether the criteria used and the goals sought to be served by various choices of enforcement strategy can be made known to the public and be subject to input from the public. The other question bearing directly on accountability is how to measure the relative effectiveness and impact of various approaches, and how to combine the best of all approaches to achieve a comprehensive response.

Broadly speaking, Administration policies, consistent with the aspirations for partnership and cooperation embodied in the President's NFI and consistent with the belief that information dissemination and technical assistance represent the best long-range strategies for fostering inclusion and full participation, have tended to deemphasize traditional law enforcement sanctions as a means for achieving progress toward equality. But no less than with strategies for responding to human needs in other areas, the principles of accountability must likewise be

applicable here. The Administration and the public need to know whether the deemphasis on enforcement is, in fact, resulting in greater progress toward equality of opportunity than a traditional approach to vigorous enforcement would. Based on the available data, there is yet no way to know.

Along with the growing attention to accountability as a touchstone of public policy, our nation must strive to develop techniques for answering the questions that accountability raises. We do not presume to know at this point exactly what methodology would provide sufficient rigor for reliable comparison of alternative or competing approaches to civil rights achievement. But we know that in an age of accountability, the need to evaluate all policies and approaches cannot be avoided or denied. It may be that current, nonconfrontational strategies have resulted in more access, at less cost, and with less disruption or animosity than would otherwise have been the case. But if the lack of progress toward reducing the unemployment rates among people with disabilities (see Chapter Seven) can in any way be related to the way the government approaches the question of employment discrimination, then perhaps accountability leads to different conclusions.

In this connection, NCD is concerned that cost-benefit analysis of the sort supported by OMB appears to focus largely on the potential costs to industry of various civil rights measures, while largely lacking the means or sources of information for tracking other key elements of the overall cost-benefit equation.<sup>28</sup> Consideration of the alleged costs to one sector of society, without equal reference to a variety of other costs and of potential benefits to others, is tantamount to conducting a trial at which only one side is allowed to introduce evidence or is called to testify. Once again, a true commitment to accountability as a guiding principle requires better methodology and broader input than often appears to be forthcoming. Until or unless the costs of exclusion in the lives of untold millions of people can be measured with as much certainty as are the costs of civil rights enforcement on identifiable institutions, until or unless the benefits of inclusion command as much of our attention as do its burdens, we cannot say that we have

achieved either accountability or balance in the implementation of our civil rights laws or in the pursuit of our civil rights goals.

## **Genetic Discrimination**

Going back to its white paper on the subject<sup>29</sup> and in detail in its annual progress reports over the past three years, NCD has called attention to the dangers of genetic discrimination in insurance, employment, and other areas, and to the pressing need for legislation barring employers, insurers, and others from making decisions about people's lives based on their genetic makeup.

Having previously set forth the issues in detail, little purpose would be served by their repetition here. However, it is important to note three major changes in the context of the discussion that have taken place over the past year. First, the Senate adopted the Genetic Information Nondiscrimination Act of 2003,<sup>30</sup> which would bar the use of genetic information in most employment and insurance decisions. NCD commends the Senate for its action and recommends the House of Representatives follow suit as early as possible.

The second major change in the context of the genetic discrimination discussion is the implementation in spring 2003 of the regulations implementing the medical-records privacy provisions of the Health Insurance Portability and Accountability Act of 1996 (HIPAA).<sup>31</sup> To whatever degree arguments may have existed for delaying genetics nondiscrimination legislation until the potential of HIPAA to safeguard genetic privacy could be determined, these arguments would appear to no longer apply. HIPAA is not expected, even by its strongest adherents, to curtail current uses, or to prevent expanded future collection and use, of genetic information.

No evidence is known to NCD that acquisition of or access to genetic testing and information by employers, health insurers, or others has been materially reduced or prevented as a result of HIPAA. Nor is there any reason to believe that HIPAA, whatever bearing it may have on the transfer or sharing of sensitive information, will prevent employers, insurers, even landlords from conducting blood, urine, or other tests or otherwise requiring information that can yield

genetic data. As a result, the legal case for genetic antidiscrimination legislation is stronger than ever.

The third, and in some ways perhaps the most profound, new development occurring within the past year is the publication in October of *Beyond Therapy: Biotechnology and the Pursuit of Happiness*, a report of the President's Council on Bioethics.<sup>32</sup> This thoughtful analysis strives to distinguish between the legitimate uses of our growing potential for genetic engineering and manipulation, and those uses that, while conducive to our vanity, our desire for greater intelligence, enhanced beauty, or longer life, are more questionable or even at variance with basic moral values. But if genetic science cannot properly or morally be used to enhance our prospects in romance, competitive sports, or intellectual pursuits, how can it simultaneously be allowable for such information to be used by institutions that would deny people full freedom of opportunity and choice?

It may be argued that the insurers or employers or landlords who deny insurance coverage or employment or housing based on perceived genetic risk or vulnerability are not manipulating genes, and hence are not implicated by the findings and warnings of the bioethics report. But the matter is more complex. How can any reasonable person expect individuals to forgo any possibility, however spurious, for genetic enhancement or correction, so long as they know that others, with potentially immense power over their lives, will be utilizing genetic information to exercise that power?

## **Voting Rights**

Few attributes of citizenship can be more important than the right to vote, and NCD was proud to have occasion in last year's annual progress report to hail the passage of the Help America Vote Act of 2002 (HAVA).<sup>33</sup>

For people with disabilities, the right to vote privately and safely requires more than a statute. It requires facilities that are accessible and voting machines that are independently usable. HAVA established for the first time a national commitment and the right to these opportunities.

NCD remains mindful, though, that no rhetorical commitment or statutory requirement is any better than the day-to-day willingness and ability of a variety of participants in the process to make it work. As that awareness relates to the achievement of voting rights under HAVA, it means that congressional appropriations, HHS oversight (including through the development, in collaboration with the Federal Elections Commission and DOJ, of voluntary guidelines), state decisions, and continued voter involvement are all critical to the success of the law.

Subject to several concerns (including those relating to adequacy of HAVA appropriations, to availability of appropriate technology to meet the independent voting aspirations of people with various disabilities, to resistance by some state and local elections officials, and to potential apathy among large segments of the voting public), NCD believes that significant progress has been made during the year toward implementation of HAVA. We particularly note with appreciation the indication given by DOJ in December that it intends, as of the law's January 1, 2006, effective date, to enforce the law literally, so far as its applicability to each polling place is concerned.<sup>34</sup>

Because HAVA will not come fully into effect for another two years, the risk that many Americans with disabilities will be excluded from the national election process of 2004 must be confronted. In that connection, while there is little that HAVA can do to overcome this problem, there are other legal issues that may bear significantly on the enfranchisement of Americans with disabilities before and in tandem with HAVA.

A number of cases currently making their way through the courts appear to indicate that the ADA plays a role in voting rights.<sup>35</sup> Litigation and related advocacy in the District of Columbia

have contributed to the implementation of unprecedented accessible voting rights for D.C. residents this year, and cases underway in Florida and elsewhere suggest similar possibilities.<sup>36</sup>

NCD recommends that DOJ support the applicability of the ADA to the polling place and the voting booth by initiating cases or intervening in cases where reasonable measures on the part of state and local elections officials could result in meaningful increases in the independent and accessible voting opportunities for Americans with disabilities.

One issue that has emerged as an area of increasing concern is the verifiability of the vote totals reported by touchscreen or other so-called direct recording equipment (DRE) voting machines. NCD takes no position on whether current models of these machines are sufficiently reliable, or on whether the lack of a so-called audit trail imperils the integrity of the electoral process. NCD does insist, however, that no changes be made that would compromise or jeopardize the levels of accessibility and independent voting mandated in HAVA.

The disability community is also concerned with the possible use of accessibility as a pretext for DRE manufacturers' refusal or inability to modify their systems. We cannot believe that it is beyond the technical ingenuity of these manufacturers to modify their designs in ways that meet election security concerns while preserving the hard-won rights and legitimate expectations of Americans with disabilities.

## **Conclusion**

This chapter has addressed a number of perceived threats to the progress of civil rights for individuals with disabilities. It has indicated why these trends are regarded as dangerous and also suggested means by which they can be reversed. It has also addressed fundamental questions that must be asked and answered through public dialogue and through research in the formulation of strategies and procedures for effectuating a broad range of civil rights goals.

## **Recommendations Summary**

### **Recommendations to the Judicial Conference and the Administrative Office of the Courts**

*Recommendation 2.1*—NCD recommends that attorneys and judges with disabilities be invited to participate in seminars at institutes and meetings of and for federal judges held under various auspices.

*Recommendation 2.2*—NCD recommends that, in several sample federal districts and circuit courts of appeals, the courts undertake a comprehensive ADA self-assessment, including physical, programmatic, and communications barriers.

*Recommendation 2.3*—NCD recommends that the Judicial Conference of the United States adopt the standards and protocols for Web site accessibility and document formatting and design embodied in Section 508 of the Rehabilitation Act; seek and provide the technical assistance resources that each court will need to implement these principles; establish realistic but meaningful timetables for completion of the work; and seek the input of persons with disabilities, including attorneys, litigants, and court employees, as well as jurists, to provide input and feedback as the process goes forward.

### **Recommendations to Congress**

*Recommendation 2.4*—NCD recommends that Congress enact an ADA Restoration Act that will responsibly recalibrate the balance between fairness and individual dignity on the one hand, and institutional costs and convenience on the other, by addressing many of the interpretive and procedural issues.

*Recommendation 2.5*—NCD urges the House of Representatives as early as possible in the second session of the Congress to join the Senate in adopting genetic antidiscrimination legislation.

## **Recommendations to the Department of Justice**

*Recommendation 2.6*—NCD recommends that DOJ reactivate and support the work of the Interagency Disability Coordinating Committee, with a view to developing, publicizing, and implementing a cross-agency plan for the implementation and administration of Section 504 that will ensure clarity, consistency, and predictability for both individuals with disabilities and entities receiving federal financial assistance.

*Recommendation 2.7*—NCD recommends that, pending the full implementation of the Help America Vote Act, DOJ support the applicability of the ADA to the polling place and the voting booth by initiating cases or intervening in cases where reasonable measures on the part of state and local election officials could result in meaningful increases in the independent and accessible voting opportunities for Americans with disabilities.





# Chapter Three

## Education

### Introduction

Discussion of the education of children and youth with disabilities involves the identification and integration of educational knowledge and practice, along with an understanding of issues, barriers, methods, and technologies that are of particular relevance to the education of students with disabilities. Thus, for example, as discussed in our previous reports,<sup>37</sup> provisions of the No Child Left Behind Act of 2002 (NCLB)<sup>38</sup> (which applies to all public schools and public school students across our nation) must be interpreted and applied in the context of special education. At the same time, the Individuals with Disabilities Education Act (IDEA) must be developed and applied in ways that are consistent with and complementary to NCLB, but that still recognize the issues and situations that IDEA and special education are intended to address. This chapter addresses some of the key issues currently raised by that intersection. It also discusses issues of higher education and of transition from school to adult life outside of education.

It looks at the forthcoming reauthorization of IDEA, coordination between IDEA and NCLB, higher education, and school-to-work transition.

### IDEA Reauthorization

IDEA was scheduled for reauthorization last year, ordinarily an occasion for amending the law to reflect the issues and experience accrued during the period since the last reauthorization. Congress did not complete the reauthorization process in 2003, but instead extended the existing law for a year.<sup>39</sup> Meanwhile, the two houses have continued working on their respective versions of the reauthorization statute.

With a version of IDEA reauthorization legislation already passed by the House, and with the Senate's version<sup>40</sup> well along and awaiting action, NCD recognizes that this second session of

the 108th Congress does not come to the issue of IDEA reauthorization with the same range of options and choices that would be available if legislation were being considered from scratch. There are a number of key differences between the House-passed bill and the version pending in the Senate. Whatever language the Senate eventually adopts, there will be opportunities for the conference committee to reconcile the House-Senate differences and attempt to craft new language that will satisfy both houses.

This being so, NCD wishes to direct the attention of the Senate and the House-Senate conferees to a number of key issues and to the impact that Congress's imminent decisions will have on the lives and destinies of students with disabilities, as well as for education as a whole. NCD therefore directs congressional attention to the following key issues.

### **Student Discipline**

IDEA includes procedures for the discipline of students with disabilities receiving special education services. Perhaps because of the existence of these specific provisions, some people seem to believe that students with disabilities are somehow exempt from the normal rules of school discipline or, worse, from responsibility for the consequences of their actions.

In fact, as has been made clear by NCD in a number of reports, no such free pass exists. There is, of course, legitimate scope for debate over whether the disciplinary procedures specified for use under IDEA do or should differ from those in effect for school students generally, and if so, in what ways and to what extent. NCD believes that they do need to differ in certain key respects, and we believe there are strong reasons this remains so.

Addressing these questions, Congress should bear in mind the following points. All students have the right to an education, which means as a practical matter that they have the right to various educational and related services. No parents would be permitted to withdraw their child from school because of their determination that the child was incorrigible, uneducable, or unable

to attend or learn. Yet some would argue that school districts should, in effect, be permitted to do so.

Because education is not something to which children somehow earn or forfeit a right, Congress should ensure that, when disciplinary considerations require the removal of students with disabilities from the mainstream, integrated classroom, such students are ensured the right to uninterrupted education, special education, and related services consistent with their Individualized Education Program (IEP) and with evolving assessments and needs in the most appropriate educational settings. In this way, no child will be left behind.

### **Full Funding**

In previous reports NCD has advocated strongly for full funding of special education. NCD recognizes that in the current budgetary climate, significantly increasing the percentages of special education costs met out of federal funds is not realistically possible. NCD applauds the efforts made by Congress and the Administration to maximize funds for special education within current fiscal constraints.

But NCD also trusts that, were the fiscal situation different, congressional and Administration leaders would join with advocates in the belief that full funding (meaning approximately 40 percent of total special education expenses) is a desirable goal. Therefore, while continuing to maximize current funding, NCD recommends that Congress and the Administration undertake a study of possible methods and sources for increasing, over time, the level of federal participation in special education to 40 percent. Several potential sources are recommended for investigation in this regard. For instance, substantial savings are expected to accrue to the educational system through reduction of paperwork, elimination of reporting requirements, and other administrative reforms already embodied in NCLB and likely soon to be paralleled by reforms in the reauthorized IDEA. To the extent that the Administration and Congress are proved correct in their expectations for such savings, consideration might be given to earmarking some of these recovered resources for use in raising the federal participation rate in special education.

Accordingly, NCD recommends that Congress establish a commission to study the long-term costs of special education and to recommend strategies for ensuring the financial stability of state education agencies (SEAs) and local education agencies (LEAs) in meeting national educational goals for students with disabilities.

### **Due Process**

Many people have expressed considerable concern about the role of parental due process as a cause of inadvertent delay or complication of the provision of special education services to students with disabilities. Some, including the President's National Commission on Excellence in Special Education report,<sup>41</sup> have argued that the right to file administrative complaints or lawsuits has been abused, in part because of the law's provision for reimbursement of attorneys' fees to parents who prevail in their claims.<sup>42</sup> Accordingly, many people have come to believe that, however we may favor measures to increase parental involvement in the educational process, the legal process is not an effective or appropriate tool for achieving such empowerment.

NCD believes that rather than focusing on real or presumed abuse demonstrated by isolated incidents or widely reported anecdotes, Congress should focus on the question of what means and resources are available to parents for providing input to schools about the services their children need and in seeking to find and develop the documentation necessary to bring those services to bear. Equally, from the standpoint of balance, no one has ever suggested that school districts should be denied access to legal counsel in even the most routine or trivial of matters, and no one has ever suggested that such counsel should not be fully compensated at prevailing rates for their work. Similarly, no one has ever suggested that school district determinations about the contents of students' IEPs are always correct or based strictly on educational, non-cost-related considerations. Given these indisputable facts, the question Congress must ask before it curtails parents' right to counsel is: How, in the absence of the right to retain counsel and prosecute appeals, can parents' input and parents' knowledge about their children be fully, clearly, and reliably reflected in school system IEP decisions?

In its last reauthorization of IDEA, Congress established procedures for limiting frivolous complaints and suits. It also established procedures for mediation and arbitration before the bringing of suit, as well as requirements of sufficient notice of pending complaints to give school officials ample time to review student records and modify their decisions before litigation begins.<sup>43</sup> In light of this background, NCD recommends that before the enactment of any further curbs or restrictions of a procedural or economic nature, Congress should fully review the impact and efficacy of these provisions. Under a legal framework that precludes the award of attorneys' fees to other than "prevailing parties," and in light of other legal developments since the last reauthorization of IDEA narrowing the definition of the term "prevailing party" for purposes of a variety of right-to-counsel laws, it seems improbable, indeed little short of incredible, that unmeritorious suits could in any way be motivated or fueled by attorneys' desires for fees or by parents' expectations of having nothing to lose if suit is filed.

If, after such an in-depth inquiry, Congress believes that the current level of IDEA due process litigation is injurious to the goals or the operation of the special education system, or that the educational resources soaked up by even meritorious litigation could be used more effectively in other pursuits, then Congress should authorize a controlled experiment to test what the effects of further restricting or completely eliminating parental appeals from school-district IEP decisions or IEP implementation practices would be. NCD would be happy to work with Congress in the design of such a study, which would invite school districts to offer themselves for controlled, empirical, outcomes-based research, as test sites for a detailed comparison between current and litigation-free special education environments.

Accordingly, NCD recommends that, because adequate data does not yet exist to justify the curtailment of parental due process rights in special education, Congress undertake definitive research that would provide empirical evidence on the subject of the impact of appeals and of attorneys on special education before further restricting family rights.

## **Textbook and Multimedia Accessibility**

Essential to mainstream school participation is access to the curriculum and to the instructional media and technology that are central to education. For that reason, it is critically important that school technology and educational resources, including software, textbooks, and multimedia instructional materials used by students, are accessible to all students, including students with disabilities.

In the 2002 *Progress Report*, NCD recommended that the Department of Education (ED) take steps to adopt a national file format (NFF) to help ensure that access occurs. The NFF would specify certain technical standards, having nothing whatever to do with content, that textbook and other media producers and providers would have to meet in order to ensure that their products can be made accessible to students with a variety of disabilities. The NFF would also require that electronic files embodying these features be made appropriately available along with actual printed textbooks, videos, or other media.

NCD has questioned the approach adopted by ED for developing the NFF. The Department sought agreement on the appropriate technical standards among the textbook-publishing, educational, and disability communities through a voluntary and nonbinding standards-setting process. We had expressed concern that wholly voluntary, open-ended efforts might not be successful, because, though negotiating in total good faith, the needs and views of the key stakeholders might be too far apart to allow them to reach agreement.

Against this backdrop, we are gratified to report that developments of 2003 appear to have produced consensus recommendations and have garnered the support of the textbook-publishing industry for a set of voluntary standards that they can implement and that should go a long way toward meeting students' and educators' needs.<sup>44</sup>

Voluntary standards will go only part of the way toward solving the problem, for they will not fully reconcile the numerous and inconsistent state requirements bearing on this issue, which

have contributed substantially to the need and demand for a strong national standard in the first place. If the voluntary NFF is adopted, it will not necessarily supersede inconsistent or even conflicting state laws, and it will not by itself bring about the national standardization that is desirable.

Accordingly, NCD recommends that Congress, in its reauthorization of IDEA, include provisions calling for adoption of ED's consensus NFF (or, if a comment period reveals that this standard is unsatisfactory, then for development of another one) that would have to be met as a condition for textbook purchase. Congress should also adopt the provision in the Senate draft bill calling for the establishment of a national repository of computer files so that books can effectively and promptly be made available to those schools and students that need them in accessible formats.<sup>45</sup>

### **Coordination of IDEA and NCLB**

If IDEA is to be effective and if it is to achieve consistency with national educational principles and goals, IDEA must be written and interpreted with NCLB in mind. NCD commends ED and its Office of Special Education Programs (OSEP) and Rehabilitation Services Administration (RSA) components for their efforts during 2003 toward development and dissemination of teacher-training and teacher-qualification standards and guidelines. NCD commends the Department for its provision of technical assistance to the states in the area of teacher qualifications and certification, including for special education teachers.<sup>46</sup> Most of all, NCD applauds ED for its efforts to clarify the interaction between standardized schoolwide performance testing of students on the one hand, and the need for alternative achievement methods and reasonable accommodations for students with disabilities on the other. NCD urges that these efforts be continued and wishes to offer several specific recommendations on how these initiatives can be carried forward most effectively.



## **Application of Average Yearly Progress**

At the heart of NCLB accountability lies the concept of adequate yearly progress (AYP). Based on year-to-year comparisons of student performance on standardized tests, federal funding, technical assistance, and other resources are allocated to schools. In cases where schools fail to demonstrate the requisite AYP over two or more years, students of those schools are given transfer rights that would not otherwise be available.

From the beginning, the application of AYP has created controversy. Many of the controversies surrounding application of the concept are well known and beyond the scope of this report. Several of the key issues relate directly and specifically to the status of students with disabilities, however.

In this connection, one question of concern to special education advocates, school district administrators, and parents has been whether or when schools' AYP figures must count all students, including students with disabilities. Schools have argued that because some students with disabilities learn differently or perhaps less quickly than other students, use of the same standardized testing strategies and methods to evaluate them would result in the lowering of aggregate student scores. This, they argue, is unfair to the schools and school districts, which stand to lose funding or prestige if scores are not seen to increase as rapidly as expected.

In December 2003 ED issued regulations clarifying that, while all students must be counted when determining school test performance, some students with severe cognitive disabilities can be tested through the use of alternate achievement or assessment methods. Subject to temporary waiver by the Secretary of Education, not more than 1 percent of the students in a designated student population can be assessed with alternative methods.<sup>47</sup>

While this rule represents an important example of how the needs for uniformity on the one hand and for individualization on the other can be balanced, it goes only part way toward answering the many serious and often perplexing questions that still surround AYP and students with

disabilities. If school districts are to be given a full and fair opportunity to maximize their scores, and, as important, if students with disabilities are to be given an adequate opportunity to learn, compete, and demonstrate what they know, as well as to avoid being scapegoated, a number of other critical issues must be addressed.

We address two of the most pressing among them here. First is the question of reasonable accommodations. Not only may students with disabilities sometimes learn differently, they may also often need different resources and technology to fully demonstrate what they know. Sometimes testing conditions are suitable for or are modified to allow for these differences; sometimes they are not. Even when they are, the goals of comparability are undermined if standardized and well-understood requirements for and definitions of appropriate, necessary accommodations do not exist or are not applied.

For example, students who are blind will obviously perform differently on written tests if the test questions are available in an accessible format—such as Braille, synthetic speech, or large print—than if the students have to squint at standard print or interpret material read by a third party whose reading style and level of knowledge also have an impact on the test-taking experience. Likewise, students who are deaf will hardly be able to show what they have learned when responding to oral tests if sign-language interpretation is not available; moreover, the skill and experience of an available interpreter will be a variable, albeit an imprecisely measured one, in the equation of the final outcome.

Schools vary widely in their awareness of and responsiveness to reasonable accommodations. People who think about reasonable accommodations usually do so in the context of the ADA. While the issue has been widely discussed in the context of requests for extra time, such requests, so far as they are deemed to raise legal issues, have generally been decided under the ADA<sup>48</sup> and have not necessarily been decided with a view to educational policy. But whether in the area of extra time, accessible media, or assistive technology, rationalization of our nation's

reasonable accommodations policy remains vitally necessary if the goals of school-system accountability and individual achievement are to be reconciled.

Accordingly, NCD recommends that Congress include in the IDEA reauthorization provisions and resources supporting the conduct of a detailed national study on the availability of, need for, and impact of a variety of accommodations that have been used in various school settings. This study should be conducted with a view to identifying approaches to the development of a national strategy that will meet the ultimately complementary needs of students with disabilities and needs of school systems. The study should also attempt to assess the impact of various accommodations on test outcomes, so their impact can be taken into account in the norming of tests and in ensuring fairness and compatibility of results.

The second key issue surrounding the AYP arises directly out of the first. To the degree that schools do provide reasonable accommodations in test taking, the success of these measures depends in large measure on the availability of suitable training in their use and on instructional resources that allow the educational process to succeed for those with varying learning styles. To say that a given accommodation is available is not to say that its impact will not be subject to the experience of the school in administering it and to the ability of the student to utilize it. NCLB has made an understanding of these variables more important than ever before.

Like it or not, NCLB already has changed special education. Twenty years ago, the notion was enshrined in law that IDEA requirements were satisfied by resources and services that provided a minimally adequate education. But now that NCLB requires across-the-board improvement in student performance each year, mere adequacy is no longer enough; definite progress, meaning something more than maintenance of baseline performance or results, is clearly required.

Congress, in its reauthorization of IDEA, must therefore articulate standards, not only for outcomes, but also for resources and services that will ensure such steadily improving outcomes. And Congress must at least acknowledge, whether or not it has material means to address the

problem at this time, that it is easy to mandate outcomes, but that without the resources to reasonably achieve them, the responsibility cannot be carried out by those charged with its fulfillment, no matter their levels of creativity and commitment.

For these reasons, NCD recommends that Congress include in the reauthorized IDEA an instruction to the Secretary of Education to collect data on the availability and utilization of accessible instructional materials and assistive technology in the schools, and collect all available data on the connection between the application of such resources and a variety of reasonable accommodation strategies with measures of the status and outcomes of students with disabilities.

### **Teacher Qualifications**

NCD commends ED for the outreach efforts it has undertaken to acquaint states and local school districts with the requirements of NCLB regarding teacher training and qualification, and for the technical assistance it is providing to states in this critical area. Nonetheless, we remain concerned that key issues regarding the application of NCLB professionalization requirements to special education remain inadequately addressed and unresolved.

The list of disciplines, graduate programs, and types of expertise available to and potentially necessary for the provision of special education or related services is long. The circumstances under which students receive educational and related services vary, and as with so much of public education, issues of supply and demand play heavily into the deployment of resources and into the matching of teachers and other professionals with students and classrooms. Congress and ED need to decide whether and how the professionalism requirements for staff providing services under IDEA can or should be identical or similar to those generally applicable under NCLB. For this reason, NCD recommends that the Department of Education promulgate detailed policy guidance that applies, so far as deemed appropriate and with such differences as are deemed necessary, the teacher qualification provisions embodied in NCLB to the unique needs and conditions existing in special education and to the special education and related services

disciplines deemed to come within the scope of NCLB. In this regard, NCD further urges Congress to incorporate in the reauthorized IDEA resources and authority for the Secretary of Education to conduct a detailed assessment of the personnel and personnel-preparation needs for students with disabilities, of the current resources available for training specialized personnel, and of means by which the resources required to fulfill identified intermediate- and long-term specialized training and personnel needs can be reliably and stably met.

### **Educational Technology**

Pursuant to the provisions of NCLB requiring iteration of a new National Education Technology Plan (NETP),<sup>49</sup> NCD recognizes the efforts of ED to seek input in the development of such a plan. Where we have concerns is in the extent to which this plan incorporates awareness of the technology issues and options that bear most heavily on students with disabilities.

Specifically, NCD believes that no plan can fulfill the NETP designation unless it includes a recognition that all educational technology used in or by schools must be accessible to all students. Accordingly, NCD recommends that the NETP set forth as a cornerstone and a fundamental requirement of America's education technology policy that all technology resources and tools created or used must be accessible to and usable by all students, irrespective of disability. If preparation for living in the 21st century is at issue, as the Department has indicated in formulating the NETP, then such preparation cannot be denied to students with disabilities, any more than it can be withheld from students on the basis of the economic status of their communities or the ethnic composition of their schools.

### **Accountability**

A perhaps even broader question posed by the interplay between IDEA and NCLB is this: To the degree that accountability has been made the touchstone of educational practice in this country for all students, how can it be likewise incorporated into special education in ways that retain the needed individuality and flexibility that create incentives for positive results without

stigmatizing the work and efforts of those schools and education professionals whose achievements cannot always be measured in conventional or statistical terms, or who lack adequate resources or training to effectively bring about the requisite outcomes?

While most people share the same goals of full participation and high achievement for students with disabilities as for all students, it is not clear that aggregate school-by-school, district-by-district, or state-by-state statistical comparisons are the best or even an appropriate basis for rewarding progress or measuring outcomes. An example of the problem can be seen in the recently issued alternative-methods regulations discussed above. School districts are permitted to include scores achieved with alternative testing methods for up to 1 percent of their students, but what expectations and what measurement tools apply to the remainder of students with severe cognitive disabilities, if such students amount to more than 1 percent of the potential test population and no Secretary of Education waiver of the limit is forthcoming? How are schools to be made accountable for their performance? Even with regard to students whose alternative-testing scores are counted, how will IDEA relate to NCLB in ensuring that these students also matter on an individual level? How will the law ensure that these students, too, make progress from year to year, and how will it monitor whether they, as a subset of the entire student population, do make such progress? Can the individualization necessary for special education be squared with the NCLB's statistical approach? And if schools receive extra help, or if their students are allowed to transfer because a school falls short of AYP, what measures are in place for ensuring that the extra help is meaningful for and accessible to all students, or that available transferee schools are accessible to all students, including those with disabilities?

It should be borne in mind that all of IDEA is not in need of reauthorization. Several of its key components, including Part B, dealing with state grants for special education, do not in fact sunset. Accordingly, NCD recommends that if Congress cannot address these substantive issues in a manner that their complexity and importance warrant, and in a manner that ensures the necessary level of program accountability, Part B should not be modified or changed but should be left in tact until the necessary further deliberations can take place.

## **Higher Education**

With unemployment among persons with disabilities remaining stubbornly high despite a variety of federal initiatives and public-private partnerships designed to improve the situation, and with long-term job prospects and income potential for people without college education looking increasingly grim, it should be more apparent than ever before that, wherever possible, higher education is key to the economic prospects and aspirations for independence of youth with disabilities. In this connection, as Congress also turns its attention to reauthorizing the Higher Education Act,<sup>50</sup> it is particularly important and timely to note and commend to congressional attention the findings and recommendations in the September 2003 report of NCD's Youth Advisory Committee (YAC).<sup>51</sup> The YAC's findings and recommendations are too detailed and far-reaching for full recounting here. The report is highly recommended, both for its analysis and for the fact that to a great extent the issues it raises are framed and portrayed in the voices of those whose futures and destinies are most at issue—our youth themselves.

Perhaps most disturbingly, the report shows that significant financial barriers to higher education exist for many students with disabilities and suggests that these barriers are made worse by their persistence, notwithstanding a number of provisions in the current Higher Education Act that, to the casual observer, appear sufficient to eliminate or prevent them. As only a report based on the experiences of people affected can do, this YAC study documents and humanizes many of these barriers.

Specific findings include the following:

- Owing to a lack of coordination among vocational rehabilitation, student financial aid, Social Security, and medical assistance programs, benefits and services forthcoming under one program can inhibit eligibility for needed services under another.
- Contrary to provisions in the Higher Education Act allowing for student financial aid awards to be increased where circumstances give rise to added disability-related

educational expenses, student financial aid officers are reluctant to exercise their discretion to increase financial aid to help meet such costs.

- Tension or even conflict exists between vocational rehabilitation and student disability services offices as to the allocation of costs and responsibility for various needs and services, and students have no leverage for bringing about any reliable measure of coordination or cooperation between these entities.
- Students with disabilities are often excluded from work study jobs or paid internships in a discriminatory manner, thus depriving them of opportunities for earning income that are available to other students.

NCD recommends that Congress hold hearings on the barriers facing students with disabilities as part of its consideration of the Higher Education Act reauthorization, and that students with disabilities be invited and encouraged to share their views and experiences with lawmakers.

Because many of the issues that are addressed by IDEA are also pertinent to postsecondary students with disabilities, NCD recommends that Congress expand its assessment by incorporating into the Higher Education Act provisions paralleling the textbook and technology accessibility measures recommended above for IDEA. NCD recommends that if Congress lacks time or inclination to conduct a thorough review of higher education in relation to students with disabilities at this time, Congress should include in the reauthorization an instruction and resources for the Secretary of Education to conduct a thorough study of these issues, through the appointment of a national commission composed of representatives and members of all relevant constituencies, including youth with disabilities. The mandate and work of this commission should mirror that of the President's Commission on Excellence in Special Education. Its report should be submitted to Congress within one year after the commission meets, with the understanding that the Administration, to the extent the recommendations are credible and persuasive, will work energetically with Congress to adopt necessary reforms, and that the Administration will expeditiously implement those reforms that are within its regulatory and oversight authority.



## **School-to-Work Transition**

Not all students graduate from high school, and not all those who do go on to postsecondary education. While some will pursue vocational education and other forms of training, many will seek to enter the adult world without benefit of additional formal training or certification.

Recognizing both the importance and the cost of higher education, our nation has developed many strategies to assist students and families in paying the costs of college. In addition to the federal student financial aid system, we have utilized a number of tax-based strategies to help pay for a college education.<sup>52</sup> For students with disabilities who face larger expenses than others or who come from families of lesser means, the effectiveness of many of these measures is questionable. For students with disabilities seeking to transition into adult life, the relative absence of parallel strategies and resources to assist or empower them financially must be a matter of concern.

NCD has analyzed the problem of transition at great length and has made detailed recommendations in our recent annual progress reports as well as in other major studies. Instead of repeating those recommendations here, we wish to offer additional proposals, modeled on the measures we use to facilitate college attendance, but aimed at facilitating transition for youth with disabilities who do not pursue higher education.

### **Transition Savings Accounts and IRAs**

Many readers will be familiar with Section 529 education savings accounts; with tax-deductible, prepaid state school tuition plans; and with related measures designed to help build resources for college, and in some cases for primary and secondary education. Might it not be useful if families of children with disabilities were allowed to broaden the use of such accounts or prepayments, so that they would become not merely education savings but transition savings vehicles? NCD recommends that the Department of the Treasury study and report to Congress on the potential, from revenue and administrative standpoints, of establishing tax-deductible, contributory transition savings accounts, the proceeds of which would remain tax-exempt when

spent for qualifying transition activities, services, or purposes. In conducting this study, which should be completed within one year, Treasury should seek the input of the disability community regarding all key points, including the potential impact of such a program; the range of activities, goods, and services that should be eligible to qualify for transition expenditure; and the time frames within which funds should be expended.

### **Individual Development Accounts**

Many young people with disabilities come from lower-income families, and the benefit from tax-based strategies such as those suggested in the previous section will be limited for them. NCD believes that other measures are needed to infuse capital and resources into the transition process to facilitate entry into higher education, vocational education, or other pursuits. In particular, we believe that expanded use of individual development accounts (IDAs) could perform several important functions in this regard.

As established under both the Assets for Financial Independence Act of 1998 (AFIA)<sup>53</sup> and the Personal Responsibility and Work Opportunity Reconciliation Act (the welfare reform law) of 1996,<sup>54</sup> IDAs are savings accounts that allow specified categories of individuals and entities to contribute money for designated asset-building and life-enhancing purposes, ranging from job training to first-time home ownership. While there are various kinds of IDAs, applicable to different categories of people and having differing permissible savings goals and administrative rules, all IDAs have two basic features in common. They involve contributions by the saver and matching contributions from other public or nonprofit entities, and the funds saved in the IDA are not ordinarily countable in determining eligibility for other benefits or programs. Less clear, in the case of some IDA types, is the tax status of the funds when they are withdrawn.

In order to make IDAs a more effective tool for facilitating asset accumulation and entry into mainstream society, NCD urges Congress to commission a feasibility study of the broadening of the IDA concept to make this modality available to all students with disabilities for transitional purposes and to clarify the availability of a broad range of expenditure categories as permissible

within this framework. The tax deductibility of all contributed funds and the tax-exempt status of all properly withdrawn funds should also be made clear, as should the exclusion of IDA funds from means-testing under any other federal or state program.

## **Conclusions**

This chapter has addressed issues faced by Congress in the reauthorization of IDEA and a variety of pressing issues that require coordination between IDEA and NCLB for their resolution. It has also covered procedures for addressing concerns relating to the accessibility of school technology. The chapter addresses key concerns recently identified in higher education access and suggests innovative new strategies for helping to meet the seemingly intractable problems associated with transitional programs and services.

## **Recommendations Summary**

### **Recommendations to Congress**

*Recommendation 3.1*—Congress should ensure that when disciplinary considerations require the removal of students with disabilities from the mainstream, integrated classroom, such students are ensured the right to uninterrupted education, special education, and related services consistent with their IEPs and with evolving assessments and needs in the most appropriate educational settings.

*Recommendation 3.2*—NCD recommends that Congress and the Administration undertake a study of possible methods and sources for increasing over time the level of federal participation in special education to 40 percent.

*Recommendation 3.3*—NCD recommends that Congress establish a commission to study the long-term costs of special education and to recommend strategies for ensuring the financial stability of state and local education agencies in meeting national educational goals for students with disabilities.

*Recommendation 3.4*—NCD recommends that before the enactment of any further curbs or restrictions of a procedural or economic nature on the due process rights of parents, Congress fully review the impact and efficacy of these existing provisions designed to curb litigation and complaints.

*Recommendation 3.5*—NCD recommends that because adequate data does not yet exist to justify the curtailment of parental due process rights in special education, Congress undertake definitive research that would provide empirical evidence on the impact of appeals and of attorneys on special education before further restricting family rights.

*Recommendation 3.6*—NCD recommends that Congress, in its reauthorization of IDEA, include provisions calling for adoption of ED’s consensus NFF (or if a comment period reveals that this standard is unsatisfactory, then for development of another one) that would have to be met as a condition for textbook purchase. Congress should also adopt the provision in the Senate draft bill calling for the establishment of a national repository of computer files so that books can effectively and promptly be made available in accessible formats to those schools and students who need them.

*Recommendation 3.7*—NCD recommends that Congress include in the IDEA reauthorization provisions and resources supporting the conduct of a detailed national study on the availability, need for, and impact of a variety of accommodations that have been used in various school settings. This study should be conducted with a view to identifying approaches to the development of a national strategy that will meet the ultimately complementary needs of students with disabilities and the needs of school systems. The study should also attempt to assess the impact of various accommodations on test outcomes, so their impact can be taken into account in the norming of tests and in ensuring fairness and compatibility of results.

*Recommendation 3.8*—NCD recommends that Congress include in the reauthorized IDEA an instruction to the Secretary of Education to collect data on the availability and utilization of

accessible instructional materials and assistive technology in the schools, and to collect all available data on the connection between the application of such resources and of a variety of reasonable accommodation strategies, with measures of the status and outcomes of students with disabilities.

*Recommendation 3.9*—NCD recommends that the NETP set forth as a cornerstone and a fundamental requirement of America’s education technology policy that all technology resources and tools created or used must be accessible to and usable by all students, irrespective of disability.

*Recommendation 3.10*—NCD recommends that if Congress cannot address these substantive issues in a manner that their complexity and importance warrant, and in a manner that ensures the necessary level of program accountability, Part B of IDEA should not be modified or changed but should be left in tact until the necessary further deliberations can take place.

*Recommendation 3.11*—NCD recommends that Congress hold hearings on the barriers facing students with disabilities as part of its consideration of the Higher Education Act reauthorization, and that students with disabilities be invited and encouraged to share their views and experiences with lawmakers.

*Recommendation 3.12*—NCD recommends that Congress expand its assessment by incorporating into the Higher Education Act provisions paralleling the textbook and technology accessibility measures recommended above for IDEA. NCD recommends that if Congress lacks time or inclination to conduct a thorough review of higher education in relation to students with disabilities at this time, Congress should include in the reauthorization an instruction and resources for the Secretary of Education to conduct a thorough study of these issues, through the appointment of a national commission composed of representatives and members of all relevant constituencies, including youth with disabilities.

*Recommendation 3.13*—NCD urges Congress to commission a feasibility study of the broadening of the IDA concept to make this modality available to all students with disabilities for transitional purposes and to clarify the availability of a broad range of expenditure categories as permissible within this framework. The tax deductibility of all contributed funds and the tax-exempt status of all properly withdrawn funds should also be made clear, as well as the exclusion of IDA funds from means-testing under any other federal or state program.

### **Recommendation to the Department of Education**

*Recommendation 3.14*—NCD recommends that ED promulgate detailed policy guidance that applies, so far as deemed appropriate and with such differences as are deemed necessary, the teacher qualification provisions embodied in NCLB to the unique needs and conditions existing in special education and to the special education and related services disciplines deemed to come within the scope of NCLB. In this regard, NCD further urges Congress to incorporate in the reauthorized IDEA resources and authority for the Secretary of Education to conduct a detailed assessment of the personnel and personnel-preparation needs for students with disabilities, of the current resources available for training specialized personnel, and of means by which the resources required to fulfill identified intermediate- and long-term specialized training and personnel needs can be reliably and stably met.

### **Recommendation to the Department of the Treasury**

*Recommendation 3.15*—NCD recommends that the Department of the Treasury study and report to Congress on the potential, from revenue and administrative standpoints, of establishing tax-deductible, contributory transition savings accounts, the proceeds of which would remain tax-exempt when spent for qualifying transition activities, services, or purposes. In conducting this study, which should be completed within one year, Treasury should seek the input of the disability community regarding all key points, including the potential impact of such a program; the range of activities, goods, and services that should be eligible to qualify for transition expenditure; and the time frames within which funds should be expended.

# Chapter Four

## Health Care

### Introduction

This chapter presents current issues and concerns about the health care system. It highlights issues of general concern in terms of the particular ways they affect people with disabilities, and it addresses issues that are likely to become more widely discussed in the near future, as well as several issues that have resisted solution for some years.

The first section addresses the Medicaid program. The next section reviews testing and approval of assistive technology (AT) devices by the Food and Drug Administration (FDA) and by the Centers for Medicare and Medicaid Services (CMS). The following section concerns the implications of the new HIPAA privacy regulations for people with disabilities. Later sections address Medicare at the dawn of its coverage of prescription drugs, revisit the dual Medicare- and Medicaid-eligible population, consider issues of mental health services and parity, and discuss possible tax-based strategies for making health insurance more affordable.

### Medicaid

Medicaid is the primary program for the provision of health care to low-income Americans, including older persons, children, and people with disabilities. The past year has been a tumultuous and important one in the history of Medicaid, as this and the next few years promise to be. Because most of the discussion of Medicaid's future appears to take place with little reference to the specific concerns of beneficiaries with disabilities, NCD deems it extremely important, as we have in a succession of annual progress and specialized reports,<sup>55</sup> to continue addressing these concerns and bringing them within the focus of the overall public policy and budgetary debate.

## **Institutional Bias**

Because Medicaid pays for nursing home care for eligible persons, including many older Americans and Americans with disabilities, it is more than a conventional health insurance program. We will discuss its central role in our nation's long-term care strategy in the next chapter. Here it is enough to reiterate the concerns voiced by many in the disability community that the legal structure of the Medicaid program includes powerful financial disincentives against allowing people to age-in-place, remain in their own homes, and live and die in their own communities. Instead, the structure of the program creates conditions that force people into institutions who would not choose to go into an institution if given a full and free choice in the matter, and who would not need to if services now provided only in institutions were available in home and community settings. Proposed legislation could assist the needs that are unmet in these areas.<sup>56</sup>

As a program established a generation ago, before the notion of aging-in-place or of community-based services and supports was widely known or well-established, and because it is a program that was established 25 years before the ADA enshrined the values of community integration in federal law, Medicaid's favoritism for nursing home placements and services over in-home supports and community services can initially be understood as an artifact of history. But as the issues and options become better known, more widely understood, and more pressing, contemporary causes play a larger and larger role in explaining the program's structure.

How does Medicaid foster and perpetuate a bias in favor of institutions over homes and communities? It does this in two main ways. First, the services authorized under the Medicaid law are divided into two major categories: those that are mandatory (meaning that states must provide them as a condition for participation in and receipt of federal funds under the program) and those that are optional (meaning that, with certain minor exceptions, states are free to provide them or not, and in some instances to define them as they see fit).<sup>57</sup> In addition, a third category of Medicaid services includes those provided under what are known as waiver programs.<sup>58</sup> Nursing home services are among the mandatory services, but the variety of in-home



services required by people who wish to and who could remain in their own homes and communities are either optional or are provided as waiver services.

Faced with dramatic budget shortfalls over the past three years, many states, called on to make difficult choices among conflicting expenditure and taxing priorities and confronted with rapidly rising Medicaid costs, have taken steps to curtail Medicaid expenditures. Because cutting mandatory services is difficult or even impossible, this has meant cutting optional or waiver services, which can be cut with much less need of federal approval or risk of federal disapproval.

Various studies have estimated that some 70 percent of Medicaid long-term care expenditures currently go to institutional care.<sup>59</sup> Although the President's NFI under the Choice Program and through other efforts has included a number of infrastructure, experimental, and direct-services grants aimed at enhancing community-based services, no data is known to us showing whether these initiatives have generated sufficient additional support for home and community-based services to offset the impact of state budget cuts on these optional Medicaid services or to lower the percentages of Medicaid long-term care expenditures going to institutional services.

As a starting point for understanding and addressing the institutional bias problem, NCD recommends that Congress hold hearings on the issue as early as possible in the second session of the 108th Congress in 2004. Such hearings are particularly urgent because other major reforms in Medicaid are under consideration.

In conjunction with such hearings, NCD recommends that CMS (the agency that administers the Medicaid program) begin publishing and updating on a regular basis detailed information on the proportion of Medicaid, Medicare, and other federal health care funds going to the provision or support of institutional versus home and community-based services and care. For people of low and moderate means living in or planning for retirement, such information may be as important as many other datasets and indexes the government publishes, such as nursing home quality data.<sup>60</sup>

## **Medicaid Waivers**

In an effort to facilitate experimentation and innovation, and in order to maximize state flexibility in the administration of the Medicaid program, CMS has made extensive use of its authority to grant states various waivers.<sup>61</sup> This means that states are exempted from provisions of the Medicaid law in order to provide different services or to provide established services in different ways that would otherwise be impossible. A sense of what Medicaid waivers were intended to do can perhaps be gleaned from what is still the best-known waiver, namely, the Katy Beckett waiver.<sup>62</sup> Dating back to 1982, this waiver was created to allow Medicaid services to be provided in the homes of children with disabilities. This occurred under circumstances in which family income would have entitled them to services only if the children entered nursing homes.

In view of attempts to broaden the mix of services available under Medicaid, waivers have generally been regarded as either benign or positive by advocates and beneficiaries alike. But recent indications are that the intention and impact, as well as the scope, of waivers may be changing in order to facilitate not the provision of new services, but the reduction or elimination of existing ones.

As waivers have proliferated in number, often each with its own eligibility rules, budget allocation, or waiting list, tracking them and using them to coordinate services has, according to many accounts reaching us, become increasingly complex and difficult. Recent reports suggest that the Administration is considering offering states a new kind of waiver.<sup>63</sup> Under this approach, states would receive both short-term financial relief and much greater administrative flexibility, but they might receive these in return for agreeing to long-term limits on how much they could spend on the program.<sup>64</sup>

Medicaid has traditionally been an entitlement program, in the sense that states were ensured of their applicable match (somewhere between 50 percent and 80 percent, depending on the amount of their permissible Medicaid expenditures and other factors). There was no absolute dollar limit

on what they could receive or spend. Eligibility standards and the medical needs of beneficiaries would determine their expenditure and reimbursement levels.

But by agreeing to long-term expenditure caps in return for short-term financial relief and greater management flexibility, states and the Federal Government risk fundamentally changing the structure of the program. Under this new waiver approach, states would agree to caps on how much they could receive. In essence, a contractual approach aimed at capping Medicaid expenditures would be used where a statutory authorization is unavailable.

The word “flexibility” is often heard in discussion of such potential waivers, but it can be used to justify many things, including potential cuts in availability or narrowing the definitions of various services; reduction of eligibility criteria to lower caseloads; changes in fee schedules or capping of expenditures for various services; limitations in the number of procedures, services, or visits allowed; and a host of other measures, all of which have been used in one place or another to help stem the steep rise in Medicaid costs.

NCD lacks sufficient information to offer an opinion on the desirability of these so-called super waivers. But we are certain that if they are to be fully evaluated, their potential impact on Medicaid beneficiaries with disabilities, including beneficiaries with low-incidence disabilities or unusual medical conditions, needs to be fully analyzed.

NCD also believes that because of the growing importance of waivers in the lives of Medicaid recipients, the process by which state waiver applications are developed, reviewed, and approved needs to be overhauled, regularized, and standardized. Transparent, open, and accountable procedures, which give due and guaranteed scope for beneficiary and public input and comment, must be developed and implemented without delay. In too many states, administrative procedure acts do not provide means for the public to participate in the development of waiver proposals or in the setting of budgetary or service priorities. The current system excludes the public and, most important, those segments of the public most profoundly affected by changes from any

meaningful opportunity to take part in the development of Medicaid policy. Accordingly, NCD recommends that the Department of Health and Human Services (HHS) require that state Medicaid plans include detailed descriptions of how waiver requests will be developed in ways that permit and encourage public and community input, and that each waiver request include detailed information about the nature of public and community input, pro and con, that was received. Further, to make certain that the waiver process is as open and accountable as the regulations that waivers modify, NCD recommends that HHS's own Medicaid waiver review processes be opened to public participation through publication of all waiver requests in the *Federal Register* with opportunity for comment, that the substance of comments be published with HHS decisions on them, and that all waivers be initially approved on a time-limited basis and be subject to review and renewal or modification after a specified period of time. If HHS determines that it lacks statutory authority to implement these reforms, or if HHS otherwise declines to take these steps, NCD recommends that Congress amend the Medicaid law to empower or require the Department to take the necessary steps.

### **Consumer-Directed Services**

NCD commends CMS for its efforts to evaluate, test, and expand the use of self-directed, cash-and-counseling, waiver-based, and other strategies for increasing the opportunities for Medicaid recipients to select their own services and service-providers and to take an increased role in the management of their own services.<sup>65</sup> Such efforts should continue and need to be fully incorporated into any comprehensive Medicaid reform effort.

Important questions exist about the extent to which such efforts can be expanded beyond home care services into some of the more traditional areas of medical care, and how these traditional medical services can be most effectively linked with community resources. The crucial role of patients and their families as active participants in the planning and implementation of their own treatment plans has become widely recognized and accepted. Medicaid (and Medicare) need to take as broad a look as possible into how these practices can be introduced into all phases of the federal health insurance programs. Even if only as a means of encouraging patient compliance

with treatment plans, such participation is increasingly central to the efficacy of all medical treatment and care. It needs to be no less a part of the federal health care programs as it is coming to be in those operating in the private sector. Accordingly, NCD recommends that Congress establish a national commission to study the question of how consumer participation and direction can be maximized throughout the federal health insurance programs, with a view to adding the findings and recommendations of this study to such Medicaid reform proposals as the Administration and Congress may in due course develop.

Pending the report of this commission, NCD recommends that Congress enact the Money Follows the Person (MFP) legislation currently before it.<sup>66</sup> Apart from its possible role in defining the scope of services that Medicaid will support, MFP would substantially enhance patients' participation in and consumers' direction of the Medicaid health care services they receive. Enactment of MFP would not be premature. As it relates to the prospective reform of Medicaid as a whole, MFP (and Medicaid Community Attendant Services and Supports Act [MiCASSA], discussed in the next chapter) would provide a template for consideration of other major reforms.

### **Medicaid Buy-In**

Though the reasons are complex and controversial, current trends point to the continuation of a long-term crisis in the availability of health insurance in our country. Whatever the reasons and whatever the solutions, large numbers of Americans, including children, are denied access to meaningful health insurance by cost, by preexisting condition exclusions, by lifetime cost caps, or by other factors outside their control. Medicaid buy-in programs, which encourage and assist states to offer insurance coverage on a sliding-scale cost basis to persons above the normal federal poverty lines, represent one viable strategy for dealing with this problem.

Elsewhere in this report we discuss the role of buy-in as a tool for reducing work disincentives for persons with disabilities. But this by no means represents the entirety of what such programs can do. NCD recommends that Congress begin the process of facilitating expanded use of

Medicaid buy-in programs, in light of their potential to reduce the number of uninsured Americans, by adopting the Family Opportunity Act.<sup>67</sup> This legislation would expand buy-in opportunities for families with children, contributing in many ways to the health and well-being of generations to come and to the functionality and stability of families today. NCD urges Congress to enact the Family Opportunity Act without delay.

## **Medical Device Review**

In 2002 Congress passed and the President signed the Medical Device User Fee and Modernization Act (MDUFMA).<sup>68</sup> In last year's progress report, NCD expressed both its hopes for and its concerns about this new law. The intervening year has not witnessed the progress or yielded the clarifications that we had hoped for.

MDUFMA was enacted in response to backlogs in the review of medical devices by FDA. Through a combination of user fees paid by device manufacturers and increased budget appropriations, the Act sought to reduce the time periods required for device review and otherwise to reform and rationalize the review process. What continues to concern NCD is the extent to which AT devices or universally designed devices that fall within the medical-device orbit can or will receive adequate attention under this new system.

FDA's device review program should take steps to ensure that persons with knowledge of disability and AT will be available, either as regular staff members or as consultants, to help review devices designed for use by, or with particular implications for, persons with disabilities. To the degree that user fees may permissibly and openly play a role in the prioritization accorded to the products of particular manufacturers, FDA should also bear in mind that the producers of assistive and universally designed technology may often be small companies with little capacity to pay such fees.

Because AT devices may serve low-incidence populations and seemingly rare needs, FDA should remember that many such devices are also highly innovative and unique, and that their

availability or unavailability can make critical differences in the lives of prospective users and in the prospects of the companies that manufacture and distribute them. The small number of people sometimes affected is outweighed by the large impact AT devices can have on users' lives. For these reasons, NCD recommends that FDA develop and publish a comprehensive plan for ensuring that assistive and universally designed devices with particular applicability to the lives of people with disabilities are evaluated on a priority basis by people who are knowledgeable about the issues and people such technology is designed to address.

An important parallel development that underscored the need for effective coordination must also be noted. The Medicare reform legislation enacted in December 2003, commonly known as the Medicare Modernization Act (MMA),<sup>69</sup> includes provisions to expedite Medicare review of medical devices for coverage under the program. Specifically, the law provides for national coverage decisions governing the availability of various devices to be issued within specified periods. It seems likely that the activities of FDA and CMS do, or should, overlap significantly in this area. Accordingly, NCD requests information from HHS, as the cabinet department with jurisdiction over both FDA and CMS, on the nature and extent of FDA and CMS interactions in the device review realm, and the measures taken to ensure the requisite coordination, cooperation, and sharing of information and of what may be limited resources and expertise in the AT area. Based on the results of this inquiry, NCD recommends that HHS develop and implement a comprehensive plan for ensuring that the resources of FDA and CMS will be brought to bear in a coordinated fashion to assess and review AT and universally designed medical devices. This coordination will ensure the earliest and most effective determinations possible on the suitability of such equipment for coverage under Medicare and other insurance programs.

## **HIPAA Privacy Regulations**

One milestone of 2003 was the coming into force of major new patient privacy guidelines under the Health Insurance Portability and Accountability Act.<sup>70</sup> These HIPAA regulations give patients increased rights with respect to the dissemination and use of their personal medical

information, but the methods used to implement the law raise some important issues for people with disabilities. Research and monitoring are needed to determine how and how well the rights afforded to patients by the law are being made known and available to persons with intellectual or sensory disabilities that may prevent them from reading, understanding, or otherwise accessing legalistic written forms. Are consent forms or informed consent notices made available in clear and understandable language, and, when necessary, are they being supplemented by individualized explanation? Are printed materials pertaining to rights under the law being made accessible in alternative, nonprint formats to persons with visual impairments? Are suitably skilled and discreet interpreters available when persons who are deaf or hard of hearing have questions about their rights or about the forms?

NCD is aware of no broad-based effort to describe or evaluate the accessibility practices of health care practitioners, hospitals, insurers, or other relevant entities in the HIPAA implementation context. Such data is vitally needed, especially in light of the further complexity resulting from the involvement of third parties as sign-language interpreters, people who read material aloud, or other intermediaries in the creation of media or exchange of information. Accordingly, NCD recommends that HHS, through its Office on Disability or such other unit as the Secretary deems appropriate, undertake a study into the methods used for implementation of HIPAA requirements for people with disabilities, and into the effectiveness of these methods as they relate to the particular access needs faced by various subgroups of people with disabilities. To do less runs the risk that HIPAA will become beneficial to only some Americans.

## **Medicare Reform**

Although the Medicare reform legislation enacted in late 2003 has been discussed by the press largely in terms of its impact on the availability of prescription drugs for older Americans, the new law in fact changes the Medicare program in many ways and raises important questions for people with disabilities. At this early point, as implementation of transitional prescription drug availability through drug discount cards begins on June 1, 2004, and as longer-term plans are made for full implementation of the law beginning in 2006, time is still available for ensuring



that the new law does not unknowingly harm Medicare recipients with disabilities, whether over or under the age of 65. This section of our report alerts policymakers, insurers, health care practitioners, and Medicare beneficiaries to some of these emerging concerns.

### **Choosing Coverage**

A variety of competitive interim drug benefit plans, offering the drug discount card, are likely to be made available to Medicare beneficiaries. While the broad parameters of income eligibility and amount of subsidy are standard, many other features of the program, including the precise range of pharmaceuticals to be covered under each company's discount card and the sources for obtaining them, are likely to vary. The variety of options and plans will undoubtedly include some plans that are more or less appropriate for every need, but their variety and complexity may also impose a heavy burden of knowledge and choice on consumers to select the plan, if any, that is best for them. For this reason, it is imperative that background information about the plans, sign-up forms, and other key consumer information not only exist, but be accessible to people with disabilities. Therefore, NCD recommends that in its oversight of the discount-card program and its role in approving proposals from insurers or drug providers, CMS require (and thereafter monitor for evidence of compliance) that all materials utilized or published by discount-card providers be available in a variety of written, accessible Web-based, telephone-based, and other formats. CMS should also ensure that reliable and readily accessible sources of assistance in understanding and comparing program provisions, and thereafter in negotiating the details of program participation, are available. At a minimum, this includes accessible Web sites, alternative formats, accessible facilities, and potentially individualized or auxiliary measures when necessary for Medicare recipients with disabilities. To accomplish these goals, NCD recommends that CMS provide appropriate mechanisms with precise guidelines for ensuring that the requirements in Sections 504 and 508 of the Rehabilitation Act for nondiscrimination and equal access are applicable to all documentation and outreach activities undertaken by private sector providers under the new law. To the extent that private sector managed care organizations and other drug and Medicare benefit and services providers will be federally financed to encourage their participation in the Medicare program, NCD recommends that CMS clarify

whether it regards these entities as coming within the coverage of the antidiscrimination provisions of Section 504 of the Rehabilitation Act. Moreover, to the degree that these entities provide information to the public, directly or indirectly via electronic and information technology, on behalf of the Federal Government and about federal programs, their communications with the public should be subject to the provisions of Section 508 as well.

### **The Mix of Services**

Although it is likely that discount-card providers will offer one or more medications in each of a number of major drug categories and for the treatment of most common conditions, the law vests broad discretion in providers to develop the drug formularies that best meet the needs of their programs and the needs of the intended target audiences. This still leaves open the possibility that, short of intentional discrimination, some plans may make choices that result in the relative unavailability of key medicines and services to persons with high-cost or low-incidence disabilities. As a result, the benefits of heightened consumer choice may, in practice, be denied to some Medicare beneficiaries with disabilities.

CMS needs to ensure that all eligible Medicare beneficiaries who choose to avail themselves of the prescription drug discount program can in fact get the prescribed drugs they need. More broadly, and on a long-term basis, CMS must ensure that Medicare beneficiaries with disabilities who elect to seek their Medicare services through managed care or another private-sector program partner (as the incentive systems being put in place under the new law will inevitably lead many people to do) will have access, irrespective of disability, to all the Medicare-covered services and facilities that they need. Accordingly, NCD recommends that CMS begin a planning process designed to ensure that the individual decisions of providers will not result in any Medicare recipients with disabilities being forced to choose between the increasing advantages of managed care and access to the particular treatments, modalities, and practitioners they need. If Medicare beneficiaries with low-incidence, high-cost disabilities are to have access to the advantages of drug discounts and managed care, it is important for this consideration to be incorporated into the planning process from the earliest days of the program.

## **Dual Medicaid and Medicare Eligibility**

Because low-income Medicare recipients are often eligible for Medicaid, too, they become what are known as dual eligibles. Although two insurance coverages would normally be assumed to be better than one, this is not always the case. As we have pointed out in prior reports, and as has been the subject of several major federal court cases,<sup>71</sup> the two insurance programs have some contradictory procedures.

For example, Medicaid payment for many durable medical equipment (DME) devices requires prior authorization by the state Medicaid agency. A Medicaid recipient, even if somehow able to afford such devices, could not go out and buy them first, then seek Medicaid reimbursement afterward. By contrast, Medicare coverage for such equipment is determined in most cases only when the beneficiary seeks reimbursement after having already purchased the device. Under Medicare, denial of a request for DME is generally not appealable unless the individual has already paid for the device and is seeking reimbursement for its cost.

So what do dual-eligible individuals do? If they somehow manage to go out and buy the device, they forfeit Medicaid coverage, with no certainty that Medicare will cover it. If they await Medicaid prior authorization and appeal any denial, they cannot in most situations hope to get any payment from Medicare. So in the end, the choice of either funding source, though made with no certainty as to the outcome, precludes recourse to the other funding source.

Very good reasons may exist for operating each of these programs in different ways. It is not our purpose to condemn or prefer either model. The problem, though, is that real people seeking assistive technology mobility devices (ATMD) or other DME are affected by the jagged interface between the two programs.

Faced with this situation, NCD recommends that Congress enact legislation providing for a pilot demonstration study under which the prior-authorization approach would be used exclusively with one group of dual-eligibles and the purchase-first approach with another matched group.

The results and implications should then be compared, and the solution and best practices that emerge from the research should be implemented.

## **Mental Health Parity and Services**

As we have done in previous reports,<sup>72</sup> NCD continues to recommend to Congress that it adopt legislation to ensure that all health insurance provides benefits for mental health treatment that are equal to the benefits it provides for the treatment of physical illness. In an era when separation of the mind and the body, of the physical, mental, emotional, and spiritual, have come to be recognized as outmoded, the justification for maintaining separate reimbursement systems and categories is no longer sustainable. Furthermore, by enshrining pharmaceuticals as the primary treatment modality for mental and emotional illness, we have acknowledged the primacy of organic factors in both physical and mental conditions. If both physical and mental illnesses are treated as organic conditions, the question of how insurance companies can justify systemic differences in payment for medical and pharmaceutical services becomes more compelling.

To the degree that a specialized system for the diagnosis and treatment of mental and emotional health conditions does exist, the year 2003 witnessed an important contribution to our knowledge about that system. Confirming many of the findings of NCD's own earlier study, the report of the President's New Freedom Commission on Mental Health was issued.<sup>73</sup> This report, like NCD's, identified major shortcomings—coordination and systemic problems—in our current arrangements for the provision of mental health treatment and services and made important and far-reaching recommendations for reform.

In view of the accumulating weight of findings and data, NCD recommends that Congress take steps to implement the major recommendations of these reports. To that end, NCD also recommends that the Administration publish detailed, point-by-point reactions to the findings and recommendations, and that OMB be instructed by the President to prepare detailed estimates of the costs, savings, and benefits that would accrue from the adoption of each of the recommendations.

## **Insurance Premiums**

Universal agreement exists for the proposition that too many Americans are without health insurance. But as widespread as the conviction that something must be done may be, opinions and proposals for how to reduce these numbers vary widely.

Consistent with its approach to various problems, the Administration has indicated its support for tax-based measures as one major technique for tackling the affordability problem. NCD notes that a number of tax-based strategies have already been brought to bear in this connection. From increased deductibility of the health and long-term care premiums paid by self-employed persons,<sup>74</sup> to the health care tax credit (HCTC)<sup>75</sup> that helps defray the costs of health insurance premiums for persons who have lost jobs due to certain developments in international trade or whose retirement pensions have been taken over by the Pension Benefit Guaranty Corporation, the tax system has been utilized to subsidize largely individually purchased insurance coverage.

While taking no position on the wisdom of further use of tax subsidies to achieve coverage goals, let alone on the utility of any particular proposal, NCD recommends that as a prerequisite to the adoption or modification of the law in this area, Congress instruct the Internal Revenue Service (IRS) to undertake a study of the relative potential of such measures to reduce levels of noncoverage and to make coverage more affordable to moderate- and lower-income persons. The study should also include information on the likely impact of such subsidization on the premiums charged and the rating and other actuarial practices that health insurers use.

## **Conclusion**

This chapter addressed major developments in the health care system during 2003, specifically as they affect and relate to persons with disabilities. It dealt with the ability of the government to formulate and execute health policy and discussed the implications of a number of proposals.

## **Recommendations Summary**

### **Recommendations to Congress**

*Recommendation 4.1*—NCD recommends that Congress hold hearings on the issue of institutional bias in Medicaid as early as possible.

*Recommendation 4.2*—NCD recommends that Congress amend the Medicaid law to empower or require HHS to take the necessary steps to make the Medicaid waiver process open and accountable to the citizenry.

*Recommendation 4.3*—NCD recommends that Congress establish a national commission to study the question of how consumer participation and direction can be maximized throughout federal health insurance programs, with a view to adding the findings and recommendations of this study to such Medicaid reform proposals as the Administration and Congress may in due course develop.

*Recommendation 4.4*—NCD recommends that Congress enact the Money Follows the Person legislation currently before it.

*Recommendation 4.5*—NCD recommends that Congress begin the process of facilitating expanded use of Medicaid buy-in programs by adopting the Family Opportunity Act.

*Recommendation 4.6*—NCD recommends that Congress enact legislation that would provide for a pilot demonstration study under which the prior-authorization approach would be used exclusively with one group of dual-eligibles and the purchase-first approach with another matched group. The results and implications of the study should be compared and the solution and best practices that emerge from the research should be implemented.

*Recommendation 4.7*—NCD continues to recommend to Congress that it adopt legislation to ensure that all health insurance provides benefits for mental health treatment that are equal to the benefits it provides for the treatment of physical illness.

*Recommendation 4.8*—NCD recommends that Congress take steps to implement the major recommendations of the reports by NCD and the President’s New Freedom Commission on Mental Health.

### **Recommendation to the Administration**

*Recommendation 4.9*—NCD recommends that the Administration publish detailed, point-by-point reactions to the findings and recommendations of the report of the NFI Mental Health Commission, and that OMB be instructed by the President to prepare detailed estimates of the costs, savings, and benefits that would accrue from the adoption of each of the recommendations.

### **Recommendations to CMS**

*Recommendation 4.10*—NCD recommends that CMS (the agency that administers the Medicaid program) begin publishing and updating on a regular basis detailed information on the proportion of Medicaid, Medicare, and other federal health care funds going to the provision or support of institutional versus home- and community-based services and care.

*Recommendation 4.11*—NCD recommends that in its oversight of the Medicare discount-card program and its role in approving proposals from insurers or drug providers, CMS require (and thereafter monitor for evidence of compliance) that all materials utilized or published by discount-card providers be available in a variety of written, accessible Web-based, telephone-based, and other formats, and that reliable and readily accessible sources of assistance in understanding and comparing program provisions, and thereafter in negotiating the details of program participation, be available.

*Recommendation 4.12*—NCD recommends that CMS provide appropriate mechanisms with precise guidelines for ensuring that the requirements for nondiscrimination and equal access embodied in Sections 504 and 508 of the Rehabilitation Act are applicable to all documentation and outreach activities undertaken by private sector providers under the new law.

*Recommendation 4.13*—NCD recommends that CMS clarify whether it regards private sector managed care organizations and other drug and Medicare benefit and services providers as covered by the antidiscrimination provisions of Section 504 of the Rehabilitation Act.

*Recommendation 4.14*—NCD recommends that CMS begin a planning process designed to ensure that the individual decisions of providers will not result in any Medicare recipients with disabilities being forced to choose between the increasing advantages of managed care and access to the particular treatments, modalities, and practitioners they need.

### **Recommendations to HHS**

*Recommendation 4.15*—NCD recommends that HHS require state Medicaid plans to include detailed descriptions of how waiver requests will be developed in ways that permit and encourage public and community input, and that each waiver request be required to include detailed information about the nature of public and community input, pro and con, that was received.

*Recommendation 4.16*—NCD recommends that HHS’s own Medicaid waiver review processes be opened to public participation through publication of all waiver requests in the *Federal Register* with opportunity for comment, that the substance of comments be published with HHS decisions in response to them, and that all waivers be initially approved on a time-limited basis and be subject to review and renewal or modification after a specified period of time.

*Recommendation 4.17*—NCD recommends that HHS develop and implement a comprehensive plan for ensuring that the resources of FDA and CMS will be brought to bear in a coordinated



fashion to assess and review AT and universally designed medical devices to ensure the earliest and most effective possible determinations on the suitability of such equipment for coverage under Medicare and other insurance programs.

*Recommendation 4.18*—NCD recommends that HHS, through its Office on Disability or such other unit as the Secretary deems appropriate, undertake a study into the methods used for implementation of HIPAA requirements for people with disabilities, and into the effectiveness of these methods as they relate to the particular access needs faced by various subgroups of people with disabilities.

#### **Recommendation to FDA**

*Recommendation 4.19*—NCD recommends that FDA develop and publish a comprehensive plan for ensuring that assistive and universally designed devices with particular applicability to the lives of people with disabilities are evaluated on a priority basis and by people who are knowledgeable about the issues and people such technology is designed to address.



# **Chapter Five**

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

### **Introduction**

Through Social Security, our nation provides a system of income support for its senior citizens. Through Medicare, these citizens, as well as many younger people with disabilities, are also provided with health insurance and medical care, including most recently some assistance in meeting prescription drug costs. While both of these programs are buttressed by recipients' personal resources and by a variety of nongovernmental institutions, Social Security and Medicare programs are the bulwark of the security to which many people reasonably aspire.

However, with respect to long-term care not necessarily of a medical nature, ranging from help with activities of daily living (ADL) to institutional or custodial care, it does not seem unreasonable to say that America is without a system. Medicaid is probably the largest source of public sector participation in the provision and financing of long-term services and supports, both for older Americans and for many Americans with disabilities of all ages. Yet Medicaid was not designed to meet the range of needs that the aging of the U.S. population is bringing into ever-sharper focus.

This chapter attempts to articulate the scope of the challenge faced and to suggest some parameters for analyzing and responding to it. It describes the looming crisis that the country faces, introduces the concept of community integration, addresses the role of insurance, and urges application of the concepts of accountability and cost effectiveness to current policy.

### **The Looming Crisis**

Although it is not widely appreciated today, one of the major reasons President Franklin D. Roosevelt proposed Social Security as a cornerstone of the New Deal in 1935 was to facilitate national economic recovery. Economists reasoned that, beyond the reduction of poverty and the

easing of suffering, Social Security would free up large amounts of private capital for investment.<sup>76</sup>

Instead of having to spend their income to support their elderly parents, people of working age could invest that money in houses, cars, appliances, and other goods and services that would create demand and stimulate economic recovery. As the situation was with income replacement and maintenance in 1935, so is it rapidly becoming with long-term services and care today. With life expectancy increasing, unless our nation finds some way to reallocate the growing costs of long-term care, many middle class baby-boomers will live long enough to be driven into poverty, and many of their children will be forced to bear long-term care cost burdens. Such expenses could starve the economy of the capital needed for investment, purchase of housing, and stimulation of consumer demand.

When one considers how the costs of education for these caregivers' children are also rising, the consequences of this ticking social time bomb become even more frightening. Hence, long-term services are not just an issue for the people who need them today. They may be the most significant domestic economic issue facing this country. In an increasingly interdependent world, they may also have implications for our competitiveness, standing, and influence in the world that reach far beyond U.S. borders.

To draw out the comparison between Social Security and long-term services, this report also notes that income replacement at less than 100 percent was the issue for Social Security. With long-term services and supports, by contrast, the costs of minimally necessary measures may in some cases exceed what income replacement would have cost. That is to say, one would not ordinarily ever expect a social insurance program to replace 100 percent of a retiree's full-time earnings during the peak earning years. Yet with long-term care, the costs of even a modest array of services can easily exceed what the individual earned. In the case of persons with disabilities who receive personal assistance services while working, the costs can exceed what they are currently earning and certainly what they are able to pay.

While awaiting the results of NCD's study on long-term services and supports,<sup>77</sup> raising awareness around the scope and seriousness of the problem is necessary. That consciousness requires attention to the following key facts:

- In any discussion of the economics and demographics of long-term care, issues of disability and of aging converge.
- The number of people likely to need some sort of assistance in daily living, wherever they live, will increase dramatically as the population ages.
- Americans trumpet the medical advances that have prolonged life but appear to have little appreciation for the quality-of-life and resource allocation issues that come with responsible application of these medical advances.
- Thus far, funding for long-term services and supports overwhelmingly is directed toward nursing homes and other forms of institutional care. This occurs largely because programs such as Medicaid that channel long-term services funds derive from an acute care model of medical care, and the assumption has built up that those people who need nursing home care face more acute situations than people who do not.
- There has been reliance on unpaid family labor to subsidize a considerable portion of the costs of home care, and little data regarding the impact of such subsidization on the economy or on the ability of families to sustain or improve their standard of living has been collected.
- We have failed to develop partnerships (other than several developed experimentally in a few states) between government, employers, and insurers. Such partnerships would help middle class families to meet the costs of in-home support services associated with advancing age and with disability.

## **Community Integration**

Without identifying the source from which needed long-term support resources will come or how large those resources will need to be, the fundamental allocation questions facing society are:

What resources and services are provided with the funds, and to whom are the funds provided? As discussed in the preceding chapter on health, to the extent that Medicaid—the principal source of federal involvement in long-term care funding—maintains policies that favor institutional placement over home and community living, to continue the favoritism flies in the face of, and resists, a number of powerful and countervailing values and trends. Relying on experience under ADA—with its commitment to full participation, to the values of consumer-directed service-planning and individual choice, to the value placed on maintaining the family, to intensifying concerns for cost effectiveness—it is clear that these countervailing factors combine to necessitate a fundamental reassessment of Medicaid's role in long-term care as part of the thorough review of the entire Medicaid program that is likely to become a part of deliberations in the next Congress.

Regarding the equitable availability of home- and community-based services under Medicaid, the argument is not that institutional care should be denied to those who need and want it. Nor should the range of intermediate residential options, including various assisted living and group residential models that define the spectrum between one's own home and nursing home living, be excluded. All that is being argued is that people should have a fair and free choice, and that resources to support all choices should be available to support individual and family decision making.

The Supreme Court's now-famous 1999 *Olmstead v. LC* decision is the most powerful legal support for the current rebalancing effort.<sup>78</sup> It is not disputed in the wake of *Olmstead* that needless segregation of persons with disabilities in institutional settings violates ADA. However, because the *Olmstead* decision is not self-executing, the articulation and application of the community-based living realization have proved slower and more difficult than many advocates and supporters had hoped.

To facilitate the process, the Federal Government has adopted a variety of means to encourage and oblige states to enter into formal *Olmstead*-implementation planning processes. In this

regard, NCD particularly commends the Administration's decision to include in its federal budget funds for incentive and demonstration programs designed to assist and reward states in their *Olmstead* implementation efforts.<sup>79</sup> NCD also commends the Administration for sponsoring important research into a number of key related issues. While these measures, and the actions of states to date, will surely yield impressive, replicable, and persuasive models and findings that can become the norm and point the way to best practices over time, the harsh truth may be that we do not have the luxury of time to await percolation of the experiments and examples through the relevant official and consumer communities. More forceful and focused federal responses are urgently needed.

Research suggests that nursing home reimbursement has been far more resistant to, if not immune from, state budget cuts than home- and community-based services have been over the past five years (in other words, since *Olmstead*).<sup>80</sup> In light of the discussion of institutional bias in the previous chapter on health, this is not surprising. What findings such as these clearly indicate is this: In view of the variety of legal and economic forces operating to slow *Olmstead* implementation, strong and concerted measures are required at the national level to overcome the barriers and the inertia that perpetuate the design and habits of any long-established program.

### **Key Pending Legislation**

Two legislative proposals currently making their way through Congress represent a readily available point for jump-starting this reform effort. They are Money Follows the Person (MFP),<sup>81</sup> already discussed in the previous chapter, and the Medicaid Community Attendant Services and Supports Act (MiCASSA).<sup>82</sup>

Taken together, these two laws would go a long way toward making Medicaid more equitable. MFP would give Medicaid beneficiaries greater choice in how funds are allocated among existing covered services. MiCASSA would expand the home- and community-based services from which beneficiaries could choose and, hence, the services their money could follow.

Accordingly, NCD recommends that Congress adopt MFP legislation and MiCASSA without delay, as keystones in the new arch of long-term services policy in this country.

### **Actions Necessary**

Community integration has been a hallmark of this Administration's commitment since its earliest days in office. A number of innovative and exciting NFI initiatives in choice and in the design of services, involving various federal agencies, continue to reflect this profound commitment.<sup>83</sup> Yet, consistent with NFI, there is still much the Federal Government can and should do to increase *Olmstead* implementation and achieve NFI's outcome goals for community integration and living for all Americans.

First and foremost, measurable outcome goals and time frames must be established for state *Olmstead* planning and implementation efforts. Indeed, it may not be unreasonable to suggest that something akin to the adequate yearly progress (AYP) approach used in the education arena is applied here to require states to demonstrate measurable progress year after year toward the achievement of *Olmstead* NFI goals. For this reason, NCD recommends that CMS require timely planning for and documented achievement of *Olmstead* goals as a condition for states to receive federal funds under the Medicaid program. It would be one thing if the incentive funding currently available were enough to make a real difference in most or all states. In the absence of such funding, the pairing of incentives with the prospect of significant sanctions for noncompliance will bring about the requisite level of effort and change within a reasonable period of time.

Second, action is necessary to ensure that the CMS time frames, planning requirements, and outcome measures and the implementation strategies states develop for themselves will be achievable and responsive to the needs and concerns of all Medicaid constituencies. In this regard, NCD recommends that CMS initiate a formal and intensive information-gathering process. This should be preparatory to rulemaking and designed to result in the issuance, within 18 months, of proposed regulations governing the new *Olmstead* priority. Furthermore, NCD



recommends that if CMS believes that it is not authorized by the existing Medicaid statute, ADA, or the Supreme Court's *Olmstead* decision to take these actions, HHS should immediately seek from Congress the necessary legislative authorization.

To expedite the articulation and achievement of *Olmstead* NFI goals, NCD believes there are a number of powerful incentive measures that the Federal Government could take that would contribute to the speed and effectiveness of *Olmstead* implementation by states. In FY 2004, states received a three-percent increase in the federal matching percentage under the Medicaid program.<sup>84</sup> It is widely believed that the federal budget deficit plus an improving state revenue picture will preclude the extension of this one-time bonus. Nonetheless, the effect of selective extension of an enriched match formula could be disproportionate, if targeted to the key planning and implementation efforts critical to the success of *Olmstead*.

For this reason, NCD recommends to Congress that the three-percent increase in federal matching percentage be retained, but specifically for application to those reimbursable Medicaid activities and services that are related to the development and provision of home- and community-based services. To that end, CMS should develop guidelines to clarify exactly when and for what expenditures such heightened reimbursements will be available, so that, assuming Congress adopts this recommendation, states will be in no doubt regarding their options.

A third necessary action pertains to a measure Congress should take to ease the short-term problem related to helping current family caregivers cope with their burdens. Specifically in this regard, NCD recommends enactment of the Lifespan Respite Care Act.<sup>85</sup> Along with this legislation, Congress should authorize the Secretary of HHS, in conjunction with the Secretary of Labor, to conduct a study of the costs to the economy, in terms of education, employment, income forgone, and transfer payments, due to the demands of family caregiving on parents, spouses, siblings, and children.

## **Insurance**

Much attention in our nation is directed toward the number of Americans without health insurance. Surprisingly little attention, by contrast, seems to be directed toward the nature and availability of long-term care insurance. For example, especially lacking is attention to long-term care insurance that provides meaningful coverage for home- and community-based services and supports, as distinguished from or in addition to, nursing home care.

Even if Medicaid buy-in, MiCASSA, and MFP are all enacted, it is highly unlikely that Medicaid will ever be able to cover, or should ever cover, anything approaching the majority of people who will need help in paying for long-term services and care. Without significant partnership and involvement of the nation's insurance industry, no solution to this problem is possible. Yet these matters need to be addressed, whether through expansion of the scope of Medicare, redefinition of existing lines of disability insurance, or the creation of entirely new insurance options and products. NCD recommends that Congress hold hearings to fully explore the potential role of the insurance industry, the tax code, the employer community, and existing programs in fashioning experimental models of coverage that can be tested and studied.

In order that Congress has the benefit of the most accurate and up-to-date information, NCD recommends that these hearings be scheduled to coincide with the completion and publication of the study of long-term care financing being undertaken by NCD this year. Pending the findings of this important study, NCD will withhold any recommendations on the scope or sources of funding and organizational and statutory change that may be necessary to meet the foreseeable demand for long-term services and supports, home as well as institutional, in this country. However, one point is critical to keep in mind, even as the results of the study are awaited. The economic assumptions underlying current federal policies relevant to long-term care have never been subjected to rigorous evidentiary testing.

## **Cost Effectiveness and Accountability**

It is conventionally assumed that incorporation of home- and community-based services into the federal budget on a level equal to that of nursing home or other institutional services would be exceedingly expensive. Needless to say, if Congress believed community-based services would be significantly cheaper, it would probably have adopted the policy of directing of funds in that area by now. However widespread, the belief that major policy change would entail substantial additional cost remains unproved. It is strange indeed that in this era of evidence-based policymaking, when even the smallest programs are obliged to demonstrate their effectiveness and value, the assumption on which turns the expenditure of literally billions of dollars in public funding has never, to our knowledge, been subjected to rigorous testing or disciplined analysis.

Evidence submitted to the courts in a variety of deinstitutionalization cases, as well as the results of other studies, consistently indicate that on a per-capita basis, in-home and community supports are generally less expensive than the costs of nursing home care.<sup>86</sup> How then do we entertain what may be contradictory beliefs?

Part of the answer may lie in numbers. Largely unexamined, it may seem superficially obvious to policymakers that if home care services and supports were paid for on the same basis as institutional care, any per-capita savings that might be accrued would be offset by the potentially large number of people who would be eligible for and who would want such services. Moreover, if Medicaid undertook greater responsibility for these services, to what degree would the unpaid attendant-services labor of family caregivers need to be made reimbursable?

As related to people with significant disabilities, above and below the age of 65, at risk of nursing home placement, little information is available on these questions. In addition, thus far little is known about how much the demand for nursing homes for these same populations could be reduced through the provision of comprehensive community-based alternatives, enhanced screening of nursing home admissions, regular periodic review of placements, and nursing home preventive services delivered in the community and in the home. A broad understanding is

lacking with regard to the meaning of community supports, including integrated housing and transportation policy, and how support would affect the balance of choices between nursing home and personal home or the relative costs, per capita and in the aggregate, of the two systems.

It is expected that NCD's long-term care financing study will shed light on some of these questions and will point the way to the further research needed to answer other questions. NCD looks forward to the discussion that will result from publication of this long-term care financing study and to contributing to the innovative strategies and new solutions that will be fashioned in the coming months and years.

## **Conclusion**

A long-term care crisis has stolen upon us, almost unnoticed and unannounced. This chapter attempted to soberly suggest the severity of the problem. It has identified possible strategies for analyzing and responding to the growing need for long-term care and has identified assumptions and institutions that can play an instrumental role in responding to this need.

## **Recommendations Summary**

### **Recommendations to Congress**

*Recommendation 5.1*—NCD recommends that Congress adopt Money Follows the Person (MFP) and the Medicaid Community Attendant Services and Supports Act (MiCASSA) without delay, as keystones in the new arch of long-term services policy in this country.

*Recommendation 5.2*—NCD recommends to Congress that the three-percent increase in federal matching be retained, but specifically for application to those reimbursable Medicaid activities and services that are related to the development and provision of home- and community-based services.

*Recommendation 5.3*—NCD recommends enactment of the Lifespan Respite Care Act.

*Recommendation 5.4*—NCD recommends that Congress hold hearings to fully explore the potential role of the insurance industry, the tax code, the employer community, and existing programs in fashioning experimental models of long-term care coverage that can be tested and studied.

### **Recommendations to CMS**

*Recommendation 5.5*—NCD recommends that CMS require timely planning for and documented achievement of *Olmstead* goals as a condition for states to receive federal funds under the Medicaid program.

*Recommendation 5.6*—NCD recommends that CMS initiate a formal and intensive information-gathering process, preparatory to rulemaking, designed to result in the issuance, within 18 months, of proposed regulations governing the new *Olmstead* priority.

*Recommendation 5.7*—NCD recommends that if CMS believes that neither the existing Medicaid statute, ADA, nor the Supreme Court’s *Olmstead* decision authorizes it to take these actions, HHS should immediately seek from Congress the necessary legislative authorization.



# Chapter Six

## Youth

### Introduction

Separating out youth issues is always difficult. Everything that we do affects our children. In recent years people have seemed to demonstrate awareness of how tax policy has been affected by concerns for children—for example, in the increase in the child tax credit—yet no one would initially think of tax policy as a subject for inclusion in a chapter about the young.

Elsewhere, this report discusses a number of issues of concern to children and youth. For example, the discussion of education in Chapter Three, most notably of transition services, is about youth; and a number of the issues raised in Chapter Seven on employment will also have particular importance for youth. Nevertheless, this chapter attempts to identify a number of issues and themes that uniquely or disproportionately affect youth that are not covered under education, health, employment, or elsewhere in this report.

The first section concerns the treatment of youth with disabilities in the juvenile justice system. The next two sections address leadership and empowerment programs for youth and examine alternative definitions of youth as they relate to funding sources for youth development programs.

### Juvenile Justice

#### Recognizing the Problem

In May 2003 NCD issued its paper, *Addressing the Needs of Youth with Disabilities in the Juvenile Justice System: The Status of Evidence-Based Research*.<sup>87</sup> Paralleling in many important ways the findings of major reports by the Government Accountability Office (GAO)<sup>88</sup> and the President's New Freedom Commission on Mental Health,<sup>89</sup> NCD's study points up

issues that cannot be overlooked or minimized, if we value the human potential of our young and believe in fairness.

The report findings will not be reiterated here. However, certain key points are worth mentioning:

- There is little dispute that persons with disabilities are significantly overrepresented in the juvenile justice system, particularly as inmates or residents of juvenile corrections facilities.
- Existing delinquency prevention and juvenile justice programs do not, by and large, take cognizance of the existence, characteristics, or size of this subpopulation or of the issues involved in working effectively with it.
- Limited overall knowledge of how to prevent delinquency and redeem youth who are in the juvenile justice system indicates that the issues are even less explored or understood in relation to youth with disabilities.

### **Coordination**

An all-too-familiar theme runs through the reports mentioned above. It is the lack of coordination. Although the NCD report identified an existing interagency council on delinquency and a presidential task force, and saw both as potentially useful coordinating bodies, whatever latent potential they possess has yet to be realized for the most part. For an effective response to be fashioned nationally to the issues facing youth with disabilities in the juvenile justice system, education, law enforcement, civil rights, medical, and other program areas need to be involved and effectively coordinated.

### **Outcomes**

As important as aligning the players, and potentially more difficult, will be the clarification of assumptions and objectives. At a time in our nation when the juvenile justice system is generally tending to emphasize punishment and personal accountability over rehabilitation, causation, and



education, the danger must be candidly confronted that efforts to address the specific needs and situations of youth with disabilities can all too easily be misinterpreted as leniency or excuse-making. Nothing could be further from the truth.

What concerns NCD here, pending the conduct of further research, is that whatever policy initiatives come to characterize our juvenile justice system and guide its course in the coming years, they be developed and implemented with attention to some key variables and with a clear sense of who are the objects of system interventions. For instance, pretrial diversion programs (that is, programs that give many youth and adults charged with minor or first offenses the opportunity to avoid conviction or imprisonment by participating successfully in certain programs) that offer educational options cannot be fairly or effectively administered unless their design incorporates certain elements. For example, the programs must recognize that youth with reading difficulties or other learning disabilities need appropriate instructional techniques, resources, supports, and accommodations to produce highly positive results.

Similarly, aggressive behavior can, in many instances, be the result of emotional or behavioral illness. With no wish to excuse such behavior, only serious efforts to find and treat its causes can hold out meaningful, cost-effective hope of preventing its recurrence. In this light, NCD recommends that DOJ appoint a high-level national commission to authoritatively and accountably review all available evidence on juvenile justice systems and disability interconnections. We need to be sure that assessment and screening procedures for youth coming into the system are adequate to identify youth with disabilities; that court and agency procedures are fully accessible and afford youth with disabilities the fullest opportunity to participate in and understand the legal process and the related psychosocial assessments in which they are involved; that juvenile detention and treatment facilities have the knowledge and resources necessary to ensure that youth with disabilities will be able to participate in and benefit from the training that is made generally available to other youth, and have the knowledge and resources to identify and obtain specialized resources and training that may be necessary for youth with disabilities; and that we ensure that postrelease or alternative-to-incarceration programs and

supports are serving the needs of youth with disabilities as well as they are intended to serve other participants.

In order to ensure continuity in the way we deal with these issues, NCD recommends that the findings of the above-recommended national commission be formally reviewed, adopted, rejected, or otherwise responded to by a federal official with authority to speak for the Administration, and that those findings that are accepted be implemented under conditions that include accountability time frames against which success or failure can be measured.

For the sake of accountability, the national commission should include in its deliberations as detailed an assessment as available data will permit of the degree to which deficiencies in the juvenile justice system's recognition and treatment of youth with disabilities may be contributing to increases in the proportion of individuals with disabilities among the adult offender and prison population. Additionally, the national commission should explore the potential for timely and effective intervention with youthful offenders with disabilities to reduce the overall long-term costs to our nation of youth and adult corrections. Finally, the national commission should address the role of health insurance in addressing and combating behavioral health issues that may lie at the root of some antisocial or delinquent conduct.

We may decide as a society that the offense—not its cause, prevention, or treatment—is the key or sole relevant event in determining our handling of delinquent youth and lawbreaking adults. But if that is to be our decision, it should be one based on full knowledge, for only then can such a decision be adequately justified. Above all, whatever our objectives, common sense and accountability require that we take all possible steps to determine whether we are succeeding.

## **Youth Leadership Development and Empowerment**

Too often, programs that bear heavily on the lives of young people are devised by people with expertise and commitment, but exclude direct input from young people. To know what youth are

thinking, or how they are reinterpreting, articulating, and answering the fundamental questions for their generation, direct input is essential.

### **The Youth Advisory Committee**

As discussed elsewhere in this report, youth not only have the most vital stake in the programs that centrally affect them, but they may have unique and highly valuable contributions to make in the formulation of policy in education, career development, health promotion, and other areas. Beyond the specifics arising out of their experience, young people can also learn valuable lessons of leadership, civic responsibility, and democracy through participation in forums and activities that give them an opportunity to express their views on matters of concern and to be heard by others with an interest in them, their opinions, or their programs.

In support of all of these goals, NCD is proud of the work done by its Youth Advisory Committee (YAC).<sup>90</sup> Rather than reviewing the contents of our recent report here, we commend it to the attention of readers. Also, NCD recommends that the Administration instruct each federal agency that deals in any particular way with youth with disabilities or their families to develop means by which the opinions, experiences, and recommendations of this constituency or target population can be obtained and taken into account in future program planning. Given the wide range of mechanisms available for doing this, NCD does not suggest any particular approach or structure. The approach taken by NCD with the YAC has been noted as an effective approach, but there will be many other appropriate strategies as well. The point is that agencies should be encouraged to experiment with these strategies, to make use of the input and feedback, and to share with one another and with the public information about what works.

In the area of disability, such an approach may be particularly important, because even agencies with considerable expertise in various subject-matter areas may have no means for anticipating or assessing the impact of their decisions upon youth with disabilities.

## **National Youth Leadership Network**

In its annual progress reports over the past three years, NCD has discussed the work of the National Youth Leadership Network (NYLN).<sup>91</sup> Having done so, we will not repeat that discussion here. We do, however, feel compelled to reiterate a concern that has been growing ever more urgent. NCD recommends that the Administration make clear at the earliest possible moment its intentions with respect to its opinion and use of the work of the NYLN to date, and its intentions regarding continued federal support for the work of this project. If federal support is, for whatever reason, to be withdrawn, then time will still exist for consideration of structural and financial alternatives.

## **Definitions**

Somewhere between childhood and adulthood we find youth. No overall legal definition of the term has ever been needed or desirable. Each federal program that specifically addresses youth adopts the definition of this population that best suits the purpose of the law that authorizes each program.

In that connection it is interesting to note a recent decision by the Social Security Administration (SSA). In October 2003 SSA announced its Youth Transition Process Demonstrations (YTPD).<sup>92</sup> While the YTPD is interesting in several respects, its main importance here lies in the fact that it defined eligible youth as being between the ages of 10 and 25.

Though important in itself as a basis for broadening the jurisdiction and the sweep of important programs operating under various agencies' auspices, SSA's definition is important for another, very practical reason as well. It creates funding opportunities for a variety of not-for-profit and faith-based organizations that may seek to work with young people but may find conventional definitions of youth too narrow from the standpoint of the early intervention strategies or other modalities they seek to utilize. Such entities and those who fund them should be alerted by this action on SSA's part to the fact that considerably more discretion than they had supposed may exist for defining the youthful population to be served. For this reason, NCD recommends that

OMB develop and disseminate a brief statement, to be included on all relevant federal transmittals, grant applications, and contract documents and notices, reminding partners of the importance of establishing clearly under each program and with each agency with which they may work the parameters of “youth” under applicable law. Agencies should also be encouraged and authorized to approach the definition of youth in as flexible a manner as possible, consistent with the goals of the governing statute and the purposes of the program in question.

## **Conclusion**

This chapter has addressed issues of concern to youth that do not readily lend themselves to discussion under broad areas such as health, education, or employment. We have suggested areas in which, while inseparable from those of the population as a whole, the issues affecting, and the resources available for, youth with disabilities may differ from those applicable to the general population.

## **Recommendations Summary**

### **Recommendations to the Administration**

*Recommendation 6.1*—NCD recommends that the findings of the recommendations of a national commission appointed by the Administration be implemented. The findings must be formally reviewed, adopted, rejected, or otherwise responded to by a federal official with authority to speak for the Administration. Findings that are adopted must be implemented under conditions that include accountability time frames against which success or failure can be measured.

*Recommendation 6.2*—NCD recommends that the Administration instruct each federal agency that deals in any way with youth with disabilities or their families to develop means by which the opinions, experiences, and recommendations of this constituency or target population can be obtained and taken into account in future program planning.

*Recommendation 6.3*—NCD recommends that the Administration make clear at the earliest possible moment its intentions with respect to its opinion and use of the work of the National Youth Leadership Network to date, and its intentions regarding continued federal support for the work of this project.

**Recommendation to DOJ**

*Recommendation 6.4*—NCD recommends that DOJ appoint a high-level national commission to authoritatively and accountably review all available evidence on juvenile justice systems and disability interconnections.

**Recommendation to OMB**

*Recommendation 6.5*—NCD recommends that OMB develop and disseminate a brief statement, to be included on all relevant federal transmittals, grant applications, and contract documents and notices, reminding partners of the importance of establishing clearly under each program and with each agency with which they may work the parameters of “youth” under applicable law.

## **Chapter Seven**

### **Employment and the Workforce Development System**

#### **Introduction**

This chapter focuses on the major entities, programs, and issues involved in the effort to increase the number of people with disabilities who work and the quality, stability, and productivity of the jobs they hold. It deals with this broad and complex subject in two ways. First, it addresses specific employment and career-development programs that are of primary importance to job seekers with disabilities. Second, it analyzes some of the key linkages among these programs, with a view to developing mechanisms for enhancing their coordination. This chapter also seeks to stimulate discussion about how to create and apply critical concepts of accountability on a systemwide basis to public sector efforts and public-private partnerships in the job training and employment development and support arenas.

The first section considers the Workforce Investment Act, including the nation's One-Stop Centers. The next section examines the separately funded and administered vocational rehabilitation system for individuals with disabilities. The final section reviews a number of other resources and issues of relevance to the employment prospects of Americans with disabilities, including loan programs, tax incentives, and programs designed to reduce work disincentives in the Social Security system.

We undertake this discussion against a particularly sobering backdrop. For NCD, no less than for the Administration as a whole, employment is understood to be one of the most crucial issues facing Americans with disabilities. Indeed, within days of his inauguration, President Bush laid special stress on this concern in announcing his New Freedom Initiative (NFI).<sup>93</sup> For this reason, the apparent resistance of the problem to many of the new and creative approaches adopted under NFI must give grounds for reflection and concern.

Experts and advocates from all parties and perspectives recognize the extent and severity of the problem. A number of emerging trends suggest that the problem is about to take on a new urgency and new forms. While discussion of these trends is outside the scope of this report, their existence and implications for employment of Americans with disabilities cannot be ignored in the assessment of current measures or the development of strategies for the future. These trends include the following:

- A changing fit between labor market demand and worker training and skill sets (which bears on assessment and training options offered to those job seekers with disabilities who do not already have established career patterns or goals, or who need retraining if their skills are to be brought into line with employer needs);
- The aging of the workforce (which foretells a growing proportion of people with disabilities among the nation's workforce, and which raises new issues surrounding the kinds of interventions and resources that will prove effective in enabling people with adult-onset disabilities to remain productive for as long as possible); and
- The outsourcing (including the off-shoring) of jobs.

At the same time, indications are that the traditional safety net, which cushioned some of the consequences of joblessness for many persons with disabilities, may be coming under unprecedented pressure as an aging nation seeks ways to deal with growing long-term budgetary challenges. As attention turns to curtailing the growth and costs of Medicaid and to the solvency and long-term viability of all Social Security trust funds and funding streams, the assumptions for various income-support programs, including the Social Security Disability Insurance (SSDI) and Social Security Insurance (SSI) programs that play a major role as sources of income support in the lives of many people with disabilities, must inevitably be subject to careful reassessment.

In an era of heightened concern for program outcomes, no program or approach can be exempt from accountability for its results. We discuss this issue further in the third section of this



chapter. For the moment, it is enough to say that what most concerns NCD, above and beyond the efficacy of numerous worthy but isolated employment and training initiatives, is how evolving principles of accountability can be applied in ways that will enhance the ability of the workforce development system, in its mainstream and specialized components, to respond most effectively to the employment needs and aspirations of Americans with disabilities.

Few challenges have proved as resistant to our efforts as that of facilitating the entry of Americans with disabilities into productive employment on a par with that expected by other Americans. Indeed, perhaps in no area of civic, economic, or personal life has the experience of people with disabilities so radically diverged from that of the population as a whole. Consider what would be the effect—psychological, economic, and political—if more than 60 percent of adults of working age were unemployed. Rates of unemployment estimated at half that much during the Great Depression produced consequences that have continued to guide our public policy and sear our memories for three generations. Yet precisely these rates of unemployment remain the lot of Americans with disabilities, largely resistant thus far to all efforts at reform.

NCD commends the Administration for its focus on reducing these tragic disparities. With continued innovation, emphasis on applying new concepts of coordination and accountability to all the interconnected components of the employment development system, and attention to matters such as those discussed in this chapter, NCD hopes that the ongoing commitment by so many in this area can begin to yield meaningful statistical results and meaningful outcomes in the lives of Americans with disabilities, as well as yield attendant benefits to society, taxpayers, and the economy.

### **The Workforce Investment Act**

The Workforce Investment Act of 1998 (WIA)<sup>94</sup> was scheduled for reauthorization in 2003. In anticipation of that reauthorization, NCD's annual progress report issued in July 2003 included detailed recommendations and analysis regarding the Act.<sup>95</sup>

WIA is important to Americans with disabilities for two reasons. First, it sets out the parameters of and requirements for the One-Stop Centers system, which forms the core of federal job placement services for all Americans; and second, it encompasses the federal-state vocational rehabilitation (VR) system, which provides specialized vocational services to individuals with disabilities.

WIA was not reauthorized as scheduled, but during the period covered by this report, it was expected to be reauthorized during the second session of the 108th Congress during 2004. Because a version of the legislation passed the House in 2003<sup>96</sup> and a Senate bill was well along<sup>97</sup> at the writing of this report, NCD recognizes that the opportunity for additional input to the legislation at this juncture may be limited. The majority of the discussion here therefore pertains to features of the bill that are likely to emerge as part of the final legislation and pose issues that can and should be addressed by the administrative agencies vested with responsibility for implementing the law.

### **Antidiscrimination and Accessibility**

Section 188 of the existing WIA<sup>98</sup> contains important antidiscrimination requirements applicable to the One-Stop Centers and other entities operating under the Act. NCD commends the Department of Labor (DOL) for its issuance in 2003 of a Section 188 checklist designed to assist program operators in identifying their antidiscrimination obligations, assessing their performance, and identifying resources that can be of assistance.<sup>99</sup> But valuable as this checklist unquestionably is, we are concerned about whether this form of technical assistance is sufficient to ensure that One-Stop Centers are able to provide the degree of physical, information-technology, and programmatic accessibility required by the law and by the practical realities of full participation for people with disabilities. For example, if One-Stop Centers lack neither the resources nor the communications technology to implement accessibility of their facilities, neither the checklist nor associated technical assistance will solve the problem.

In order to determine whether One-Stop Centers are complying with the law and, as important, the reasons they do not succeed in complying, DOL needs to be vigorous in its monitoring and enforcement of the law. This is one key means for ensuring full participation in the workforce and employment development system by all job seekers, irrespective of disability. Various means of maintaining strengthened enforcement are therefore recommended for DOL's consideration. NCD recommends that DOL establish and publicize a complaint procedure for use by individuals who have been denied access, incorporate accessibility guarantees in requirements for state workforce development plans, and insist on inclusion of representatives of people with disabilities (or at least of state VR agencies) on state and local workforce investment boards (WIBs). To achieve these ends, NCD recommends that DOL, acting through its Office of Disability Employment Policy (ODEP) or through its Office of Inspector-General (OIG), jointly develop with DOJ a plan for vigorous and proactive enforcement of the antidiscrimination and accessibility requirements of the law bearing on the ability and willingness of One-Stop Centers to serve customers with disabilities.

### **Outcome and Performance Measures**

NCD supports ongoing efforts to develop outcome measures and performance indicators through which the efficacy and impact of the One-Stop Centers and WIA as a whole can be assessed. But we remain concerned that simple formulas such as those that place a premium on per capita cost or even on per-employment-outcome cost could have the unintended and counterproductive effect of discouraging One-Stop Centers from working with people who need extensive or individualized services, including persons with disabilities.

If program evaluation formulas are to be used that make no allowance for the potentially higher-than-average costs that may be incurred in working with individuals with disabilities, then at the very least NCD urges DOL, led by ODEP, to adopt a formula that takes equal account (through use of actuarial, survey, and other data) of the savings to the Treasury that result from successful job placement of individuals with disabilities. In evaluating the cost effectiveness of One-Stop Centers, it would be both unnecessary and unfair to take into account the add-on costs of

working with job applicants with disabilities while failing to acknowledge the potentially more-than-offsetting savings to the public resulting from the successful employment of such applicants. Accordingly, NCD recommends that DOL develop outcome measures that take due account of all the relevant variables involved in working with job seekers with disabilities, including not only the potential costs of working with this population within a mainstream setting, but also the benefits to the taxpayers of commitment and success in such work.

WIA recognizes the obligation of the One-Stop Centers to work with hard-to-serve individuals who may need specialized or individualized services. In fulfillment of that recognition, NCD commends DOL for the demonstration customized employment grants it has made. Preliminary figures indicating achievement of gainful employment by 595 of the first 1,292 persons served suggest that such programs have a role to play within even a system as large as that created under WIA.

### **Aging of the Workforce**

Our nation's workforce is aging, perhaps even faster than the population as a whole is. In addition to demographics, dramatic losses in middle class wealth stemming from stock market declines in the 2000–2002 period, coupled with the raising of the retirement age for receipt of full Social Security retirement benefits, along with likely declines in the provision of employer-sponsored retiree health insurance, are all likely to combine to increase the number of older persons remaining in our workforce.

Any increase in the number of older workers portends a substantial increase in the proportion of the workforce with disabilities, given the strong correlation between disability and aging.<sup>100</sup> If the economic stability of these workers and their families is to be preserved, and if potentially large and unnecessary increases in the costs of public and private disability pensions and other services due to early retirement are to be avoided, the Federal Government needs to begin fashioning a strategy in concert with industry to ensure that the productive work lives of these workers are not cut short. Indeed, the very stability of the retirement system may depend in part

on our ability to maintain older workers, with and without disabilities, in employment for as long as they are willing and able to perform their jobs.

Clearly, the job resumption or retention issues surrounding older workers with late-onset disabilities—many with established careers and premium skills—differ from the issues faced by younger persons with disabilities seeking to enter the workforce. Urgent research is needed on the role and capabilities of the VR system, the disability insurance system, the range of federally supported technical assistance and informational programs, and a variety of other resources and strategies as tools for facilitating retention of productive employment by older workers who incur disabilities but who need not leave work prematurely on that account. To this end, NCD recommends that the Administration establish a blue-ribbon task force to study this topic on an expedited basis and to make recommendations to Congress on measures that could be taken to strengthen the capacity of the economy to retain and benefit from the services and experience of older workers with adult-onset disabilities.

### **The Navigator Program**

The workforce development system established under WIA, while centrally focusing on the One-Stop Centers as a single entry point for access to information and services, ultimately depends for its effectiveness on the coordination, cooperation, and capacity of a variety of community partners, including “mandatory partners” under the law.<sup>101</sup> The process of coordination among both mandatory and voluntary partners is never an easy one, even when they share the same objectives and the same knowledge base.

In the case of individuals with disabilities seeking services from mainstream sources such as the One-Stop Centers system, one key problem relates to the strategies available for enabling One-Stop Centers’ staff to be apprised as fully as possible of the range of specialized resources and services that can be brought to bear on behalf of customers with disabilities. A closely related problem involves how different elements in the workforce development system, including DOL, SSA’s recently established area work incentive coordinators (AWICs), and SSA’s work

incentive cadres, can work together most effectively. In the efforts to improve this coordination and maximize the sharing of information and resources, NCD congratulates DOL and SSA on their establishment, on a pilot basis, of the Disability Navigator Program,<sup>102</sup> which should go a long way to ensuring that the needed expertise will be available and accessible to One-Stop Centers staff and service users.

The Navigator Program places in One-Stop Centers staff members who are knowledgeable about the range of specialized services available to assist job seekers with disabilities. With the Navigator Program, along with other strategies such as co-location of VR and One-Stop Centers facilities, NCD is hopeful that seamlessness will be attained to the highest possible degree. Yet more may be necessary to ensure that One-Stop Centers do all they can and should in providing effective services to all people who seek their assistance.

### **Outreach by One-Stop Centers**

Earlier in this chapter we discussed the critical importance of One-Stop Centers accessibility, in terms of access to facilities, to information technology used in the job-training and job-search processes, and to all aspects of the One-Stop Centers program. In ensuring this needed level of accessibility, one key step we believe needs to be taken involves the community partners—employers, training entities, referral sources, schools, employer associations, and others—with which One-Stop Centers and WIBs work and with which they have referral and planning relationships. Without imposing burdens on them that risk inhibiting their willingness or ability to cooperate in the creation of a coherent labor market system, means should be found by which One-Stop Centers can work to ensure that these entities, too, are as responsive and welcoming as possible to individuals with disabilities.

As important as it is for One-Stop Centers to be accessible, that accessibility may in the end do little good if the employers or training programs to which the One-Stop Centers refer job seekers are not. While One-Stop Centers lack legal authority or practical leverage to enforce consistently high accessibility standards on the variety of entities in the communities with which they deal, a

number of ways and a variety of situations may exist in which One-Stop Centers can tip the balance in favor of reasonable accommodation, accessibility, and success. As a first step, NCD recommends that DOL survey One-Stop Centers and people with disabilities who have received referral services through them to determine the measures the One-Stop Centers have used to monitor the treatment that people with disabilities receive at the hands of community partners, and the means the One-Stop Centers have developed for sharing expertise and resources with such providers in ways aimed at ensuring accessibility.

## **The Vocational Rehabilitation System**

As part of WIA, NCD expected that the Rehabilitation Act, governing the VR system for persons with disabilities, would be reauthorized before the publication of this annual progress report.<sup>103</sup> Accordingly, as with WIA as a whole, attention here is directed primarily to issues and provisions that are not likely to be modified by the new law, as indicated by the versions currently making their way through Congress.

### **Order of Selection**

Well over half the states are currently operating their VR systems under what are called orders of selection.<sup>104</sup> An order of selection is imposed when the state agency lacks funds to meet all the legitimate demands of eligible individuals for service. The order of selection declaration authorizes the state to limit and prioritize services to those persons with the most significant disabilities.

In rationing VR services under an order of selection, states are required to use criteria that will ensure that distinctions between people who will and who will not receive services are made solely on the basis of severity or significance of disability.<sup>105</sup> While critical attention has tended to focus on the fairness of orders of selection and on the appropriateness of the selection criteria used by states to determine which persons have the most significant disabilities, less attention appears to have been paid to other potentially serious consequences of the use of orders of

selection. Before these service-rationing procedures become so commonplace as to be more or less taken for granted, NCD believes that some of these other consequences should be explored and questioned.

The widespread and increasing use of orders of selection by many states for all or parts of consecutive years suggests a serious disjuncture between resources on the one hand and statutory obligations, as well as consumer need and demand, on the other. If resources are so chronically inadequate as to render it impossible year after year for many states to meet their full obligations under the law, then a very serious problem exists. Beyond urging due attention to the matter, NCD believes that suggesting specific solutions would be premature at this juncture. In order to better understand the problem and identify the most appropriate solutions, NCD recommends that Congress fully explore the consequences arising from the fact that the eligibility standards the law prescribes and the services it authorizes may not, in fact, be making their way through the pipeline to all intended end-users and service providers in communities around the country. If the VR system is not to reach all the people nominally eligible for its services, or is to provide a narrower range of services than officially prescribed, our nation ought to have a full and open dialogue about whether the scope of VR should be curtailed, whether new avenues for the delivery of necessary services need to be developed, or whether the resources available to the system should be increased and, if so, how.

In its actual effects even on people who make the cut and continue to receive the services they need, order of selection poses significant risks. The VR system functions as a primary service provider of course, and also as a key link in a larger service system, through a web of partnerships and reciprocal relationships, including mandatory partnerships with One-Stop Centers and WIBs, relationships with Ticket to Work and Work Incentives Improvement Act (TWWIA) employment networks, connections with school systems through joint responsibility for transitional services, relationships with SSA, and a host of other interactions through which services and resources are developed and provided. Under the law applicable to order of selection, people referred by or in need of referral to any of these partners, and people receiving



joint services (such as AT from the VR agency and placement services from another source) are accorded no special preference or priority. Some of the people affected by these referral relationships, joint service situations, or memoranda of understanding may well qualify for continued services under order of selection criteria; and some partners such as the TWWIIA program may have developed certain prioritized rights to VR services on behalf of ticket holders, but others may not. The results can be confusing and devastating.

So far as NCD can determine, the impact of order of selection on the ability of a variety of mainstream partners to adequately and fully serve the specialized needs of job seekers with disabilities has never been assessed. Nor, to our knowledge, has the impact been assessed of order of selection on the level of trust and confidence mainstream entities have in the reliability of VR as a partner. For a seamless, coordinated system to develop and take root, these dimensions of the subject need to be explored and analyzed.

As an indispensable adjunct to the building of effective collaboration, RSA must identify all the consequences of chronic and intermittent reliance on orders of selection. Accordingly, NCD recommends that RSA establish an investigative procedure to determine, through outreach to a variety of VR partners, the extent to which the aspirations and obligations of these partners to work collaboratively and smoothly with VR are adversely affected or unduly complicated by recourse to orders of selection. Persons with disabilities who have experienced breakdowns or time-sensitive discontinuities in services should be included in this research so the human dimensions of the problem will not be overlooked in favor of mere statistical presentations alone. It is one thing to find that X percent of partners were affected to this or that degree. It is quite another to say that actual people were deprived of services under circumstances that contributed to their failure to obtain or retain employment, or that tended to undermine the effect and value of other services for which the public has paid.

### **Technical Assistance**

Beyond the strengths and weaknesses of state VR agencies as direct-service providers, as purchasers of services, or as referral sources, one of the important and emerging roles for these agencies is that of providing technical assistance to partners in the workforce development system. Because this role is a rapidly evolving one, NCD believes that more information is needed on how it is being performed and with what results. Accordingly, NCD urges RSA to survey state VR agencies on their outreach and technical assistance activities and, depending on the findings, to consider including in state VR plans a requirement that states describe their activities and relationships in these areas.

### **Other Resources and Issues**

The job training, job placement, and employment support system of this country is composed of a large, if not bewildering, array of entities. For people with disabilities this can be even more the case than for the population at large. A number of new entities and programs have become part of the employment development system, and these must be taken into account in planning and evaluation.

### **Loan Programs**

In the past three years, two major AT loan programs have been developed for people with disabilities. Operating under the authority of Title III of the Assistive Technology Act of 1998<sup>106</sup> and under the combined rubric of alternative financing mechanisms, these are the Alternative Financing Program (AFP) for equipment loans and the Access to Telework Fund aimed at enhancing opportunities for telework by people with disabilities. Whereas the AFP program makes equipment loans available for a variety of purposes, whether self-employment or employment by a company or other entity, the telework program is exclusively focused on the latter and is regarded as a major component of NFI.

While such loan programs are valuable in extending available resources, drawing in new community partners, and allowing persons with disabilities to exercise new options for self-determination, their impact on the ways existing programs perform their statutory obligations and their impact on the creation of employment, the generation of borrower income, and the improvement in quality of life needs to be carefully evaluated. Likely a number of years will be required before any meaningful statements about the overall impact of these programs can be made.

In this connection, NCD applauds the National Institute on Disability and Rehabilitation Research (NIDRR) for the provision of technical assistance to these state-based programs through the Rehabilitation Engineering and Assistive Technology Society of North America (RESNA), and we commend the parallel activities of a group of federal agencies to evaluate the suitability of various categories of home-based employment as sources of employment for persons with disabilities. We are concerned, though, at how the job categories to be studied were selected. A news release about the program indicates that call centers and medical transcription are the two areas to be studied. NCD wonders whether these were selected based on data suggesting that they represented areas of potential demand and of reasonable income levels for home-based workers within the United States.<sup>107</sup>

NCD is also concerned about certain administrative features of the programs, such as why there needs to be the complexity, or the potential overlap or gaps, resulting from the existence of two such closely related but separate programs. Concern may also be warranted as to whether the targeting of funds specifically for telework or telecommuting, rather than for employment broadly, may not inadvertently create a tilt in favor of work at home that may not be entirely consistent with the values of community integration and mainstream participation.

A third concern is that state AT Act projects or newly created state loan program-administering entities have expressed worry about the nature of federal matching fund requirements applicable to state participation in the loan program.<sup>108</sup> Concerns have reached us about requirements for

upfront cash derived from state coffers, which may inhibit program effectiveness and prevent the development of new and creative partnerships utilizing noncash resources of potential importance to end-users. Accordingly, NCD recommends that, at least until states' fiscal situations improve significantly, NIDRR waive upfront cash requirements and accept a variety of other forms of documentable matching contributions, including noncash matches, so long as these in-kind or other noncash resources are reasonably amenable to valuation.

Yet a fourth concern with these AT loan programs relates to their potentially salient role in helping to establish the creditworthiness of borrowers. Numerous anecdotal reports indicate that, although borrower defaults can readily be reported to credit reporting agencies, timely and successful compliance with loan repayment obligations are much harder to put into an individual's credit record. This anomaly appears to result from the fact that the major credit reporting agencies will not accept favorable reports on individuals, but require such reports to be bundled so that at least a minimum of 100 at a time are transmitted to them. Because the loan funds are still relatively small and do not yet serve large numbers of individuals at one time, any aggregation requirement for the reporting of positive credit history data may work a hardship on these programs and on loan recipients. To investigate the extent of and bases for this problem, NCD recommends that the Department of Education, through its Office of Civil Rights (OCR), open an inquiry into the sources of these policies, and if they are found to exist as described to us, seek to remove this barrier to the establishment of positive credit history records by borrowers with disabilities. If possible, representations should be made to the major credit reporting agencies that would allow for avoidance of the aggregation requirement for these small loan programs, and for community development credit unions and other community-based organizations that deal with relatively small numbers of people for whom establishment of credit histories reflective of their demonstrated levels of responsibility and commitment would make a big difference.

## **Tax Incentives**

With the expiration on December 31, 2003, of the current version of the Work Opportunity Tax Credit,<sup>109</sup> attention once again turns to the question of tax incentives for the employment of underemployed populations, including persons with disabilities. The work opportunity credit (which was expected to be reauthorized before publication of this report) subsidizes a portion of first-year wages paid by employers to new hires from “targeted” groups. People with disabilities have been one of the targeted groups, but only indirectly. That is, recipients of SSI and VR systems referrals, both of which groups are likely to be largely or exclusively composed of people with disabilities, are two of the targeted groups.

NCD has long advocated, and reiterates its recommendation here, that if Congress deems this credit worth renewing, the credit’s availability should be extended to all persons with disabilities in need of employment. That is, the credit’s availability should not be limited to the two disability subgroups just noted, but should be extended to jobless persons with disabilities who are recipients of SSDI, participants in Ticket to Work programs, and any long-term unemployed persons who are otherwise readily verifiable as meeting established definitions of disability. Accordingly, NCD recommends that Congress revise the Work Opportunity Tax Credit so that all long-term unemployed persons with disabilities are eligible to benefit from the incentives it offers, and so that employers are free to hire any appropriate person with a disability and still receive this credit.

Another problem with the credit up to now is that it has not been available for rehires. Yet, for persons with disabilities seeking to return to the workplace, often after lengthy periods of unemployment, frequently doing very different work, return to a previous employer may be far more like starting a new job than like recommencing an established one. Job duties may be quite different, and the reciprocal fears and expectations of both employee and supervisors may belie and strain any preexisting relationship. Under these circumstances, NCD recommends that any reenactment of the credit, or any review of the credit in the context of broader tax legislation,

include provisions making it available for people returning to their former employers following significant periods of separation after the onset of a disability.

### **Ticket To Work**

When it was enacted at the end of 1999 as the last piece of major federal legislation of the 20th century, the Ticket to Work and Work Incentives Improvement Act (TWWIIA)<sup>110</sup> was hailed as a landmark development in providing new employment opportunities and resources for people with disabilities and in removing the disincentives to employment associated with the risk of losing health insurance as a result of earning income.

In its July 2003 annual progress report, NCD noted a number of problems that have been identified with the design of the program and with the interface between TWWIIA and the Social Security Act.<sup>111</sup> This year, the ongoing monitoring of the program is expected to result in the issuance of a number of important reports and findings by the TWWIIA advisory panel (TWWIAP) (including the congressionally mandated Adequacy of Incentives [AOI] report),<sup>112</sup> established by the law to advise SSA on the efficacy and implementation of the law. Should these reports disclose opportunities to improve the program, NCD recommends that the Administration move swiftly to remedy the problems uncovered, either by interagency, executive branch action or by proposing and supporting appropriate legislation, as the case may be.

Pending the results of this review of the TWWIIA program, NCD will refrain from making further recommendations at this time. We do note, however, that given the twofold purpose of TWWIIA to increase the range of employment-services options available to Social Security program beneficiaries and to reduce the disincentives resulting from the risk of loss of income or of health-insurance coverage under Social Security programs, any attempt to thoroughly assess and to fully effectuate the goals of TWWIIA requires us to take full account of the intersection between employment policy and health policy. And reference to the potentially significant but indirect results for employment of policies in the health care area brings us back to where we began, to the issues of coordination and accountability.

It may be that erosion of TWWIIA is among the prices that must be paid for needed budget cuts, such as cuts in Medicaid made by many states over the past three years; but if that is so, the choice should be made known in a manner that supports informed decision making and demonstrates accountability to citizens with disabilities and to the public at large.<sup>113</sup>

Accordingly, NCD recommends that Congress study the health insurance-related work disincentives problem anew, in the context of Medicaid cutbacks. This matter is further discussed in Chapter Four on health care.

## **Conclusion**

Beginning with the reasons for believing that unemployment among persons with disabilities is on the point of becoming a national crisis, this chapter has addressed the overall workforce development system as it relates to individuals with disabilities. It has also reviewed the specialized programs that attempt to enhance training and employment for members of this population, along with a discussion of tax incentives designed to promote the employment of people with disabilities and loan programs designed to augment existing resources.

## **Recommendations Summary**

### **Recommendations to Congress**

*Recommendation 7.1*—NCD recommends that Congress fully explore the consequences arising from the fact that because of order of selection, the eligibility standards the VR law prescribes and the services it authorizes may not, in fact, be making their way through the pipeline to all intended end-users and service providers in communities around the country.

*Recommendation 7.2*—NCD recommends that Congress revise the Work Opportunity Tax Credit so that all long-term unemployed persons with disabilities are eligible to benefit from the incentives it offers, and so that employers are free to hire any qualified person with a disability and still receive this credit.

*Recommendation 7.3*—NCD recommends that any congressional reenactment of the Work Opportunity Tax Credit, or any review of the credit in the context of broader tax legislation, include provisions making it available for people returning to their former employers following significant periods of separation after the onset of a disability.

*Recommendation 7.4*—NCD recommends that Congress study the health insurance-related work disincentives problem anew, in the context of state Medicaid cutbacks.

### **Recommendations to the Administration**

*Recommendation 7.5*—NCD recommends that the Administration establish a blue-ribbon task force to study the aging of the workforce on an expedited basis and to make recommendations to Congress on measures that could be taken to strengthen the capacity of the economy to retain and benefit from the services and experience of older workers with adult-onset disabilities.

*Recommendation 7.6*—NCD recommends that the Administration move swiftly to remedy any problems uncovered by forthcoming studies on the Ticket to Work program, either by interagency or executive branch action or by proposing and supporting appropriate legislation, as the case may be.

### **Recommendations to DOL**

*Recommendation 7.7*—NCD recommends that DOL establish and publicize a complaint procedure for use by individuals who have been denied access to One-Stop Centers, incorporate accessibility guarantees in requirements for state workforce development plans, and insist on inclusion of representatives of people with disabilities (or at least of state VR agencies) on state and local WIBs.

*Recommendation 7.8*—NCD recommends that DOL, acting through its ODEP or through its OIG, jointly develop with DOJ a plan for vigorous and proactive enforcement of the



antidiscrimination and accessibility requirements of the law bearing on the ability and willingness of One-Stop Centers to serve customers with disabilities.

*Recommendation 7.9*—NCD recommends that DOL develop outcome measures that take due account of all the relevant variables involved in working with job seekers with disabilities, including not only the potential costs of working with this population within a mainstream setting, but also the benefits to the taxpayers of commitment and success in such work.

*Recommendation 7.10*—NCD recommends that DOL survey One-Stop Centers and people with disabilities who have received referral services through them to determine the measures the One-Stop Centers have used to monitor the treatment that people with disabilities receive at the hands of community partners, and the means they have developed for sharing expertise and resources with such providers in ways aimed at ensuring accessibility.

### **Recommendations to ED**

*Recommendation 7.11*—NCD recommends that the Department of Education’s RSA establish an investigative procedure through outreach to a variety of VR partners to determine the extent to which the aspirations and obligations of these partners to work collaboratively and smoothly with VR are adversely effected or unduly complicated by recourse to orders of selection.

*Recommendation 7.12*—NCD recommends that, at least until states’ fiscal situations improve significantly, ED through NIDRR should waive upfront cash requirements and should accept a variety of other forms of documentable matching contributions, including noncash matches, so long as these in-kind or other noncash resources are reasonably amenable to valuation.

*Recommendation 7.13*—NCD recommends that ED, through its OCR, open an inquiry into the sources of policies that may hinder establishment of positive credit histories, and if they are found to exist as described to us, seek to remove this barrier to the establishment of positive credit history records by borrowers with disabilities.



## Chapter Eight

# Welfare Reform

### Introduction

This country operates numerous programs that provide federal subsidies to individuals on various bases. Some of these programs are grouped under the imprecise heading of “welfare.” The definition of what programs are considered welfare, what programs are subsidies, what programs are investments, and so forth is largely a function of the observer’s beliefs and priorities. Whatever one’s definition of the scope of welfare, it seems clear that the term has acquired a deeply pejorative meaning. When someone describes a program as welfare, often the comments are generally disparaging the program to a greater or lesser degree.

Various programs that seek to aid people of low income, including food stamps programs, nutrition programs such as the Special Supplemental Nutrition Program for Women, Infants and Children (WIC), and state and local general assistance, have widely been characterized as welfare. Yet the one program that has most universally received this designation, whether as condemnation or tribute, is Temporary Assistance to Needy Families (TANF), formerly known as Aid to Families with Dependent Children (AFDC).

Since enactment of the Personal Responsibility and Work Opportunity Reconciliation Act of 1996 (PRWORA),<sup>114</sup> which changed the program name, dramatically overhauled the system by incorporating benefit-amount limits and time limits, and established work requirements for recipients, the number of families receiving welfare has fallen steeply. While these declines in the welfare rolls have been widely hailed, concern has grown as to how recipients with disabilities have fared under the new law.

Perhaps because TANF was not viewed as a disability program, little data is available on the specific experience of people with disabilities under the 1996 legislation or its impact on their lives. Such data would be extremely valuable, however, in view of a GAO report that found that

some 40 percent of TANF recipients were either individuals with disabilities or the parent or caretaker in families containing one or more children or other persons with a disability.<sup>115</sup> As welfare caseloads have continued to shrink, leaving only a more hard-to-employ population among recipients, it is likely that this 40 percent figure may be even higher today.

PRWORA was scheduled for reauthorization in 2003. In the hope of assisting Congress in its deliberations, NCD published a major report on TANF in 2003,<sup>116</sup> and our 2003 annual progress report also contained detailed recommendations on provisions that NCD's research found to be critical to the effective implementation of the law.

Although a reauthorization bill was passed in the House<sup>117</sup> and a version was marked-up in the Senate,<sup>118</sup> Congress did not reauthorize the law. Instead, temporary extensions were used, and it was expected that the reauthorization legislation would be adopted in the second session of the 108th Congress during 2004. Based on the importance of the issues and because the concerns they reflect can be addressed in a variety of forums, including the adoption and revision of regulations implementing the new law, NCD believes it useful to summarize our major concerns and recommendations here.

The sections that follow discuss time limits and benefits caps, consider recipient work requirements, describe the potential of individual development accounts, and examine how individuals with disabilities may end up on welfare or as SSDI/SSI recipients.

### **Time and Benefits Limits**

Two of the features of the current law certain to be retained in the reauthorization of TANF are lifetime limits on the length of time to collect benefits and the amount of funding available to individuals and families under the program. For most people, transition to employment within these parameters (five years under the current program, for example) should be possible. But for some recipients with disabilities, these limitations can pose a problem.

While the law cannot be expected or designed to anticipate every individual circumstance, Congress should bear in mind that for many people with disabilities, the ability to enter or maintain gainful employment will depend on the availability of specialized support services and resources of a nature that would not be needed by other recipients and that may be unfamiliar to program administrators or evaluators. For these reasons, we continue to advocate two key measures. First, NCD recommends that Congress grant state TANF administrators expanded discretion to waive time or benefits limits in those cases where the support services needs resulting from disability cannot be sufficiently met to facilitate successful employment. From rehabilitation training, to assistive technology, to accessible transportation, to appropriately skilled child or spousal care, to adequate health insurance coverage, to the ability and willingness of employers to provide reasonable accommodations—any or all of these may prove crucial for the desired employment outcome to be achieved and sustained.

Second, to ensure that these key resources are identified in a timely fashion and are incorporated in the recipient's Personal Responsibility Plan (PRP), NCD recommends that the Secretary of HHS issue regulations requiring state TANF program administrators to set up screening and cooperative service-provision partnerships with state VR agencies (or where orders of selection prevent the state VR agencies from effectively offering their services to new people, with other appropriate entities) that can offer the expertise needed to ensure that TANF recipients' disability-related training and other employment-support needs will be properly identified and effectively met.

## **Work Requirements**

To ensure that people progress satisfactorily toward employment, the law is certain to retain work requirements bearing on how many hours a week recipients must engage in work activities during the transition period. The law is also certain to retain sanctions for those recipients who do not comply and are not excused from these requirements.

An important question for people with disabilities relates to the definition of work activities, specifically to whether and how much participation in rehabilitation or vocational training programs can count toward fulfilling the work requirements of the law.

The Pathways to Independence Act (S. 1523) was introduced by a bipartisan group of senators in 2003 and provided for up to six months of participation in rehabilitation services counting toward meeting the work requirement. NCD recommends that Congress adopt the Pathways to Independence Act as part of, or as an amendment to, the overall PRWORA reauthorization. We also recommend that Congress grant states the discretion to waive this six-month limit in cases where additional time would likely make the difference in bringing about long-term gainful employment.

### **Individual Development Accounts**

In our society, access to lifelong education and training is increasingly essential to meaningful employment. At the same time, the ability to amass financial assets, ranging from home ownership to retirement savings, has emerged as the indispensable pathway to long-term financial independence. For people who work regularly in reasonably well-paying employment, it is generally expected that the proceeds from their wages will be available as the basis for the creation of such financial assets.

For low-income people, including those leaving welfare for entry-level jobs, the resources necessary to begin the accumulation of assets may often be quite limited and elusive. For any number of reasons, opportunities for savings, investment, or access to credit may be quite limited.

Recognizing this and wishing to experiment with new modalities and partnerships for breaking the cycle of poverty, Congress enacted the Access to Financial Independence Act of 1998 (AFIA).<sup>119</sup> Among other things, AFIA provided for the creation and use of individual development accounts (IDAs) in a number of settings to help designated categories of people

accumulate the resources necessary to achieve employment and other important life goals. IDAs supplement earnings or other funds and are saved toward the attainment of designated, predetermined goals. They allow the accountholders to save funds, without penalties from other means-tested programs, and they allow these saved funds to be matched by various public and not-for-profit sources.

PRWORA carries this principle further with specific reference to welfare recipients by establishing what are known as TANF IDAs.<sup>120</sup> These accounts would appear to have great potential for all TANF work aspirants, but their applicability to TANF recipients with disabilities is limited in easily correctable ways.

Under current law, TANF IDAs can be created for three purposes: education and training, first-time home ownership, and small-business capitalization. Clearly, any and all of these are of as much pertinence to people with disabilities as to people without, but there are other categories of expenditure that people with disabilities confront in returning to work, categories that are often more difficult to fund, that TANF IDAs should be expanded to cover.

Assistive technology and accessible transportation are two leading examples of such costs. Difficulty in meeting the costs associated with these two resources surely plays a role in preventing many motivated people with disabilities from entering, retaining, or advancing in work. For this reason, NCD recommends that Congress broaden the definition of qualifying savings goals for TANF IDAs to include assistive or universally designed technology and modified vehicles or other specialized transportation services needed in order to work.

With respect to the existing TANF IDA provisions specifying first-time home acquisition as a qualifying IDA savings objective, NCD also recommends that DOJ evaluate whether, in order to comply with ADA, the definition of permissible acquisition expenses should be broadened to include the costs of home modifications where such modifications are necessary to make the home accessible for a person with a disability.

## **The Streaming Problem**

Although no data is known to exist, there is reason to suspect that of the 40-percent disability rate among TANF recipients found by the GAO, a number of people are eligible for Social Security Disability Insurance (SSDI) benefits. Nor is it unreasonable to suppose that happenstance or randomness played a role in determining which system these people were channeled into. Their status as welfare recipients versus SSDI recipients could result less from any systematic assessment than from the vagaries of who they spoke to, what office they went to, or what agencies they contacted. As important as it is that all people, with and without disabilities, and regardless of what benefits they receive, have their employment potential maximized, it would be both arbitrary and unjust for people who cannot readily work to be sanctioned or otherwise denied benefits without a full assessment of their overall circumstances.

Accordingly, NCD recommends that Congress require that before sanctioning any individual with a significant disability, or before curtailing benefits due to exhaustion of time limits to persons who may have a hidden disability or whose service needs as primary caregivers for family members with disabilities have not been fully assessed by knowledgeable persons, states ensure that these persons are offered the opportunity for a full medical-vocational assessment through the state's Office of Disability Determination and its VR agency.

## **Conclusion**

This chapter has addressed some of the major features of the welfare system as they relate to the circumstances faced by many individuals with disabilities. Believing that all people can and should work, NCD has proposed measures that would ultimately facilitate that goal for the largest number of people, while avoiding undue harshness to those who cannot readily be absorbed or accommodated in the current labor market.



## **Recommendations Summary**

### **Recommendations to Congress**

*Recommendation 8.1*—NCD recommends that Congress grant state TANF administrators expanded discretion to waive time or benefits limits in those cases where the support services needs resulting from disability cannot be sufficiently met to facilitate successful employment.

*Recommendation 8.2*—NCD recommends that Congress adopt the Pathways to Independence Act as part of, or as an amendment to, the overall PRWORA reauthorization. We also recommend that Congress grant states the discretion to waive the Act’s six-month limit in cases where additional time would likely make the difference in bringing about long-term gainful employment.

*Recommendation 8.3*—NCD recommends that Congress broaden the definition of qualifying savings goals for TANF IDAs to include assistive or universally designed technology and modified vehicles or other specialized transportation services needed in order to work.

*Recommendation 8.4*—NCD recommends that Congress require that before sanctioning any individual with a significant disability, or before curtailing benefits due to exhaustion of time limits to persons who may have a hidden disability or whose service needs as primary caregivers for family members with disabilities have not been fully assessed by knowledgeable persons, states ensure that these persons are offered the opportunity for a full medical-vocational assessment through the state’s Office of Disability Determination and its VR agency.

### **Recommendation to HHS**

*Recommendation 8.5*—NCD recommends that the Secretary of HHS issue regulations requiring state TANF program administrators to set up screening and cooperative service-provision partnerships with state VR agencies (or where orders of selection prevent the state VR agencies from effectively offering their services to new people, with other appropriate entities) that can

offer the expertise needed to ensure that TANF recipients' disability-related training and other employment-support needs will be properly identified and effectively met.

**Recommendation to DOJ**

*Recommendation 8.6*—NCD also recommends that with respect to the existing TANF IDA provisions specifying first-time home acquisition as a qualifying IDA savings objective, DOJ evaluate whether, in order to comply with ADA, the definition of permissible acquisition expenses should be broadened to include the costs of home modifications where such modifications are necessary to make the home accessible for a person with a disability.

# Chapter Nine

## Housing

### Introduction

Affordable housing is a serious and growing problem throughout our nation. But for people with disabilities, who typically have lower incomes than other citizens and who have nearly twice the poverty rate as the population as a whole, the problem of affordability is compounded. Added to the basic affordability problem is the scarcity of accessible housing for those who need it. And finally, overarching all, is the widely perceived failure of housing programs to address the specific educational, informational, financial, and other issues confronting many people with disabilities.

NCD has addressed the subject of housing in a number of studies and settings, including our in-depth report of two years ago.<sup>121</sup> In last year's annual progress report, we followed up the *Reconstructing Fair Housing* study with an inquiry into the extent to which the Department of Housing and Urban Development's (HUD's) five-year planning process succeeded in taking into account the issues facing people with disabilities.<sup>122</sup>

This year, we focus on issues surrounding the linkages needed to maximize the effectiveness of a number of housing programs for people with disabilities and on measures that HUD and Congress can take to improve the supply of accessible housing.

This chapter addresses coordination in the creation and implementation of national housing policy, reviews existing housing programs of special interest to people with disabilities, discusses civil rights enforcement, and introduces a number of strategies for increasing the accessibility of the housing stock through incentives to the public and private sectors.

## **Coordination**

NCD recognizes that HUD does not have the kind of comprehensive jurisdiction or oversight responsibility that would allow it to be held accountable for the success or failure of all federal housing policy in relation to people with disabilities. Depending on whether the goal is rental or home ownership, numerous other entities—ranging from Fannie Mae to local public housing agencies (PHAs) to mortgage brokers and lenders to community-based organizations (CBOs) to benefits counselors (who may need to assist people under means-tested benefits programs to understand the pitfalls and overcome the program participation disincentives)—may all need to be involved.

But even if all these entities are willing and able to work together to maximize the number of people with disabilities who can find affordable housing, widespread and systemic problems, such as the imperative to increase the proportion of accessible housing in the nation's housing stock, require the participation of yet additional entities. From DOJ (in its enforcement of ADA, the Fair Housing Act [FHA], the Architectural Barriers Act, and other laws) to the successive Administrations and Congresses (in their failure thus far to target the considerable incentive power of the home mortgage interest deduction or the low-income housing tax credit toward the building and renovation of accessible housing) to many other institutions that could be mentioned, any systematic effort to address the housing needs of persons with disabilities must necessarily require levels of coordination and partnership, not to mention vision, that simply do not exist and for which we have no proven models.

As the population ages, the critical problems of affordability and accessibility are likely to grow more pressing. Faced with this chronic but potentially worsening situation, NCD recommends that the Administration appoint a high-level national commission—composed of economists, housing and transportation experts, tax practitioners, legal analysts, architects, land-use planners, and individuals with disabilities—to map a long-term strategy for steadily increasing the proportion of the nation's housing stock that meets standards of accessibility.

## **Existing Programs**

All housing programs, whether aimed at supporting rental or ownership or designed to facilitate construction, have the capability and effect of benefiting people with disabilities along with everyone else. But a number of programs either have features that operate differently for people with disabilities or are designed specifically for this population. For example, HUD's Housing Choice Voucher program includes one competitive grant program specifically designated for rental housing assistance for families including members with disabilities.<sup>123</sup> Local PHAs apply specifically for these funds. Similarly, under the Section 8 home ownership program, individuals with disabilities may be eligible for mortgage assistance with lower annual incomes than would otherwise be the case.<sup>124</sup>

Taken together, programs such as these, along with other initiatives such as Fannie Mae's 3-percent down payment Home Choice Mortgage program,<sup>125</sup> the set-asides and savings achievable under the Family Self-Sufficiency (FSS) program, and the use of IDAs, can contribute significantly to the ability of many people with disabilities to obtain quality, affordable housing.

While these programs, used individually or in combination, can never be large enough to make a material dent in the problem, it is nevertheless important that they are utilized as effectively, and by as many people, as possible. The questions NCD believes need to be asked in this connection are: How widely are these programs known, understood, and, above all, utilized by the housing community and by people in search of housing? What resources exist or are needed to ensure maximum access to and utilization of these programs by people with disabilities? And what linkages and community partnerships need to be put in place to ensure that these programs can be effectively accessed?

Concern exists that the complexities attaching to these programs and the barriers to accessing them may well undermine their potential to a troubling degree. Income eligibility, documentation

requirements, timing, and many other issues must be confronted in identifying the barriers and making these programs work.

For example, IDAs are one vehicle for amassing capital for home buying. But for IDAs to be fully excluded from the computation of assets under means-tested benefits programs such as SSI, it is generally necessary that the matching funds going into them come from public rather than nonprofit sources. Similarly, while people who establish IDAs as a means of transitioning out of welfare under the TANF program are generally required to fund their portion of their IDAs solely out of earned income, this may not always be the case with other IDAs. How many community-based organizations understand these nuances, and how many low-income individuals with disabilities feel fully confident to use them, or even know about them, are all open to question and concern.

Through such resources as the Protection and Advocacy Services program for Benefits Planning, Assistance and Outreach (BPA&O), many people with disabilities can find assistance in understanding and resolving these and other disincentive conundrums in the law. Untangling the knots can still be extremely difficult and time-consuming and presents unique challenges in individual cases.

NCD commends HUD for the variety of technical assistance and outreach efforts it has launched in conjunction with other agencies to acquaint the housing community with the requirements of fair housing and to provide technical assistance in other areas. But we believe that to deal with this dimension of the housing gap (namely, access to the variety of specialized, small, but instrumental programs mentioned in this section), additional measures and new strategies are required. Accordingly, NCD recommends that HUD develop and disseminate a comprehensive publication explaining all the rental and home ownership programs available, with particular reference to the specific provisions dealing with people with disabilities. Through illustrations and case studies, HUD should be explaining all major potential interactions with other laws and benefit programs. This publication should be made widely available in a variety of accessible

formats and should be supplemented with one-to-one assistance via a toll-free line or Internet where required (as is provided for the Medicare drug-discount program by HHS or for the tax code by IRS). To ensure the responsiveness of the publication to a broad range of concerns, an advisory committee including housing advocates and community and disability groups should be convened to oversee and review the development of the document.

## **Civil Rights**

NCD wishes to commend HUD for the commitment to civil rights awareness and enforcement reflected in a number of its ongoing initiatives. From its conduct of an increased number of Section 504 compliance reviews, to its establishment of a Fair Housing Training Academy, to its plans to create a unit within the Office of Fair Housing and Equal Opportunity (FHEO) to investigate complex cases and pattern-and-practice cases, HUD's efforts represent an important commitment to the vital role of civil rights laws and civil rights enforcement in the implementation of federal housing policy.<sup>126</sup> In a spirit of constructiveness and encouragement, NCD would like to continue the dialogue with HUD and make several suggestions that we believe can improve the focus and outcomes of these efforts.

## **Interagency Efforts**

While HUD's involvement in and sponsorship of a number of interagency efforts is gratifying, we continue to be concerned about serious discontinuities in policies arising from gaps in the relationship between HUD and DOJ. Recognizing that these are not necessarily within HUD's control, their centrality to effective enforcement of civil rights laws in the housing area nevertheless requires that they be discussed here.

In a recent letter to NCD, following up on the recommendations in last year's progress report and responding to additional inquiries,<sup>127</sup> HUD described a number of joint efforts with DOJ, including operation since 1991 under a memorandum of understanding (MOU) that governs the referral of Fair Housing Act cases by HUD to DOJ.<sup>128</sup> Whether comparable MOUs exist in

connection with referrals under the other key fair housing jurisdictions—Section 504 of the Rehabilitation Act, and Titles II and III of ADA—was not made clear. However, somewhat shocking was the indication, elsewhere in the letter, that HUD’s referral to DOJ of recently uncovered Section 504 violations by the City of Baltimore’s Housing Authority represents the first instance in which such a referral has been made.

It is by no means clear that in the instances where cases have been referred to DOJ, HUD carries out any follow-up with regard to DOJ’s disposition of matters referred to it, that DOJ has procedures in place for seeking and incorporating HUD’s expertise in its disposition of such cases, or that HUD and DOJ have collaborated in ways that would ensure the presentation of referred cases in a way most useful to DOJ.

HUD’s letter indicates the expectation that referral of the Baltimore case to DOJ will send a powerful message to other housing authorities that HUD is serious about Section 504, but NCD is concerned that without equally resolute DOJ follow-up, much of this lesson may be lost. Under these circumstances, NCD recommends DOJ and HUD systematically address each of these issues and jointly publish and thereafter adhere to guidelines delineating the management of cases from HUD (or Fair Housing Assistance Program) complaints to DOJ or judicial disposition.

### **Voluntary Compliance Agreements**

HUD’s letter recounts the undertaking of some 93 Section 504 compliance reviews of housing agencies throughout the country operating HUD-funded programs during FY 2003. The letter indicates that four of these reviews were managed out of the department’s headquarters office. The letter further notes that four (possibly the same four as were centrally conducted) of the reviews found some degree of noncompliance sufficient to result in the commencement of negotiations to remedy these defects through entry into voluntary compliance agreements (VCAs) between the Department and the municipalities in question.



Left unanswered is the key question of what these compliance reviews tell us about the nature and level of noncompliance in the creation of accessible housing units and in other dimensions of Section 504 adherence by local PHAs. If these four major urban housing authorities were selected for review because of reports or complaints of noncompliance, that is one thing. But if they were selected randomly, then the fact that they all had problems is a matter of grave concern. Even if only 4 of 93 agencies were found to have problems, the question remains, is this number dangerously high or acceptably low?

As part of its effort to identify the nature and extent of discrimination in publicly supported housing, NCD therefore recommends that HUD undertake a study aimed at determining the extent and nature of noncompliance not only with Section 504, but also with Title II of ADA by local housing authorities and state PHAs.

### **Research**

NCD looks forward to the publication this fall of the results of HUD's research, utilizing matched pairs of testers, into the extent and nature of housing discrimination against people with disabilities.<sup>129</sup> While unquestionably very useful in uncovering certain types of housing discrimination, there remain many other forms of serious discrimination that are not likely to be detected by these techniques. The failure of architects and builders to incorporate required accessibility features into their designs or major renovations may occur long before there is any prospective buyer or renter to look at the property. While the failure to maintain working elevators, accessible paths of travel, or safe walkways, does not amount to the denial of accommodations, it achieves the same result by indirect, perhaps even unintended, means.

Accordingly, while encouraging HUD to publish the findings of its research on schedule, and while commending the several federal agencies that have devoted considerable effort to the dissemination of technical assistance to the architectural and building-management communities, NCD recommends that HUD develop research strategies, going beyond the use of testers in

matched pairs, aimed at identifying instances of discrimination occurring at nonpublic points in the housing process.

### **Training and Technical Assistance**

Through programs like its Fair Housing Accessibility First Initiative (the FIRST program), HUD has devoted important resources to the provision of training and technical assistance and to the dissemination of information to architects, builders, and others in the housing community. HUD's letter indicates that this program has had successful initial results in the broadening of knowledge.

While NCD is pleased at this assessment, we are concerned that in this era of accountability the Department's conclusions are too vague and subjective to dispel serious worries. By what standard does the Department purport to know that the hotline and related modalities used for this information dissemination have resulted in a sustained increase of relevant knowledge in the housing community? If by caller self-assessment, is such verification regarded as valid or reliable in the research community? If by random follow-up sampling, what level of specificity and what time frames were involved?

More significant than the question of whether knowledge was disseminated is the question of whether it is knowledge at all, rather than behavior, that matters. People know that they should not smoke, drink, eat to excess, or drive without seat belts, yet we hardly measure the effectiveness of public health interventions by the abstract knowledge gained by information recipients or by the volume of information disseminated. So, too, with housing discrimination or the accessibility requirements of the law, it is not people's knowledge that matters, but whether their behavior and practices are changed as a result of the training and technical assistance they receive.

While recognizing the notorious difficulty of deriving meaningful, objective evidence of the long-term impact of training and technical assistance programs, NCD believes that HUD must

devise methods for assessing these outcomes of its work. This need is particularly great where, as is currently the case, the Federal Government has not demonstrated its regard for traditional means of enforcement as the primary means for vindicating the law or the rights it protects. For this reason, NCD recommends that HUD, in collaboration with OMB, develop a research model for assessing behavior or other actual change, and thereafter conduct in-depth follow-up interviews after 6 and 12 months with a random sample of training and technical assistance recipients across the spectrum of programs utilizing these resources. The purpose of the research and follow-up is to determine the actual impact of this training on the way recipients carry out their work, on the manner in which they make decisions, and on the content of those decisions.

In this connection, the differences between new laws and those that have been in existence for 14 to 21 years (as have Sections 504, the Fair Housing Act Amendments, and ADA) must be emphasized. Technical assistance aimed at acquainting people with the existence and scope of new laws is one thing. But when technical assistance is still thought necessary to familiarize housing industry professionals with the provisions of laws that have been on the books for years, then some more fundamental questions need to be asked and some rethinking is in order. In an age of accountability, we have neither the time nor the funds to continue pouring out mere informational pieces, under circumstances where we have no evidence of how well they work, by themselves or relative to other strategies. Until or unless we know what works and why, the folly of continuing to do what we have been doing is clear, and the failure to analyze our approach is increasingly untenable.

### **Disability and Homelessness**

NCD appreciates HUD's important contributions to the work and recommendations of the NFI Mental Health Report published in 2003. Perhaps because of its engagement with the difficult issues surrounding discrimination, homelessness, and support services for persons with mental illnesses, much of HUD's discussion in its letter (which we continue to use as the basic source of reference for these comments) concerns itself with a variety of initiatives designed to prevent homelessness. Where NCD wishes HUD were more expansive is in the elaboration of its views

on the connection between disability and homelessness, its views on whether people with disabilities are at greater risk of homelessness than other populations, and its assessment of what is cause and what effect in any such relationship.

By and large, HUD programming in the disability and homelessness arena appears to take as its point of departure that economics, need for support services, lack of job or negotiating skills, and perhaps discrimination all combine to explain the occurrence of the problem. Albeit on a small and experimental scale, the variety of worthy, competitive grant programs HUD runs to address all these issues are likely to amass valuable data on best practices and to create replicable program models. Although programs like the Section 811 program need enhanced funding to meet existing needs, Section 811 and the other programs designed to break the link between disability and homelessness appear to reflect little recognition of other major factors that may be involved.

Even if we succeed in preventing homelessness among people with disabilities, we will have done little to alleviate the other problems associated with a shortage of affordable and accessible housing. As discussed in the first section of this chapter, HUD appears to not yet have an overall plan for how to make America's housing stock accessible, except to wait for its complete replacement by new housing over what could prove to be a century or more.

Even when not homeless, people with disabilities suffer many distortions and disruptions in their lives due to the shortage of accessible housing. HUD needs to know by how much the relative scarcity of accessible dwellings may itself contribute to the circle by exacerbating, as so many forms of social instability tend to do, the stress and sense of dislocation underlying much mental and emotional illness. HUD needs to know how much low incomes, per se, and how much higher housing costs contribute to such phenomena as the shockingly low rate (estimated at less than 10 percent, compared to more than 60 percent for the general population) of home ownership among persons with disabilities. HUD needs to understand whether people with disabilities who commute to their jobs are obliged to live further from their work, owing to the

shortage of accessible, affordable housing, than the average employee; and HUD needs to have some sense of whether such longer commutes, if found to exist, could contribute in any way to the high levels of unemployment among people with disabilities. HUD needs to know whether local agencies and private sector partners who build accessible housing units do so in any consultation with transit agencies. And HUD needs to know what, if anything, local housing agencies carrying out federally funded programs are doing to respond to the *Olmstead* mandate, given that the inability of some people, perhaps many, to leave or avoid institutions may result from the unavailability of accessible and affordable housing or from the lack of any nexus between housing and transportation.

Accordingly, as a basis for establishing coherence and priorities in housing planning and policy, NCD recommends that the high-level national commission recommended above to study how to expand the nation's accessible housing stock also be charged by executive order to include these issues in its mandate.

### **Incentivizing Accessibility**

Pending the completion of the research recommended above, NCD believes there are a number of measures that can be taken to improve the accessibility supply-and-demand equation.

#### **Disclosure**

NCD has made recommendations over the years for a number of measures that could bring economic incentives to the incorporation of accessibility features into residential properties of various types. We have suggested, for example, that consideration might be given to making the accessibility status of property a disclosure item for purposes of property sale or purchase. Such a requirement, while imposing no new mandate of any kind on the private sector or the real estate market, could go a long way to demonstrating that, far from being a negative factor in home valuation, accessibility, particularly in an aging population, contributes positively to the value and attractiveness of many properties. Accordingly, NCD recommends that Congress

authorize an experiment in a number of diverse states or regional housing markets under which accessibility status, as defined by HUD, would be added to the list of disclosure items under the Real Estate Settlements Procedure Act.

By way of additional measures aimed at encouraging voluntary efforts to make residential units and property accessible, NCD recommends that Congress study the feasibility and impact of tax-based and other measures for increasing the economic attractiveness of accessibility, such as measures that would speed up the recovery period for the costs of accessibility modifications, measures that would increase the availability of federally backed mortgage funds for the construction or transfer of accessible units, and measures that would target benefits under the housing tax credit to projects that incorporate universal accessibility.

### **Definitions**

The definitions of several key concepts used in the implementation of federal law are in need of updating. For instance, responding to NCD's questions about the meaning and application of the requirement of the law that 2 percent of federally financed housing units must be accessible to persons with sensory disabilities, HUD indicates that the meaning of this requirement is determined under the Uniform Federal Accessibility Standards (UFAS). The UFAS are 20 or more years old, were adopted long before the enactment of ADA, and contain no reference to or awareness of a variety of technologies and design strategies that have come into existence in the intervening decades, and that for all practical purposes have come to define what accessibility actually entails. Continuing to make policy decisions based on such outmoded guidelines is tantamount to making public health decisions based on what we knew about cigarettes or diet a generation ago.

HUD cannot and should not be expected to address these issues alone. The involvement of other public sector and nongovernmental partners will be needed if the work is to be done. However, HUD can and should show leadership and vision in laying out the research agenda and

challenging us to identify policy options and data sources that reflect contemporary values and knowledge.

A related definitional issue concerns how we measure disparities in housing to begin with. We have traditionally defined adequate housing in such terms as whether people's housing costs exceed 30 percent of their income; in terms of minimal square footage per person; in terms of heat, light, air, insulation, and other features. Are these still the parameters of adequate housing, or do definitions need to be updated to take account of new values, technologies, and needs, such as accessibility? And even using just the traditional criteria, is there a significant disparity between the percentage of people with disabilities who can find adequate housing and the percentage of people without disabilities who can? If there is significant disparity, what should be done about accepted definitions of minimally acceptable housing?

Faced with the necessity of reviewing and updating these and other key definitions of what we do, what we require and how we assess our progress, NCD recommends that HUD undertake a study of these and other definitions to determine what, if any, changes, through administrative action or legislative change, need to be made to bring definitions, technical requirements, and standards into compliance with modern precepts, and to ensure that what we ask members of the housing community to do continues to represent the most effective allocation of public and private resources.

### **Visitability**

Short of achieving full accessibility in all new construction or major renovations, visitability (involving a degree of accessibility that, while short of complete, at least allows persons with disabilities to enter and avail themselves of the basic amenities of buildings) appears to represent one of the most exciting interim strategies for broadening the social and residential choices available to Americans with disabilities and to those without disabilities who would welcome them into their homes. NCD gratefully acknowledges HUD's indication of support for this concept, but we believe more can be done to hasten its progress.

Since 1998 preferences have been given in competitive HUD funding awards under several Notice of Funds Availability (NOFA) competitions to applicants who include visitability in their plans or facilities.<sup>130</sup> But these competitive funding programs represent only a small and relatively temporary portion of HUD expenditures, let alone total housing-related, federal expenditures. To increase the use of visitability, NCD recommends that Congress study ways through which visitability could be incorporated into all federal funding streams. Such a study should include a review of ways that the tax subsidies associated with the building and ownership of residential property could be enhanced for properties that are made visitable or accessible.

The resources emanating from the Federal Government in the form of direct and indirect subsidies and incentives constitute a mighty engine. Few better ways could be found to enlist those resources on the side of full inclusion and opportunity, and in the service of the President's oft-stated and deeply held goals, than these that encourage and reward the important work that needs to be done.

## **Conclusion**

This chapter has examined some of the structural and systemic problems faced in increasing the supply of affordable and accessible housing for people with disabilities. Recommendations for research, experimentation, and statutory change were presented that would have significant short- and long-term potential to bring about greater equality in the housing expectations and opportunities available to Americans with disabilities.

## **Recommendations Summary**

This chapter includes recommendations to Congress, the Administration, the Department of Justice, the Office of Management and Budget, and the Department of Housing and Urban Development.



## **Recommendations to Congress**

*Recommendation 9.1*—NCD recommends that Congress authorize an experiment in a number of diverse states or regional housing markets under which accessibility status, as defined by HUD, would be added to the list of disclosure items under the Real Estate Settlements Procedure Act.

*Recommendation 9.2*—NCD recommends that Congress study the feasibility and impact of tax-based and other measures for increasing the economic attractiveness of accessibility, such as measures that would speed up the recovery period for the costs of accessibility modifications, measures that would increase the availability of federally backed mortgage funds for the construction or transfer of accessible units, and measures that would target benefits under the housing tax credit to projects that incorporate universal accessibility.

*Recommendation 9.3*—NCD recommends that Congress study ways through which visitability could be incorporated into all federal funding streams. Such a study should include a review of ways that the tax subsidies associated with the building and ownership of residential property could be enhanced for properties that are made visitable or accessible.

## **Recommendations to the Administration**

*Recommendation 9.4*—NCD recommends that the Administration appoint a high-level national commission—composed of economists, housing and transportation experts, tax practitioners, legal analysts, architects, land-use planners, and individuals with disabilities—to map a long-term strategy for steadily increasing the proportion of the nation’s housing stock that meets standards of accessibility.

*Recommendation 9.5*—NCD recommends that the high-level national commission recommended above to study how to expand the nation’s accessible housing stock also be charged by executive order to include these issues in its mandate.

## **Recommendations to HUD**

*Recommendation 9.6*—NCD recommends that HUD develop and disseminate a comprehensive publication explaining all the rental and home ownership programs available, with particular reference to the specific provisions dealing with people with disabilities, and, through illustrations and case studies, explaining all major potential interactions with other laws and benefits programs.

*Recommendation 9.7*—NCD recommends that DOJ and HUD jointly publish and thereafter adhere to guidelines delineating the management of cases from HUD (or Fair Housing Assistance Program) complaint to DOJ or judicial disposition.

*Recommendation 9.8*—NCD recommends that HUD undertake a study aimed at determining the extent and nature of noncompliance not only with Section 504, but also with Title II of ADA by local housing authorities and state PHAs.

*Recommendation 9.9*—NCD recommends that HUD develop research strategies, going beyond the use of testers in matched pairs, aimed at identifying instances of discrimination occurring at nonpublic points in the housing process.

*Recommendation 9.10*—NCD recommends that HUD, in collaboration with OMB, develop a research model for assessing behavior or other actual change, and thereafter conduct in-depth follow-up interviews after 6 and 12 months with a random sample of training and technical assistance recipients across the spectrum of programs utilizing these resources. The purpose of the research and follow-up is to determine the actual impact of this training on the way recipients carry out their work, on the manner in which they make decisions, and on the content of those decisions.

*Recommendation 9.11*—NCD recommends that HUD undertake a study of definitions to determine what, if any, changes, through administrative action or legislation, need to be made to

bring definitions, technical requirements, and standards into compliance with modern precepts, and to ensure that what we ask members of the housing community to do continues to represent the most effective allocation of public and private resources.



# Chapter Ten

## Transportation

### Introduction

In a June 18, 2004, letter to Congress, NCD recognized there has been significant progress in the accessibility of public transportation systems since enactment of the Americans with Disabilities Act and the supporting provisions of the Transportation Equity Act. Yet a substantial portion of the disability population is still unable to participate fully in many aspects of community life as a result of inadequate accessible transportation options. To continue the progress experienced to date in the growth and accessibility of the nation's transportation system, to address the problems and barriers remaining for people with disabilities in accessing transportation, and to meet the transportation challenges of the future, NCD presented four recommendations for congressional support: (1) House bill (H.R. 3550) approach to funding for New Freedom Initiatives that establish transportation solutions as a separate and distinct program with more flexibility and greater opportunities than other proposals by offering consumer-directed, innovative transportation solutions and allowing for the development of promising practices; (2) House bill approach to funding for Project Action, a highly successful federal program that brings transportation providers and people with disabilities together to improve access to transportation; (3) express inclusion of individuals with disabilities in all aspects of transportation plans and projects, as was done in identified sections of the House bill; and (4) provisions in the House bill that call for coordination of transportation resources at the federal, state, and local levels. (See [http://www.ncd.gov/newsroom/correspondence/2004/conrad\\_06-18-04.htm](http://www.ncd.gov/newsroom/correspondence/2004/conrad_06-18-04.htm).)

Transportation is often thought of as a subject in its own right. It is governed by laws and administered by agencies with the word "transportation" in their titles. While it is, of course, true that transportation is a distinct subject matter, it is equally true that it interacts with every other subject we consider.

Transportation options and systems affect our ability to get to school or work, to obtain health care, or to live independently in the community. Without recognition of its role in each of these areas of our lives, we cannot hope to understand the importance or grasp the complexity of the issues raised in any discussion of transportation policy in our country.

This chapter on transportation addresses the legal framework surrounding disability-related transportation issues, examines air travel, discusses issues and programs under the Transportation Equity Act for the 21st Century, and addresses concerns related to paratransit systems.

## **The Legal Framework**

Discussion of national transportation policies and resources for Americans with disabilities requires consideration of three important statutes: the Americans with Disabilities Act (ADA),<sup>131</sup> the Air Carrier Access Act (ACAA),<sup>132</sup> and the Transportation Equity Act for the 21st Century (TEA-21),<sup>133</sup> scheduled for reauthorization this year. Responsibility for implementing regulations, administrative oversight, and budgetary appropriations is distributed among at least three cabinet-level departments and many sub-agencies.

For this reason as much as for any other, NCD's assessment, while beginning with commendation for a number of ongoing implementation strategies and innovative efforts undertaken by the agencies involved, must also draw attention to emerging transportation issues that do not yet clearly fall within the scope of existing agency jurisdictions or oversight responsibilities.

## **Community Integration**

Requirements for accessible mass transit, antidiscrimination rules, and paratransit services have contributed greatly to the ability of Americans with disabilities to lead full lives within their communities; but shifting demographics, changing patterns of residency and employment, and cutbacks in mass transit may all be combining to blunt this positive momentum. Given the focus

of NFI on transportation access, and given the inclusion in recent federal budget proposals of important seed funds and authorization for innovative and experimental, community-based transportation projects, it would be especially regrettable if unmet challenges undermined the progress we have made.

One such new challenge exists in the area of paratransit, which was designed to provide parallel transportation access to people with disabilities who, for various reasons, cannot access or use fixed-route transit. But will paratransit's relevance be reduced if the role of fixed-route mass transit in our society continues to decline? Data from the 1990s suggests that the average commuting distances Americans traveled to and from work grew. With increasing suburban sprawl, Americans are not abandoning their use of the private automobile, and in many cases have no practical alternative to it. Soaring real estate markets continue to push moderate and low-income workers further and further from centers of employment in their search for affordable places to live. Funding cutbacks have resulted in the reduction or elimination of many mass transit options for all people.

While these circumstances create problems for many people, their impact may prove especially severe for those with disabilities who cannot drive or who lack the funds to purchase accessible vehicle modifications. Indeed it may not be too great a stretch to suggest that in today's America, inability to drive (most often resulting from disability) is itself a major disability, leading as it does to limitations of almost every major life activity and of every form of participation in economic, community, and family life.

We will discuss paratransit in more detail in the final section of this chapter. For the moment, the question must be asked whether a paratransit system that provides alternatives to fixed-route transit is meeting a sufficient part of the need for transportation alternatives where fixed-route service itself is a meaningful option for fewer and fewer people. Paratransit essentially duplicates fixed-route service so far as hours of service, coverage areas, and other features are concerned. If

the fixed-route service is declining, it is inevitable, if paradoxical, that paratransit service will decline as well.

### **Olmstead**

Considerable controversy surrounds the planning efforts undertaken by states and the leadership and resources offered by the Federal Government in meeting the community-integration requirements of ADA as embodied in the Supreme Court's 1999 *Olmstead* decision.<sup>134</sup>

Incorporation of transportation as an integral element of *Olmstead* planning appears to be less widespread than is necessary to make community integration successful. Anecdotal information suggests that for substantial numbers of people (particularly people living in depopulating agricultural and rural areas), the decision to enter a nursing home may frequently be predicated in whole or in part on the unavailability of adequate transportation and to the isolation and vulnerability that follow in its wake, rather than to any literal need for the care services such institutions may offer.

The time may be at hand when, if we are to decrease unnecessary institutionalization and promote return to the community where possible, we must take a fundamental and thorough look at the role of transportation in our society. Many variables that are not initially obvious bear heavily on this matter. Even such questions as the availability of volunteer drivers are adversely influenced by current automobile insurance practices that make it increasingly risky for community volunteers to transport passengers in private vehicles. This risk is not entirely offset by recent volunteer liability protection laws.

Accordingly, NCD recommends that the Administration undertake a comprehensive study into the need for, availability of, and prospects for transportation resources and services in this country, not as an end in themselves but as they relate to the achievement of a variety of other national priorities and objectives, with a view to developing and documenting measures for assessing the impact of transportation investments, resources, and facilities on the participation of people with disabilities in employment, education, and community living. The report on



personal transportation discussed in the next sub-section could have furnished a model for such a study, but regrettably, it fails to connect the dots or facilitate coordinated problem solving.

### **Assistive Technology Mobility Devices**

The Assistive Technology Mobility Devices (ATMDs) Task Force report, ordered by presidential executive memorandum in February and published in August 2003,<sup>135</sup> raises important questions about the necessary relationships between transportation planning and other programs. While the task force dealt with funding sources for, and access to, personal ATMDs (powered wheelchairs, scooters, manual wheelchairs, etc.), the charge of the task force was too limited in scope to adequately address the full range of issues and barriers confronted by people with disabilities in obtaining ATMDs.

Although commissioned out of the recognition that personal mobility is an element of transportation and the further recognition that transportation plays a key role in access to education and employment, the ATMD report does not offer a comprehensive approach for improving access to appropriate ATMDs for people with disabilities. The report does contain valuable information about the efforts underway at several federal agencies regarding improving access to ATMDs, and a helpful list of potential ATMD funding sources. NCD recommends that the ATMD Task Force be reconvened and given a broader charge to evaluate the aggregate impact of all personal mobility-related policies and programs on the ability of Americans with disabilities to get to and from work or school on terms of rough equality with other Americans, and to make comprehensive recommendations to ensure our nation is meeting the need for ATMDs to enhance access to education and employment for all people with disabilities.

### **Air Travel**

Broadly speaking, the process of traveling by air begins with making a reservation and ends with arrival at one's destination. For people with disabilities, each step of this process poses some issues that differ from those faced by other travelers.

## **Civil Rights and Nondiscrimination**

A variety of laws and oversight agencies are implicated in the effort to ensure access to air travel for people with disabilities. Depending on whether an air carrier, airport operating authority, terminal business concession, or contractor is involved, issues of access to air travel may be governed by Titles II or III of ADA, Section 504 of the Rehabilitation Act, ACAA, or even state and local law. Likewise, on the federal level, a number of agencies, ranging from the Department of Transportation (DOT), the Department of Homeland Security (DHS), and DOJ, as well as various sub-agencies, may have responsibility.

Because of the potential confusion arising from this complexity, NCD, in last year's progress report, requested clarification on several key questions of jurisdiction and agency responsibility. NCD appreciates DOT's response to our inquiry. Significant further guidance is needed if air travel consumers, airlines, and airports are to fully understand their rights and responsibilities.

In previous reports, NCD has commended the combined work of several federal agencies in producing fact sheets and other materials dealing with the interplay between disabled passenger rights and airport security. We now believe that a new type of fact sheet is urgently needed, prepared with input from DOT's Office of General Counsel's Office of Aviation Enforcement and Proceedings, the Federal Aviation Administration (FAA), the Transportation Security Administration (TSA), and DOJ's Disability Rights Section, addressing actual or foreseeable situations encountered in the course of air travel. The fact sheet should specify the following for each situation:

- What service does the passenger have a right to expect?
- What rights does a passenger have to refuse some or all demands or proffered services?
- What rights does a passenger have in connection with services offered to the public by various components of the travel industry before and outside the airport?
- What entity or official at the airport can be contacted if the required service is not provided or the passenger believes that discrimination has occurred?

- What documentation or other records can or should be sought or created?
- What recourse is available through federal oversight agencies, and how can such agencies be contacted (by phone and, if so, what hours, in writing, or by email)?
- What potential remedies are available, and what follow-up is appropriate?

The scenarios included in the new fact sheet, together with the way these questions are answered, should be extremely specific and field-tested with passengers, as well as staff of airlines, airports, and private vendors to make certain the scenarios are clear.

### **ACAA Enforcement**

During 2003, DOT's Office of Aviation Enforcement and Proceedings instituted a number of actions against domestic airlines for various violations of ACAA.<sup>136</sup> Most of these arose from consumer complaints, but at least one resulted from the agency's proactive investigation.<sup>137</sup> Each case was resolved by a settlement, which included imposition of a fine against the carrier. As part of the settlements, however, these fines were waived, provided that the funds would be used for staff training or other ACAA awareness and compliance activities.

While NCD agrees that cases should be resolved as quickly and equitably as possible, and that fines generally represent a far less productive use of resources than staff training or education, we are nevertheless concerned that such settlements, unless accompanied by appropriate follow-up, may inadvertently send the message to air carriers that ACAA violation bodes no serious consequences. NCD is concerned about the absence from published reports about the settlements of any information about monitoring or follow-up aimed at ensuring full and continuing adherence by the carriers to the terms of their agreements. NCD is also concerned about the apparent lack of any clear statement from DOT in the context of these settlements that repeated violations, violations that jeopardize passenger health or safety, or violations that reflect severe disregard for passenger dignity will be viewed and dealt with more harshly.

For this reason, while favoring an approach that emphasizes technical assistance, customer and staff education, and cooperative effort, NCD recommends that in order to make the ACAA complaint process meaningful for both passengers and carriers, DOT make clear by regulation or other appropriate advisory that serious or repeat violations of the law will and must be dealt with by imposing significant sanctions, and not merely by obliging carriers to use fine remittances for activities that under the law they already should have been carrying out.

### **Ticket Machines and Other Technologies**

From devices for weighing and measuring baggage, to self-service cafeterias, to automated monorails, airport passenger services and airport commerce are making increased use of technology. More and more, this technology allows or requires passengers to interact directly with various devices.

One labor- and time-saving technology that has proved particularly popular is the airport ticket machine used for paying for tickets with credit cards and for issuing boarding passes. While these machines have unquestionably resulted in significant time savings for many passengers, they have also created significant new disparities between the travel experiences of those people for whom they are a convenience and those to whom they are inaccessible. As airlines continue to reduce the number of counter agents, these new inequalities can only grow.

Because such machines are inaccessible and unusable by persons who are blind and potentially by persons with other disabilities, NCD, in last year's annual progress report, raised the question of which law governed these machines (ADA or ACAA). In a letter to the Council, DOT indicated that these machines were governed by ACAA.<sup>138</sup> Acknowledging that their inaccessibility and the inequalities that result are a matter of legal concern, the Department suggested that passengers could speed up their check-in process by using first-class ticket lines. Even as a short-term measure, we believe this suggestion would neither equalize waiting times nor remedy fundamental inequality.

Resentment by other passengers of apparent line-jumping, along with inevitable disputes over who did and did not have a relevant disability, would certainly arise. Ongoing training efforts would be required to ensure that airline personnel were aware of the policy and followed it. Moreover, the increasingly prevalent, low-cost, no-frills airlines typically offer only one class of service, so have no first-class lines at all.

From bank ATMs to mass transit fare machines, building directories, and voting machines, access technology is widely in use that allows people with disabilities to independently access and use a variety of information technology and terminal machines (ITMs). Given the wide deployment, broad experience, and demonstrated cost effectiveness of accessible electronic and information technology, there is absolutely no reason to believe that airport ticket machines cannot be made accessible, and there is no justification for the apparent failure of the airline industry to investigate, let alone attempt to do, this given that airport ticket machines came into use long after access technology had been successfully deployed and widely publicized in a variety of comparable settings. NCD recommends that DOT immediately require, as a critical dimension of ACAA compliance, that all ticket machines hereafter designed, installed, or modified be made accessible. Because machines are being rolled out rapidly, failure to act immediately could result either in the long-term loss of a precious opportunity to achieve equality of access to air travel, or in retrofitting costs that will greatly exceed what doing the job right in the first place would have cost.

As suggested at the beginning of this sub-section, ticket machines are not the only example of interactive technology coming into increasing use at airports. Passengers may soon be weighing their own carry-ons, measuring their check-ins, and even screening their own checked bags at security kiosks and sensors. They may be interacting with biometric identification systems, using specialized identification documents to qualify for less intrusive screening, and purchasing their snacks from self-service or even automated food-service facilities. All of these new technologies, and others now on the drawing board, have potentially important access and dignity implications for passengers with disabilities. Within the framework of current or needed law and technology

development, DOT must find means to anticipate and address the implications of new labor-saving and security-enhancing technologies for their impact on travelers with disabilities.

Accordingly, NCD recommends that FAA, the Secretary of Transportation, and TSA develop mechanisms to ensure that whenever new airport technology is designed or tested, passengers with disabilities are included in the evaluation and testing processes. Such participation and the findings that result must be a standard, formal, and documented part of the development and testing phases of all new airport technology.

### **The Transportation Act**

With the anticipated reauthorization of TEA-21<sup>139</sup> scheduled for 2003, NCD's *2002 Annual Progress Report* made recommendations for provisions that we believe should be retained in or added to the law. The law, which is most commonly and most significantly called the nation's highway bill, was not rewritten during the time expected.

NCD recognizes that as a practical matter, our opportunity for further input to the reauthorization debate may be limited. Many provisions of the bill are already determined, and the bill was expected to be enacted before publication of this report. Bearing in mind the many and important ways in which the legislation influences the lives of Americans with disabilities, we wish to urge consideration by Congress of several key points, whether in this bill or in other related legislation.

### **Budget**

NCD has been heartened by the inclusion of funds in Administration budget requests for NFI appropriations for innovative community-based transportation experiments and demonstrations designed to increase community participation for people with disabilities. NCD urges the Administration to continue its support for such programs in its FY 2005 budget proposal and urges Congress to include such funds in any continuing resolutions or regular appropriations it

adopts for the remainder of FY 2004. We also urge Congress to include appropriate funding authorization in TEA-21 reauthorization and in its FY 2005 budget resolution.

As important as the inclusion of maximum possible funding for the conduct of NFI initiatives and projects is, though, something else is of great importance. NCD recommends that Congress, in addition to adequate funding authorization, include in the transportation legislation authority for NFI funds to be used for a wide variety of programs, including operating assistance, and that funds not be limited to the purchase or modification of vehicles.

In this connection, we also wish to note the Section 5310 program that provides funds for a variety of transportation projects aimed specifically at enhancing transportation access and options for people with disabilities, particularly in underserved areas, that is operated primarily through not-for-profit entities. NCD recommends that the funding and authority for this program be retained and optimized by Congress, and that its resources continue to flow to the nonprofit sector, without restrictions or limitations that would in any way inhibit the development of projects that serve people with disabilities in an integrated or community-based setting.

Some may argue that, though small, we cannot afford these expenditures in light of current budgetary pressures on domestic spending. However, in view of the large size and many interlocking purposes, including job creation, of the federal highway program, these small but highly leveraged expenditures on behalf of community integration and personal empowerment of people with disabilities can hardly be regarded as less worthy than many of the other projects supported under the bill.

### **Olmstead**

Much controversy surrounds the adequacy of states' responses to the *Olmstead* decision. One 2003 study indicated that many states did not have adequate plans in effect.<sup>140</sup> In view of the centrality of transportation to the ability to live and remain in the community, as well as its central role in employment, education, and receipt of health care, NCD believes the time has

come when full and formal integration of transportation planning and other services and systems must be made obligatory. For this reason, NCD recommends to Congress that, just as the level of federal highway funds over the years has been tied to state adoption of many national policies and priorities ranging from lowered blood alcohol levels to mandated seatbelt use, so now the availability of highway funding should be partially conditioned on state efforts to meaningfully incorporate transportation policy and agencies into the *Olmstead* implementation process. Accordingly, NCD recommends that the Secretaries of Health and Human Services and of Transportation require joint certification of such incorporation each year before states' full allocation of highway funds can be released.

### **Other Accessibility Issues**

As discussed in earlier reports, there are a number of key overlaps, points of connection, and areas for coordination between TEA-21 and ADA. For example, it is vital that pedestrian access and safety, including for people with disabilities, are incorporated into the design of federally supported transportation projects. Such measures include safe and accessible pathways between bus and light-rail stations and the commercial, cultural, or other facilities they serve.

The law must also strengthen its support for research into traffic management systems that appropriately balance the unimpeded flow of vehicular traffic with the safety of those seeking to cross busy thoroughfares. In this regard, NCD is particularly mindful of the support for accessibility-related pedestrian-safety research emanating from a number of federal agencies and conducted under a number of program rubrics.

Against this backdrop, NCD recommends that Congress vigorously support research into issues ranging from audible traffic signals and textured surfaces to traffic light placement and intersection design. The costs of such research and thereafter for strong federal financial support for the dissemination of successful strategies and models are small and become even smaller when balanced against the number of lives that will be saved.



In this connection, a further issue relates to the efficacy of state statutes known as “white cane laws.” Adopted between the 1930s and 1960s, these statutes generally impose obligations on motorists to yield the right-of-way to blind pedestrians using white canes or dog guides. These statutes also modify the allocation of responsibility when accidents occur, holding motorists more strictly responsible than when they hit other pedestrians.

Anecdotal reports reaching NCD from around the country indicate that these statutes are not well known to drivers or sometimes even to law enforcement officers, and that even when known are rarely applied or enforced. Indeed, the pattern in these disturbing reports is sufficiently consistent to suggest the belief on the part of some police and prosecutors that blind people (and therefore by implication surely others with disabilities as well) who venture out on the streets alone are inherently negligent and do so at their own risk.

Admittedly, road systems, traffic laws, and driver attitudes have changed a great deal since these laws were passed, but until the extent of current enforcement and impact can be better understood, the possible need for their updating or revision cannot be adequately assessed. Therefore, NCD recommends that Congress authorize a study of the contents, utilization, impact, relevance, and possible need for modernization of state white cane laws.

## **Paratransit**

The first section of this chapter raised questions about the future viability of paratransit in a changing transportation environment. Concerns also exist, however, regarding the way paratransit works today, and how well it is meeting its current responsibilities.

In last year’s report, NCD expressed concerns about the practice unofficially but commonly known as “conditional eligibility.” This practice, also known as “trip eligibility,” involves determining eligibility for paratransit service on a trip-by-trip basis. Trip eligibility applies when an individual is capable of making some trips using fixed-route service, but is in need of

paratransit service for other trips. The paratransit provider determines when paratransit service will actually be provided.

In its response to our inquiries on this point, DOT made clear its belief that adequate monitoring and oversight are in effect to ensure that trip eligibility is being implemented in a legally acceptable fashion. DOT is satisfied that both the procedures and the criteria used to evaluate trip requests are consistent with the law.

NCD is concerned that much more needs to be known about how trip eligibility works, especially in light of indications that its use is increasing and will increase further as demand for services grows. Moreover, to say that trip eligibility is being administered within the law still does not tell us how paratransit operators are prioritizing various trips or what aggregate impact their decisions are having on the lives of Americans with disabilities.

For this reason, NCD recommends that DOT undertake intensive inquiries in a random sample of locations in order to determine what the real impact of trip eligibility has been and whether the practice is enhancing the independence of people with disabilities.

## **Conclusion**

This chapter has addressed changing transportation needs as they affect people with disabilities in such areas as paratransit and federal transportation legislation. It has examined the need for new resources and initiatives in the air transportation arena, and it has discussed informational needs critical to the formulation of public policy in the transportation sector. It has also addressed the need for integration of transportation and other major areas of planning if the goals of NFI are to be fully achieved.

## **Recommendations Summary**

### **Recommendations to Congress**

*Recommendation 10.1*—NCD recommends that Congress, in addition to adequate funding authorization, include in the transportation legislation authority for NFI funds to be used for a wide variety of programs, including operating assistance, and that funds not be limited to the purchase or modification of vehicles.

*Recommendation 10.2*—NCD recommends that the funding and authority for the Section 5310 program be retained and optimized by Congress, and that its resources continue to flow to the nonprofit sector, without restrictions or limitations that would in any way inhibit the development of projects that serve people with disabilities in an integrated or community-based setting.

*Recommendation 10.3*—NCD recommends to Congress that, just as the level of federal highway funds over the years has been tied to state adoption of many national policies and priorities ranging from lowered blood alcohol levels to mandated seatbelt use, so now the availability of highway funding should be partially conditioned on state efforts to meaningfully incorporate transportation policy and agencies into the *Olmstead* implementation process.

*Recommendation 10.4*—NCD recommends that Congress vigorously support research into issues ranging from audible traffic signals and textured surfaces to traffic light placement and intersection design.

*Recommendation 10.5*—NCD recommends that Congress authorize a study of the contents, utilization, impact, relevance, and possible need for modernization of state white cane laws.

### **Recommendations to the Administration**

*Recommendation 10.6*—NCD recommends that the Administration undertake a comprehensive study into the need for, availability of, and prospects for transportation resources and services in

this country, not as an end in themselves, but as they relate to the achievement of a variety of other national priorities and objectives, with a view to developing and documenting measures for assessing the impact of transportation investments, resources, and facilities on the participation of people with disabilities in employment, education, and community living.

*Recommendation 10.7*—NCD recommends that the ATMD Task Force be reconvened with the charge of going beyond the list of agencies and their statements of what they do, to an assessment of whether, in fact, there are any Americans who face barriers to education, employment, or health care that could be overcome by the heightened availability of ATMD for personal transportation, and if so, how federal programs can be modified or better coordinated to bring about greater access.

### **Recommendations to DOT**

*Recommendation 10.8*—NCD recommends the development of a fact sheet that addresses actual or foreseeable situations encountered in the course of air travel, and for each, lists the key points included in the text accompanying this recommendation.

*Recommendation 10.9*—NCD recommends that in order to make the ACAA complaint process meaningful for both passengers and carriers, DOT make clear by regulation or other appropriate advisory that serious or repeat violations of the law will be and must be dealt with by imposing significant sanctions, and not merely by obliging carriers to use fine remittances for activities that under the law they should have been carrying out already.

*Recommendation 10.10*—NCD recommends that DOT immediately require, as a critical dimension of ACAA compliance, that all ticket machines hereafter designed, installed, or modified be made accessible.

*Recommendation 10.11*—NCD recommends that FAA, the Secretary of Transportation, and TSA develop mechanisms to ensure that whenever new airport technology is designed or tested, passengers with disabilities are included in the evaluation and testing processes.

*Recommendation 10.12*—NCD recommends that joint certification of incorporation of transportation policy and agencies into the *Olmstead* implementation process be required by the Secretaries of Health and Human Services and of Transportation each year before states' full allocation of highway funds can be released.

*Recommendation 10.13*—NCD recommends that DOT undertake intensive inquiries in a random sample of locations in order to determine what the real impact of trip eligibility has been, and whether the practice is enhancing the independence of people with disabilities.



## **Chapter Eleven**

### **Assistive Technology and Telecommunications**

#### **Introduction**

Technology in general and telecommunications in particular are the daily tools with which we live our lives. Who could imagine going through an ordinary day without using a telephone, a computer, an electrical appliance, a radio or TV, or a motor vehicle? Technology has become an increasingly central tool for employment, education, and personal communication for all Americans; but for people with disabilities, its potential benefits if accessible and usable, and its potential harm if not, may well be magnified beyond what most people experience.

This chapter discusses a number of technology issues currently before key governmental decision makers that have highly significant implications for people with disabilities. The first section focuses on the Assistive Technology Act. The next section addresses several key issues before the Federal Communications Commission (FCC). The final section concerns Section 508 of the Rehabilitation Act.

#### **The Assistive Technology Act**

The Assistive Technology Act of 1998,<sup>141</sup> successor to the Technology-Related Assistance for Individuals with Disabilities Act of 1988, has technically expired, but, pending reauthorization, has been kept in operation through the appropriations process. That is, although the statutory authorization for the program has sunset, funds have been appropriated for two years in a row to keep the program components in operation. The program has three components, including, under Title I, the state-based AT programs operating in all 56 states and territories. The AT Act also supports several protection and advocacy (P&A) programs that also operate in all states and territories. Finally, the AT Act provides the authority for the alternative financing loan program that allows states to establish AT loan programs with a combination of federal and state matching funds.

Based on what is believed to be the crucial role played by the AT Act programs, NCD recommends that Congress reauthorize the program this year and provide not only an additional year's funding, but statutory authorization for the program's existence, so that a measure of stability and the means to engage in planning and capacity-building can be restored. While it may be feasible to use continuing resolutions to extend the operation of certain programs pending longer-term decisions and arrangements, this approach cannot be used for long for small and vulnerable programs such as those under the AT Act. Unlike larger programs, whose continuation in one form or another is ensured, year-to-year extension-by-funding of the AT Act has left open the fundamental question of whether the Act and its important work would be continued at all and, based on discussions with AT Act personnel, has engendered great instability.

As indicated by our recommendation above, NCD believes that the work of the AT Act has contributed in important and irreplaceable ways to the incorporation of AT and universally designed technology into the consciousness and practices of state governments. Without the state-based AT Act programs, the interests and the cause of technology on behalf of people with disabilities might receive scant attention and be little understood by state and local decision makers or by the AT projects' many community partners.

Through such activities as technology demonstration sites, conferences, informational hotlines, equipment recycling programs, and other forms of outreach, the state-based AT Act programs have also provided invaluable information and resources to individuals with disabilities, employers, educators, and others.

If the AT Act program were to go out of operation, these valuable functions would be put at risk and in many cases would cease to be performed. Although the projects are not highly visible and sometimes not easily documented, NCD is convinced that the role played by the AT Act projects, while differing from state to state, remains crucial. Although the technical assistance these projects offer could theoretically be provided by others, it is not at all clear who those



others would be or how they would be able to parlay the expertise and credibility the AT Act projects have built up over the years. Likewise, while independent entities have been created to operate loan funds in the states where they exist thus far, the AT Act projects have been instrumental in launching these programs and helping to form the management entities. Hence again, NCD is not certain who would play this role in the remaining states where AT loan funds, which are an important component of the President's NFI, have yet to be established.

## **The Federal Communications Commission**

At first it may be difficult to imagine how the FCC could find itself at the center of a number of the most pressing disability rights debates of our day. Yet, when one considers the growing importance of telecommunications technology in all our lives, this regulatory agency's growing and unique importance becomes easier to understand.

### **Cell Phone Access for Hearing Aid Users**

NCD has taken issue with the action, or what was believed to be the inaction, of the FCC in a number of contexts over recent years. For this reason, NCD is particularly pleased to begin this section by commending the Commission for the important steps it took in 2003 to ensure the accessibility of cell phones for people who use hearing aids. Acting under the Hearing Aid Compatibility (HAC) Act, the FCC initiated a process—with timelines, industry performance targets, and monitoring provisions—that should result in the availability in the market of a significant range and number of accessible handsets.<sup>142</sup> NCD applauds both the Commission's commitment and its approach.

### **Section 255**

Precisely because of the FCC's energy and focus in responding to the aspirations of hearing aid users for cell phone access in this wireless age, NCD remains saddened and puzzled by the Commission's seemingly lesser engagement in the application of these same values to the implementation of Section 255 of the Telecommunications Act of 1996.<sup>143</sup> Data provided by the

FCC indicates that 145 informal complaints and one formal complaint were filed during 2003. Apart from the number of these that related to telecommunications equipment versus the number concerning telecommunications services, NCD has no information about how these complaints were resolved or what role was played by the Commission; and whether the outcomes vindicate the public interest remain open questions.

Based on anecdotal information reaching us, it appears that the FCC's policy might be to leave it largely to the parties to resolve Section 255 disputes between themselves. Given the disparity in resources and information that individual consumers and large telecommunications companies bring to the fact-finding process and the negotiating table, NCD has long believed that the Commission needs to take a more active role. Therefore, NCD recommends that the FCC publish standards for the review of proposed Section 255 settlements to ensure that they are in the public interest, and that they reflect accurately an understanding of the relevant and applicable technology and law on the part of the parties. Put simply, the Commission has an obligation to make sure that Section 255 complainants are not overreached by respondents.

In a related vein, there has been no indication in many years that the FCC engages in any systematic process or periodic review to determine exactly what accessibility features are now "readily achievable" that formerly might not have been. For instance, the one formal complaint before the Commission during 2003 resulted in a settlement between a consumer and a cell phone manufacturer, which led to the introduction into the market by the manufacturer and a cooperating service provider of a cell phone handset incorporating a number of accessibility features critical to effective phone use by customers who are blind.<sup>144</sup>

Since the law does not require manufacturers or service-providers to implement telecommunications accessibility features that are not "readily achievable,"<sup>145</sup> and since there is no indication that the FCC put any pressure on the respondent manufacturer to settle the complaint advantageously to the complainant, NCD can only conclude that the state of technology and design have advanced to the point where the manufacturer concluded that

implementation of the enhancements (in this case, voice output of a substantial proportion of cell-phone screen information to make the phone accessible to blind persons) is now readily achievable.

If inclusion of speech-output in cell-phone handsets is now readily achievable, NCD wonders why the Commission has not more actively encouraged its incorporation in cell phones, given the fact that for one group of customers with disabilities it represents the only viable strategy for accessing and utilizing most phone features and functions with any degree of reliability or speed. At this point, however, the Commission appears to have no mechanism for monitoring the state of technological development in this or other areas, and little apparent interest in setting forth standards and expectations that, based on what is readily achievable, manufacturers and service providers will be expected to meet.

Section 255 was adopted precisely because the marketplace would not readily respond to the needs of low-incidence populations with disabilities and because of the critical importance of bringing the benefits of telecommunications technology to all Americans. Initially, through the Market Monitoring Reports that the Commission used in the first year of Section 255 implementation,<sup>146</sup> it was possible to assess the state of technology and the level of need in any given major product area. With the discontinuance of such studies and the failure to develop any alternative, this vital resource has been lost. Accordingly, NCD recommends that the FCC revive the Market Monitoring Reports as a tool for assessing the needs and potential for greater product accessibility in various key areas of telecommunications technology.

Even as NCD calls for more effective implementation of Section 255, the issues surrounding its interpretation and application grow more complicated than ever before. Today, the issues of Section 255 implementation and enforcement must be addressed against the increasingly complicated backdrop of broadband. Historically, broadband services have been denominated as “information” services. This is important for Section 255, because it applies to

“telecommunications” services. As a result, great concern has been expressed over whether the protections of Section 255 have any role to play in the development of broadband.

Mindful of these concerns, the FCC issued a Notice of Proposed Rulemaking in 2002, inviting comment on, among other things, how and whether this distinction between telecommunications and information services would or should affect Section 255, and, both directly and by implication, posing the question whether the definition of information services needed to be crafted in a way that protects the essential right and aspiration of people with disabilities to telecommunications and Internet access.<sup>147</sup> In another manifestation of what can be characterized as strange silence, the Commission as of this writing had yet to publish any findings, institute any rulemaking, issue any orders, or otherwise follow up in any discernible way on this inquiry. Meanwhile, the dramatic growth, and the Commission’s unqualified support for, Voice Over Internet Protocol (VOIP) technology has put into question even the residual protection of accessibility rights that would remain if all broadband were exempt from Section 255.

Traditionally, one widely used rule of thumb for distinguishing “telecommunications” from “information” services had to do with the medium being transmitted. Generally, voice communication, which typically occurred over the telephone, was considered to be telecommunications, whereas transmission and receipt of data and video were more often regarded as falling within the information services domain. But now, through VOIP, even voice communication is migrating to the Internet, where, because of the modes of transmission used, it may also fall outside the shrinking scope of telecommunications.

Imagine if laws in this country banned discrimination in the provision of horse-and-buggy services or steam railroad transportation, but did not cover diesel trains, high-speed rail, interstate buses, or air travel. The approach is inevitable toward a point where, if the FCC does not take action in asserting some leadership and commitment, Section 255 will be like a ban on discrimination in the provision of horse-drawn transportation.

NCD believes the FCC possesses the authority to apply Section 255 to VOIP. To that end, NCD recommends that the Commission initiate the development of a record for use in a rulemaking procedure aimed at applying Section 255 to VOIP. If the Commission believes it lacks this authority, it should immediately join with NCD and with appropriate representatives of the telecommunications industry and disability community to make recommendations to Congress for the necessary legislation.

### **Closed Captioning**

NCD commends the FCC for its approach to the phasing-in, monitoring, and publicizing of requirements regarding the amount and types of TV programming that must be captioned. A new stage in this phase-in process was scheduled to begin January 1, 2004. NCD also commends the Commission both for developing procedures whereby exemption requests can be filed and for its continued commitment to increased captioning in the face of these challenges.<sup>148</sup>

But this recent emphasis on what program producers and distributors must do should not lead to complacency. For, once again, technological change may be poised to threaten hard-won gains. Changes in over-the-air, cable, and satellite television technology, high-definition TV, and other developments give grounds for concern that current methods for creating, transmitting, and receiving captions may come under pressure and may need revision. Rather than waiting for issues to arise and rather than taking a piecemeal approach, NCD recommends that the Commission initiate regulatory proceedings designed to anticipate all the technological issues that may be reasonably foreseeable in the continued availability and increased utilization of captioning, and promulgate rules that will ensure, while there is still time for manufacturers and carriers to respond effectively, that the availability and quality of captioning will be in no way compromised or endangered.

## **Video Description**

Video description does for people who are blind what captioning does for people who are deaf. Through the insertion of spoken narrative into gaps in the program dialogue, video description (also sometimes called descriptive video or audio description) provides access to the key visual elements of the program.

Pursuant to the Telecommunications Act of 1996, the FCC conducted a study and, based on that study's results, implemented minimal requirements for video description in broadcast and cable network TV programming. Opposed by various groups, including the motion picture production industry, these requirements were challenged and struck down by the courts in November 2002 on the grounds that only the study, not follow-up implementation of video description requirements, was authorized by the statute.<sup>149</sup>

In the 2002 annual report, NCD urged the FCC to seek the necessary legislative authorization from Congress to overturn this court decision and to allow the Commission to promulgate reasonable requirements for video description. Without Commission support and leadership, the prospects for enactment of such legislation are negligible.

NCD is unaware of any moves by the FCC in this direction. It is not clear that the Commission has even shared with Congress the data on the basis of which its original rules were promulgated, and there is no indication that the Commission has surveyed advances in technology occurring since the conduct of that research that may further reduce the costs or other burdens associated with the provision of video description.

While NCD commends the Commission for having sought to make video description available and appreciates its defense of its rule in the courts, concern remains that the value of these efforts will be largely nullified unless the Commission endeavors to educate Congress as to the potential, feasibility, and need for video description. Accordingly, NCD recommends that the FCC consult with interested industry groups and representatives of the disability community,

through its Consumer Advisory Committee or other appropriate forums, with a view to developing recommendations for video description legislation that can be submitted to and supported in Congress.

### **E-Rate**

Since enactment of the Communications Act of 1934, our nation has had a commitment to universal telephone service. In recent years, that commitment has been tested in application to electronic communications and Internet access. One means for preserving that commitment and for bringing affordable telecommunications services to schools and libraries in underserved areas with low-income populations has been the program known as the E-rate.

Currently, schools and libraries applying for discounts and funding under the universal service program, commonly known as the E-rate, are not required to certify that the equipment and services funded with the discounts or subsidies are accessible to users, library patrons, students, or faculty with disabilities. Applicants are notified that they may be subject to ADA and other accessibility civil rights laws (as one assumes they are subject to all laws), but we know of no effort ever to have been made by any responsible entity of the Federal Government, including the FCC and the Department of Education, to make this possibility a reality.

It should be noted that in 2002, the FCC did issue an advance Notice of Proposed Rulemaking (NPRM) seeking comment on whether and how accessibility certification requirements should be imposed.<sup>150</sup> Here again, though no time limits apply to the closing of these dockets, no follow-up appears to have taken place and the FCC has issued no information on the nature or number of responses or comments that may have been received. NCD is concerned that no sense of urgency surrounds this proceeding.

Because of their receipt of federal financial assistance (including through the E-rate program itself), and in view of the fact that many schools and libraries are public institutions or public accommodations, it seems highly likely that many, if not most, of the entities eligible to

participate in the E-rate program are subject to legal requirements for nondiscrimination and equal access to information. Public schools and libraries subject to Title II of ADA, schools and libraries receiving federal financial assistance within the meaning of Section 504 of the Rehabilitation Act, and private libraries serving as federal depositories subject to Section 508 of the Rehabilitation Act are all likely to have accessibility obligations under the law.

Apart from the basic equity arguments, it may therefore be the case that by failing to require certification of this compliance, the FCC, far from easing the burdens of E-rate recipients, may be unwittingly leaving them open to the risk of litigation under these or parallel state civil rights statutes. If and when, as surely will happen sooner or later, citizens seek to assert their access rights to the information technology and services provided with public subsidies under the E-rate, neither the taxpayers nor the institutions that they challenge will have benefited from the FCC's failure to do more than issue a notice essentially to the effect that funds recipients are subject to the laws of the land.

The current notice requirement serves to give applicants no useful information about what the law requires of them. With the widespread exposure in the Federal Government and elsewhere to accessibility standards, such as those required and widely in use under Section 508, there is little occasion for the FCC or any other regulatory, oversight, or contracting agency to defer enforcement for lack of a clear sense of what standards or procedures to apply. Accordingly, NCD recommends that the FCC initiate a rulemaking designed to require appropriate accessibility certification and guarantees as a condition for receipt of E-rate subsidies.

## **Section 508**

Since its adoption in its current form as a component of the Workforce Investment Act of 1998,<sup>151</sup> Section 508 of the Federal Rehabilitation Act (Title IV) has been a subject of great interest. In the early days following its enactment, as guidelines for its implementation were being developed by the Architectural and Transportation Barriers Compliance Board (the Access Board),<sup>152</sup> and at the time when these and the related regulations adopted by the General Services



Administration (GSA)<sup>153</sup> came into effect, there were those who hailed 508 as the dawn of a great new era, and others who saw it as ushering in an era of chaos.

The greatest significance of Section 508 is that it undertook to harness the government's enormous purchasing power on behalf of accessibility. By providing that the government purchase accessible "electronic and information technology" (E&IT), Section 508 sought to incentivize the design, production, and use of accessible devices, as well as to bring about adherence to accessibility standards by federal and certain government-related Web sites.

Section 508, like the rest of WIA, was due for reauthorization in 2003, but that action was put off for a year and the law was extended unchanged. NCD has heard nothing to indicate that major changes in 508 are expected, nor does the Council wish to propose any at this time. NCD does, nevertheless, regard it as important to try to assess the impact the law has had thus far, and to identify strengths and weaknesses that can help guide the efforts of the many public and private sector organizations involved in its implementation and growth.

### **Monitoring**

Overall, NCD wishes to express its appreciation for the Administration's repeated expressions of strong support for Section 508 and for the values of inclusion it embodies and promotes. Primary monitoring responsibility for Section 508 was vested in DOJ. The attorney general was tasked with sending regular reports to the President and Congress reviewing the performance of the government in enforcing the law and making such recommendations for its modification as may be needed.

NCD has been concerned at the failure of DOJ to issue a timely report in the last cycle. For this reason, NCD is gratified to note that a data collection effort, undertaken by covered federal agencies, was expected to result in the issuance of the statutorily required report during 2004. NCD trusts this report will contain valuable information and data that can be used in evaluating the impact of Section 508 and in identifying areas where more technical assistance, monitoring, or other resources need to be focused. NCD also recommends that the forthcoming DOJ report,

while maintaining the focus on progress toward Web site accessibility that characterized DOJ's earlier report, place emphasis on the categories of equipment covered by the law. NCD continues to believe that in tandem with the invaluable technical information DOJ will be collecting, more process information is also needed for a full assessment of Section 508's impact. For this reason, NCD recommends that GSA, in conjunction with DOJ, undertake a study of such matters as how and when federal agencies are utilizing the statutory exceptions and defenses to the imposition of 508 requirements on particular procurements, how these instances are being documented, how accessibility is being scored in the evaluation of competitive bids in relation to other procurement requirements, and whether agencies have developed plans for making information resources accessible to appropriate staff or members of the public when the technology that produces them cannot itself be made accessible.

### **Outstanding Legal Issues**

Although the combined research efforts described above will go a long way toward describing the practices of federal agencies and in measuring their success in implementing the law, these monitoring projects will not answer several key questions that remain unresolved. Perhaps the most pressing of these relates to this question: If Section 508, as a law primarily aimed at providing access to information, requires the government to use accessible E&IT, does it also require that the information produced with such technology be accessible? For example, if a printer has to be independently usable by an employee with a disability, must some provision be made so that such employee, or the member of the public who receives a letter generated on that printer, can access the information it produces? Similarly, if an informational kiosk generates forms or other documents, must these be accessible in the same way that the machine that produces them must be accessible?

This report is not the place to debate the answer to these questions. Suffice it to say, there are plausible readings of Section 508 that would support a "yes" answer in certain cases. Because of the importance of this question, NCD recommends that DOJ undertake proceedings to identify

the subsisting interpretive questions surrounding Section 508 and that it provide authoritative indications of its views concerning the answers.

## **Conclusion**

This chapter discussed the need to extend the Assistive Technology Act. It also reviewed the need for action by the FCC in a number of areas of emerging technology and technology change that have profound implications for the participation in society of Americans with disabilities—commending the Commission for its actions in some instances, making recommendations to address its inaction in others. Finally, this chapter discussed informational and interpretive needs that must be addressed in order for the law to be fully effective and understood.

## **Recommendations Summary**

### **Recommendation to Congress**

*Recommendation 11.1*—NCD recommends that Congress reauthorize the Assistive Technology Act this year and provide not only an additional year’s funding, but also statutory authorization for the program’s existence, so that a measure of stability and the means to engage in planning and capacity-building can be restored.

### **Recommendations to the FCC**

*Recommendation 11.2*—NCD recommends that the FCC publish standards for the review of proposed Section 255 settlements to ensure that they are in the public interest and that they reflect accurately an understanding of the relevant and applicable technology and law on the part of the parties.

*Recommendation 11.3*—NCD recommends that the FCC revive the Market Monitoring Reports as a tool for assessing the needs and potential for greater product accessibility in various key areas of telecommunications technology.

*Recommendation 11.4*—NCD recommends that the FCC initiate the development of a record for use in a rulemaking procedure aimed at applying Section 255 to Voice Over Internet Protocol. If the Commission believes it lacks this authority, it should immediately join with NCD and with appropriate representatives of the telecommunications industry and disability community to make recommendations to Congress for the necessary legislation.

*Recommendation 11.5*—NCD recommends that the FCC initiate regulatory proceedings designed to anticipate all the technological issues that may be reasonably foreseeable in the continued availability and increased utilization of captioning, and to promulgate rules that will ensure, while there is still time for manufacturers and carriers to respond effectively, that the availability and quality of captioning will be in no way compromised or endangered.

*Recommendation 11.6*—NCD recommends that the FCC consult with interested industry groups and representatives of the disability community, through its Consumer Advisory Committee or other appropriate forums, with a view to developing recommendations for video description legislation that can be submitted to and supported in Congress.

*Recommendation 11.7*—NCD recommends that the FCC initiate a rulemaking designed to require appropriate accessibility certification and guarantees as a condition for the receipt of E-rate subsidies.

### **Recommendations to DOJ**

*Recommendation 11.8*—NCD recommends that the forthcoming DOJ Section 508 report, while maintaining the focus on progress toward Web site accessibility that characterized DOJ's earlier report, also place emphasis on the categories of equipment covered by the law.

*Recommendation 11.9*—NCD recommends that DOJ undertake proceedings to identify the subsisting interpretive questions surrounding Section 508 and that it provide authoritative indications of its views concerning the answers.

**Recommendation to GSA**

*Recommendation 11.10*—NCD recommends that GSA, in conjunction with DOJ, undertake a study of such matters as how and when federal agencies are utilizing the statutory exceptions and defenses to the imposition of 508 requirements on particular procurements, how these instances are being documented, how accessibility is being scored in the evaluation of competitive bids in relation to other procurement requirements, and whether agencies have developed plans for making information resources accessible to appropriate staff or members of the public when the technology that produces them cannot itself be made accessible.



# Chapter Twelve

## International Affairs

### Introduction

NCD has long been concerned with the impact of U.S. bilateral and multilateral relationships on both Americans with disabilities and citizens with disabilities in other nations. This chapter deals with mechanisms by which that concern can be expressed and addressed.

In 1996 NCD published a major report on American foreign policy as it relates to this subject.<sup>154</sup> In 2003 NCD revisited this issue in another major study.<sup>155</sup> In addition, our study of the implementation of the major civil rights statute, Section 504 of the Rehabilitation Act, chose the Department of State as a federal agency for particular attention and focus.<sup>156</sup>

While the issues confronting our foreign policy and international commitments have undergone dramatic change in the years since the 1996 NCD report, the opportunities for enhancing the status of people with disabilities remain great and timely.

This chapter reviews the laws defining the intersection between disability and foreign policy, discusses means for incorporating disability rights concerns into foreign assistance programs, discusses the particular role and implementation of Section 504 protections in our international relationships, considers the status of the pending United Nations Convention on the Rights of Persons with Disabilities, and suggests the possibilities for positively influencing the practices of other nations by harnessing technical assistance resources available in this country.

### The Legal Framework

When speaking of the laws governing American foreign policy, two principal sources of authority are in mind: our own domestic laws, including the Foreign Assistance Act,<sup>157</sup> that structure our relations with other nations, and civil rights laws that bear on nondiscrimination and equal access in the interaction between U.S. Government agencies and U.S. citizens.

In the case of programs operated by the Department of State or other U.S. Government agencies in foreign nations and that involve Americans abroad and citizens of such other nations, complex questions regarding the scope and applicability of U.S. domestic civil rights laws such as ADA also emerge. Broadly speaking, such civil rights laws can apply in two ways. First, they help determine the opportunities and accommodations available to American citizens either working for or otherwise involved with State Department programs. Second, domestic civil rights laws can also apply by imposing obligations or requirements on non-American recipients of U.S. funds, overseas contractors, grantees, foreign governments, and others.

Any discussion of international disability rights is also affected by internal law [of sovereign nations], including bilateral and multilateral treaties, customary international law, and international conventions (including the UN Convention on the Rights of Persons with Disabilities). These dimensions of the subject will be further addressed in the last section of this chapter.

## **Foreign Assistance**

U.S. law imposes numerous requirements and conditions that recipients of foreign aid must meet. It also includes reporting requirements, such as the Department of State's annual Country Reports, designed to assess performance and progress in a variety of areas, including human rights. U.S. law also includes sanctions, in the form of reductions in financial aid, trade preferences, or other relationships, of either a mandatory or discretionary nature, when progress in various areas is not sufficient. From drug interdiction to protection of ethnic and religious minorities to opening of markets to U.S. products, our relations with other nations are significantly influenced by their conduct in a number of key areas of cooperation and responsibility.

While the question of how human rights concerns can be most effectively advanced within this framework has never proved simple, our nation has long recognized that only through promotion of human rights and individual dignity throughout the world can these values prevail. The key



first step in elevating disability rights and opportunities requires action to broadly instill and institutionalize the recognition that these concerns are human rights issues. Well-developed models exist—for example, in the areas of women’s rights and development and in connection with vulnerable populations, including nonmainstream religious, ethnic, or diverse racial groups—that can be applied to people with disabilities.

In our previous reports NCD has made detailed recommendations for the linkage of disability rights, as embodied in major civil rights laws, to those individuals and organizations that implement, and those that receive or benefit from, the range of foreign assistance programs operated or funded by the United States. Some important progress has been made by the Department of State in this area, and NCD wishes to note it here, as well as to indicate our appreciation of the unique issues that the Department faces in fully or consistently implementing reasonable accommodation and accessibility policies. At the same time, it is precisely because of those special difficulties that efforts must be sustained and intensified to overcome the obstacles posed by work in the international arena.

### **Section 504 and ADA**

NCD commends the Department of State for the major steps it has taken to ensure equal opportunity, including in overseas postings, for its employees with disabilities. In particular, NCD notes the efforts to identify and meet reasonable accommodation needs in the AT area before posting, and its efforts to publicize both the existence of its reasonable accommodation program and the availability of recourse if reasonable accommodations are not forthcoming.

NCD also commends the Department for its Barrier-Free Access program, which attempts to make overseas diplomatic facilities accessible and compliant with standards of physical and architectural accessibility applicable to public buildings in this country. NCD understands that the Department is not always free, even if it had the financial resources, to implement needed modifications or to choose properties that meet all accessibility requirements. Nevertheless, NCD recommends that the Department adopt a prospective policy that would establish

accessibility as a key criterion in the selection, lease, purchase, modification, or occupancy of sites. Specifically, NCD recommends that the Department of State require that all buildings and facilities hereafter used by U.S. personnel or paid for with U.S. funds meet the same accessibility standards as would apply to public buildings in the United States. The Secretary of State should retain the authority to waive this requirement where specific considerations of local law, security, location, or other considerations make this unwise or impractical. In all such cases, a statement of the reasons for the waiver should be maintained on file.

NCD also commends the Department for requiring all grantees to certify their compliance with Section 504 of the Rehabilitation Act.<sup>158</sup> NCD is concerned, however, about several points in this connection. First, NCD is concerned with the mechanisms used by the Department to monitor compliance with Section 504 and the availability of technical assistance to help covered entities comply. Second, NCD believes that the reference to grantees should be clarified, for if use of the term “grantees” is intended to draw a distinction between grantees and others such as contractors, vendors, consultants, and so forth, it would be too technical and narrow to be broadly effective. NCD believes that all those who do business with the State Department and who receive U.S. funds through State, Defense, Commerce or other departments’ programs, whether they are grantees, contractors, or otherwise, should be required to comply and be assisted in complying with Section 504. They should also be evaluated, in part, on their level of success in and commitment to meeting this obligation. Accordingly, NCD recommends that government-wide regulations, backed up by suitable monitoring and technical assistance, be put into place requiring and empowering all overseas recipients of U.S. federal funds to comply with the provisions of Section 504 in their use of such funds.

NCD recommends that the Administration establish a national commission to review the entire range of U.S. international assistance programs and other commitments under the Foreign Assistance Act and other laws to determine the extent to which full access and participation by persons with disabilities is incorporated in governing regulations, contract terms, oversight, and reporting criteria. If guarantees of equal access and opportunity are not incorporated in the

governance or the oversight of any program, the commission, which should include representatives of national and international disability groups—including people with disabilities among the participants—should make specific recommendations for the elevation and recognition of these concerns.

To the degree that the recommendations can be implemented by executive branch action, including executive orders, policy guidance, contract amendments, or otherwise, the responsible agency (be it the Department of State, the Department of Defense, the Department of Justice, the Department of Commerce, or other) should be expected to respond to the recommendations within 90 days, either implementing them or indicating why they cannot be implemented. In the event that any of the recommendations may be deemed sound but beyond the agencies' scope of authority under current law, the Administration should propose the necessary statutory amendments to Congress and work with the appropriate congressional committees to ensure that the legislation is adequately considered and expeditiously moved forward.

As far-reaching as the work of such a commission may be, means must also be found for preserving the focus and the momentum resulting from its work. To ensure sustained attention to the issues, NCD recommends that the permanent post of disability advisor should be created, as a counselor to the Department of State, reporting directly to the Secretary and having a collegial and consultative relationship with all bureaus of the Department, and through the Department with such other agencies as may be deemed appropriate.

## **UN Convention**

For the past several years, the United Nations (UN) has been engaged in the process of developing an international treaty, the Convention on the Rights of People with Disabilities. NCD has reported extensively on this effort in a number of briefing papers and progress reports.<sup>159</sup> NCD has also urged the full and active participation by the United States on a number of levels, ranging from active participation in the deliberations, to inclusion of persons with

disabilities in the U.S. delegation, to provision of technical support to other delegations, to eventual ratification of the Convention when, with our input, it is completed.

In May 2003 the UN body responsible for the treaty established a working group to bring together representatives of the delegations of concerned member states and interested nongovernmental organizations (NGOs) to draft and refine the text of a proposed treaty. A meeting of the working group was scheduled for early January 2004, and successive meetings are expected to result in the submission of a draft treaty to the General Assembly before the end of the year.

Meanwhile, in June 2003 the House of Representatives passed a nonbinding resolution expressing the sense of Congress that the United States should participate actively and constructively in the development of the treaty.<sup>160</sup> Despite the strong bipartisan support demonstrated by the House vote, NCD remains concerned that a great opportunity for U.S. leadership and for the sharing of U.S. experience and expertise stands in jeopardy of being lost.

The Administration apparently has taken the position that the United States will not be a signatory to the convention and that the convention will not be submitted to the Senate for ratification.<sup>161</sup> The reasons for this position appear to include the belief that our laws already exceed all of the standards and requirements that could conceivably be included in the convention, making our participation superfluous. In addition, there may be concerns about subjecting U.S. policies and practices to additional international oversight, under circumstances where the methods and entities that will be involved in monitoring the convention have yet to be determined.

While respecting these identified considerations, NCD believes that other imperative considerations outweigh them.

Historically, it has not been the practice of the United States to refrain from entry into treaties simply because those treaties would not impose requirements that exceed those already

applicable under domestic law. Indeed, if it were U.S. policy to enter into treaties and covenants only when the documents required something more or different than our law already provides, the role of treaties would be greatly narrowed from what it has traditionally been.

Treaties and international conventions serve many purposes, including important symbolic ones. Given the leadership the United States has shown over the past half century in the articulation and advancement of human rights for people with disabilities, it would be a shocking reversal of policy and regard for bipartisan precedent were the United States to miss the opportunity to join with other nations of the world in furthering more fully the values of human rights in international consciousness and law.

Although the United States has announced its intention to not sign the treaty, opposition to its adoption has not been expressed. Rather, the United States has taken what has been described as a neutral position. The United States has remained willing to provide technical assistance, but surely the receptiveness of other countries to that assistance and the opportunities for providing it would be greater if this country also wholeheartedly embraced the process and its outcome as a full participant, rather than as a mere spectator.

Effective participation on any level by the United States requires an actively committed delegation—not one that pledges to sign any treaty that may emerge, but one that works actively to develop a treaty of which this country and the entire world can be proud.

To that end, it is also critical that individuals with disabilities play a large role in articulating and representing the positions of the disability community. It may not matter whether the participation is as official members of the U.S. delegation or as representatives of NGOs admitted to full participation in the deliberative process, so long as the necessary central role of people with disabilities is achieved.

For these reasons, NCD recommends that the Administration announce its intention to participate fully and actively in the deliberations of the working group, with a view to helping to

develop a treaty that, if consistent with U.S. values and reflecting the input of persons with disabilities from around the world, will be signed by the United States and thereafter submitted to the Senate, with active support from the Administration for its ratification.

## **Technical Assistance**

As a world leader in all forms of human rights, including the rights of people with disabilities, the United States has achieved a record of which to be proud. Through our landmark laws such as ADA and through the practices, accommodations, standards, and definitions that have evolved, the United States has amassed an unmatched level of knowledge and expertise and gained admiration and emulation around the world.

In light of this background, the United States should always seek methods for voluntarily sharing and disseminating our experience and expertise, which are very likely to be eagerly welcomed by partners around the world. One way of sharing may be through technical assistance (TA) of an organized sort. From the design of accessible buildings and telecommunications technologies, to the development and evaluation of program guidelines to ensure maximum inclusiveness, many federal agencies and programs have tremendous experience working with state, local, and private organizations here at home in bringing about these goals and in promoting best practices in a variety of settings. NCD believes that this wealth of experience and resources could play an important role in empowering governments and private organizations in other nations to achieve progress in the integration of their citizens with disabilities. There is a need to determine the capacity of federal agencies and programs to share their experience and expertise internationally in this way, and to assess the range of resources that could be provided and the practicality and feasibility of beginning a program to do this. Accordingly, NCD recommends that the Administration establish a commission to survey all existing federally funded or federally administered TA programs in the areas of accessibility and full participation. This should occur with a view to (a) identifying those programs that may have some applicability to activities being supported with U.S. funds in the international arena, and (b) establishing mechanisms and linkages to enable these resources to be brought to bear on the world stage in those cases where

the content or methods of such TA are deemed pertinent. In particular, the expertise developed by many programs in addressing and reaching culturally diverse populations should be tapped.

## **Conclusion**

This chapter has described the contexts in which U.S. values in the area of disability rights impact other nations. It has also made recommendations for practices and laws that will facilitate the maximum dispersion of our values with a minimum of coercion or imposition on the sovereign prerogatives and cultural traditions of other nations.

## **Recommendations Summary**

### **Recommendations to the Administration**

*Recommendation 12.1*—NCD recommends that government-wide regulations, backed by suitable monitoring and technical assistance, be put into place requiring and empowering all overseas recipients of federal funds to comply with the provisions of Section 504 in their use of such funds.

*Recommendation 12.2*—NCD recommends that the Administration establish a national commission to review the entire range of U.S. international assistance programs and other commitments under the Foreign Assistance Act and other laws to determine the extent to which full access and participation by persons with disabilities is incorporated in governing regulations, contract terms, oversight, and reporting criteria.

*Recommendation 12.3*—NCD recommends that the Administration announce its intention to participate fully and actively in the deliberations of the working group considering the UN Convention on the Rights of People with Disabilities, with a view to helping develop a treaty that, if consistent with U.S. policies and practices and reflecting the input of persons with disabilities from around the world, will be signed by the United States and thereafter submitted to the Senate, with active support from the Administration for its ratification.

*Recommendation 12.4*—NCD recommends that the Administration establish a commission to survey all existing federally funded or federally administered TA programs in the areas of accessibility and full participation, with a view to identifying those which may have some applicability to activities being supported with U.S. funds in the international arena, and with a view to establishing mechanisms and linkages to enable these resources to be brought to bear on the world stage in those cases where the content or methods of such technical assistance are deemed pertinent.

### **Recommendations to the Department of State**

*Recommendation 12.5*—NCD recommends that the Department adopt a prospective policy that would establish accessibility as a key criterion in the selection, lease, purchase, modification, or occupancy of sites.

*Recommendation 12.6*—NCD recommends that the permanent post of disability advisor be created as a counselor to the Department of State, reporting directly to the Secretary and having a collegial and consultative relationship with all bureaus of the Department and, through the Department, with such other agencies as may be deemed appropriate.



# **Chapter Thirteen**

## **Homeland Security**

### **Introduction**

The tragic events of three years ago have made homeland security, both as a concept and as an agency of government, an important element of our lives. For people with disabilities, no less than for all Americans, homeland security is vital and has brought about changes in our lives. And for people with disabilities, as for all Americans, balancing the new demands of security with our traditional values of freedom and openness remains a delicate and complicated process.

But for people with disabilities the rights and values that can collide with security are themselves fairly new. They are the rights to nondiscrimination and equal access and opportunity embodied in a number of laws over the past 20 years.

This chapter addresses the interface between a number of major homeland security initiatives and the rights and expectations of people with disabilities. It considers the relationship between nondiscrimination and security generally, concentrates on people with disabilities in emergency preparedness planning, and focuses on some of the nondiscrimination issues raised by the involvement of private organizations in protection of our security.

### **Nondiscrimination**

Nondiscrimination and equal opportunity for people with disabilities were not on the radar screen when most federal agencies were created. Thus, implementing them is usually a matter of retrofitting existing practices and structures. With the creation of the Department of Homeland Security (DHS), our nation had an opportunity to incorporate the values of nondiscrimination and equal opportunity into an important federal agency from the ground up. While the agencies brought together to create DHS all had their own histories and internal cultures, a new, overriding approach was nevertheless being created.

NCD congratulates DHS for its attention to citizens with disabilities and the issues that concern them. Amidst the urgent effort to form disparate entities into a single working whole, DHS has repeatedly taken time and shown willingness to respond in this key area. In particular, we have had occasion to note the efforts and accomplishments of the Transportation Security Administration, itself a completely new entity, in developing procedures and implementing training to ensure that the rights of air travelers with disabilities are respected. NCD has also had occasion to commend the Bureau of Citizenship and Immigration Services (BCIS) (formerly the Immigration and Naturalization Service) for significant accommodations incorporated, both as a matter of policy and in response to individual needs, in the cherished process of gaining U.S. citizenship.

Naturally, awareness will vary from agency to agency within DHS, but NCD is confident that similar responsiveness will be experienced across the spectrum of DHS activities and units.

## **Emergency Preparedness**

One area of ongoing importance in the work of DHS that directly impacts the public is emergency preparedness. Here, too, NCD appreciates the efforts that have been made to ensure that people with disabilities be taken into account in emergency response planning, such as in the interagency seminar, “Emergency Preparedness for Persons with Disabilities,” hosted by DOL’s Office of Disability Employment Policy.<sup>162</sup> In focusing on the exchange of information and best practices among federal managers, the seminar sought to reinforce the leadership of the Federal Government in this area. But NCD continues to have a number of concerns that we believe DHS can help to address.

Emergency preparedness involves and depends on the effective planning of numerous partners. Information is scarce regarding how well state and local government or the private sector is doing in incorporating workers, customers, visitors, and citizens with disabilities into emergency planning at all levels. NCD believes that baseline data must be collected in this area as a means for needs assessment and for fashioning appropriate technical assistance.

Therefore, as a first step in assessing the state of emergency preparedness planning around the country, DHS should survey its state and local governmental partners, whose responsibilities in such areas as first-responder training and evacuation planning place them in the forefront of emergency preparedness planning. NCD recommends that DHS survey all state and local partners and affiliates involved in emergency planning to (a) identify the measures they have taken to address the full inclusion of persons with disabilities in their preparedness and emergency-response planning, (b) evaluate the training and TA resources these partners may need to more effectively carry out this element of their work, and (c) identify and disseminate model practices discovered in states and communities around the country.

From the design of informational resources to be used to warn people of danger, to the delineation and marking of escape routes, to the distribution of emergency supplies, vaccines, or protective equipment, people with disabilities may have experiences and needs that differ in crucial ways from those of the rest of the general public and that are not necessarily obvious to local planners and decision makers. Accordingly, NCD recommends that whenever state or local governments involve local institutions or members of the public in emergency preparedness planning or exercises, individuals with disabilities are consciously sought out and included in these efforts.

## **Private Organizations**

In much of its work, DHS operates with the help of private organizations and provides contractual or other funds for their use. Ranging from computer security firms that develop new strategies for protecting the nation against cyber-attack, to pharmaceutical companies engaged in the development of vaccines to protect the nation against biological attack, to schools that train linguists or other specialized experts, DHS works with and through an enormous range of private entities, both for-profit and nonprofit in nature.

It is vitally important that these organizations understand and share the concern for the rights and interests of people with disabilities. It is also crucial that they possess the knowledge and

resources to implement such concern in their work. Implementation barriers and the need for knowledge and resources may include, but are not limited to, the following:

- A vaccine warning label that cannot be read by a person with a visual disability
- A computer security system that locks out users of TTYs
- A telephone-based information system that presents information in ways that cannot be slowed down or otherwise accessed and understood by people with intellectual disabilities
- A biometric identification system that assumes everyone has 2 eyes, 2 hands, 10 fingers, or a voice that can be scanned in standardized ways.

Whether in day-to-day use or in moments of crisis, the impact of these barriers is not lessened by the fact that it was never anyone's intent that people with disabilities be excluded or disadvantaged.

This is why DHS must ensure both awareness and action on the part of all its private sector, nongovernmental contractors and other partners. To achieve this goal, NCD recommends that DHS develop contract, grant, and other agreement language requiring contractors, grantees, and other partners to certify that they will seek out and incorporate input from people with disabilities at the earliest possible stages of product and system development, consistent with the demands of secrecy and national security. DHS should also develop mechanisms for monitoring contractor performance in these areas and means for providing TA and remedial guidance where adequate performance is found to be lacking.

## **Conclusion**

As a new cabinet department, DHS has had a unique opportunity to incorporate concerns for accessibility and equality into its development and procedures. NCD believes the Department has justified itself well in many areas so far, and here suggested additional steps that evolving conditions make timely and appropriate.

## **Recommendations and Summary**

### **Recommendations to the Department of Homeland Security**

*Recommendation 13.1*—NCD recommends that DHS survey all state and local partners and affiliates involved in emergency planning to (a) identify the measures they have taken to address the full inclusion of persons with disabilities in their preparedness and emergency-response planning, (b) evaluate the training and technical assistance resources these partners may need to more effectively carry out this element of their work, and (c) identify and disseminate model practices discovered in states and communities around the country.

*Recommendation 13.2*—NCD recommends that whenever state or local governments involve local institutions or members of the public in emergency preparedness planning or exercises, individuals with disabilities are consciously sought out and included in these efforts.

*Recommendation 13.3*—NCD recommends that DHS develop contract, grant, and other agreement language requiring contractors, grantees, and other partners to certify that they will seek out and incorporate input from people with disabilities at the earliest possible stages of product and system development. This needs to be consistent with the demands of secrecy and national security.



# **A Compilation of Report Recommendations to Congress, the Administration, and Federal Agencies**

In this final section, all of the report recommendations have been compiled according to the target audiences. There are three parts that provide specific recommendations to Congress, to the Administration, and to federal agencies. The numerals within the text are consistent with the way recommendations are identified at the end of the various topical chapters of the report.

## **Recommendations to Congress**

### **Chapter One—Disability Statistics and Research**

*Recommendation 1.3*—NCD recommends that Congress authorize research studies into the effectiveness of a number of leading programs and intervention strategies. Initially, this might begin by assessing key indicators, such as the employment and income status of persons with disabilities who have been placed in employment following successful completion of VR programs.

Compare the information obtained to the disability population generally and the working-age population as a whole. Additional avenues of study should look at the employment and income status of persons with disabilities who have graduated from a four-year or community college and/or those who are in a pilot experiment, ensured of full and uninterrupted access to comprehensive medical care after entering employment.

Other research should address the impact—again through a pilot study, if necessary—of the provision of adequate transportation in rural areas on nursing home admissions and care costs. Finally, the research could focus on the level of employment sustainability achievable in a sample of persons who are allowed to retain their SSI cash benefits for two years after entering work, subject to gradual phase-out over a multiyear period thereafter.

## **Chapter Two—Civil Rights**

*Recommendation 2.5*—NCD recommends that Congress enact an ADA Restoration Act that will responsibly recalibrate the balance between fairness and individual dignity on the one hand, and institutional costs and convenience on the other, by addressing many of the interpretive and procedural issues noted above.

*Recommendation 2.6*—NCD urges the House of Representatives to follow the Senate’s lead as early as possible in the second session of the 108th Congress and to join the Senate in adopting genetic antidiscrimination legislation.

## **Chapter Three—Education**

*Recommendation 3.1*—Congress should ensure that when disciplinary considerations require the removal of students with disabilities from the mainstream, integrated classroom, such students are ensured the right to uninterrupted educational, special education, and related services consistent with their IEPs and with evolving assessments and needs in the most appropriate educational settings.

*Recommendation 3.2*—NCD recommends that Congress and the Administration undertake a study of possible methods and sources for increasing over time to 40 percent the level of federal participation in special education.

*Recommendation 3.3*—NCD recommends that Congress establish a commission to study the long-term costs of special education and to recommend strategies for ensuring the financial stability of state and local education agencies in meeting national educational goals for students with disabilities.

*Recommendation 3.4*—NCD recommends that before the enactment of any further curbs or restrictions of a procedural or economic nature on the due process rights of parents, Congress



fully review the impact and efficacy of existing provisions designed to curb litigation and complaints.

*Recommendation 3.5*—NCD recommends that inasmuch as adequate data does not yet exist to justify the curtailment of parental due process rights in special education, Congress undertake definitive research that would provide empirical evidence on the subject of the impact of appeals and of attorneys on special education before further restricting family rights.

*Recommendation 3.6*—NCD recommends that Congress in its reauthorization of IDEA include provisions calling for adoption of ED’s consensus NFF (or if a comment period reveals that this standard is unsatisfactory, then for development of another one) that would have to be met as a condition for textbook purchase. Congress should also adopt the provision in the Senate draft bill calling for the establishment of a national repository of computer files so that books in accessible formats can effectively and promptly be made available to those schools and students that need them.

*Recommendation 3.7*—NCD recommends that Congress include in the IDEA reauthorization provisions and resources supporting the conduct of a detailed national study on the availability, need for, and impact of a variety of accommodations that have been used in various school settings. This study should be conducted with a view to identifying approaches to the development of a national strategy that will meet the ultimately complementary needs of students with disabilities and needs of school systems. The study should also attempt to assess the impact of various accommodations on test outcomes, so their impact can be taken into account in the norming of tests and in ensuring fairness and compatibility of results.

*Recommendation 3.8*—NCD recommends that Congress include in the reauthorized IDEA an instruction to the Secretary of Education to collect data on the availability and utilization of accessible instructional materials and assistive technology in the schools, and collect all available data on the connection between the application of such resources and of a variety of

reasonable accommodation strategies with measures of the status and outcomes of students with disabilities.

*Recommendation 3.9*—NCD recommends that the national education technology plan set forth as a cornerstone and a fundamental requirement of America’s education technology policy that all technology resources and tools created or used must be accessible to and usable by all students, irrespective of disability.

*Recommendation 3.10*—NCD recommends that if Congress cannot address these substantive issues in a manner that their complexity and importance warrant, and in a manner that ensures the necessary level of program accountability, Part B of IDEA should not be modified or changed but should be left in tact until the necessary further deliberations can take place.

*Recommendation 3.11*—NCD recommends that Congress hold hearings on the barriers facing students with disabilities as part of its consideration of the Higher Education Act reauthorization, and that students with disabilities themselves should be invited and encouraged to share their views and experiences with lawmakers.

*Recommendation 3.12*—NCD recommends that Congress expand its assessment by incorporating into the Higher Education Act provisions paralleling the textbook and technology accessibility measures recommended above for IDEA. NCD recommends that if Congress lacks time or inclination to conduct a thorough review of higher education in relation to students with disabilities at this time, Congress should include in the reauthorization an instruction and resources for the Secretary of Education to conduct a thorough study of these issues, through the appointment of a national commission composed of representatives and members of all relevant constituencies, including youth with disabilities.

*Recommendation 3.13*—NCD urges Congress to commission a feasibility study of the broadening of the IDA concept to make this modality available to all students with disabilities for transitional purposes and to clarify the availability of a broad range of expenditure categories

as permissible within this framework. The tax deductibility of all contributed funds and the tax-exempt status of all properly withdrawn funds should also be made clear, as well as the exclusion of IDA funds from means-testing under any other federal or state program.

#### **Chapter Four—Health Care**

*Recommendation 4.1*—NCD recommends that Congress hold hearings on the issue of institutional bias in Medicaid as early as possible in the second session of the 108th Congress in 2004.

*Recommendation 4.2*—NCD recommends that Congress amend the Medicaid law to empower or require HHS to take the necessary steps to make the Medicaid waiver process open and accountable to the citizenry.

*Recommendation 4.3*—NCD recommends that Congress establish a national commission to study the question of how consumer participation and direction can be maximized throughout the federal health insurance programs, with a view to adding the findings and recommendations of this study to such Medicaid reform proposals as the Administration and Congress may in due course develop.

*Recommendation 4.4*—NCD recommends that Congress enact the Money Follows the Person (MFP) legislation currently before it.

*Recommendation 4.5*—NCD recommends that Congress begin the process of facilitating expanded use of Medicaid buy-in programs by adopting the Family Opportunity Act.

*Recommendation 4.6*—NCD recommends that Congress enact legislation providing for a pilot demonstration study under which the prior-authorization approach would be used exclusively with one group of dual-eligibles and the purchase-first approach with another, matched group.

The results and implications should then be compared, and depending on the findings, the solution and best practices that emerge from the research should be implemented.

*Recommendation 4.7*—NCD continues to recommend to Congress that it adopt legislation to ensure that all health insurance provides equal benefits for mental health treatment as it does for the treatment of physical illness.

*Recommendation 4.8*—NCD recommends that Congress take steps to implement the major recommendations of the President’s New Freedom Commission on Mental Health and of NCD’s reports on mental health services.

*Recommendation 4.9*—NCD recommends that the Administration publish detailed, point-by-point reactions to the findings and recommendations of the NCD and President’s Commission reports, and that OMB be instructed by the President to prepare detailed estimates of the costs, savings, and other benefits that would accrue from the adoption of each of the recommendations.

## **Chapter Five—Long-Term Services and Supports**

*Recommendation 5.1*—NCD recommends that Congress adopt MFP legislation and the Medicaid Community Attendant Services and Supports Act (MiCASSA) without delay, as keystones in the new arch of long-term services policy in this country.

*Recommendation 5.2*—NCD recommends to Congress that the three-percent increase in federal matching percentage be retained, but specifically for application to those reimbursable Medicaid activities and services that are related to the development and provision of home- and community-based services.

*Recommendation 5.3*—NCD recommends enactment of the Lifespan Respite Care Act.

*Recommendation 5.4*—NCD recommends that Congress hold hearings to fully explore the potential role of the insurance industry, the tax code, the employer community, and existing programs in fashioning experimental models of coverage that can be tested and studied.

## **Chapter Six—Youth (no specific recommendations to Congress)**

### **Chapter Seven—Employment and the Workforce Development System**

*Recommendation 7.1*—NCD recommends that Congress fully explore the consequences arising from the fact that because of order of selection, the eligibility standards the VR law prescribes and the services it authorizes may not, in fact, be making their way through the pipeline to all intended end-users and service providers in communities around the country.

*Recommendation 7.2*—NCD recommends that Congress revise the Work Opportunity Tax Credit so that all long-term unemployed persons with disabilities are eligible to benefit from the incentives it offers, and so that employers are free to hire any qualified person with a disability and still receive this credit.

*Recommendation 7.3*—NCD recommends that any congressional reauthorization of the Work Opportunity Tax Credit or any review of the credit in the context of broader tax legislation include provisions making it available for people returning to their former employers following significant periods of separation after the onset of a disability.

*Recommendation 7.4*—NCD recommends that Congress study the health insurance-related work disincentives problem anew, in the context of state Medicaid cutbacks.

### **Chapter Eight—Welfare Reform**

*Recommendation 8.1*—NCD recommends that Congress grant state TANF administrators expanded discretion to waive time or benefits limits in those cases where the support services needs resulting from disability cannot be sufficiently met to facilitate successful employment.

*Recommendation 8.2*—NCD recommends Congress adopt the Pathways to Independence Act as part of, or as an amendment to, the overall PRWORA reauthorization. We also recommend that Congress grant states the discretion to waive the act’s six-month limit in cases where additional time would be likely to make the difference in bringing about long-term gainful employment.

*Recommendation 8.3*—NCD recommends that Congress broaden the definition of qualifying savings goals for TANF IDAs to include assistive or universally designed technology and modified vehicles or other specialized transportation services needed in order to work.

*Recommendation 8.4*—NCD recommends Congress require that before sanctioning any individual with a significant disability, or before curtailing benefits due to exhaustion of time limits to persons who may have a hidden disability or whose service needs as primary caregivers for family members with disabilities have not been fully assessed by knowledgeable persons, states ensure that these persons are offered the opportunity for a full medical-vocational assessment through the state’s Office of Disability Determination and its VR agency.

## **Chapter Nine—Housing**

*Recommendation 9.1*—NCD recommends that Congress authorize an experiment in a number of diverse states or regional housing markets under which accessibility status, as defined by HUD, would be added to the list of disclosure items under the Real Estate Settlements Procedure Act.

*Recommendation 9.2*—NCD recommends that Congress study the feasibility and impact of tax-based and other measures for increasing the economic attractiveness of accessibility, such as measures that would speed up the recovery period for the costs of accessibility modifications, measures that would increase the availability of federally backed mortgage funds for the construction or transfer of accessible units, and measures that would target benefits under the housing tax credit to projects that incorporate universal accessibility.

*Recommendation 9.3*—NCD recommends that Congress study ways through which visitability could be incorporated into all federal funding streams. Such a study should include a review of ways that the tax subsidies associated with the building and ownership of residential property could be enhanced for properties that are made visitable or accessible.

## **Chapter Ten—Transportation**

*Recommendation 10.1*—NCD recommends that Congress, in addition to adequate funding authorization, include in the transportation legislation authority for NFI transportation funds to be used for a wide variety of programs, including operating assistance, and that funds not be limited to the purchase or modification of vehicles.

*Recommendation 10.2*—NCD recommends that the funding and authority for the Elderly and Persons with Disabilities Program (49 U.S.C. §5310) be retained and optimized by Congress, and that its resources continue to flow to the nonprofit sector, without restrictions or limitations that would in any way inhibit the development of projects that serve people with disabilities in an integrated or community-based setting.

*Recommendation 10.3*—NCD recommends to Congress that, just as the level of federal highway funds over the years has been tied to state adoption of many national policies and priorities ranging from lowered blood alcohol levels to mandated seatbelt use, so now the availability of highway funds should be partially conditioned on state efforts to meaningfully incorporate transportation policy and agencies into the *Olmstead* implementation process.

*Recommendation 10.4*—NCD recommends that Congress vigorously support research into issues ranging from audible traffic signals and textured surfaces to traffic light placement and intersection design.

*Recommendation 10.5*—NCD recommends that Congress authorize a study of the contents, utilization, impact, relevance, and possible need for modernization of state white cane laws.

## **Chapter Eleven—Assistive Technology and Telecommunications**

*Recommendation 11.1*—NCD recommends that Congress reauthorize the Assistive Technology Act this year and provide not only an additional year’s funding, but also statutory authorization for the program’s existence, so that a measure of stability and the means to engage in planning and capacity-building can be restored.

## **Chapter Twelve—International Affairs (no specific recommendations for Congress)**

## **Chapter Thirteen—Homeland Security (no specific recommendations for Congress)**

## **Recommendations to the Administration**

### **Chapter One—Disability Statistics and Research**

*Recommendation 1.1*—NCD recommends that the U.S. Government’s Interagency Committee on Disability Research be given all possible resources, status, and visibility by the Administration to carry out the interagency research and coordination so vitally necessary to the collection and rationalization of disability statistics.

*Recommendation 1.2*—NCD recommends that the Administration appoint a high-level presidential task force—including leaders in such fields as economics, demographics, health, education and law, and including leaders from within the disability community—to begin the admittedly daunting task of identifying those econometric, statistical, observational, forecasting, and other techniques and tools that may be available for bringing greater accountability to disability policy, and for identifying the range of outcomes, consequences, implications, and relationships that must be taken into account in designing policy and assessing its effects.



## **Chapter Two—Civil Rights (no specific recommendations to the Administration)**

## **Chapter Three—Education (no specific recommendations to the Administration)**

## **Chapter Four—Health Care**

*Recommendation 4.9*—NCD recommends that the Administration publish detailed, point-by-point reactions to the findings and recommendations of the report of the President’s New Freedom Commission on Mental Health, and that OMB be instructed by the President to prepare detailed estimates of the costs, savings, and other benefits that would accrue from the adoption of each of the recommendations.

## **Chapter Five—Long-Term Services and Supports (no specific recommendations to the Administration)**

## **Chapter Six—Youth**

*Recommendation 6.1*—NCD recommends that the Administration take steps to ensure that recommendations of a national commission appointed by the Administration are implemented. The findings must be formally reviewed, adopted, rejected, or otherwise responded to by a federal official with authority to speak for the Administration. Findings that are adopted must be implemented under conditions that include accountability time frames against which success or failure can be measured.

*Recommendation 6.2*—NCD recommends that the Administration instruct each federal agency that deals in any particular way with youth with disabilities or their families to develop means by which the opinions, experiences, and recommendations of this constituency or target population can be obtained and taken into account in future program planning.

*Recommendation 6.3*—NCD recommends that the Administration make clear at the earliest possible moment its intentions with respect to its opinion and use of the work of the National Youth Leadership Network to date, and its intentions regarding continued federal support for the work of this project.

## **Chapter Seven—Employment and the Workforce Development System**

*Recommendation 7.5*—NCD recommends that the Administration establish a blue-ribbon task force to study the aging of the workforce on an expedited basis and to make recommendations to Congress on measures that could be taken to strengthen the capacity of the economy to retain and benefit from the services and experiences of older workers with adult-onset disabilities.

*Recommendation 7.6*—NCD recommends that the Administration move swiftly to remedy any problems uncovered by forthcoming studies on the Ticket to Work program, either by interagency or executive branch action or by proposing and supporting appropriate legislation, as the case may be.

## **Chapter Eight—Welfare Reform (no specific recommendations for the Administration)**

### **Chapter Nine—Housing**

*Recommendation 9.4*—NCD recommends that the Administration appoint a high-level national commission composed of economists, housing and transportation experts, tax practitioners, legal analysts, architects, land-use planners, and individuals with disabilities to map a long-term strategy for steadily increasing the proportion of the nation’s housing stock that meets standards of accessibility.

*Recommendation 9.5*—NCD recommends that the high-level national commission recommended above to study how to expand the nation’s accessible housing stock also be tasked by executive order to include these issues in its mandate.

### **Chapter Ten—Transportation**

*Recommendation 10.6*—NCD recommends that the Administration undertake a comprehensive study into the need for, availability of, and prospects for transportation resources and services in this country, not as an end in themselves but as they relate to the achievement of a variety of other national priorities and objectives, with a view to developing and documenting measures for

assessing the impact of transportation investments, resources, and facilities on the participation of people with disabilities in employment, education, and community living.

*Recommendation 10.7*—NCD recommends that the ATMD Task Force be reconvened with the charge of going beyond the list of agencies and their statements of what they do, to an assessment of whether, in fact, there are any Americans who face barriers to education, employment, or health care that could be overcome by the heightened availability of ATMD for personal transportation, and if so, how federal programs can be modified or better coordinated to bring about greater access.

## **Chapter Twelve—International Affairs**

*Recommendation 12.1*—NCD recommends that government-wide regulations, backed up by suitable monitoring and technical assistance, be put into place requiring and empowering all overseas recipients of federal funds to comply with the provisions of Section 504 in their use of such funds.

*Recommendation 12.2*—NCD recommends that the Administration establish a national commission to review the entire range of U.S. international assistance programs and other commitments under the Foreign Assistance Act and other laws to determine the extent to which full access and participation by persons with disabilities is incorporated in governing regulations, contract terms, oversight, and reporting criteria.

*Recommendation 12.3*—NCD recommends that the Administration announce its intention to participate fully and actively in the deliberations of the working group considering the UN Convention on the Rights of People with Disabilities, with a view to helping develop a treaty that, if consistent with U.S. policies and practices and reflecting the input of persons with disabilities from around the world, will be signed by the United States and thereafter submitted to the Senate, with active support from the Administration for its ratification.

*Recommendation 12.5*—NCD recommends that the Administration establish a commission to survey all existing federally funded or federally administered TA programs in the areas of accessibility and full participation, with a view to identifying those which may have some applicability to activities being supported with U.S. funds in the international arena, and with a view, in those cases where the content or methods of such TA are deemed pertinent, to establishing mechanisms and linkages to enable these resources to be brought to bear on the world stage.

## **Chapter Thirteen—Homeland Security (no specific recommendations for the Administration)**

### **Recommendations to Federal Agencies, Offices, and Courts**

#### **Chapter One—Disability Statistics and Research**

##### *Recommendations to the Census Bureau*

*Recommendation 1.4*—NCD recommends that disability-related questions be retained and improved in the 2010 Census, and that if the Census Bureau believes that it lacks legal authority to retain or enhance these questions, it immediately seek the necessary legislative authorization from Congress.

#### **Chapter Two—Civil Rights**

##### *Recommendations to the Judicial Conference and the Administrative Office of the Courts*

*Recommendation 2.1*—NCD recommends that attorneys and judges with disabilities be invited to participate in seminars at institutes and meetings of and for federal judges held under various auspices during the year.

*Recommendation 2.2*—NCD recommends that, in several sample federal districts and circuit courts of appeals, the courts undertake a comprehensive ADA self-assessment, including physical, programmatic, and communications barriers.

*Recommendation 2.3*—NCD recommends that the Judicial Conference of the United States adopt the standards and protocols for Web site accessibility and document formatting and design embodied in Section 508 of the Rehabilitation Act; seek and provide the technical assistance resources that each court will need to implement these principles; establish realistic but meaningful timetables for completion of the work; and seek the input of persons with disabilities, including attorneys, litigants, and court employees, as well as jurists, to provide input and feedback as the process goes forward.

*Recommendations to the Department of Justice*

*Recommendation 2.6*—NCD recommends that DOJ reactivate and support the work of the Interagency Disability Coordinating Committee, with a view to developing, publicizing, and implementing a cross-agency plan for the implementation and administration of Section 504 that will ensure clarity, consistency, and predictability for both individuals with disabilities and entities receiving federal financial assistance.

*Recommendation 2.7*—NCD recommends that, pending the full implementation of the Help America Vote Act, DOJ support the applicability of ADA to the polling place and the voting booth by initiating cases or intervening in cases where reasonable measures on the part of state and local election officials could result in meaningful increases in the independent and accessible voting opportunities for Americans with disabilities.

**Chapter Three—Education**

*Recommendation to the Department of Education*

*Recommendation 3.14*—NCD recommends that ED promulgate detailed policy guidance that applies, so far as deemed appropriate and with such differences as are deemed necessary, the teacher qualification provisions embodied in NCLB to the unique needs and conditions existing in special education and to the special education and related services disciplines deemed to come within the scope of the NCLB. In this regard, NCD further urges Congress to incorporate in the

reauthorized IDEA resources and authority for the Secretary of Education to conduct a detailed assessment of the personnel and personnel-preparation needs for students with disabilities, of the current resources available for training specialized personnel, and of means by which the resources required to fulfill identified intermediate- and long-term specialized training and personnel needs can be reliably and stably met.

*Recommendation to the Department of the Treasury*

*Recommendation 3.15*—NCD recommends that the Department of the Treasury study and report to Congress on the potential, from the revenue and administrative standpoints, of establishing tax-deductible contributory transition savings accounts, the proceeds of which would remain tax-exempt when spent for qualifying transition activities, services, or purposes. In conducting this study, which should be completed within one year, Treasury should seek the input of the disability community regarding all key points, including the potential impact of such a program, the range of activities, goods and services that should be eligible to qualify for transition expenditure, and the time frames within which funds should be expended.

**Chapter Four—Health Care**

*Recommendations to the Centers for Medicare and Medicaid Services*

*Recommendation 4.10*—NCD recommends that CMS (the agency that administers the Medicaid program) begin publishing and updating on a regular basis detailed information on the proportion of Medicaid, Medicare, and other federal health care funds going to the provision or support of institutional versus home- and community-based services and care.

*Recommendation 4.11*—NCD recommends that in its oversight of the Medicare discount-card program and its role in approving proposals from insurers or drug providers, CMS require (and should thereafter monitor for evidence of compliance) that all materials utilized or published by discount-card providers be available in a variety of written, accessible Web-based, telephone-based, and other formats, and that reliable and readily accessible sources of assistance in

understanding and comparing program provisions, and thereafter in negotiating the details of program participation, be available.

*Recommendation 4.12*—NCD recommends that CMS provide appropriate mechanisms with precise guidelines for ensuring that the requirements for nondiscrimination and equal access embodied in Sections 504 and 508 of the Rehabilitation Act are applicable to all documentation and outreach activities undertaken by private sector providers under the new law.

*Recommendation 4.13*—NCD recommends that CMS clarify whether it regards private sector managed care organizations and other drug and Medicare benefit and services providers as covered by the antidiscrimination provisions of Section 504 of the Rehabilitation Act.

*Recommendation 4.14*—NCD recommends that CMS begin a planning process designed to ensure that the individual decisions of providers will not result in any Medicare recipients with disabilities being forced to choose between the increasing advantages of managed care and access to the particular treatments, modalities, and practitioners they need as individuals.

#### *Recommendations to the Department of Health and Human Services*

*Recommendation 4.15*—NCD recommends that HHS require that state Medicaid plans include detailed descriptions of how waiver requests will be developed in ways that permit and encourage public and community input, and that each waiver request be required to include detailed information about the nature of public and community input, pro and con, that was received.

*Recommendation 4.16*—NCD recommends that HHS's own Medicaid waiver review processes be opened to public participation through publication of all waiver requests in the *Federal Register* with opportunity for comment, that the substance of comments be published with HHS decisions on them, and that all waivers be initially approved on a time-limited basis and subject to review and renewal or modification after a specified period of time.

*Recommendation 4.17*—NCD recommends that HHS develop and implement a comprehensive plan for ensuring that the resources of FDA and CMS will be brought to bear in a coordinated fashion to assess and review AT and universally designed medical devices to ensure the earliest and most effective possible determinations regarding the suitability of such equipment for coverage under Medicare and other insurance programs.

*Recommendation 4.18*—NCD recommends that HHS, through its Office on Disability or such other unit as the Secretary of HHS deems appropriate, undertake a study into the methods used for implementation of HIPAA requirements for people with disabilities, and into the effectiveness of these methods as they relate to the particular access needs faced by various subgroups of people with disabilities.

*Recommendation to the Food and Drug Administration*

*Recommendation 4.19*—NCD recommends that FDA develop and publish a comprehensive plan for ensuring that assistive and universally designed devices with particular applicability to the lives of people with disabilities are evaluated on a priority basis, and by people who are knowledgeable about the issues and people such technology is designed to address.

**Chapter Five—Long Term Services and Supports**

*Recommendations to the HHS Centers for Medicare and Medicaid Services*

*Recommendation 5.5*—NCD recommends that CMS require timely planning for and documented achievement of *Olmstead* goals as a condition for states receiving federal funds under the Medicaid program.

*Recommendation 5.6*—NCD recommends that CMS initiate a formal and intensive information-gathering process, preparatory to rulemaking, designed to result in the issuance within 18 months of proposed regulations governing the new *Olmstead* priority.



*Recommendation 5.7*—NCD recommends that if CMS believes that neither the existing Medicaid statute, ADA, nor the Supreme Court’s *Olmstead* decision authorize it to take these actions, HHS should immediately seek from Congress the necessary legislative authorization.

## **Chapter Six—Youth**

*Recommendation to the Department of Justice*

*Recommendation 6.4*—NCD recommends that DOJ appoint a high-level national commission to authoritatively and accountably review all available evidence on juvenile justice system and disability interconnections.

*Recommendation to the Office of Management and Budget*

*Recommendation 6.5*—NCD recommends that OMB develop and disseminate a brief statement, to be included on all relevant federal transmittals, grant applications, and contract documents and notices, reminding partners of the importance of establishing clearly under each program and with each agency with which they may work, the parameters of “youth” under applicable law.

## **Chapter Seven—Employment and the Workforce Development System**

*Recommendations to the Department of Labor*

*Recommendation 7.7*—NCD recommends that DOL establish and publicize a complaint procedure for use by individuals who have been denied access to One-Stop Centers, incorporate accessibility guarantees in requirements for state workforce development plans, and insist on inclusion of representatives of people with disabilities (or at least of state VR agencies) on state and local workforce investment boards.

*Recommendation 7.8*—NCD recommends that DOL, acting through its Office of Disability Employment Policy or through its Office of Inspector-General, jointly develop with DOJ a plan for vigorous and proactive enforcement of the antidiscrimination and accessibility requirements

of the law bearing on the ability and willingness of One-Stop Centers to serve customers with disabilities.

*Recommendation 7.9*—NCD recommends that DOL develop outcome measures that take due account of all the relevant variables involved in working with job seekers with disabilities, including not only the potential costs of working with this population within a mainstream setting, but also the benefits to the taxpayers of commitment and success in such work.

*Recommendation 7.10*—NCD recommends that DOL survey One-Stop Centers and people with disabilities who have received referral services through them to determine the measures the One-Stop Centers have used to monitor the treatment that people with disabilities receive at the hands of community partners, and the means they have developed for sharing expertise and resources with such providers in ways aimed at ensuring accessibility.

*Recommendations to the Department of Education*

*Recommendation 7.11*—NCD recommends that ED's Rehabilitation Services Administration establish an investigative procedure to determine through outreach to a variety of VR partners the extent to which the aspirations and obligations of these partners to work collaboratively and smoothly with VR are adversely effected or unduly complicated by recourse to orders of selection.

*Recommendation 7.12*—NCD recommends that, at least until states' fiscal situations improve significantly, ED, through NIDRR, waive upfront cash requirements and accept a variety of other forms of documentable matching contributions, including noncash match, so long as these in-kind or other noncash resources are reasonably amenable to valuation.

*Recommendation 7.13*—NCD recommends that ED, through its Office of Civil Rights, open an inquiry into the sources of policies that may hinder establishment of positive credit histories, and

if they are found to exist as described to us, seek to remove this barrier to the establishment of positive credit history records by borrowers with disabilities.

## **Chapter Eight—Welfare Reform**

### *Recommendation to the Department of Health and Human Services*

*Recommendation 8.5*—NCD recommends that the Secretary of HHS issue regulations requiring state TANF program administrators to set up screening and cooperative service-provision partnerships with state VR agencies (or where orders of selection prevent the state VR agencies from effectively offering their services to new people, with other appropriate entities) that can offer the expertise needed to ensure that TANF recipients’ disability-related training and other employment-support needs will be properly identified and effectively met.

### *Recommendation to the Department of Justice*

*Recommendation 8.6*—NCD also recommends that with respect to the existing TANF IDA provisions specifying first-time home acquisition as a qualifying IDA savings objective, DOJ evaluate whether, in order to comply with ADA, the definition of permissible acquisition expenses should be broadened to include the costs of home modifications where such modifications are necessary to make the home accessible for a person with a disability.

## **Chapter Nine—Housing**

### *Recommendations to the Department of Housing and Urban Development*

*Recommendation 9.6*—NCD recommends that HUD develop and disseminate a comprehensive publication explaining all the rental and home ownership programs available, with particular reference to the specific provisions dealing with people with disabilities, and, through illustrations and case studies, explaining all major potential interactions with other laws and benefit programs.

*Recommendation 9.7*—NCD recommends that DOJ and HUD jointly publish and thereafter adhere to guidelines delineating the management of cases from HUD (or Fair Housing Assistance Program) complaint to DOJ or judicial disposition.

*Recommendation 9.8*—NCD recommends that HUD undertake a study aimed at determining the extent and nature of noncompliance not only with Section 504, but also with Title II of ADA by local housing authorities and state public housing agencies.

*Recommendation 9.9*—NCD recommends that HUD develop research strategies, going beyond the use of testers in matched pairs, aimed at identifying instances of discrimination occurring at nonpublic points in the housing process.

*Recommendation 9.10*—NCD recommends that HUD, in collaboration with OMB, develop a research model for assessing behavior or other actual change, and thereafter conduct in-depth follow-up interviews after 6 and 12 months, with a random sample of training and technical assistance recipients across the spectrum of programs utilizing these resources, with a view to determining the actual impact of this training on the way they carry out their work, on the manner in which they make decisions, and on the content of those decisions.

*Recommendation 9.11*—NCD recommends that HUD undertake a study of definitions to determine what if any changes, through administrative action or legislation, need to be made to bring definitions, technical requirements, and standards into compliance with modern precepts, and to ensure that what we ask members of the housing community to do continues to represent the most effective allocation of public and private resources.

## **Chapter Ten—Transportation**

### *Recommendations to the Department of Transportation*

*Recommendation 10.8*—NCD recommends the development of a fact sheet that addresses actual or foreseeable situations encountered in the course of air travel and that specifies for each the key points listed in the text accompanying this recommendation.

*Recommendation 10.9*—NCD recommends that in order to make the ACAA complaint process meaningful for both passengers and carriers, DOT make clear by regulation or other appropriate advisory that serious or repeat violations of the law will and must be dealt with by imposing significant sanctions, and not merely by obliging carriers to use fine remittances for activities that under the law they should have been carrying out already.

*Recommendation 10.10*—NCD recommends that DOT immediately require, as a critical dimension of ACAA compliance, that all ticket machines hereafter designed, installed, or modified are made accessible.

*Recommendation 10.11*—NCD recommends that FAA, the Secretary of Transportation, and TSA develop mechanisms to ensure that whenever new airport technology is designed or tested, passengers with disabilities be included in the evaluation and testing processes.

*Recommendation 10.12*—NCD recommends that the Secretaries of HHS and Transportation require joint certification each year of incorporation of transportation policy and agencies into the *Olmstead* process before states' full allocation of highway funds can be released.

*Recommendation 10.13*—NCD recommends that DOT undertake intensive inquiries in a random sample of locations to determine what the real impact of trip eligibility has been and whether the practice is enhancing the independence of people with disabilities.

## **Chapter Eleven—Assistive Technology and Telecommunications**

### *Recommendations to the Federal Communications Commission*

*Recommendation 11.2*—NCD recommends that the FCC publish standards for the review of proposed Section 255 settlements to ensure that they are in the public interest and that they reflect accurately an understanding of the relevant and applicable technology and law on the part of the parties.

*Recommendation 11.3*—NCD recommends that the FCC revive the Market Monitoring Report as a tool for assessing the needs and potential for greater product accessibility in various key areas of telecommunications technology.

*Recommendation 11.4*—NCD recommends that the FCC initiate the development of a record for use in a rulemaking procedure aimed at applying Section 255 to Voice Over Internet Protocol. If the Commission believes it lacks this authority, it should immediately join with NCD and with appropriate representatives of the telecommunications industry and disability community to make recommendations to Congress for the necessary legislation.

*Recommendation 11.5*—NCD recommends that the FCC initiate regulatory proceedings designed to anticipate all the technological issues that may be reasonably foreseeable in the continued availability and increased utilization of captioning, and to promulgate rules that will ensure, while there is still time for manufacturers and carriers to respond effectively, that the availability and quality of captioning will be in no way compromised or endangered.

*Recommendation 11.6*—NCD recommends that the FCC consult with interested industry groups and representatives of the disability community, through its Consumer Advisory Committee or other appropriate forums, with a view to developing recommendations for video description legislation that can be submitted to and supported in Congress.

*Recommendation 11.7*—NCD recommends that the FCC initiate a rulemaking designed to require appropriate accessibility certification and guarantees as a condition for the receipt of E-rate subsidies.

*Recommendations to the Department of Justice*

*Recommendation 11.8*—NCD recommends that the forthcoming DOJ Section 508 report, while maintaining the focus on progress toward Web site accessibility that characterized DOJ’s earlier report, place emphasis on the categories of equipment covered by the law.

*Recommendation 11.9*—NCD recommends that DOJ undertake proceedings to identify the subsisting interpretive questions surrounding Section 508, and that it provide authoritative indications of its views concerning the answers.

*Recommendation to the General Services Administration*

*Recommendation 11.10*—NCD recommends that GSA, in conjunction with DOJ, undertake a study of such matters as how and when federal agencies are utilizing the statutory exceptions and defenses to the imposition of 508 requirements on particular procurements, how these instances are being documented, how accessibility is being scored in the evaluation of competitive bids in relation to other procurement requirements, and whether agencies have developed plans for making information resources accessible to appropriate staff or members of the public when the technology that produces them cannot itself be made accessible.

**Chapter Twelve—International Affairs**

*Recommendations to the State Department*

*Recommendation 12.5*—NCD recommends that the State Department adopt a prospective policy that would establish accessibility as a key criterion in the selection, lease, purchase, modification, or occupancy of sites.

*Recommendation 12.6*—NCD recommends that the post of permanent disability advisor be created, as a counselor to the Department of State, reporting directly to the Secretary of State and having a collegial and consultative relationship with all bureaus of the Department and through the Department with such other agencies as may be deemed appropriate.

### **Chapter Thirteen—Homeland Security**

#### *Recommendations to the Department of Homeland Security*

*Recommendation 13.1*—NCD recommends that DHS survey all state and local partners and affiliates involved in emergency planning to (a) identify the measures they have taken to address the full inclusion of persons with disabilities in their preparedness and emergency-response planning, (b) evaluate the training and technical assistance resources these partners may need to more effectively carry out this element of their work, and (c) identify and disseminate model practices discovered in states and communities around the country.

*Recommendation 13.2*—NCD recommends that whenever state or local governments involve local institutions or members of the public in emergency preparedness planning or exercises, individuals with disabilities are consciously sought out and included in these efforts.

*Recommendation 13.3*—NCD recommends that DHS develop contract, grant, and other agreement language requiring contractors, grantees, and other partners to certify that they will seek out and incorporate input from people with disabilities at the earliest possible stages of product and system development, consistent with the demands of secrecy and national security.



# Appendix I

## Mission of the National Council on Disability

### Overview and Purpose

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

### Specific Duties

The current statutory mandate of NCD includes the following:

- Reviewing and evaluating, on a continuing basis, policies, programs, practices, and procedures concerning individuals with disabilities conducted or assisted by federal departments and agencies, including programs established or assisted under the Rehabilitation Act of 1973, as amended, or under the Developmental Disabilities Assistance and Bill of Rights Act, as well as all statutes and regulations pertaining to federal programs that assist such individuals with disabilities, to assess the effectiveness of such policies, programs, practices, procedures, statutes, and regulations in meeting the needs of individuals with disabilities.
- Reviewing and evaluating, on a continuing basis, new and emerging disability policy issues affecting individuals with disabilities at the federal, state, and local 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.
- Preparing and submitting to the President and Congress an annual report titled *National Disability Policy: A Progress Report*.

## **International**

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

## **Consumers Served and Current Activities**

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

NCD plays a major role in developing disability policy in America. In fact, NCD originally proposed what eventually became ADA. NCD's present list of key issues includes improving personal assistance services, promoting health care reform, including students with disabilities in

high-quality programs in typical neighborhood schools, promoting equal employment and community housing opportunities, monitoring the implementation of ADA, improving assistive technology, and ensuring that people with disabilities who are members of diverse cultures fully participate in society.

### **Statutory History**

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



## Appendix II

### List of Acronyms

ACAA	Air Carrier Access Act
ACS	American Community Survey
ADA	Americans with Disabilities Act
ADL	activities of daily living
AFDC	Aid to Families with Dependent Children
AFIA	Assets for Financial Independence Act
AFP	Alternative Financing Program
AOI	Adequacy of Incentives
AT	assistance technology
ATMD	assistive technology mobility device
AWIC	area work incentive coordinator
AYP	adequate yearly progress
BCIS	Bureau of Citizenship and Immigration Services
BPA&O	Benefits Planning, Assistance, and Outreach
CBO	community-based organizations
CDC	Centers for Disease Control and Prevention
CMS	Centers for Medicare and Medicaid Services
DHS	Department of Homeland Security
DME	durable medical equipment
DOJ	Department of Justice
DOL	Department of Labor
DOT	Department of Transportation
DRE	direct recording equipment
E&IT	electronic and information technology
ED	Department of Education
EEOC	Equal Employment Opportunity Commission
FAA	Federal Aviation Administration
FCC	Federal Communications Commission
FDA	Food and Drug Administration
FHA	Fair Housing Act
FHEO	Office of Fair Housing and Equal Opportunity
FIRST	Fair Housing Accessibility First Initiative
FSS	Family Self-Sufficiency program
GAO	Government Accountability Office
GSA	General Services Administration
HAC	Hearing Aid Compatibility Act
HAVA	Help America Vote Act
HCTC	health care tax credit
HHS	Department of Health and Human Services
HIPAA	Health Insurance Portability and Accountability Act

HUD	Department of Housing and Urban Development
ICDR	Interagency Committee on Disability Research
ICF	International Classification of Functioning, Disability, and Health
IDA	Individual Development Account
IDCC	Interagency Disability Coordinating Committee
IDEA	Individuals with Disabilities Education Act
IEP	Individualized Education Program
IRS	Internal Revenue Service
ITM	information technology and terminal machine
LEA	local education agency
MDUFMA	Medical Device User Fee and Modernization Act
MFP	Money Follows the Person
MiCASSA	Medicaid Community Attendant Services and Supports Act
MMA	Medicare Modernization Act
MOU	memorandum of understanding
NCD	National Council on Disability
NCLB	No Child Left Behind Act
NETP	National Education Technology Plan
NFF	national file format
NFI	New Freedom Initiative
NGO	nongovernmental organization
NIDRR	National Institute on Disability and Rehabilitation Research
NOFA	Notice of Funds Availability
NOI	Notice of Inquiry
NPRM	Notice of Proposed Rulemaking
NYLN	National Youth Leadership Network
OCR	Office of Civil Rights
ODEP	Office of Disability Employment Policy
OIG	Office of Inspector-General
OMB	Office of Management and Budget
OSEP	Office of Special Education Programs
P&A	protection and advocacy
PHA	public housing agency
PRP	Personal Responsibility Plan
PRWORA	Personal Responsibility and Work Opportunity Reconciliation Act
RESNA	Rehabilitation Engineering and Assistive Technology Society of North America
RSA	Rehabilitation Services Administration
SEA	state education agency
SSA	Social Security Administration
SSDI	Social Security Disability Insurance
SSI	Social Security Insurance
TA	technical assistance
TANF	Temporary Assistance for Needy Families
TEA-21	Transportation Equity Act for the 21st Century
TSA	Transportation Security Administration

TWWIAP	TWWIIA Advisory Panel
TWWIIA	Ticket to Work and Work Incentives Improvement Act
UFAS	Uniform Federal Accessibility Standards
UN	United Nations
VCA	voluntary compliance agreement
VOIP	Voice Over Internet Protocol
VR	vocational rehabilitation
WIA	Workforce Investment Act
WIB	workforce investment board
WIC	Special Supplemental Nutrition Program for Women, Infants and Children
YAC	Youth Advisory Committee
YTPD	Youth Transition Process Demonstration





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<sup>7</sup> *Clackamas v. Wells*, 538 U.S. 440 (2003).

<sup>8</sup> *Raytheon Company v. Hernandez*, 540 U.S. 44 (2003).

<sup>9</sup> *Barden v. City of Sacramento*, 292 F.3d 1073 (9th Cir. 2002); *City of Sacramento v. Barden*, 537 U.S. 1231 (2003).

<sup>10</sup> *Hason v. Medical Bd. of California*, 279 F.3d 1167 (9th Cir. 2002), cert. dismissed 2003 U.S. LEXIS 2897 (2003).

<sup>11</sup> Although *Tennessee v. Lane* was argued and decided in 2004 (after the period covered by this report), its importance requires that reference be made to its outcome. The Supreme Court ruled that at least where fundamental rights such as access to judicial services is concerned, private citizens can sue states for money damages under Title II of ADA. Further court decisions will be required before the broad range of Title II cases will be available for use in this way.

<sup>12</sup> Compare *Board of Trustees of the University of Alabama v. Garrett*, 531 U.S. 356 (2001) with *Tennessee v. Lane*, 315 F.3d 680 (6th Cir. 2003), *Tennessee v. Lane*, 124 S.Ct. 1978 (2004).

<sup>13</sup> Linda Greenhouse, “Justices to Hear Case on Whether the Disabled Can Sue States on Access to Courtrooms,” *New York Times*, June 23, 2003.

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<sup>15</sup> *Tennessee v. Lane*, No. 02-1667, 2002 U.S. Briefs 1667, November 12, 2003, On Writ of Certiorari to the United States Court of Appeals for the Sixth Circuit, brief for the United States. <http://www.bazelon.org/issues/disabilityrights/lane/index.htm>.

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<sup>18</sup> National Council on Disability, *Policy Brief Series*, “Righting the ADA Papers, October 16, 2002–October 21, 2003.” <http://www.ncd.gov/newsroom/publications/2003/policybrief.htm>.

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<sup>124</sup> See HUD letter, endnote 127.

<sup>125</sup> See HUD letter, endnote 127.

<sup>126</sup> Initiatives in this area recently summarized by HUD include the Fair Housing Training Academy; Section 504 Self-Evaluation; development of a joint statement with DOJ on reasonable accommodation requirements under the Fair Housing Act; study of discrimination in rental housing; creation of a unit within the Office of Fair Housing and Equal Employment (FHEO) concentrating on pattern and practice and on systematic discrimination cases; and planned conduct of events during 2004, including a Fair Housing Policy and Research Forum. See HUD letter, endnote 127.

<sup>127</sup> Letter to NCD of February 2, 2004, from the U.S. Department of Housing and Urban Development, Deputy Assistant Secretary for Enforcement and Programs (responding to NCD's inquiry regarding steps taken by HUD to implement recommendations made in NCD's 2002 annual progress report). The letter is on file at NCD.

<sup>128</sup> HUD letter, endnote 127.

<sup>129</sup> HUD letter, endnote 127.

<sup>130</sup> HUD letter, endnote 127.

<sup>131</sup> P.L. 101-336, codified at 42 U.S.C. §12101 et seq.

<sup>132</sup> 14 CFR Part 382.

<sup>133</sup> P.L. 105-178 (1998).

<sup>134</sup> 527 U.S. 581 (1999).

<sup>135</sup> Interagency Working Group on Assistive Technology Mobility Devices, *Report on Assistive Technology Mobility Devices*, August 5, 2003. [http://www.icdr.us/atmd\\_report/index.htm](http://www.icdr.us/atmd_report/index.htm).

<sup>136</sup> For example, Delta Air Lines Consent Decree (Department of Transportation, November 10, 2003). <http://dms.dot.gov/search/document.cfm?documentid=258977&docketid=16507>.

<sup>137</sup> Frontier Air Lines Consent Decree (Department of Transportation, Docket OST 2003-14194, November 13, 2003). <http://dms.dot.gov/reports/reports.aviation.asp>.

<sup>138</sup> Department of Transportation letter to NCD (responding to inquiries made and issues raised in the 2002 NCD annual progress report).

<sup>139</sup> P.L. 105-178 (1998). See also 108th Congress, H.R. 3550.

<sup>140</sup> But for a report of activities from the states' point of view, see, W. Fox-Grage, D. Folkemer, and J. Lewis, *The States' Response to the Olmstead Decision: How Are States Complying?* <http://www.ncsl.org/programs/health/forum/olmsreport.htm>.

<sup>141</sup> P.L. 105-394 (1998).

<sup>142</sup> Hearing Aid Compatible Telephones Report and Order, WT Docket No. 01-309, Federal Communications Commission, July 10, 2003.

<sup>143</sup> P.L. 104-104, §255, codified at 47 U.S.C. §255.

<sup>144</sup> *In The Matter of O'Day v. Audiovox*, FCC File No. EB-03-TC-F-004, Docket DA 03-4116 (complaint dismissed December 30, 2003). <http://www.fcc.gov/cgb/dro/section255.html#skiptopics>.

<sup>145</sup> 47 U.S.C. §255(a)(2).

<sup>146</sup> U.S. Architectural and Transportation Barriers Compliance Board (Access Board), *The Access Board's Market Monitoring Report on Accessible Telecommunications*. <http://www.access-board.gov/telecomm/marketrep>.

<sup>147</sup> Notice of Proposed Rulemaking, CC Docket 02-33, FCC, February 2002. See also NCD letter to FCC, August 6, 2002. [http://www.ncd.gov/newsroom/correspondence/2002/fcc\\_08-06-02.htm](http://www.ncd.gov/newsroom/correspondence/2002/fcc_08-06-02.htm).

<sup>148</sup> The FCC has dismissed a number of petitions for exemption from its closed-captioning requirements, most brought by religious organizations claiming that the requirements placed an unreasonable financial burden upon their television broadcasting.

<sup>149</sup> *Motion Picture Association of America, Inc. v. FCC*, 309 F.3d 796 (D.C. Cir. 2002).

<sup>150</sup> *Schools and Libraries Universal Service Support Mechanism*, CC Docket No. 02-6, Notice of Proposed Rulemaking and Order, 17 FCC Rcd 1914 (2002) (Notice and Order). In the Notice and Order, the Federal Communications Commission sought comment on a wide range of issues relating to the schools and libraries mechanism, including the treatment of unused funds.

<sup>151</sup> P.L. 105-220, §408(b), codified at 29 U.S.C. §794d.

<sup>152</sup> 36 CFR Part 1194.

<sup>153</sup> Federal Acquisition Regulation (FAR). <http://www.arnet.gov/far>.

<sup>154</sup> National Council on Disability, *Foreign Policy and Disability*, August 1, 1996. <http://www.ncd.gov/newsroom/publications/1996/foreign.htm>.

<sup>155</sup> National Council on Disability, *Foreign Policy and Disability: Legislative Strategies and Civil Rights Protections to Ensure Inclusion of People with Disabilities*, September 9, 2003. <http://www.ncd.gov/newsroom/publications/2003/foreign03.htm>.

<sup>156</sup> <http://www.ncd.gov/newsroom//publications/2003/section504.htm#ChapterII>.

<sup>157</sup> Foreign Assistance Act of 1961 as amended, 22 U.S.C. §2151 et seq.

<sup>158</sup> Letter from the Department of State to NCD, June 7, 2004, responding to inquiries made pursuant to publication of NCD's 2002 annual progress report.

<sup>159</sup> For example, *UN Disability Convention—Topics at a Glance: History of the Process*, NCD briefing paper, November 2003. [http://www.ncd.gov/newsroom/publications/2003/history\\_process.htm#skip](http://www.ncd.gov/newsroom/publications/2003/history_process.htm#skip).

<sup>160</sup> House Concurrent Resolution 169 (June 12, 2003).

<sup>161</sup> No official government document embodying this position has been located, but this is widely reported to be the Administration's view.

<sup>162</sup> <http://www.dol.gov/odep/pubs/ep/index2.htm>.