

National Disability Policy: A Progress Report



National Council on Disability
January 15, 2008

National Council on Disability
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National Disability Policy: A Progress Report

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National Council on Disability

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

Letter of Transmittal

January 15, 2008
The President
The White House
Washington, DC 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.

This report covers the period from December 2005 through December 2006. It reviews federal policy activities by issue areas, noting progress where it has occurred and making further recommendations where necessary to the executive and legislative branches of the Federal Government.

As noted in the report, NCD has observed many examples of continued progress in disability policy. Among these are the Help America Vote Act for increasing access to elections for Americans with disabilities, developments under the Assistive Technology Act that hold out the promise for enhanced coordination in the delivery of services, and the positive role of the Department of Justice in a recent Detroit public transit case. This is just some of the positive progress we note as a result of the Administration's leadership through the New Freedom Initiative.

Notwithstanding this progress, many challenges remain for our citizens who are living with disabilities and who wish to be more independent, more productive, and more actively involved in their families and communities. Far too many Americans are desperately trying to improve the quality of their lives, but they are frustrated by a lack of affordable accessible housing, transportation, and long-term services and supports. NCD will continue to develop policy recommendations to address these issues.

In the past year, NCD has undertaken and completed a number of projects that support the Administration's New Freedom Initiative and that respond to NCD's statutory mission. In particular, NCD has issued a series of policy evaluations and evidence-based studies that measure progress toward implementation of the Americans with Disabilities Act.

NCD encourages all government agencies and Congress to use our work as a reference point and source of data for recommendations and as a basis for further examination of issues that affect the lives of people with disabilities. NCD will continue

to work with the Administration and Congress to ensure that every individual with a disability has access to the American dream.

Thank you for your continuing leadership on these issues, and please contact me if you have any questions.

Sincerely,

A handwritten signature in black ink, appearing to read "John R. Vaughn", with a long horizontal stroke extending to the right.

John R. Vaughn

Chairperson

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

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Executive Summary

This NCD annual progress report to the President and Congress covers the period December 2005 through December 2006. The report is divided into 13 chapters, each dealing with a major area of public policy.

These subject-specific chapters are preceded by an introductory Major Trends section that identifies overarching themes and issues that are pertinent to many of the specific topics discussed throughout the report. Each year's Major Trends section addresses recurrent or important themes that have come to the fore during the reporting period. In that light, this year's Major Trends section reflects themes and concerns that emerge throughout the report, dealing with such urgent matters as the need for better data in the making of public policy, the chronic problem of unemployment among Americans with disabilities, the continuing high levels of dependency on public benefits among many Americans with disabilities, the absence of effective coordination in the design of various federal programs and in the activities of different federal agencies bearing on the same subjects or outcomes, and the need for greater accountability in the design of programs and in the assessment of agency performance.

The Major Trends section highlights emerging issues that have come to the fore during the reporting period, and that NCD believes will be significant in policy discussion and program development during 2007. These emerging issues are as follows: pay-as-you-go budgeting, market-based regulation, asset-accumulation, and the Key National Indicators.

Chapter One of the report deals with statistics. Its focus reflects the central importance of statistical data in the formulation and evaluation of policy and programs in all areas. It underscores NCD's commitment to the provision of and reliance on quality data when making recommendations and evaluating programs. NCD's authorizing legislation requires that we use extant data to inform our federal policy research, legal analysis, and program evaluations. In a very real sense, our work as an advisory body for Congress and the White House depends directly on the quality and availability of federal

agencies' data collections. Accordingly, the chapter begins with a review of the fundamental problems surrounding the collection and use of disability data, emphasizing the distinctions between data collection methods and data categories, on one hand, and the purposes for which the data are or should be used, on the other.

Data collection issues surrounding the work of the Census Bureau are specifically discussed, because these data are of great importance and receive considerable attention. The role of program-specific data, as distinguished from demographic data on the prevalence of disability in the population, is then discussed, with a view to identifying some of the key policy questions regarding the design and effectiveness of various programs that such data can be expected to ask and answer. Finally, the chapter proposes some new initiatives in data collection, designed to broaden the range of inputs into the effort and to ensure that the criteria used by the Administration and Congress in evaluating disability programs are appropriate in light of the kinds of data that are reasonably available.

Chapter Two addresses civil rights. It begins with an extensive discussion of issues and opportunities under the Americans with Disabilities Act (ADA). It makes recommendations for legislation to restore what NCD believes to be the intention of Congress in drafting the ADA and to reverse the impact of court decisions narrowing and distorting the law. The chapter then goes on to address both new and long-standing issues in the enforcement of the law, ranging from new issues posed by the use of biomarkers to identify people, to the ongoing problems posed by the application of the ADA in cyberspace.

The chapter then discusses a suit over the accessibility of U.S. currency to blind people and some of the complexities involved in trying to balance competing interests when enforcing civil rights laws.

The next section of the chapter deals with voting. It discusses continuing progress under the Help America Vote Act, and addresses the interface between that law and the Voting Rights Act.

The next section addresses concerns regarding the Civil Rights of Institutionalized Persons Act (CRIPA), which is the law that protects institutionalized people from mistreatment. Building on NCD's major 2005 report on the subject, the section commends the Department of Justice (DOJ) for its vigor in enforcing the law during 2006, while noting the need for thorough oversight and concerted action.

The chapter's final section renews NCD's call for genetic nondiscrimination legislation, explaining how the development of thinking around reforming our nation's health care system has made national legislation in this area all the more imperative.

Chapter Three concerns education. Education differs from other major life activities and settings in one unique way: It is the only sphere in which society has seen fit to create and enforce a universal legal entitlement or mandate. Among such basic pillars of life as housing, health, and employment, our society has not seen fit to create a categorical legal right to these for all people. Only with the right to education have we created laws entitling every child to an education, and requiring parents or other caregivers to cooperate and meet certain standards in its provision.

For this reason alone, education plays as central a role in public policy as does any other activity or service of government. Education is the crucible in which all of society's struggles are fought out and in which the decisions made by each generation become the guideposts for forming the next generation.

Consistent with our commitment to universal free public education, it has been established for a generation that students with disabilities are entitled to a free and appropriate public education in the most integrated setting possible. What this means, who will pay for it, how it is to be monitored, and what will be the consequences of failure to achieve it are questions that have continued to frame the education debate over the past 30 years.

The chapter discusses the two major federal laws affecting education in this country: the Individuals with Disabilities Education Act (IDEA), which has just been reauthorized, and

the No Child Left Behind Act (NCLB), which is scheduled to be reauthorized in 2007. The first two sections of this chapter deal with key issues emerging in the wake of IDEA reauthorization and with disability-related issues implicated in the forthcoming reauthorization of NCLB. It also addresses several key points of interface between the two laws that must be harmonized if either is to be fully effective. Issues addressed include the interpretation and applicability of such key NCLB concepts as the requirement for adequate yearly progress and corrective action, because these concepts relate to the rights and circumstances of students with disabilities.

The chapter proceeds to a discussion of trends that threaten to further close the courts to due process and civil rights litigation by and on behalf of children with disabilities whose rights are at risk of being abridged. Next the chapter discusses possible incentives for increasing the number of qualified special education teachers. Following that discussion, the chapter addresses the potential for full inclusion of students with disabilities in general education classrooms, as proposed by a major Florida school district. The chapter concludes with a review of recent DOJ civil rights enforcement initiatives in higher education, noting the efforts DOJ has made in the area of physical accessibility, but also observing the absence of parallel efforts or vigor in the area of program or information accessibility.

Chapter Four focuses on health care. Today, no area of domestic public policy affects everyone as profoundly and inescapably as does health care. What services and modalities exist, who is eligible to receive them, and how they are paid for all represent subjects of growing and continual interest, and, too often, problems of intractable and unfathomable complexity.

News broadcasts may focus on new discoveries and treatments, horror stories, or accounts of near miracles and shocking neglect, but the core discussions of health care in America increasingly are driven by economics. In the end, it seems more and more likely that the costs of health care will determine the answers to the question of what our health care system will include and how much care is available. But the equally

profound questions of how those services and care will be allocated remain topics best addressed through the evolution of law and public policy.

Although health policy affects everyone, it affects the lives of people with disabilities in several distinctive ways. These include (1) the specialized nature of the services that people with disabilities may need; (2) the sources of payment for those services; (3) the accessibility of those services; and (4) the attitudes of society, lawmakers, and practitioners toward the aspirations of people with disabilities for autonomy and self-determination in the selection and management of services. This chapter addresses this range of issues, with emphasis on choices and debates that have emerged during 2006 and that are likely to prove important in 2007.

Accordingly, the chapter begins with a discussion of Medicaid, which faces growing demands for cost reduction. The chapter discusses opportunities for accommodating these pressures in ways that reduce the adverse impact on beneficiaries with disabilities. The discussion of Medicaid turns to the situations faced by people dually eligible for both Medicaid and Medicare. The chapter then discusses means for accelerating the shift of Medicaid funding from institutional to community-based services and the implications of that rebalancing for the solvency of the program. Last, important new innovations in Medicaid, focusing on consumer-directed services, are discussed.

The chapter then considers Medicare. Recent changes in rules governing the availability of powered mobility devices are discussed, both on their own merit and for the broader insight they offer into the philosophy and direction of the program. Through discussion of the work of the Medicare Ombudsman, the program's ability to include beneficiaries with disabilities in its planning and experimentation is assessed.

The chapter turns to issues of particular concern to people with mental illness, including health insurance coverage and the tragic rise of imprisonment as a means of filling the vacuum caused by the lack of adequate treatment options. The chapter concludes with a reminder that returning veterans are coming to represent an increasing and important

segment of the disability community, whose health care needs and experiences are unique and whose needs and potential must receive our highest, sustained attention.

Chapter Five brings us to long-term services and supports. This chapter begins with an attempt to put the issue of long-term services and supports (LTSS) into context. It does this by addressing some of the definitional complexities surrounding efforts to address the subject. Citing (see notes 66 through 68) NCD's three major related reports on livable communities and LTSS published between 2004 and 2006, the section notes that traditional demarcations between medical and personal services, and conventional programmatic categories that separate housing from transportation from personal assistance, further complicate the effort to come to terms with long-term care.

Recognizing that some elements of the definition and some perspectives on the problem confronting society are widely understood and shared, the chapter then considers the institutional bias in Medicaid and other human services programs that favors nursing home or other institutional settings over aging in place or living in one's own home and community. Because Medicaid is the largest source of funding for LTSS in this country, the section offers a brief history of Medicaid to explain how the bias came about. It discusses the strategies that have been used to incorporate greater flexibility into the funding formula and that have resulted in the emergence of important new options for home and community-based services and care. A number of these options are discussed, with emphasis on recent changes in the law, including the enactment of Money Follows the Person (MFP), which reflects an awareness of the need to rebalance Medicaid expenditures in ways that will increase the resources for LTSS.

In a related discussion, the chapter turns to recent changes in the Older Americans Act that likewise reflect the growing policy consensus around home-based services and around consumer-controlled and cash-and-counseling models of service delivery in a growing array of program settings.

Key changes in the law expanding the availability of cash and counseling are discussed in this connection. Great hope attaches to these approaches and NCD attempts to set forth some of the major reasons this model is creating so much interest.

Following this discussion, the chapter returns to the pressing questions surrounding private sector long-term-care insurance. Issues in the state partnership program are discussed, and recommendations are offered for a study of means to make such insurance more widely available. Finally, in an effort to build on the long-term-care insurance concept, attention is directed to the highly innovative AmeriWell plan described in NCD's 2005 long-term services report. Further research into the potential of this model is recommended in light of its great potential to resolve many of the difficulties that have stymied other proposals.

Chapter Six concerns children and youth. A chapter dealing with youth necessarily differs from other chapters in this report. Whereas such a chapter should address specific laws and regulations, successes and failures, reports and budgets, it must also address questions of leadership development. Even more, it must find a way to capture the voices of youth, as they identify their issues and priorities, and as they learn and express anew the challenges of life in their own words and their own way.

In this light, the chapter begins with a discussion of NCD's Youth Advisory Committee. It then describes the National Youth Leadership Network. While offering specifics respecting the activities of both, the chapter also attempts to convey a sense of their more intangible, longer-term goals, and attempts to convey a sense of the issues and concerns expressed by youth themselves.

The chapter commends White House efforts to direct attention and resources to the needs of youth, expressing the hope that these efforts are inclusive. Next the chapter considers foster care. A major forthcoming NCD study will provide comprehensive and valuable data for assessing the effectiveness of current policies and programs, and should offer insights into areas in need of reform. The chapter's final section addresses resources for transition and for youth employment, noting the existence of several

valuable resources and suggesting ways that their relevance to the needs of youth with disabilities can be more fully ensured.

Chapter Seven addresses employment. The year 2007 promises to be a watershed year for employment policy. A major NCD report on the subject, including several issue briefs, will be published. Another landmark NCD report dealing with federal employment programs in the broader context of financial incentives in the lives of people with disabilities also will be published. Finally, the long-awaited reauthorization of the Workforce Investment Act of 1998, including the vocational rehabilitation system for individuals with disabilities, is likely to take place.

These watershed events, however, unfold against an increasingly ominous backdrop. Research findings indicate that, after peaking in 1994, the percentage of adults with disabilities who are employed has fallen steadily. Moreover, although stimulation of mainstream participation in society through employment was one of the primary objectives of President Bush's New Freedom Initiative, the negative employment trajectory, which began in the mid-1990s, spanning administrations of all parties and a wide variety of economic conditions, has continued through this decade.

Consistent with the centrality of employment to the destinies and aspirations of all Americans, NCD has maintained a keen awareness of, and has paid close attention to, the subject of employment over the years, including in major reports and in analyses of various dimensions of the issue in each of its annual status reports. NCD is obliged by statute to address employment in its annual reports to the President and Congress, but that obligation has been merely the starting point for the Council's involvement and concern.

In an effort to contextualize the issues, the chapter begins with a discussion of the changing role of employment in the economy, and the rapidly changing nature of employer expectations and labor market demands. It raises questions about whether our approach to fostering employment relationships takes full account of all the things that today's employers want and need. The chapter considers other systemic changes

in the labor market, such as the changing role of fringe benefits and the decline of single-employer careers, with a view toward initiating discussion of their implications for our approach to the stubborn persistence of high unemployment among people with disabilities who are willing and able to work.

Turning to the specifics that are likely to dominate policymaking and discussion this year, the chapter addresses the core problem of work disincentives in social programs. After reviewing the nature of the problem, the chapter discusses dramatic proposals for work-incentives reform that NCD believes hold significant promise.

Owing to the emphasis currently placed on education and outreach to employers, the chapter next addresses questions concerning the impact of these efforts. While appreciating the timeliness and accuracy of the information conveyed to employers, NCD suggests that better data are needed on what kinds of marketing efforts work and why.

In connection with another alarming statistic, the decline in the number of workers with disabilities in Federal Government employment, the chapter applauds the concern already shown about this issue and suggests specific questions and sources of data to fully analyze and respond to the problem. Finally, the chapter discusses two lesser-known employment and small-business development programs, suggesting that their role and relevance needs to be reassessed in light of contemporary conditions and needs.

Chapter Eight covers welfare reform. This chapter discusses the reauthorization of the nation's welfare reform law, reiterating concerns that NCD has noted regarding the status of people with disabilities who remain on the rolls and whose needs the welfare reform process appears largely unable to meet. Gaps in services are discussed with a view toward identifying strategies that could increase the ability of many of these people to find and retain employment.

The chapter next considers several issues in the administration of Temporary Assistance to Needy Families (TANF) and related programs that pose issues for accessibility and participation by people with disabilities. The chapter raises concerns relating to the relative lack of asset development strategies in the law. Fear is expressed that shrinking the welfare rolls has been the easy part of a two-part effort that needs to include assisting former beneficiaries—particularly those with disabilities who face barriers to the establishment of conventional career paths—in securing better and more stable economic circumstances.

Asset development represents the increasingly indispensable companion to job placement. A study of the status and well-being of former recipients with disabilities is recommended to clarify the role that asset development might play. The chapter also endorses financial education and financial literacy as elements that should be included in the TANF program, noting the importance of accessibility and culturally sensitive outreach if these resources are to be effective in achieving their intended goals.

Chapter Nine deals with housing. This chapter addresses issues relating to the supply, affordability, and accessibility of housing for people with disabilities, including people seeking to remain in or return to their community in this era of deinstitutionalization. The chapter seeks to draw out the commonalities and the differences in the issues facing people with disabilities and issues facing all Americans, particularly people of limited means, in the current housing environment. The chapter addresses these issues in light of the turbulence that has affected the housing market since our last report.

The chapter opens with a discussion of affordable housing, analyzing the role of the low-income housing tax credit and the various housing voucher subsidy programs in the affordability equation. The chapter next turns to civil rights issues in fair housing, examining the adequacy of procedures to monitor previously achieved civil rights settlements, and the nature of current reasonable accommodations enforcement litigation in the housing area. The Civil Rights section concludes with a discussion of the application of the newly enacted MFP provisions of the Medicaid law to housing as an integrally related community resource.

In light of our nation's efforts to mobilize tax law and other incentives on behalf of environmental-protection and energy-conservation goals, the chapter next explores whether any of the strategies used in these areas might also be applied to the goals of housing accessibility. The chapter considers the links that current policy requires to be forged among housing, transportation, and health policy, discussing ways that housing and transportation planning have been brought together and identifying tools that are needed to make such collaborations and joint planning processes more effective.

In its last section, the chapter returns to the familiar theme of barriers to homeownership facing Americans with disabilities. But in light of the sober realizations that in the past year have undermined many of our assumptions about how homeownership programs are working for all Americans, the section proposes some new approaches, including tax-based and asset-accumulation strategies, for increasing homeownership for Americans with disabilities.

Chapter Ten focuses on transportation. This chapter begins with a discussion of United We Ride (UWR), one of the major local and regional transportation initiatives undertaken pursuant to the Administration's human services transportation coordination and improvement efforts. The very existence of this effort reflects the growing awareness of people whose circumstances and lives are complicated or restricted by their being what may be called transportation disadvantaged. Among this group people with disabilities are heavily represented and have been the object of particular concern. The chapter discusses organization and recent developments in the UWR program and makes suggestions for its enhancement, including recommendations to make its accomplishments most tangible and recommendations bearing upon federal legislation that may be needed to maximize the potential for coordination among federally funded transportation service providers.

Another important transportation initiative, not specifically targeted toward people with disabilities but potentially of great importance to many, is the job access and reverse commute program, aimed at facilitating transportation to and from work for variously transportation-disadvantaged people. In light of the importance of such transportation as

a link in the chain of employment, the section addresses ways in which the program could be made maximally responsive and accessible to workers with disabilities.

Turning to civil rights in transit, the chapter discusses the positive role of DOJ in a recent major Detroit public transit case. Noting how issues under the ADA have evolved from matters of equipment design to issues of maintenance, program accessibility, and the fairness of transit-agency policies and procedures, NCD urges the Administration to maintain active oversight of local transit system accessibility and to incorporate this emerging set of issues into its monitoring.

Next, the ongoing development of ADA passenger vessel guidelines is described. Encouraging the Department of Transportation (DOT) to complete its work on its part of these guidelines, the section once again notes the growing role of procedure and policy in the enforcement of the ADA, and also notes the complexities created by the need for specific sets of guidelines, such as those for cruise ships, to cover unique environments.

The final section of this chapter focuses on air travel. Cutbacks in the availability of the DOT's aviation consumer protection hotline are noted, and the reasons that such cutbacks should be reversed are set forth. NCD urges DOT and the Transportation Security Administration to complete work on key guidelines relating to such matters as screening practices for use with passengers who are deaf, accessibility of self-service airport ticket machines and other kiosks, and accessibility of airline Web sites.

Chapter Eleven addresses the broad topic of technology and telecommunications. This chapter deals with a variety of issues related to assistive technology and to access to our nation's communications networks.

The chapter begins with a summary of technology access barriers set forth in NCD's December 2006 "Over The Horizon" technology report. By way of illustrating some of the problems and concerns discussed in the report, the chapter reviews recently published research findings concerning the persistence and extent of the digital divide.

In connection with specific policy contexts where opportunities for heightened communications access exist, the chapter discusses the pending revision of regulations governing the two key civil rights provisions: (1) Section 255 of the Communications Act and (2) Section 508 of the Rehabilitation Act. A number of procedural and substantive issues surrounding the content of the new guidelines and concerning oversight and implementation of these laws by federal administrative agencies are considered.

Next, the chapter reviews a number of access-related issues falling under the jurisdiction of the Federal Communications Commission (FCC), including issues concerning relay services and closed captioning, suggesting strategies for rationalizing and improving practice and policy in the oversight of these areas. The chapter discusses developments under the Assistive Technology Act that promise heightened coordination in the delivery of services and the development of programs under the Act. Finally, a recommendation to use the tax law to promote the development of accessibly and universally designed technology and services is presented.

Chapter Twelve addresses international matters. This chapter deals with a number of developments occurring in the international arena during 2006 that are of particular importance to disability policy in this country and in the world. The chapter begins with a discussion of the historic United Nations Convention on the Rights of Persons with Disabilities. It then discusses international efforts to respond to communications accessibility and efforts by the Organization of American States to harness the expertise of nongovernmental groups working in the area of disability policy.

Following this, the chapter discusses the work of the U.S. Department of State to address disability-related concerns. Finally, the chapter deals with interconnected legal and technology design issues that have arisen in the implementation of accessibility standards in recent years.

Chapter Thirteen turns to homeland security. In the past five years, the term “homeland security” has changed from an abstract concept to one with multiple meanings. These new meanings are anything but abstract, depending on how they affect one’s everyday

life circumstances. At first, we came to understand it in relation to the risk of terrorism. Then we came to recognize that natural disasters, too, such as those resulting from hurricanes, fall under the domain of homeland security. Most recently, the concept has expanded even further, as we have come to know that pandemic disease also needs to be seen as a threat to our homeland security. And the time may be near when long-term climate change will take its place alongside these other issues in the growing pantheon of concerns.

This chapter addresses a number of issues and developments from 2006 that highlight the specific ways in which homeland security affects the lives of people with disabilities. Emergency preparedness and communication, disaster relief, and other elements of homeland security are critical issues in all our lives; however, for people with disabilities, they frequently present different issues and have varying effects than may at first be apparent.

This chapter also examines the litigation that resulted in an agreement by the Federal Government to provide accessible trailers to displaced Gulf Coast residents. The chapter presents suggestions for how the need for litigation to achieve such basic access rights can be avoided in the future.

Beyond disaster relief, the chapter addresses issues surrounding the inclusion of people with disabilities in the rebuilding process, and recounts some of the observations of organizations that have been involved in consortium relief and renewal efforts. Next, to create a context for full discussion of the issues and to assess their relative impact, the chapter describes the scope of interwoven issues involved in the effort to restore normal life. Finally, the chapter reviews recent FCC enforcement action in the area of emergency broadcast communications and makes suggestions to ensure that television stations across the country comply with crucial standards for information accessibility in times of emergency. Faced with so many potential threats and difficulties, it is all too easy to give way to despair, or to conclude that emergency preparedness and response are too difficult and ever changing to be adequately addressed. But NCD believes that

with planning, attention, and outreach, the goals of inclusiveness can be achieved and enhanced security can be brought to all Americans.

Major Trends

NCD's annual report to Congress is largely governed by statute. That is, it is required by law to be submitted annually, and many of the subjects it covers are specified in the law. Thus, housing, education, health, welfare reform, and employment are subjects that we are required to address.

In addition, NCD has identified other important areas requiring attention and analysis. Most notably and most sadly among these in recent years has been the inclusion of the new chapter on Homeland Security. NCD has also recognized that there are themes, patterns, and overarching trends that cannot be addressed within the context of any single subject area. In light of this recognition, the Council has over the past three years included in its annual report a Major Trends section.

The Major Trends section attempts to distill the chief overarching themes in public policy that have emerged during the year and to show how they unite the different subject areas. Awareness of these themes and trends lends unity and coherence to all the material, puts recurrent questions and issues into perspective, and provides common language and assumptions that people working in various areas of policy can use to more effectively communicate with one another. Through this Major Trends section, NCD hopes to further stimulate dialog on the key issues, relationships, problems, and opportunities facing Americans with disabilities today.

This year's Major Trends section focuses on pay-as-you-go budgeting, market-based regulation, asset development, and consumer-directed services. NCD believes these to be among the chief policy initiatives of 2006 that affect all programs and services aimed at people with disabilities and that they are likely to influence the design of and the interactions among programs in the coming years.

Pay-As-You-Go Budgeting

Pay-as-you-go budgeting (or “pay-go,” as it is commonly known) is a budgetary principle. Put most simply, it requires that no new program, whether of direct expenditure through the appropriations process or of indirect expenditure through the reduction of taxes, can be adopted unless savings are found to offset its add-on cost to the taxpayer.

Pay-go is likely to become the de facto standard for screening of most nonnational security-related legislative or budgetary proposals in Congress. A key question for advocates and for people with disabilities is how this approach can be utilized in a manner that yields positive change and continues positive momentum toward full integration of people with disabilities in society.

Pay-go is normally understood to refer to the current budget cycle. That is, proposed new expenditures must be offset or recovered in the same period of time over which they will be made. Though most would agree that this budget discipline will contribute significantly to the nation’s fiscal health, much depends on key nuances of implementation. In this regard, three issues are of particular concern to people with disabilities:

- By placing financing requirements on new programs and expenditures that do not apply to existing or established ones, pay-go may inadvertently tip the policy balance against innovation and change in some instances. In light of the widening appreciation that many disability-oriented federal programs are in need of major reform, such an unintentional bias in favor of the current over the new could delay needed restructuring.
- Experimentation and demonstration programs will need to be at the heart of efforts to reform a variety of human services efforts carried out under federal auspices. Some of these may not bear financial fruit, in terms of savings or indirect financial benefits, for a number of years. Though Congress should always demand rigorous evidence and strong reasons for believing in the

potential efficacy of experiments and demonstrations, pay-go should at the same time retain the flexibility to accommodate savings that will be accrued in subsequent budget periods. Otherwise, impatience, however understandable, may stifle some of the most productive efforts to reengineer federal social programs. These efforts, as noted below in our discussion of the Key National Indicators, are crucial to the long-term fiscal health of the nation.

- A pay-go system that does not retain the flexibility to treat certain federal expenditures as investments runs the risk of putting reform efforts into ruinous short-term competition, both with one another and with existing program models within and without the disability policy field. Advocates for reform and experimentation in areas of disability policy ranging from education to employment should not be in the position of having to argue against unrelated programs, simply for the sake of creating budgetary headroom. Whether programs in agriculture, energy independence, medical research, or any of the innumerable other areas of governmental interest and commitment are efficient and effective can always be debated, but it should not be the responsibility of advocates who have no involvement with such programs to conduct that debate, let alone to be forced to argue against such programs for the sake of the resources they need.

Key National Indicators

GAO has consistently emphasized the need for greater accountability and oversight of all federal programs and expenditures. Most recently, in a November 17, 2006, paper, GAO listed and described key areas of concern for the incoming 110th Congress. GAO wrote:

As the pace of change accelerates, the nation is faced with new and more complex challenges, including globalization, emerging scientific and technological changes, public health, and environmental issues. One tool to help address these challenges is the development of key

national indicators to measure progress toward national outcomes, assess conditions and trends, and help communicate complex issues.

GAO's "Key National Indicators Initiative," under the auspices of the National Academies, has begun efforts to develop a national indicator system to inform strategic planning, enhance performance and accountability reporting, inform congressional oversight and decision making, facilitate oversight, and stimulate greater citizen engagement. GAO's work has pointed to the need for a government wide strategic plan, supported by key national indicators to assess performance, position, and progress. A government wide strategic plan could provide an additional tool for re-examining existing programs and proposing new programs. GAO has also called for a government wide performance report linked to key indicators to articulate the government's accomplishments. A key national indicator system for the United States, however, cannot be fully developed without the interest and critical attention that congressional involvement provides.¹

Although GAO scrupulously avoids the use of alarmist or inflammatory rhetoric, a number of its reports make clear the real sense of urgency lying behind these recommendations. Part of that urgency is fiscal. As the Comptroller-General of the United States, who heads GAO, has made clear, reform of many programs, including major entitlement programs, is critical to the fiscal health of the nation, if we are to curtail looming budget deficits and meet foreseeable long-term-care needs and other demographic shifts. Less directly stated but equally frightening is the prospect that, without appropriate and objective tools and instruments to measure the efficacy of existing programs and assess the potential impact of proposed reforms, our nation will one day feel compelled to implement draconian cuts in social programs. These cuts will result in terrible hardship to many of our society's most vulnerable members, and in potentially significant decreases in the standard of living for all.

The discussion of the long-term financing of entitlement and other social programs necessarily implicates Americans with disabilities. Programs like Medicare and Medicaid, which are central to the discussion, provide health coverage for many Americans with disabilities, to name but two of the foremost examples. Yet, strangely,

perhaps ironically, specific discussion of disability-related programs has thus far been largely absent from public debate.

Programs aimed at people with disabilities are estimated to cost between \$300 and \$400 billion per year. Efforts to get a handle on these figures have long been hindered by their diffusion among agencies and jurisdictions; however, people with disabilities, advocates, and policy analysts—as documented in a succession of NCD reports—have long noted that they lack coordination, administrative coherence, or policy consistency. Apart from anything else, there is no way that this \$300 or more billion per year can be omitted from consideration as we address the entire role and basis of government.

NCD hopes and believes that 2007 will witness major efforts to come to grips with the articulation of key indicators for disability-oriented programs. NCD pledges its maximum support to GAO in the identification of issues, barriers, opportunities, and measurement criteria.

Asset Development

Whatever may be the case in other areas of public policy, the current range of programs aimed at people with disabilities, while replete with many shining examples of leverage, achievement, and success, is widely regarded to be inefficient and ineffective in bringing about economic self-sufficiency and freeing individuals from dependency. The reasons for this are amply and often stated elsewhere; the implications must be reiterated.

If we are facing as a nation the decision that existing program models cannot be indefinitely sustained, then the need for effective alternatives becomes acute. Because we have not discovered any effective strategy for facilitating economic self-sufficiency through employment for the majority of working-age Americans with disabilities, and because we are certainly on course to curtail the subsistence that we have provided as an alternative, the question that presents itself with unprecedented starkness becomes: “What then are we to do?”

There exists a widespread perception in our nation, as reflected in the No Child Left Behind Act (NCLB), that the overall quality of American public education declined in the final years of the twentieth century. If this is so, how tragic is it that such a decline should have occurred at the very time when values of inclusion for students with disabilities were taking hold. It may be that with renewed attention to education, all of our children, with and without disabilities, may be better equipped for the economic competition of the next generation, but it is by no means clear that we even have the luxury of that time frame.

Under these circumstances, and given our lack to date of an effective strategy to ensure economic self-sufficiency through employment, new asset-based strategies to propel people with disabilities into the ownership society are urgently needed.

The asset-development movement has taken on growing importance and received increasing recognition and attention in recent years. As exemplified in program models from individual development accounts to consumer-directed health care (for example, health savings accounts) to individual budgets for the recipients of various human services, recognition of the importance of assets has increasingly influenced program design. And from policies favoring and economically rewarding homeownership, to programs that link expanded access to Medicaid in old age, to the purchase of private long-term-care insurance when younger, opportunities to enhance asset accumulation through public-private partnerships have played an important and growing role in the formulation of policy.

Yet for Americans with disabilities dependent to any degree on federal programs, asset accumulation, as documented elsewhere in this report and in prior NCD studies, has remained largely illusory. This is due primarily to needs-based concepts that penalize and prevent significant capital formation or asset accumulation by withdrawing benefits and supports at a level that greatly exceeds the rate at which they can be replaced.

Much or all of the several hundred billion per year that now goes into subsistence-oriented income support programs, into rigidly means-tested in-kind service programs,

and into institutional and custodial programs can and must be redirected into asset-building efforts that will enable people with disabilities to live with independence and dignity. If we continue to be ineffective in creating upward mobility through employment, and if we cannot much longer afford even the minimal subsistence we now provide, the only viable response is to ask, “What is the alternative?”

Market-Based Regulation

In recent years what is called market-based regulation has garnered increasing interest. Although not precisely defined, this concept is generally understood to involve the fashioning of regulations that harness market forces in the service of policy objectives and that provide market rewards or punishments among their primary enforcement mechanisms.

Perhaps the most familiar examples of market-based regulation are the use of tax preferences to encourage desired behavior and the use of fines to punish negative activity. But examples and opportunities are far more numerous and complex. When we provide more funds to schools that raise test scores, or provide funds to assist them in doing so, while reducing or withholding funds if they ultimately fail to raise scores sufficiently, we are using market-based regulation in the sense of using market forces to influence activities and bring about desired results. When we allow corporations to merge if they divest of components that pose antitrust risks, we are using market-based regulation to balance goals of economic efficiency with competitiveness. When we grant pharmaceutical companies special protection from liability in return for producing high-risk vaccines, or enhanced intellectual property protections for developing orphan drugs, we are using market-based regulation.

But in the area of disability policy we have barely scratched the surface. The possibilities of market-based regulation, through the linkage of desirable corporate practices to discretionary decisions that make those practices part of an overall profitable and positive private-public relationship, are legion. Every day the government makes discretionary decisions that give private entities something they want in return for

things the public good demands—from government research subsidies in return for public access to the fruits of research, to the use of public assets in return for payment of fees, to innumerable other examples. Yet, when it comes to our aspirations for people with disabilities, given the limited reach of governmental power, we have done shockingly little, moving barely beyond an antiquated and rigid paradigm of regulation and compliance or noncompliance.

When it comes to such tasks as employment and training for people with disabilities, the design and deployment of accessible technology or universally designed housing, the availability of accessible medical instrumentation for self-care, and an almost untold number of other issues of concern and importance, we have done little. Yet the opportunities are enormous for accommodating private sector interests through the variety of discretionary decisions government makes daily, linked to voluntary and reciprocal measures that benefit disability-related policy goals with little or no adverse impact on private sector interests or prerogatives.

Such reciprocal relationships are well-established throughout American history and are in common use today. It is past time that their applicability to disability policy be systematically explored and developed. Properly understood and used here as they are in so many other sectors, they represent a classic win-win situation, and they may in time lead to revolutionary attitudinal changes throughout society that no amount of written regulation or enforcement can by itself accomplish.

Chapter One: Disability Statistics

Introduction

It is hardly coincidental that the first chapter of each year's NCD progress report to the President and Congress has focused on statistics. As explained by an NCD staffer in an August 2006 presentation to the American Statistical Association:

NCD's authorizing legislation requires that we use extant data to inform our federal policy research, legal analysis, and program evaluations. In a very real sense, our work as an advisory body for Congress and the White House depends directly on the quality and availability of federal agencies' data collections. . . .

The simple fact is, other than the mandated administrative program data for key federal disability programs (e.g., Veterans [Affairs] data requirements, SSA data requirements, OSERS data requirements) there are few if any Congressionally authorized and mandated disability data requirements, particularly of a longitudinal nature. For instance, even the Decennial Census (and the ACS in its stead) does not operate from a legislative mandate and fiscal appropriation to ensure an accurate enumeration of tens of millions of Americans with disabilities. As a result, the amount of space devoted to disability data items on the Census (and now the ACS [American Community Survey]) remains static. This is so, despite the increasing amount of federal resources expended each year by our government for hundreds of federal disability programs and initiatives—i.e., in excess of \$200 billion federal dollars per year.²

Accordingly, this chapter begins with a review of the fundamental problems surrounding the collection and use of disability data, emphasizing the distinctions between data collection methods and data categories, on one hand, and the purposes for which the data are or should be used, on the other.

Data collection issues surrounding the work of the Census Bureau are discussed, because these data are of great importance and receive considerable attention. The role of program-specific data, as distinguished from demographic data on the prevalence of disability in the population, is then discussed, with a view toward

identifying some of the key policy questions regarding the design and effectiveness of various programs that such data can be expected to ask and answer.

Finally, the chapter proposes some new initiatives in data collection, designed both to broaden the range of inputs into the effort and to ensure that the criteria used by the Administration and Congress in evaluating disability programs are appropriate in light of the kinds of data that are reasonably available.

The Fundamental Problem

With any data collection effort, the threshold question to be asked and answered is: “What do we need to know?” From this follows the further question: “How do we find it out?” Behind these seemingly obvious and deceptively simple questions often lies a host of complexities and problems, and in few areas of government statistics is this more the case than in the area of disability statistics.

NCD has highlighted the problems of definition, data reliability, interagency communication, timeliness, and effective data utilization in its past reports. Little need exists for their reiteration here. For those wishing an up-to-date overview, the NCD paper noted above is highly recommended.

Notwithstanding the chronic nature of the issues, certain developments in 2006 and likely developments in 2007 raise key issues of data collection and analysis with renewed urgency. The remainder of this chapter addresses these critical matters.

The Census

Most Americans are familiar with the Census conducted every 10 years as required by the Constitution. Fewer people are familiar with the interim censuses and specialized inquiries that the Census Bureau conducts and publishes periodically between the 10-year major censuses.

Among these, the American Community Survey (ACS) is one of the most important and widely relied upon. The ACS has contained a disability question, designed to determine the number of people with disabilities in our population, but as noted in prior NCD reports, this question, in its varying forms, has been regarded by many as incapable of eliciting either comprehensive or reliable data.

In anticipation of the next ACS disability question, scheduled for use in 2008, the Census Bureau field tested a new version of its disability question during early 2006. The Census Bureau should be commended for the procedures it used to seek input into the formulation of its disability question and for the rigorous method it used to compare the existing and proposed questions.

On the basis of a number of important technical factors, including such things as response variation and response rate, the Census Bureau has concluded that the new question will provide better data than the old.³ Though these improvements are welcome, NCD remains concerned with the inherent limitations of self-reported data, particularly on a question that is so inherently subjective to begin with as one bearing on “functional limitation.” As indicated in prior NCD reports, the highly subjective nature of the information, the unanalyzed issues of respondent self-image that contribute to the answers, and the potential lack of respondent knowledge concerning the possible role of technology in overcoming functional limitations all contribute to making these data far more equivocal than many other kinds of self-reported data traditionally collected by the Census. To be sure, this limitation is largely beyond the Census Bureau’s ability to control or overcome, but it is a problem that nevertheless must condition our evaluation and use of the numerical data arising from the ACS, and indeed of the data that will be developed by the 2010 Census.

Program Data

From the standpoint of policy, our concern for determining the size of the overall population of people with disabilities to some degree may be misplaced. In the evaluation of specific programs, the size of the target population and the impact of the

program on that target population are important. No single disability program applies to all of the more than 50 million people who are counted as having disabilities. Education programs, employment programs, health insurance, and income support all apply to different subgroups of the population.

Even then, for program outcomes measurement purposes, it may not be the size of the potential target population but rather the impact on the actual participating population that matters. For example, while the vocational rehabilitation system for people with disabilities (discussed in Chapter Seven) deserves to be held accountable for the proportion of eligible people with disabilities seeking jobs that it does or does not reach, a far more telling assessment would surely arise from data showing the impact of the program on the vocational status and income of those who had participated in or been served by it.

From this it follows that program-specific data are critical, particularly when outcomes data and evidence-based measures of program impact are growing increasingly important as arbiters of public policy in an era of shrinking public resources.

Considerable amounts of program- and agency-specific data are collected across the spectrum of disability programs. As to the relevance, comparability, utilization, and timeliness of much of this data, we know less than we should. Though many anecdotes exist regarding the usefulness of this data collection effort, no overall sense of the scope of our efforts, the cost, or the relevance can be found.

What is needed therefore is a high-level review of all statutory and discretionary data collection efforts, including the methods used to aggregate or compare datasets, the methods of data mining available and customarily used, and, most important, the extent to which existing or readily attainable data are useful to the Office of Management and Budget (OMB) in evaluating existing programs using the Program Assessment Rating Tool or are useful to the Congressional Budget Office (CBO) in “scoring” legislative and budgetary proposals for new or modified programs.

NCD therefore recommends that the President appoint a national commission, including representatives from OMB, CBO, NCD, and the Interagency Committee on Disability Research (ICDR), to review all existing statistical and data collection efforts in light of the methodologies used by OMB and CBO in evaluating existing or proposed programs and expenditures. This should be done with a twofold purpose: (1) making the data as responsive to these evaluative practices as possible and (2) ensuring that CBO's and OMB's criteria reflect program goals and realistically recognize the limits of data in many situations. This commission should prepare a report to the President and Congress that includes specific recommendations for collecting data and updating the evaluation criteria to ensure that programs are fully and fairly vetted and judged.

Experimentation

The notion of experimentation in data collection may at first seem strange. But the notion of collecting baseline data, in the context of demonstration projects or other new initiatives, is well understood. Within this context, the paragraphs that follow include additional proposals for experimentation and innovation.

From time to time, suggestions and representations are made regarding the efficacy or impact of a given intervention or variable. One such example includes a belief commonly held over the years by educators of people who are blind that those individuals taught to be literate in Braille tend to have far higher rates of employment as adults than do those educated using synthetic speech. Additional empirical data are needed to support such key decisions in our approach to the education of children who are blind, and such targeted research emanating from the field would represent a valuable contribution to our knowledge.

In other areas, too, similar claims exist and need to be investigated fully. Therefore, NCD recommends that Congress create a disability statistics field-initiated research (FIR) program, under which advocates, researchers, and disability organizations may apply for funds, and receive other forms of technical assistance, to study claims about the efficacy or impact, positive or negative, on various major life functions (working,

learning, community living, or other) of any number of practices, interventions, or variables. Beyond investigation of claims, the new FIR program should facilitate the conduct of demonstrations and major longitudinal or other research studies designed to evaluate and maximize a wide range of interventions, approaches, and strategies in education, employment, health care, and other key spheres of life. The program should be administered by ICDR or the National Institute on Disability and Rehabilitation Research, and be based on guidelines that will allow for the selection of proposals on well-understood grounds, and that will ensure the technical support necessary for the research to be carried out effectively and disseminated fully.

Recommendations

Recommendation 1.1: NCD recommends that the President appoint a national commission, including OMB, CBO, NCD, and ICDR, to review all existing statistical collection and data collection efforts in light of the methodologies used by OMB and CBO in evaluating existing or proposed programs and expenditures.

Recommendation 1.2: NCD recommends that Congress create a disability statistics FIR program, under which advocates, researchers, and disability organizations may apply for funds, and receive other forms of technical assistance, to study claims about the efficacy or impact on various major life functions (working, learning, community living, or other) of any number of practices, interventions, or variables. Beyond investigation of claims, the new FIR program should facilitate the conduct of demonstrations and major longitudinal or other research studies designed to evaluate and maximize a wide range of interventions, approaches, and strategies in education, employment, health care, and other key spheres of life.

Chapter Two: Civil Rights

Introduction

This chapter begins with an extensive discussion of issues and opportunities under the Americans with Disabilities Act (ADA) and recommends legislation to restore what NCD believes to be the intention of Congress in drafting the ADA and to reverse the impact of court decisions narrowing and distorting the law. It addresses new and long-standing issues in the enforcement of the law, ranging from new issues posed by the use of biomarkers to identify people, to the ongoing problems posed by the application of the ADA in cyberspace.

The chapter then discusses a suit over the accessibility to blind people of U.S. currency and some of the complexities involved in trying to balance competitive interests when enforcing civil rights laws.

The next section of the chapter deals with voting. It discusses continuing progress under the Help America Vote Act and addresses the interface between that law and the Voting Rights Act.

Discussed in a subsequent section are concerns regarding the Civil Rights for Institutionalized Persons Act (CRIPA), the law that protects institutionalized people from mistreatment. Building on NCD's major report on the subject, the section commends the Department of Justice for its vigor in enforcing the law during 2006, while noting the need for thorough oversight and concerted action.

The chapter's final section renews NCD's call for genetic nondiscrimination legislation, explaining how the development of thinking around reforming our nation's health care system has made national legislation in this area all the more imperative.

The Americans with Disabilities Act

The ADA Restoration Act

The ADA of 1990 has justly been regarded as one of the civil rights landmarks of the twentieth century. But if the ADA is to remain fully vital into the twenty-first century, it is important that key clarifications and reforms be adopted. Lower-court decisions that emerged during 2006 underscore the need for action in a number of key areas. These decisions, together with the findings of NCD's ADA Implementation Project (report scheduled for publication in early 2007), have increased the sense of urgency and opportunity surrounding several measures designed to restore the law to what NCD believes was its scope as originally contemplated by Congress.

The law needs to respond to many changes that have occurred since its passage, and the harmful impact of several court decisions needs to be addressed. For this reason, NCD has proposed and now renews its call for adoption of the ADA Restoration Act.⁴

Several major NCD reports have detailed the key court decisions and analyzed their effects on the lives of people with disabilities.⁵ These reports are highly recommended to those seeking a fuller understanding of this subject. Rather than reviewing the extensive historical and legal data already amassed, the sections that follow highlight three key areas in which reform is needed.

Definition of Disability

Concerns about the definition of disability were most recently discussed in NCD's September 20, 2006, letter to the chair of the House Judiciary Committee's Subcommittee on the Constitution, in connection with its ADA oversight hearing.⁶ When the ADA was passed, it is doubtful anyone would have imagined that a large proportion of important court cases dealing with the act would concern jurisdiction. That is, the belief was that these cases would deal with whether the person seeking protection under the ADA met the statutory definition of being a person with a disability, rather than with such questions as whether discrimination had occurred, or whether a reasonable

accommodation was required, or whether a proposed accommodation was unduly burdensome to the employer or public-accommodation entity. Yet, 16 years after enactment of the law, precisely that has become and continues to be the case.

This current situation has evolved largely because of court decisions that have emphasized case-by-case determinations of whether a particular person is “an individual with a disability” subject to the protection of the law. The law provides that a person has a disability, and hence is covered, if the individual’s physical or mental impairment “substantially limits” or constitutes a limitation on one or more major life activities. But by their erratic and case-by-case methods of deciding what is an impairment, what are major life activities, what degree of limitation is substantial, and what connection is required between the particular impairment and the life activity in question,⁷ the courts have, perhaps unintentionally, created more confusion and uncertainty. A given type or level of impairment may substantially limit one major life activity but not another, and may substantially limit a major life activity in the view of one court but not in the view of another.

Furthermore, by holding that the determination of whether an individual is a person with a disability needs to be made after “mitigating measures” have been taken into account, individuals with disabilities may be facing potentially greater obstacles in seeking the protection of the ADA. These mitigating measures may involve assistive technology (AT), but far more often, judging from the cases surveyed in early 2006 by the Congressional Research Service (CRS),⁸ they involve medical treatment, principally drugs. Although the Supreme Court decision establishing the mitigation requirement⁹ and the numerous lower-court decisions interpreting and applying it are not entirely clear or consistent, it appears that the individual employee or job seeker requesting reasonable accommodations will find no protection under the ADA unless medical measures to control the condition and its substantially limiting effects, such as blood sugar or seizures, have been attempted. If they succeed and the employee no longer needs the accommodation, then there is no longer any ADA issue. If they fail, only then must the accommodation request be addressed on its merits, and even then, there are

barriers to its consideration, such as that the individual will be deemed medically unqualified to do the job though not disabled.

What the courts have not made clear is how extreme or how certain such mitigating measures must be, what weight should be given to possible side effects as a justification for an individual's refusal to use them, or how they should be paid for. Nor have the broader and most troubling questions been adequately addressed about how much control over their lives people are required to cede to physicians or employers to claim their right to work.

Once again, the specifics of all the major cases involved have been extensively explored in earlier NCD and CRS reports. Further efforts to resolve these issues through the judicial process are likely to result only in more, not less, confusion. Corrective legislation is badly needed and should do two things. First, it should set out clear standards by which courts or administrative tribunals can determine whether an impairment constitutes a substantial limitation or barrier to any of the major life activities, especially including work, covered under the ADA. Second, the law should make clear what limits exist on the extent of mitigating efforts to which people must subject themselves, the risks they must take, and the costs they must bear to remain covered by the law. Ideally, as states like California have done, with no apparent increase in litigation or costs to business, the mitigation requirement should be eliminated. The law is quite adequate without such a requirement for determining whether an individual with a disability is qualified for a job and whether a request for accommodations is reasonable.

Sovereign Immunity

The historic Supreme Court decision *Tennessee v. Lane* established the right of people with disabilities to sue states for monetary damages under Title II of the ADA when denied basic civil rights protections, such as physical access to the courts. But in itself and in light of other decisions, the *Lane* decision led to uncertainty and anxiety for

people with disabilities. These concerns have not been resolved in the intervening two years.

The uncertainty arises from two sources. First, although the *Lane* decision establishes that Congress had the constitutional authority to subject state governments to suits for monetary damages for violations of Title II of the ADA, the Court did not make clear whether all alleged violations of Title II can be redressed by suit, or only those deemed to involve denial of the most fundamental civil rights such as access to the courts. Subsequent decisions have not clarified this point.

The second problem left in the wake of *Lane* is that the Supreme Court's earlier decision in *Garrett*¹⁰ held that suits under Title I of the ADA against states for employment discrimination were not permitted. The basic reasoning for this decision was that Congress lacked constitutional power to authorize such suits. The reason Congress lacked such power was that states have sovereign immunity under the Eleventh Amendment to the Constitution. They cannot be sued by private citizens (although the Federal Government can always sue them) without their consent.

But sovereign immunity can be waived. Some states, in some circumstances, have waived it. The trouble with this voluntary waiver approach is that it results in people's rights under federal law differing from state to state, depending on what waiver the state has implemented, if any.

A solution is believed to lie in the Spending Clause of Section Eight of Article I of the Constitution. Congress has long and often conditioned the availability of federal funds to agreement by states to comply with various requirements and conditions, including, as in the case of Section 504 of the Rehabilitation Act, the waiver of sovereign immunity.

The courts have upheld the right of Congress to condition federal funds on the waiver of sovereign immunity. Legislation to incorporate such waivers in the ADA and the Age Discrimination in Employment Act was introduced in the 109th Congress.¹¹ NCD recommends that such legislation be reintroduced and enacted without delay.

Major Developments During 2006

Discussion in the preceding subsection indicates that the ADA should be updated to ensure its continued vitality. But even without these reforms, the ADA remains a powerful and important element of our lives and a cornerstone of national policy.

Project Civic Access

Project Civic Access (PCA) is a major ADA initiative by the Department of Justice (DOJ) aimed at helping local governments comply with Title II of the ADA. NCD commends DOJ for this initiative, because it directs important attention and resources to local and community services and facilities that affect the daily lives of many people, and also because it directs those resources to smaller communities that may be in particular need of the assistance. Seen in this light, ADA implementation becomes not merely the fulfillment of legal requirements but also a means to the achievement of the goals set forth in NCD's *Livable Communities* report.¹²

As part of the sixteenth anniversary celebration for the ADA on July 26, DOJ reported that PCA had reached 147 settlements with 139 local government entities. One case that is typical of the scope of these settlements was reached in the city of Waukegan, Illinois. As reported in the anniversary press release, the city agreed to implement a variety of physical improvements to public facilities and to correct deficiencies in a number of its policies and practices.¹³ But one thing that is striking about the reported settlement is that a number of the buildings and facilities involved were new, and were designed and constructed long after the ADA standards came into effect. Consequently, if the PCA project is to have maximum effect, the following key question needs to be addressed: "How was it possible that a medium-size city and its engineering or architectural contractors could engage in major public works projects either without knowledge of, or with inaccurate knowledge of, or perhaps with indifference to the applicable requirements of the ADA?"

In previous annual progress reports, NCD has raised this same question in relation to Fair Housing Act litigation and technical assistance and public education by DOJ and

the Department of Housing and Urban Development. NCD, while applauding these efforts, has urged the agencies to undertake research aimed at discovering why, after years of outreach, so many people who should be expected to know better either don't know the law or don't take it seriously. Until DOJ confronts this question, the danger is all too great that the victories won through PCA will have to be won again after the next round of public building is complete.

These concerns give rise to a related problem. What follow-up or monitoring procedures has DOJ put in place to ensure that the commitments of PCA agreements are carried out fully and to ensure that the mistakes giving rise to the need for the agreements will not recur? Typical commitments made by signatories, including commitments to staff training, suggest an appropriate and primary role for self-monitoring, but in the absence of penalties for noncompliance with the agreements, NCD remains concerned that more oversight may be necessary.

A spotlight has been shined on follow-up issues by the NCD ADA Impact Study (which was released on July 26, 2007). All outreach and enforcement efforts need to be assessed from the standpoint not only of the immediate actions and improvements they bring about, but also of the durability and continuity of the awareness and capacities required to ensure long-term compliance. Put another way, compliance without accompanying institutional change to ensure long-term adherence to the law is only half a victory.

Accordingly, NCD recommends that DOJ develop strategies to ensure that the lessons of PCA agreements can be carried forward by the local government entities involved. These efforts should include the development of measures to determine the effectiveness and impact of all the department's ADA outreach, technical assistance, training, and public education efforts. Only then are we in a position to determine what works best and why, to ascertain why and how notable failures to comply with the law have occurred, and to develop oversight mechanisms that will create the highest probability of long-term continuity in adherence to PCA agreements and the underlying law.

National Settlements

Within the same week in January 2006, DOJ reached a settlement with one national movie theater chain, and there was a court decision in the case of another.¹⁴ These cases both resulted in accessibility enhancements to several hundred stadium-seating-style theaters across the nation. In another example later in the year, DOJ reached a settlement with a national retail chain, Jo-Ann Fabric, which again means that a significant number of stores in numerous locations will become more accessible as a result.

NCD believes that efforts directed to national entities often represent the most instrumental use of scarce public sector enforcement resources. To that end, NCD is interested in the case-finding or pattern-and-practice work done by DOJ or by state human rights agencies. In this light, NCD urges the DOJ Civil Rights Division to issue technical assistance guidance describing how pattern-and-practices or multisite ADA investigations are initiated, and explaining how isolated complaints are correlated with other isolated complaints to suggest national entities or multisite public accommodations that may be appropriate for broad-based scrutiny.

The ADA Accessibility Guidelines

In last year's report, NCD commended the U.S. Access Board for its development of revised ADA Accessibility Guidelines (ADAAG) and expressed appreciation for the DOJ's intention to review, seek comment upon, and adopt these guidelines. But if the lack of published follow-up is any indication, the process has lost its momentum and DOJ has taken no further action during 2006.

NCD is very concerned with this lack of follow-up. If public comment or departmental review, both of which were understood to be well under way by the end of 2005, disclosed problems with the proposed guidelines, that should be announced and efforts to remedy the problems should be commenced through whatever procedures are considered appropriate. But if, on the other hand, the guidelines are adequate, they

should be adopted. In the meantime, the Department of Transportation has adopted those portions of the ADAAG dealing with transportation.¹⁵

NCD recommends that DOJ immediately issue an appropriate advisory indicating the current status of the revised ADAAG; clarifying its intentions or expectations with respect to their modification, acceptance, or rejection; and setting forth time frames for all anticipated actions.

Growing Concerns

A number of ongoing issues that have been discussed in previous NCD reports, as well as new ADA-related issues, warrant attention.

e-Commerce

During the final months of 2006, considerable public and press attention was directed to a lawsuit filed by the National Federation of the Blind (NFB) against the national retail chain Target. The suit alleges violation of Title III of the ADA by reason of inaccessibility of Target's Web site for people with disabilities. This inaccessibility is harmful because it prevents people with disabilities, particularly those who are blind and use screen-reader software, from shopping on or through the site. As of this writing, the federal district court has denied Target's motion for dismissal of NFB's complaint. To the degree that that motion by the defendant for dismissal of the case was predicated on the claim that the ADA has no application in cyberspace, the judge's ruling represents an interim rejection of Target's threshold claim.

Word is awaited on whether Target will appeal the judge's ruling. But for those who have followed the law in this area, the judge's ruling is no surprise. As reflected in a paper published by NCD in 2004,¹⁶ several court rulings have held that at least where there is a connection (or nexus) between the services and activities available on the Web site and those taking place at the public accommodation's physical place of business (as there apparently would be in various instances under Target's business model), commercial Web sites can be covered by the ADA.

In last year's progress report, NCD recommended that DOJ prevent further confusion and needless litigation by proposing regulations under the ADA that would implement the position that the Department first articulated almost 11 years ago in a famous letter to Senator Harkin of Iowa. In that letter, DOJ expressed the position that information made available to the public by electronic means needed to be made available in alternative formats to those prevented by disability from accessing the electronic resources. In the decade that has passed since issuance of the Harkin letter, the systems for making information electronically available to the public, and for facilitating interaction and commerce between businesses and customers, have been transformed beyond recognition. Methods for making Web sites accessible are documented and in widespread use, and e-commerce has grown exponentially in every phase of our economy.

Though the modalities have changed, there is no reason to believe that the principle of law has, and indeed nothing that DOJ has done or said in these intervening years suggests that the Department has changed its fundamental view. Yet, because of DOJ's failure to address the issue squarely, needless litigation and uncertainty have multiplied.

A December 2005 mediated settlement (discussed in the February 2006 issue of the Department's publication *Disability Rights Online News*)¹⁷ further demonstrates the need for concerted action. In this particular case, TicketMaster agreed to enhance its telephone-based resources for selling tickets for wheelchair-accessible seating. The need for upgrading this service arose from the fact that TicketMaster's Web site did not have the capacity to supply these tickets. If the Web was not covered by the ADA, there would have been no legal reason for TicketMaster to provide alternatives to its Web site for selling wheelchair seating. If DOJ were to make clear when and how requirements of Web accessibility attach under Title III of the ADA, cases like the one involving TicketMaster or the pending Target appeal might well be avoided.

If DOJ no longer believes that Title III covers the Web, and if it wishes to repudiate the court decisions that increasingly support the connection or nexus theory, then it should say so. But if the Department continues to believe that Title III has a role to play in

cyberspace, if it stands behind the several amicus briefs it has filed over the years supporting coverage in various contexts, and if it wishes to bring clarity and predictability to the law and to the decisions of consumers and businesses alike, then NCD strongly reiterates its recommendation that DOJ immediately begin the process of developing guidelines to supplement the existing ADA Standards and clarifying when and how Web sites are covered by Title III.

Biomarker Identification

If the Internet issue is a relatively old one, the questions posed by new approaches to personal identification and tracking are new and perplexing. At a time when hardly a day goes by without word of some plan to use iris scans, face recognition software, strands of DNA, or other biomarkers to verify an individual's identity, questions of how these various approaches may affect people with disabilities need to be incorporated into the discussion from the earliest possible point.

The key ADA-related questions take two basic forms. First, there are questions about whether the particular biomarker used will be available. Eye scans would be of little relevance for people who use artificial eyes, just as fingerprints are not available from people who have prosthetic upper limbs. Similarly, voice recognition will not be available with people who do not speak.

Other examples could be advanced, but the point is clear. With almost every biomarker, some backup strategy must be devised for people who, owing to disability, cannot use the primary indicator. But that is not the only concern. The second and equally important concern relates to the technology through which individuals interface with the various identification systems and equipment. For example, a person asked to look steadily into a scope so that eye scan identification can be made, even if able to provide the necessary data, may not necessarily be able to hold the scope steady or perform other physical actions incidental to the process. Likewise, if the device is unfamiliar or complex, a person with intellectual disabilities may not be able to master its use, and people with sensory impairments certainly can anticipate all manner of difficulties.

As each day brings more devices, proposals, and experiments, the danger grows that the interests of people with disabilities will be overlooked. In light of the understandable sense of urgency surrounding many of these projects, that danger is especially great. For this reason, and given the interdepartmental nature of the issues, NCD recommends that the Attorney General (pursuant to Executive Order of the President, if necessary) convene an interagency task force, including DOJ, the Departments of Homeland Security and Transportation, such other agencies as are deemed appropriate, and, to the maximum extent consistent with national security, representatives of the disability community, to develop procedures for incorporating accessibility assessments into the development and testing of all new security systems and devices.

Section 504 of The Rehabilitation Act

Perhaps not since the famous golf cart case *Casey Martin v. PGA Tour*¹⁸ has a disability-related case received as much attention as has the case involving the accessibility of our nation's currency. A federal district court has ruled that the U.S. Treasury, by failing to do anything to make it possible for people who are blind to independently distinguish the various denominations of currency, has violated Section 504 of the Rehabilitation Act.¹⁹

Amidst the storm of controversy swirling around the case, it is not NCD's place to express an opinion on the legal soundness of the decision. Even among major consumer organizations of blind people, vigorous disagreement exists. The American Council of the Blind that brought the case hails the court's decision as a great victory, but the NFB denounces the decision as, at the least, insulting and, at worst, harmful to the interests of blind people. Whatever view one adopts on the subject, and however the case is ultimately resolved, a number of the key features of the court's decision, and several of the points that have become prominent in the ensuing public debate, warrant attention and shed light on some of the important choices our nation faces.

The International Dimension

One factor that appears to have played a role in the decision was evidence regarding the practices of other nations. It appears that of 180 nations that issue paper currency, the United States may be the only one that does not use any variations in size, texture, color, or markings to distinguish the various denominations of bills.

What is significant about this is not, as some may initially think, that U.S. courts are looking to international sources for guidance in how to apply our laws. Rather, the significance of this comparison relates to the questions of cost and technical feasibility. In the modern world, however, it may be that the decisions made and the criteria used are unique to each nation, whereas the technology employed to create and protect currency are not.

Undue Burden

In the wake of the decision, opponents, including representatives of the government and representatives of various affected industries, have pointed out the high cost associated with reshaping or otherwise redesigning the currency. A representative of the vending machine industry has estimated, for example, that the change would cost that industry alone \$560 million.²⁰

From the legal standpoint, an interesting question is whether costs to a third party, not the defendant in the suit, can properly be taken into account in determining whether the proposed solution constitutes an undue burden as defined by law. From the practical or political standpoint, such costs will inevitably matter, whether formally or not. But precisely because the estimates by these and other entities are large, another key question is raised.

Leaving aside the lack of any outside verification of their accuracy, estimates of cost, even cost to the government alone, tend to be bandied about and discussed without a context. Therefore, the key question, as with all “undue burden” claims, is what cost is reasonable and what is excessive. The law sets forth a number of criteria to be

considered in answering this question,²¹ but none are terribly useful in answering the question when the defendant is the U.S. government. Assuming for purposes of argument a compliance cost of say \$1 billion, a shocking figure to be sure, how is that figure to be understood? Should it be divided by the number of people likely to benefit from the change, assuming that number can be estimated? Should it be divided by the number of people with significant visual impairments in the country? Or should it be divided by the total number of Americans, approximately 300 million, in which case a hypothetical \$1 billion cost would break down to just over \$3 a person?

Ideally, another question should be asked before deciding whether the hypothetical \$1 billion is excessive. What are the costs to blind people and to the economy of not being able to independently identify the currency? These costs might include the costs of people hired to read, the costs of mistakenly giving the wrong bill, the costs of transactions not undertaken, and potentially others. Even if we could agree on what costs should be included, there is no conceivable way to measure them. The survey techniques available are flimsy indeed when measured against the ability of large entities to estimate their costs. Yet leaving aside the difficulty of measuring, the question remains whether the costs of an accommodation by the government should be measured in terms of the cost to the government or assessed in terms of the difference between current and projected cost to the entire economy. Beyond this, should benefit to society, if measurable, ever be a consideration?

In the end, as the foregoing questions suggest, the issue in accommodations situations is rarely about actual cost. Far more, it is about cost-shifting.

Assistive Technology Versus Universal Design

In the International Dimension section above, one role for technology was noted. But technology plays another important role in this debate, a role that has not received nearly the attention that it should.

Devices exist that can identify currency. According to anecdotal information, the Department of the Treasury may even have participated in funding some of the research on these devices. One approach to an accessibility problem is to develop and provide AT to solve the problem, and presumably all blind people who wanted it could be provided with a currency identifier device. But the thrust of this case points in the direction of universal or accessible design. Rather than seeking the provision of currency identification devices to be carried around by citizens, the suit seeks to make the currency more accessible without regard to the need for AT.

Although often unstated, this dichotomy, and again the cost-shifting implications of the choice, runs through many debates over how best to meet accessibility needs. We have struck the balance differently in different contexts. Though a review of the recent history of these decisions is beyond the scope of this chapter, it is important to remember that complex interactions among technology, economics, and politics usually determine the outcome.

In any event, whatever the outcome of the case, the opportunity for thoughtful discussion and public education should not be lost. Responsibility in this regard falls most heavily on the government. For that reason, NCD recommends that the Department of the Treasury or other Administration spokespersons avoid inflammatory rhetoric and, instead, move beyond mere assertions of costliness or impracticality and explain the criteria being used and the reasoning behind their conclusions.

Voting Rights

Help America Vote Act

The Help America Vote Act (HAVA) became fully effective on January 1, 2006. The years of preparation since its enactment in 2002 came to fruition in the primary and general elections of 2006. HAVA has already done much to enhance the accessibility of the voting process to Americans with disabilities. As NCD has recently observed, it is a “work in progress” with much more positive potential to be fulfilled.

Voluntary Voting Systems Guidelines

During 2006 the U.S. Election Assistance Commission (EAC), one of the entities created by HAVA to oversee and implement the law, has been engaged in the development of voluntary voting system guidelines (VVSG). In last year's progress report, NCD commended EAC for its efforts in this regard. NCD reiterates that commendation now and expresses its appreciation for the opportunities the Council has had to advise the commission on a number of issues relating to VVSG.

The year 2007 will witness continued refinement of the guidelines, but it will be a milestone in their development in another way as well. In December 2007, each state's accessible voting machine technology will be measured against the standards of VVSG.

In this light, NCD has offered a number of suggestions to the EAC for further enhancements in the guidelines. These suggestions address the privacy of all votes cast by people using alternative voting systems. They would ensure the accessibility and privacy of all paper ballots and bring about greater comprehensibility of the ballot to voters using audio output technology. These recommendations are set forth in detail in NCD's recent statement, "Voluntary Voting System Guidelines."²² NCD recommends that the EAC adopt these recommendations and incorporate them into the VVSG.

Monitoring and Enforcement

The need for DOJ to file suit against the State of New York for failure to comply with HAVA dramatically illustrates the need for continuing monitoring and oversight through the cooperative efforts and pooled resources of the EAC and DOJ.²³ NCD is keenly interested in how DOJ approaches HAVA oversight from the standpoint of the allocation of responsibility between its disability rights and voting rights units.

The Voting Rights Act

For the goal of fully inclusive civic participation to become a reality, the integrity and accessibility of the voting system must be ensured. Only through a seamless and well-coordinated implementation of a number of related laws can these goals be met.

The previous discussion focused on HAVA, but the Voting Rights Act (VRA) is another important component of the effort.²⁴ NCD had occasion during 2006 to commend the bipartisan leadership of the Senate Judiciary Committee for their efforts on behalf of reauthorization of the VRA.²⁵ These efforts extended to outreach with civil rights organizations. Although the notion of a role for the VRA in securing voting rights for people with disabilities may at first seem strange, given that the law was clearly written with racial, ethnic, and language minorities in mind, and for the purpose of remedying historic discrimination against those voters, the spirit of the law clearly implicates it in a government-wide response to discrimination against voters on the basis of disability.

NCD believes it is of paramount importance now to establish ongoing mechanisms that ensure that the VRA will continue in the future to adequately protect the rights of all voters, including voters with disabilities as effectively as it has protected the citizenship rights of ethnic, racial, nationality, and language minorities over the years.

For the VRA to play a role in protecting the rights of people with disabilities, DOJ must be able to identify when the interests of people with disabilities are materially and adversely affected by changes in voting rules. Procedures need to be developed (possibly but not necessarily requiring congressional action) for vetting major changes in voting procedures or rules that have a significant impact on voters with disabilities, just as they are for other protected groups. For example, recent state laws imposing heightened voter identification requirements have been the subject of litigation because of their disproportionate impact on poor people who cannot afford to buy the necessary document copies, and because of their impact on other groups for other reasons. But their potential, if unintended, impact on the suppression of voter participation by people with disabilities has not been as widely discussed.

One illustration may be useful to highlight such adverse impacts. New state laws purporting to restrict perceived coercion or manipulation of voters can pose risks for those involved in voter education. For those seeking to help newly empowered voters with disabilities, including voters with intellectual or cognitive disabilities, participate

effectively in the electoral process, the risks may be especially great and brutally chilling.

Whenever the DOJ Voting Rights Section, working in conjunction with the Disability Rights Section, is called on to review voting system changes, it must be alert to the possibility that measures that are neutral on their face can have disproportionate implications for voters with disabilities. Procedures, resources, and attitudes must all be brought into alignment for this to occur.

For this reason, NCD recommends that DOJ establish procedures for incorporating disability access into its VRA reviews, and should to that end create an advisory committee drawn from the disability community to advise it of access or integrity issues arising in the elections system.

The Civil Rights of Institutionalized Persons Act

In late 2005, NCD issued a major report on the Civil Rights of Institutionalized Persons Act (CRIPA).²⁶ In that report, the Council made a number of recommendations for improving the effectiveness of the protections embodied in the Act. With the likelihood that public programs will be moving toward an approach that makes home and community-based services a more viable option for many people, the vulnerability of those who remain in institutions is likely to increase while their visibility declines.

One of NCD's recommendations was for Congress to hold detailed oversight hearings on the Act. NCD is not aware that these hearings have taken place, but NCD does commend DOJ for energetic action on behalf of institutionalized people with developmental disabilities and people with psychiatric disabilities. Major investigations into conditions at the Lanterman facility and other facilities in California, as well as into facilities in other states, have focused public attention and outrage on the deplorable conditions at these institutions, but they are likely to bring about real improvement in the conditions of life for some of our most vulnerable citizens.

Events close to home in our nation's capital have cast light on abuses that are almost impossible to conceive of in our supposedly advanced and civilized society.²⁷

NCD commends Congress for the congressional hearings into the Washington, DC, situation. But a broader review of our entire approach to the treatment and care of institutionalized people is still needed. Apart from questions of when and how people can be enabled to enter or return to the community, the conditions of life for those who remain in institutions must never be far from our thoughts.

Accordingly, NCD reiterates its recommendation for broad-based congressional oversight hearings on the operation of CRIPA and on the relationship between CRIPA and other related services, laws, and programs, with a view to identifying legislative enhancements, monitoring strategies, funding mechanisms, and other measures to ensure the health and safety of those who remain in institutions or other custodial settings throughout our nation.

Genetic Nondiscrimination and Privacy

In each of its progress reports over recent years, as well as in papers, testimony, and other venues tracking the development of the subject, NCD has explained the growing need for protection of the privacy of genetic information. As the ability to collect such data has advanced and as those collecting and using it have appeared to multiply, NCD has warned of the danger this poses to legal rights and human dignity.

The arguments favoring genetic protection do not need repetition here, nor is it necessary to catalog the harm that results from the virtually unrestricted availability of such information for almost whatever uses insurers, employers, or others choose to make of it. Beyond the known arguments, NCD would like to add two new issues that have emerged in the past year.

Although agreement has yet to emerge around the method, a general consensus has continued to grow that the American health care system has become dysfunctional. Any

major reform in the way health care is paid for will have to consider genetic testing and will have to restrict its use for the purposes of denying insurance. With states taking the lead in adopting health insurance reform plans, nothing approaching universal coverage will be possible if people can be denied insurance by reason of genetic tests that may or may not predict illness.

It has become clear that any effort to stem the rate of inflation of medical costs will require a redirection of resources toward preventive care. While properly used information on genetic predispositions and family medical history is vital to the identification of risk factors and to the fashioning of individual prevention plans, it is hard to imagine how people can be convinced to submit to the necessary testing or even to divulge details of their family medical history if they are forced to live in fear that the data will be used to deny them insurance, an apartment, a credit card, or a job.

These and other realizations lead inexorably to the conclusion that unless the collection, use and dissemination of genetic information is controlled, no meaningful progress in reforming our health care system is possible.

NCD therefore renews its recommendation for prompt adoption by Congress of genetic privacy and nondiscrimination legislation that will restrict the use of such information to legitimate medical purposes; that will bar the use of genetic predictions as an adverse selection criterion in employment, insurance, housing, or other settings; and that will include meaningful penalties to deter violations of the genetic dignity of Americans.

Recommendations

Recommendation 2.1: NCD recommends the adoption of comprehensive remedial legislation, incorporating the provisions of the ADA Restoration Act proposed in its 2006 report, *Righting the ADA*. The legislation should create objective and knowable criteria for use in determining when and whether a particular impairment constitutes a substantial limitation to a major life activity. The legislation should eliminate the mitigation requirement, as a number of state laws already do. The comprehensive

legislation should provide that state waivers of immunity from suits under Titles I or II of the ADA are conditions for receiving “federal financial assistance” under any federal program.

Recommendation 2.2: NCD recommends that DOJ endeavor to develop strategies for determining the effectiveness and impact of all its ADA outreach, technical assistance, training, and public education efforts, with a view to determining what works best and why, to ascertaining why and how notable failures to comply with the law occurred, and to developing oversight mechanisms that will create the highest probability of long-term continuity in adherence to PCA agreements and to the underlying law.

Recommendation 2.3: NCD recommends that the DOJ Civil Rights Division issue a technical assistance guidance describing how patterns-and-practices or multisite ADA investigations are initiated, and explaining how isolated complaints are correlated with other isolated complaints to suggest national entities or multisite public accommodations that may be appropriate for broad-based scrutiny.

Recommendation 2.4: NCD recommends that DOJ immediately issue an appropriate advisory indicating the current status of the revised ADAAG; clarifying its intentions or expectations with respect to their modification, acceptance, or rejection; and setting forth time frames for all anticipated actions.

Recommendation 2.5: NCD reiterates its recommendation that DOJ immediately begin the process of developing guidelines to supplement the existing ADA Standards clarifying when and how Web sites are covered by Title III.

Recommendation 2.6: NCD recommends the Attorney General convene (pursuant to an Executive Order of the President if necessary) an interagency task force, including DOJ, the Departments of Homeland Security and Transportation, such other agencies as are deemed appropriate, and, to the maximum extent consistent with national security, representatives of the disability community, to develop procedures for

incorporating accessibility assessments into the development and testing of all new security systems and devices.

Recommendation 2.7: NCD recommends that in its public statements regarding the identifiable currency suit, the Department of the Treasury, or other Administration spokespersons, avoid inflammatory rhetoric and go beyond mere assertions of costliness or impracticality by explaining the criteria they are using and the reasoning behind their conclusions.

Recommendation 2.8: NCD recommends that the EAC adopt the recommendations contained in NCD's Statement on VVSGs aimed at ensuring adequate levels of privacy and comprehensibility for voters with disabilities, whether using electronic voting equipment or paper ballots.

Recommendation 2.9: NCD recommends that DOJ establish procedures for incorporating disability access into its VRA reviews, and to that end, that it create an advisory committee drawn from the disability community to advise it of access or integrity issues arising in the elections system.

Recommendation 2.10: NCD reiterates its recommendation for broad-based congressional oversight hearings into the operation of CRIPA and into the relationship between CRIPA and other related services, laws, and programs, with a view to identifying legislative enhancements, monitoring strategies, funding mechanisms, and other measures to ensure the health and safety of those who remain in institutions or other custodial settings throughout our nation.

Recommendation 2.11: NCD renews its recommendation for prompt adoption by Congress of genetic privacy and nondiscrimination legislation.

Chapter Three: Education

Introduction

Among such basic pillars of life as housing, health, and employment, our society has not seen fit to create a categorical legal right to these for all people. Only with the right to education have we created laws entitling every child to an education, and requiring parents or other caregivers to cooperate and meet certain standards in its provision.

For this reason alone, education plays a central a role in public policy more than does any other activity or service of the government. Education is the crucible in which society's struggles are fought out and in which the decisions made by each generation become the guideposts for preparing the next generation.

Consistent with our commitment to universal free public education, it has been established for a generation that students with disabilities are entitled to a free and appropriate public education (FAPE) in the most integrated setting possible. What this means, who will pay for it, how it is to be monitored, and what will be the consequences of failure to achieve it are questions that have continued to frame the debate over the past 30 years.

This chapter begins with a discussion of the two major federal laws affecting education in this country: Individuals with Disabilities Education Act (IDEA), which has just been reauthorized, and No Child Left Behind (NCLB), which is about to be reauthorized. The first two sections deal with key issues emerging in the wake of IDEA reauthorization, disability-related issues implicated in the forthcoming reauthorization of NCLB, and several key points of interface between the two laws that must be harmonized if either is to be fully effective. Issues addressed include the interpretation and applicability of such key NCLB concepts as adequate yearly progress (AYP) and corrective action to the rights and circumstances of students with disabilities.

The chapter then discusses trends that threaten to further close the courts to due process and civil rights litigation by and on behalf of children with disabilities whose rights are being abridged.

Next the chapter discusses possible incentives for increasing the number of qualified special education teachers. Following that, it addresses the potential for full inclusion of students with disabilities in general education classrooms, as proposed by a major Florida school district.

The chapter concludes with a discussion of recent Department of Justice (DOJ) civil rights enforcement initiatives in higher education. It notes the efforts the department has made in the area of physical accessibility, but also observes the absence of parallel efforts or vigor in the area of program or information accessibility.

IDEA Regulations and NCLB Reauthorization

New IDEA Regulations

Pursuant to the reauthorization of the IDEA Amendments of 2004,²⁸ the U.S. Department of Education was called on to issue regulations interpreting and applying the law. As discussed in last year's report, temporary regulations implementing the major Part B provisions (basic state grants) were published in 2005. In August 2006 the final Part B regulations were published.²⁹ NCD commends the Department of Education's Office of Special Education and Rehabilitative Services (OSERS) for its diligence in completing this work and for its efforts to secure public input into the content of the regulations.³⁰

Excellent summaries and analyses of the law have been published, but the overriding problem remains that IDEA cannot be implemented or understood in isolation. All laws are affected by and have an impact on other laws, but with IDEA and NCLB, the interactions are particularly crucial and exceedingly complex. "Alignment" of IDEA and NCLB is one of the often repeated goals of the new regulations, and it has been the

subject of extensive discussion in previous NCD progress reports since the enactment of NCLB in 2002. The fundamental potential for tension between the two programs lies in their differing historical approaches. IDEA emphasizes an individualized needs assessment, service provision, and performance measurement approach. NCLB approaches the shared goal of quality education in a very different way, stressing statistical indicators of progress derived largely through standardized testing. In this light, one of the chief sources of tension has been over the question of how and to what extent students with disabilities, including the growing number of students recognized as having intellectual disabilities, are to be incorporated in the statistical composites by which school systems are evaluated.

NCLB Reauthorization

With reauthorization of NCLB due in 2007, Congress will revisit the issues involved in NCLB-IDEA harmonization and alignment. With this in mind, NCD reviews the following relevant issues.

Adequate Yearly Progress

AYP is at the heart of NCLB. Under this concept, states, school districts, individual schools, and subgroups of at-risk students, including students with disabilities, must demonstrate improvement in test scores from year to year. Failure of particular schools to achieve AYP will result in what, depending on one's point of view, are considered corrective actions or penalties. Ultimately, protracted failure to improve sufficiently can result in loss of funds and in the transfer of students to other schools.

Consistent with the inclusive principles of NCLB, there has always been agreement about whether students with disabilities, defined in terms of those receiving services under IDEA, should be counted for AYP-determination purposes. What has proved more problematic is how they are to be counted. Most recently, the Department of Education had ruled that 1 percent of students with disabilities could have their progress measured by "alternative" assessment standards, and 2 percent by "modified" assessment standards.³¹ Lying behind the effort is the desire to balance the counting of

students with disabilities with the inherently competitive situation facing schools and school districts. Some students with intellectual disabilities cannot perform on the same tests or prosper with the same curriculum as the general student body, and no consensus exists on how this fact can be balanced with the competing objectives of inclusion and school statistical performance.

Reauthorization of NCLB presents another opportunity to address this dilemma. AYP will be a major subject of concern, because the many issues swirling around AYP affect more than just special education students.

The application of AYP to IDEA cannot be considered in isolation from broader issues. Establishment of percentages of students who can be assessed by alternative means will not resolve the fundamental problem. Such percentages do not establish how the validity of alternative or modified assessment measures is to be determined.

Equally serious problems exist with respect to students with sensory or physical disabilities who participate in the same curriculum and take the same state-mandated performance tests as the general student body, but who need reasonable accommodations to take the tests. Much controversy has been generated by accommodation requests for extra time. But though this is certainly one type of accommodation that often may be requested or recommended, it is not where the most serious issues exist. Such measures as the provision of readers for print-impaired students or sign-language interpreters for deaf and hard-of-hearing students, or the provision or allowance of alternative writing methods such as computers for students with motor impairments are critical to effective test-taking, but they may be seen by some as creating a lack of uniformity in the assessment process.

NCD strongly believes that reasonable accommodations are designed to allow students to participate fully in school, including in demonstrating their capabilities on standardized tests. NCD recommends that, in its reauthorization of NCLB, Congress make clear that reasonable accommodations designed to make standardized test-taking accessible to students with disabilities are required in all standardized performance-

assessment settings, and that use of alternative measurement techniques where appropriate accommodations exist is not acceptable. Such a clear and unambiguous statement would align NCLB with other applicable laws, including IDEA and Section 504, and would avoid inconsistency among applicable laws.

Corrective Measures

When schools fail to achieve AYP, they are subject to corrective measures. What NCLB has not yet made clear is that corrective measures must be designed and delivered in ways that ensure their full accessibility and availability to all students, including students with disabilities. In this light, NCD recommends that all NCLB corrective action plans be required to include information on how the objectives of the plan will be met for students with disabilities. Subsequent improvement in overall school test scores should be regarded as insufficient to demonstrate success of the corrective action plan unless these results include proportional increases in the test scores achieved by students with disabilities as one of the disaggregated student subgroups for which AYP is computed.

Other Issues Under IDEA

Although IDEA and NCLB are closely linked, a number of issues are specific to IDEA. Just as the 2004 amendments answered some old questions, they inevitably created new ones that will be left to stakeholders, and ultimately to Congress in the next revision, to resolve.

NCD commends OSERS for its IDEA Amendments resources Web page.³² The various fact sheets and other tools it offers provide a valuable starting point for those interested in learning more about what the amendments mean. But key questions, which we address below, remain.

Private School Placements

Among other changes, the 2004 IDEA amendments provide for a significant shift in funding responsibility for those students placed in private schools by their parents

(parentally placed students). For purposes of IDEA funding support, there are two categories of private school placement. The first, and far less common, placement occurs when the placement decision is made by the public school system, that is, by the local education agency (LEA), and is deemed to represent FAPE for the individual student. The second type of placement involves cases of parental placement in which the LEA, although not paying tuition or other basic costs, may be asked or expected to provide special education services that the student would require wherever placed or enrolled.

One key change made by the new law is that responsibility for special education support for private school students is shifted in certain instances from the student's home LEA to the LEA in which the private school is located.³³ NCD appreciates the efforts made in the IDEA regulations to clarify these new rules, but the Council remains concerned about possible attempts at cost-shifting, about coordination and continuity in service, about records management, and about a number of other issues potentially arising from the new funding rules. NCD recommends that OSERS carefully monitor reported experience with private school placements under the new rules, with a view toward amending or amplifying the existing regulations within one year if unforeseen difficulties or situations not covered by the rules arise.

NCD also is concerned that LEAs that contain exemplary private schools within their catchments may incur unexpectedly heavy costs. To the extent that private schools exist or emerge that achieve especially good results in working with students with various disabilities, parents likely will be inclined to seek placements in such schools for their children. Other localities may find them useful in instances in which appropriate community-based resources do not exist. Provision should be made for financial and other impacts on destination LEAs. Therefore, OSERS should monitor the economic implications of this new arrangement for private schools, and for the LEA in which private schools are located that receive out-of-district disability student placements.

Private and Charter School Selection Criteria

The movement in the country toward free innovative education from the often stifling effect of education regulations and the education administrative system has resulted in states having taken steps to facilitate the creation of charter schools that, to varying degrees, operate outside the framework of many legal requirements.

One element of the charter school concept has been the right to focus on the particular type of student the charter school is designed to serve. This never has been taken so far as to allow discrimination on the basis of traditionally invidious grounds, but resistance to the recruitment, acceptance, or welcoming of students with disabilities has not been recognized for the kind of discrimination that it is. The law must be made unambiguous, and its requirements must be linked to the availability of public funds and state accreditation.

Accordingly, NCD recommends that OSERS make clear that IDEA funds may not go to charter or private schools that discriminate against students with disabilities in the admissions process or otherwise, and regulations should be implemented barring states or LEAs from providing funds on behalf of students in charter or private schools found in violation of antidiscrimination requirements of federal or state law.

School Accessibility

An area that continues to cry out for reform, whether through IDEA oversight or through attachment of specific provisions to the forthcoming NCLB reauthorization, is that of school and program accessibility. The following subsections deal with specific contexts in which this issue arises.

Facilities Accessibility

Requirements for physical accessibility of school facilities, under either the Americans with Disabilities Act (ADA) or Section 504 depending on the kind of school in question, are generally known. But it is by no means clear that the linkage between such

accessibility and availability of federal funds (or the link between program accessibility discussed below and federal funds) is as well understood or as fully implemented as it should be.

As things now stand, in cases in which the students in failing schools are given the opportunity to transfer to other schools, no requirement or guarantee in the law obligates those receiving schools to meet accessibility requirements as a condition for receipt of the new students, or as a condition for receiving special education, per capita, or other funds that will come with them.

Put more vividly, given the opportunity to move out of underperforming schools, students with disabilities should not face narrower options than do their peers without disabilities.

Program Accessibility

As important as access to the building and the classroom or auditorium is, other kinds of access are equally important but often more elusive and more difficult to assess. Grouped generally under the rubric of program accessibility, it is access to the curriculum (including textbooks and audio-visual materials), online resources and computer equipment used in the school, and other aspects of full participation on which we focus our concern.

A major step toward full program accessibility took place with the launch in December 2006 of the National Instructional Materials Access Center (NIMAC).³⁴ Textbook publishers, as part of the contracts with states, agree to deposit at NIMAC electronic copies of textbooks, formatted in the national instructional materials access standard (NIMAS) file format. These files can readily be converted to a variety of accessible formats, and are available to be downloaded for this purpose by state-authorized users who, among other things, enter into a prescribed copyright agreement.

NIMAC is the culmination of a long effort discussed in previous reports. NCD commends all those from the public, publishing, and accessibility advocacy sectors for these efforts.

NCD believes that accessible textbooks can make an important contribution to mainstreaming students with disabilities, program accessibility, and full participation. The Council is concerned, however, that rapid changes in technology and terminology could leave NIMAC behind the curve. The history of Section 255 of the Federal Communications Act of 1996 (discussed at length in Chapter Eleven of this and of previous reports) illustrates this concern. Enacted to require accessibility of a broad category of “telecommunications” services and equipment, the law has proved largely inapplicable to closely related services, known as “information services,” that came on stream after the statute’s passage.

In this case, the key concepts are not “telecommunications” equipment or services, but “instructional materials” or “textbooks.” With rapid changes in the ways technology allows information to be presented, the very meaning of the term “textbook” is in question. Textbooks may now not come in book form at all, may contain little or no text, and may rely on multimedia presentations. Moreover, through utilization of the Internet, increasing use may be made of mandatory curricular materials that were not necessarily published for sale to, or formal adoption by, states as school texts.

Principles of accessible design, such as the use of the now-familiar “alt text” and others, have resulted in significant progress in making electronically presented visual materials accessible to people who are blind. At the same time, methods for combining various forms of output in the multimedia setting have enhanced information access to people with a variety of other print and intellectual disabilities. But the effort to keep up is always a struggle. Access developers are always running in place to keep up, and as NCD’s recent assistive technology report has made clear,³⁵ rapid technological change sometimes can be a double-edged sword as far as efforts to achieve and preserve accessibility are concerned.

Therefore, for NIMAC to be successful in the long term, NCD believes three things need to happen. First, the actual accessibility of materials claimed to be accessible must be monitored carefully. Second, those who develop and deploy new methods for organizing and displaying information, or who create new interfaces between the student and the information, must be held accountable for finding ways to incorporate accessibility into their designs. Third, information access in schools should be recognized, like physical access, as a feature of the environment that must be provided, not as an individualized service to be provided as part of a student's individual education plan (IEP).

Even if full program and curriculum accessibility, including but not limited to NIMAC, is more expensive in the short run, school officials need to remember that it is manifestly in their interests. Because students with sensory disabilities will be taking standardized tests and will be counted in AYP, schools' aggregate results will inevitably be influenced by the access afforded these students to the materials making up the curriculum.

To facilitate full recognition and implementation of the fact that program access, like building access, is a component of education system design and not an individual problem, NCD recommends that the Department of Education review the current status of Part D National Media programs that use IDEA funds, with a view toward identifying what changes in the size or scope of the Part D program could facilitate full materials accessibility.

Access to the Courts

A report issued in 2006 found the achievement gap between students with and without intellectual disabilities to be narrowing.³⁶ Though many factors can be cited to account for this, and many stakeholders should be praised for helping to bring it about, NCD believes that education due process has played a major role. Due process, including the right to seek redress in the courts where all else fails, has represented an important safety valve in those cases in which the IEP process has failed to effectively identify or meet student needs.

Of course, there have been instances in which the right to seek redress may have been unwisely or even abusively exercised. No right is immune from occasional misuse. Nevertheless, out of a belief that due process, including the right of “prevailing parties” to obtain school system reimbursement for attorney fees, has hindered the education process, the 2004 IDEA amendments included a number of provisions to discourage confrontation and litigation in favor of negotiation and mediation. These changes are discussed at length in last year’s progress report. Although it is too early to tell for sure, their effect, if successful, will be to reduce the number of formal due process appeals and especially the number of court suits arising out of IDEA disputes. One of the ways the law unabashedly attempts to do this is by making it economically harder for aggrieved families to pay attorneys, as discussed in previous reports. A case will be argued in the U.S. Supreme Court in February 2007 that, if the lower-court judgment is upheld, will impose unprecedented further limitations on the opportunities of special education students and their families to defend their rights in court. In the *Winkelman* case, the lower court held that the parents of a child with a disability were not permitted to bring a *pro se* proceeding on behalf of their child’s special education rights under IDEA.³⁷

Lest this seem a narrow, technical issue, let us put it in context. The right to represent oneself in court, as part of the constitutional right to petition the government, is basic to American justice. Where a child’s rights are at stake, the parents, assuming no conflict of interest and assuming the unavailability of legal representation, are the natural and traditional people to pursue the child’s claims. Indeed, in *Winkelman*, had the parents been lawyers, it appears the court would have had no objection to their bringing the case on behalf of their child. Nor was there any indication that the nonlawyer parents had jeopardized their child’s rights by the manner of their representation. Rather, it was held that as a matter of law, these nonlawyer parents, no matter the merits of the claim, and apparently no matter the unavailability of professional representation, were barred from attempting to advance their child’s education interests under IDEA. It was reported in one account of the case that these parents may have been investigated for the

unauthorized practice of law.³⁸ The implications of the *Winkelman* case extend far beyond special education, and already, the case is beginning to cast long shadows.³⁹

In an era in which education policy has stressed parent involvement and empowerment, all would hope that the need for litigation would be reduced as parents became more aware of and skillful in participating in the education process. Nevertheless, in those rare instances in which parents in good faith have no other option but to seek redress in the courts, it is more than a little ironic that they should be barred from doing so.

Teacher and Other Personnel Issues

Recruitment of qualified personnel is a major issue throughout the education system. In view of NCLB's stringent requirements for teacher qualifications and training, the issue has become an important one all over the country. In light of the application of these same "highly qualified teacher" requirements in special education, the issue is of no less concern in this area.

Although not directly increasing the number of teachers pursuing special education credentials or careers, and although not increasing the proportion of special education teachers who meet highly qualified criteria in core academic subject areas, a little-noticed provision of the IDEA reauthorization may contribute to the supply of such teachers and help tip the balance in favor of special education teaching careers.

This provision provides for student loan forgiveness, in an amount up to \$17,500, for those who pursue highly qualified special education teacher credentials and careers.⁴⁰

NCD recommends that OSERS seek out recommendations from disability-related organizations and public policy experts regarding similar economic incentives that, along with existing training programs, could encourage talented young people to pursue special education teaching careers.

But the personnel needs of the general and special education system are not limited to teachers. Other key professional staff and consultants, called pupil services personnel

under NCLB and related services personnel under IDEA, also constitute important participants in the education process. In this connection, the Coalition of Citizens with Disabilities has recommended standardization of terminology in this and other areas.⁴¹ NCD endorses this recommendation, believing that it will help to identify and meet personnel needs in a comprehensive and efficient manner.

Mainstreaming

If students with disabilities are to be included in AYP assessments, it ultimately is desirable for these students to follow the same curriculum as their peers do. From this standpoint, as well as from the standpoint of meeting the law's least restrictive environment aspirations, mainstreaming students with disabilities in the regular classroom represents the highest ideal of special education.

It has been conventionally accepted that, as laudable as this goal might be, its 100 percent achievement is impractical. However this may be, one major school district has embarked on a bold effort to do just that. The Palm Beach County (Florida) School Board has announced its intention to include all of its 20,000-plus special education students in general education classrooms, in all of its 161 schools.⁴² NCD has not determined whether this inclusion will be total, or what arrangements will be made in terms of timing or scheduling to accommodate related services and other student support activities. Nevertheless, the Council commends this historic decision and eagerly awaits further information on its progress.

Higher Education

Unconfirmed press reports over the past year or two have indicated that the Administration is giving consideration to expanding NCLB (which now covers elementary and secondary schools) to cover postsecondary education as well. NCD expresses no view on such a proposal. But whether or not this ever comes to pass, any number of things can be done within the framework of current law to improve access, choice, participation, and outcomes for students with disabilities in college.

The long history of ADA and Section 504 involvement in the accessible design of university facilities, in the accessibility of information technology (IT) resources, and in the accessibility of curricular materials should be considered. By and large, that involvement has waxed and waned over the years. Most recently, DOJ has launched investigations into the physical accessibility of college and university campuses, reaching a highly publicized settlement with the University of Chicago in August.⁴³ Noting that the investigation was not prompted by any specific complaint, a DOJ spokesperson was further quoted in the Chicago press account, saying, “Justice Department attorneys now proactively check campuses for problems, and the University of Chicago settlement is the first resulting from this approach.”⁴⁴

The settlement covers such areas as accessible paths of travel, accessible university housing, and emergency evacuation plans. Interestingly, the agreement calls for information on travel route accessibility to be posted on the university’s Web site, but it appears to make no provision, nor evince any concern, for whether those Web sites are accessible. In this regard, the above-referenced press account also notes, “The settlement does not include academic accommodations such as technology that can make online course material available in an audio format for students who are blind.”⁴⁵

NCD highly commends DOJ for its proactive efforts to increase the accessibility of campus facilities throughout the nation. But the lack of any indication that program accessibility is receiving any of this precious attention is deeply disturbing. In its review of DOJ activities during the year, NCD can identify a number of instances in which relevant technical assistance and information have been offered, but none in which comparable enforcement action has been initiated against anyone, under any law, for failing to make electronic information accessible. NCD notes again, as it has had occasion to do in past reports, the positive role played by DOJ amicus briefs in a number of IT access–related cases.

NCD recommends that DOJ incorporate campus computer and related IT accessibility into its proactive reviews of ADA compliance among colleges and universities, particularly among public institutions covered by Title II of the ADA.

NCD also recommends that the Department of Education, in the exercise of its oversight responsibility under Section 504 of the Rehabilitation Act, undertake proactive audits of campus IT accessibility on a nationwide basis, on all campuses receiving federal funds that are covered by the law. The purpose of these audits should not be to punish or to embarrass, but rather to encourage and assist, through enforcement measures only where necessary, the implementation of full accessibility as required by law.

Recommendations

Recommendation 3.1: NCD recommends that, in its reauthorization of NCLB, Congress make clear that reasonable accommodations designed to make standardized test-taking accessible to students with disabilities are required in all standardized performance-assessment settings, and that use of alternative measurement techniques where appropriate accommodations exist is not acceptable.

Recommendation 3.2: NCD recommends that all NCLB corrective action plans be required to include information on how the objectives of the plan will be met for students with disabilities, and that subsequent improvement in overall school test scores be regarded as insufficient to demonstrate success of the corrective action plan unless these results include proportional increases in the test scores achieved by students with disabilities, as one of the disaggregated student subgroups for which AYP is computed.

Recommendation 3.3: NCD recommends that OSERS carefully monitor reported experience with private school placements under the new rules, with a view toward amending or amplifying the existing regulations within one year if unforeseen difficulties or situations not covered by these rules arise.

Recommendation 3.4: NCD recommends that OSERS make clear that IDEA funds may not go to charter or private schools that discriminate against students with disabilities in the admissions process or otherwise, and regulations should be implemented barring states or LEAs from providing funds on behalf of students in

charter or private schools found in violation of antidiscrimination requirements of federal or state law.

Recommendation 3.5: NCD recommends that the Department of Education review the current status of Part D National Media programs that use IDEA funds, with a view toward identifying what changes in the size or scope of the Part D program could facilitate full materials accessibility.

Recommendation 3.6: NCD recommends that OSERS seek out recommendations from disability-related organizations and public policy experts regarding economic incentives that, along with existing training programs, could encourage talented young people to pursue special education teaching careers.

Recommendation 3.7: NCD recommends that DOJ incorporate campus computer and related IT accessibility into its proactive reviews of ADA compliance among colleges and universities.

Recommendation 3.8: NCD recommends that the Department of Education, in the exercise of its oversight responsibility under Section 504 of the Rehabilitation Act, undertake proactive audits of campus IT accessibility on a nationwide basis.

Chapter Four: Health Care

Introduction

Today there may be no area of domestic public policy that affects everyone as profoundly and inescapably as does health care. What services and modalities exist, who is eligible to receive them, and how they are paid for all represent subjects of growing and continual interest and, too often, problems of intractable and unfathomable complexity.

While news broadcasts may continue to focus on new discoveries and treatments, horror stories, or accounts of near miracles, the core discussions of health care in America are increasingly being driven by economics. It seems more and more likely that the costs of health care will determine the answers to the question of what health care includes and how much of it is available. But the equally profound questions of how those services and care will be allocated remain topics best addressed through the evolution of law and public policy.

Although health policy affects everyone, it affects the lives of people with disabilities in several distinctive ways. These include the nature of the services that people with disabilities may need; the sources of payment for those services; the accessibility of those services; and the attitudes of society, lawmakers, and practitioners toward the aspirations of people with disabilities for autonomy and self-determination in the selection and management of services. This chapter addresses this range of issues, with an emphasis on choices and debates that have emerged during 2006 and that are likely to prove important in 2007. The chapter begins with a discussion of Medicaid, which faces growing demands for cost reduction. The chapter discusses opportunities for accommodating these pressures in ways that reduce the adverse impact on beneficiaries with disabilities.

The discussion of Medicaid next turns to the situations faced by people dually eligible for Medicaid and Medicare. The chapter then discusses means to accelerate the shift of

Medicaid funding from institutional to community-based services and the implications of that shift for the solvency of the program. Important innovations in Medicaid, focusing on consumer-directed services, are also discussed.

The chapter then considers Medicare. Recent changes in rules governing the availability of powered mobility devices are discussed, both on their own merit and for the broader insight they offer into the philosophy and direction of the program. Through discussion of the work of the Medicare Ombudsman, the program's ability to include beneficiaries with disabilities in its planning and experimentation is assessed.

The chapter then addresses issues of particular concern to people with mental illness, including insurance coverage and the tragic rise of imprisonment as a means to fill the vacuum caused by the lack of adequate treatment options.

The chapter concludes with a reminder that returning veterans are coming to represent an increasing and important segment of the disability community, whose needs and experiences are unique, and whose needs and potential must receive our highest, sustained attention.

Medicaid

Medicaid is the federal-state program designed to provide health care to those whose poverty, combined with either age or disability, makes them eligible for the program. It is not enough to meet the definition of poverty alone, to be over the age of 65, or to be a person with a disability. With minor variations on state standards, an individual must both be poor and meet one of the other demographic criteria. Because of relative poverty and because of low levels of employment, many people with disabilities rely on Medicaid for their health care coverage. For that reason, developments in the Medicaid program are of particular significance to Americans with disabilities.

Medicaid Spending

The chief concern driving federal Medicaid planning in recent years has been the concern that, at current and projected rates of growth, the program soon will consume unworkable levels of funds. The national Medicaid Commission appointed in 2005 by the Secretary of Health and Human Services, whose interim report was discussed in last year's NCD progress report, has now completed its work and made major recommendations. Consistent with its mandate to find substantial savings, means to reduce program costs, including achieving greater efficiency, were at the forefront of the Commission's recommendations.

NCD fully accepts the need for, and the inevitability of, cost savings in Medicaid. The Council does not engage in wishful thinking about how overall economic growth resulting in increased tax collections, or closing the tax gap through more effective collection of taxes now evaded, will magically close the looming budget gap as it relates to Medicaid or other human services programs. Put in starker terms, even with the greatest attention to efficiency, accountability, and cost-effectiveness—even with the intensification of waste and fraud eradication measures—some real reductions in the level of care to some people, and the entire loss of coverage for others, are going to be necessary if savings levels approaching those demanded by policymakers are to be realized. As a first step in engaging all Americans in the critical and difficult choices that must be made, NCD urges that the discussion about Medicaid, though it may be driven by dollars, be conducted in terms that openly address the questions of who will lose coverage, which services will be restricted or denied, and how our society will address the development and availability of alternative safety net protections.

Important principles must necessarily have complex effects. In supporting greater state flexibility in the implementation of the Medicaid program, the Commission and others rightfully recognize the opportunities for cost savings through efficiency, responsiveness to local conditions, experimentation, and quickness of response that such flexibility can yield. But, if meaningful savings are to be achieved, such candor requires recognition that state flexibility must entail narrowed eligibility or reductions in services and benefits.

NCD accepts the unavoidable fact that if any people suffer as a result of these reductions, people with disabilities will be among them. But what concerns the Council is that cuts may be made in ways that disproportionately burden Medicaid beneficiaries with disabilities and that cause people with disabilities to bear the brunt of cost-cutting measures.

NCD is concerned that these cuts could occur in three ways. First, it is likely that states will choose to cut first those services that are the least used or that have the smallest political constituencies—that is, the understandable path of least resistance. This will mean that so-called optional services that states have offered at their discretion will be the first to be cut. A number of these services are of particular importance to people with disabilities. Even low-volume mandatory services, which now can be reduced or eliminated to varying degrees by state use of expanded waiver authority to modify general program rules, could be affected in similar ways, with similar results for people with disabilities. Litigation around assistive technology (AT) devices, coming under various established service categories, illustrates this phenomenon.⁴⁶

The second and closely related concern is illustrated by cuts in such initiatives as the Medicaid Buy-in Program. Cuts may yield short-term or even long-term savings to the state's Medicaid budget, but who is responsible for assessing their broader financial implications for the state and nation? For example, if such cuts prevent people from establishing secure long-term employment by forcing them to choose between entry-level work and health coverage, what is the net long-term gain or loss to the public purse? No one knows, but, perhaps more seriously, neither is anyone is compelled to ask or is accountable for failing to answer such key questions.

Our third concern in this regard relates to the widespread perception, as discussed in the subsection Dual Eligibility below, that Medicaid beneficiaries with disabilities account for a disproportionately large share of overall Medicaid costs and that their per capita costs are higher than those of other beneficiaries. From that standpoint, economic logic, if not political expediency, suggests that restricting their eligibility or cutting those

services most often associated with use by people with disabilities represents the easiest way of saving substantial sums.

A partial solution to these risks may exist. It arises from parallel efforts undertaken by the Centers for Medicare and Medicaid Services (CMS) to curtail fraud and abuse in the Medicaid program. In its July 2006 announcement of an unprecedented large and comprehensive Medicaid integrity program, CMS listed a number of principles that would guide the effort. One of these is “return on investment.”⁴⁷ NCD believes that this concept, applied in a slightly expanded form, can go a long way toward ensuring that the painful cuts facing Medicaid will be implemented in ways that maximize state government and Federal Government goals.

Specifically, NCD recommends that Congress incorporate in any future Medicaid legislation provisions requiring each state, as an element of its approved state plan, to develop meaningful criteria for determining the return on investment of all expenditure increases, or expenditure cuts, contemplated in the program. Such return-on-investment assessments, or for that matter return-on-disinvestment statements, would be required to assess, so far as reasonably possible and in accordance with sound statistical research and actuarial practice, the overall cost implications to the state and to its units of regional and municipal government resulting from the proposed change.

The assessments that would be required are not limited to the Medicaid budget silo, but would extend to all facets of state revenue and expenditure. They would be conducted in a way that exposes all cost-shifting measures that move expenditures from one level or unit of government to another. These assessments would represent a great step forward in enhancing the transparency of public accounting.

Dual Eligibility

The Medicaid Commission pays considerable attention to dually eligible people (dual-eligibles), that is, people who receive coverage under both the Medicaid and Medicare programs. In light of the administrative and coverage differences between Medicare and

Medicaid, handling dual-eligibles has been vexing over the years and has been discussed in previous NCD reports. Here, however, we are concerned with the subject principally from the standpoint of cost, which was the standpoint from which the Commission approached it.

The Medicaid Commission estimates that dual-eligibles account for about 13 percent of Medicaid beneficiaries but for 40 percent of Medicaid expenditures. It attributes this fact to their being the sickest among Medicaid beneficiaries.⁴⁸

In its recommendations, the Commission emphasizes the use of managed care as a cost-saving strategy through its potential for service and benefits coordination and its other perceived benefits. What is not clear is what data the Commission relied on to estimate the extent of these possible savings.

It is unclear to what extent the Commission was apprised of managed care efforts aimed at dual-eligibles carried out pursuant to Section 231 of the Medicare Modernization Act of 2003. Although that legislation is known primarily for its creation of the Medicare prescription drug benefit, it also contains a large number of other provisions, including authorization for the creation of Special Needs Plans (SNPs), which are managed care plans for three categories of Medicare beneficiaries believed to present special challenges or to have care needs that involve high cost. Dual-eligibles are one of these three groups, and according to information provided by CMS in mid-2006, of the more than 500,000 people enrolled in SNPs since their creation, some 400,000 are dual-eligibles receiving both Medicare and Medicaid services.

NCD believes that the outcomes of such plans in reducing per capita costs by improved coordination and by providing preventive services represents an important case study in the possibilities of managed care, and by implication, a valuable window into the overall potential of managed care to reduce health care costs. In that regard, on the basis of their findings that administrative barriers were limiting the effectiveness of the SNP programs, CMS has provided a number of technical assistance resources.⁴⁹ This, in turn, redirects attention to the perennial question of whether and to what extent removal

of administrative, paperwork, and legal barriers can, without any decrease in level or quality of care, accomplish savings for this and other programs.

It is widely believed that managed care results in reduction of care levels and options for people with disabilities. It was on this basis that one member of the Medicaid Commission dissented from the vote on its recommendations.⁵⁰ NCD is interested in the experiences of dual-eligibles with disabilities specifically under these SNPs. NCD recommends that CMS augment its published data on SNPs to indicate the extent to which they meet concerns often expressed by people with disabilities, including concerns about the range and availability of specialized practitioners and services, rights to continuity of service and established practitioner relationships, and similar matters. CMS should review the regulatory and advisory guidance it gives to Medicare Advantage plan providers and state Medicaid agencies in regard to these matters, with a view toward ensuring that the full scope of rights that exists under the law is effectively communicated to program administrators and service providers.

Institutional Bias

As recognized by the Commission, Medicaid's institutional bias (that is, its complex pattern of rules and practices that make it easier or financially beneficial for people to receive nursing home or other institutional services rather than home and community-based services) represents a major area in which program costs could be greatly reduced. Although the Commission's sphere of responsibilities may not have extended to identifying or addressing ways the process of conversion from institutional to community-based services could be accelerated, the Commission's recognition of the issue, coupled with recent developments, opens the way for additional research, recommendations, and experiments aimed at bringing about this goal, both for the savings that will accrue and for the other benefits to recipients and to society that will be achieved.

Federal Funding Formulas

A landmark achievement of the past year (discussed at length in Chapter Five) was the enactment of Money Follows the Person (MFP) and the completion of the first round of grant applications under the new program.⁵¹ MFP and related changes redress Medicaid's institutional bias in two ways. First, the law provides funds for home and community-based programs, creates rebalancing goals, and, perhaps most important, provides a higher percentage of federal funding participation in the provision of certain home and community-based services than in the funding of institutional care. The importance of such measures in altering the fiscal equation for states, and tipping the balance of fiscal responsibility in favor of home and community-based services and care, cannot be overstated.

The role of federal funds in influencing state policies is widely recognized in almost all areas of life. But the potential of variable cost-sharing formulas to encourage sound practices in Medicaid has been barely explored or used thus far. Much discussion has focused on overall funding levels and on the formulas that are used to determine how much each state will receive.

NCD urges Congress to enact legislation that will differentially support community-based services in the Medicaid program.

Economic Data

Changes in federal requirements and funding formulas can speed the process of Medicaid rebalancing, but ultimately, it is the data accrued from such efforts that make the economic logic of the process as irresistible as its ethical component. Without waiting for MFP, a number of states, through the use of waiver authority or by other means, have begun making increased use of community-based resources. Data from Texas illustrate the potential savings that can be achieved.⁵² As economic logic and societal values continue to converge, both the pace of this shift and the available data concerning its implications are likely to grow exponentially. It is critically important that these data be studied, evaluated, and rigorously applied.

NCD notes that the methodology used to evaluate accrued savings or prospective costs of deinstitutionalization may not yet have evolved to the point at which all researchers will agree on basic assumptions. For example, this year's publication of analyses by a group of disability demographers substantially challenged Congressional Budget Office (CBO) estimates of how much MFP would cost. By drawing attention to several questionable assumptions in CBO's formulation, including probable overestimates of the number of people who would qualify for home and community-based services, these demographers were able to offer reputable cost projections significantly lower than those presented to Congress.⁵³

Available data suggest that the redirection of Medicaid long-term-care funds from institutional to home and community-based services is proceeding at an accelerating pace. According to one compilation of data, the ratio, which still heavily favors nursing homes and other facility-based services, decreased from 84 percent in fiscal year (FY) 1993 to 82 percent in FY 1999, to 74.9 percent in FY 2004. In the five years since the Supreme Court's 1999 *Olmstead* decision, the average decrease in the nursing home bias was 1.4 percent per year. By contrast, in FY 2005 the nursing home share was 68.5 percent, a reduction of 6.4 percent in a single year.⁵⁴ With MFP in place, this rebalancing is likely to accelerate.

It is vital that Congress and the public have accurate data on the effects of this dramatic shift on current and projected Medicaid costs. Consultation among CMS actuarial experts, disability demographers, and CBO economists is likely to yield consensus on formulas that can translate percentage shifts into dollar savings. Such data must be collected and factored into the Medicaid reform effort, as it relates to both programs and budgets.

Inasmuch as nursing home care represents the largest category of Medicaid expenditure, this impact is certain to be significant. Only when this impact is fully assessed can meaningful types and levels of additional cuts be fixed. Significant, even draconian cuts, may be unavoidable, but incorporation of these critical data elements can help ensure their humane targeting and reduce their harmful impact.

Accordingly, NCD recommends that Congress enact legislation creating a standing committee, including representatives of CBO, CMS, Office of Management and Budget (OMB), and the disability community, to monitor progress, develop forecasting tools, and assess alternative assessment models to measure and predict the budgetary impact of rebalancing on the overall fiscal status of the Medicaid program.

Cash-and-Counseling, Self-Directed Care, and Consumer-Controlled Budgets

As important as it is to create financial structures that encourage and enable people to remain in their homes and communities, the quality of service they receive in those communities may prove as decisive in determining what individual recipients choose to do. People can be as imprisoned in their homes, and as equally or even more isolated and powerless, as they can be in institutions. For this reason, beneficiary autonomy programs, including self-directed care and cash-and-counseling models, are vital.

Models and Data

Although experimental models vary, the essence of cash-and-counseling programs is that those who qualify for home health care or other services in the home are allowed to exercise control over how some or all of the funds available for this service are spent. They may be given authority to expend the funds directly or to work through a fiscal intermediary, they may be required to expend their budgets within a designated period of time, or they may be allowed to save money toward certain personal objectives.

Considerable impetus was given to consumer-directed services by changes in the law that went into effect at the beginning of 2006. As further discussed in the Chapter Five, these changes allowed states to include self-directed services in their state plans as optional Medicaid services, but without the requirement to seek approval of a waiver from the Federal Government.⁵⁵ The number of such programs is believed to be increasing rapidly, and early indications suggest they are successful on a number of levels, including better outcomes and better quality of life, as measured by consumer satisfaction and other indicators.⁵⁶

Models differ for a number of important reasons. Within the framework of the federal law, states have considerable discretion in many areas of program design. Other state laws interact with Medicaid in a variety of ways. NCD strongly endorses the expansion of all models of consumer-directed services. The Council understands that proving the worth of these models relative to other approaches will not be easy, especially if subjective variables such as consumer satisfaction, quality-of-life indicators, and social participation are to be given weight and respect.

NCD recommends that CMS create, in house or by competitive bidding, and possibly in collaboration with the National Institute on Disability and Rehabilitation Research, a national clearinghouse on consumer-controlled and self-directed human services programs.⁵⁷ This clearinghouse should collect and maintain detailed descriptive, evaluative, and outcome data on all such programs, whether operated under the auspices of the Medicaid program, by Medicaid in conjunction with other programs, entirely by other agencies (such as under the Real Choice Systems Change grant program), by states, or by private nonprofit–public sector partnerships.

Key Interfaces

Questions remain about the role of self-directed services and care programs in achieving the goals of Medicaid or other service inputs. Another, largely untapped, issue is the potential of such programs to work with other self-sufficiency programs in ways that give them increased leverage value in helping participants to move increasingly into mainstream economic and social settings.

Examples of this potential abound. If the savings from self-directed budgets could be combined seamlessly with savings in individual development accounts or plans for achieving self-support, considerable opportunity for asset accumulation and for the achievement of self-sufficiency goals would be unlocked. Unprecedented cooperation among a number of federal agencies, including at a minimum CMS and the Social Security Administration, would be required to bring about such demonstrations.

For consumer-directed services to achieve their full potential, other interfaces will be necessary. Two in particular should be noted. The first of these interfaces can be achieved with financial literacy programs, such as the Federal Deposit Insurance Corporation (FDIC) Money Smart curriculum, that offer beneficiaries information they may not have received and financial resources they may not have possessed. In this regard, FDIC's efforts to make its curriculum more accessible should be commended.

Another critical interface may be required for self-directed services and self-managed budgets to work. Several anecdotal accounts indicate that, because of conflicting laws and a lack of interagency agreement, a number of people managing their own budgets and hiring their own service providers may have inadvertently run afoul of tax laws and tax authorities by failing to withhold payroll or income taxes on behalf of those they employ, failing to pay the employer's share of such taxes, or simply failing to file the necessary forms.

If self-directed services are not to become a source of anxiety and risk to their potential beneficiaries, such unintentional disconnects must be eliminated. These and other disconnects cannot necessarily be anticipated, but when they do emerge, means must be found to resolve them.

NCD recommends that the highest levels of CMS and the Internal Revenue Service (IRS) meet to identify the extent of the problem and to jointly develop and implement strategies for its prevention, including recommendations to Congress for legislative action, if necessary.

Medicare

In general discussion, whether in the media or ordinary conversation, NCD has noticed that Medicaid and Medicare often are confused. In fact, these programs are quite different. Medicare more nearly resembles a traditional health insurance program. With a few exceptions, eligibility depends on having paid premiums, and it covers a narrower range of services that largely includes more traditional medical treatments and devices.

But if Medicare and Medicaid differ in these and other respects, including the lack of state participation in Medicare funding, they also have much in common, particularly the pressure to adapt to changing conditions and the need to preserve the integrity and basic character of the program in the face of serious budgetary stresses.

A number of developments occurring during 2006 highlight these problems and expose key options that exist for the Medicare system. Perhaps the most revealing of these, as well as one of the most important for beneficiaries with disabilities (including people under age 65 who receive Social Security Disability Insurance), involves the ongoing controversy surrounding powered wheelchairs and other mobility devices.

Powered Mobility Devices

Traditionally, Medicare provided wheelchairs when medically necessary under the service category of durable medical equipment (DME). Few people, if any, would ever request or use a wheelchair if they did not require one to get around. Wheelchairs generally were provided in the context of other medical treatment by medical facilities. Only a few, generally inexpensive models or designs were available. Moreover, people didn't necessarily go many places with them, because before the built environment began to comply with the ADA, many if not most public buildings, places of entertainment, and workplaces were more or less inaccessible. Thus, although the Medicare statute defined DME as equipment generally suited for use in the home, there were few serious problems or disputes regarding this claim.

Over the years, both mobility technology and the educational, vocational, and social opportunities available to users of any form of mobility device have grown and changed. With the advent of powered wheelchairs, scooters, and manual wheelchairs designed for sport or other purposes, and with the emergence of new sources for supplying them (other than traditional hospital or outpatient facility), Medicare has been confronted with new challenges, which it has yet to resolve or deal with effectively.

Recent Developments

CMS's efforts to deal with the powered mobility issue under Medicare were discussed in last year's report and are likely well known to all those who follow disability policy or health care funding in this country. Motivated by rapidly rising costs for powered mobility devices (PMDs), and by some alleged instances of fraudulent activity, two years ago CMS revised a variety of rules and definitions, with the apparent intention of slowing the growth in the program's provision of these devices. Three closely related approaches have been used. These include (1) increasing the level of functional limitation required to meet the medical necessity requirement,⁵⁸ (2) narrowing the range of permissible uses that would justify provision of such equipment, and (3) implementing reduced fee schedules. Finally, CMS has implemented a number of changes in terminology, which have further complicated analysis and discussion. Most recently, the particular types of equipment in question have been characterized as "medical assistive equipment."

Amid considerable controversy and opposition, CMS has revised its eligibility standards to qualify for the highest-functioning level of powered chairs, the group 3 chairs. Under the new clarifications, announced in early November, it no longer will be necessary that individuals be unable to independently "stand or pivot" to qualify for such chairs.⁵⁹

The In-the-Home Rule

As it relates to mobility devices, Medicare's rule requiring devices not only to be suitable for use in the home, but in fact to be used only in the home, has led to pernicious results. This in-the-home restriction would not present a problem with other DME. With the possible exception of some oxygen equipment meeting the DME definition, there would be little occasion to transport hospital beds or other items of DME from place to place. But with equipment designed to facilitate movement from place to place, equipment that in effect substitutes for the functionality ordinarily provided by the legs, this restriction grows more paradoxical as the capabilities of technology and the aspirations of its users grow.

To put this rule in perspective, consider the parallel of a prosthetic limb designed, like the powered wheelchair, albeit by different means, to afford mobility that normally would be achieved in other ways. It is hardly imaginable that a rule allowing the use of the prosthetic limb in one's home but requiring its removal upon going out would be deemed acceptable, no matter the technical justification. If the law allowed or required such an outcome, the law would be quickly and summarily changed.

The Fundamental Problem

NCD believes that CMS's interpretation of the law in relation to powered mobility devices is not supportable. In light of the widespread efforts in all spheres of life to foster community participation and full inclusion for people with disabilities, NCD further believes that CMS's restrictive approach in this area is contrary to some of our most basic values. It may be as much the way CMS's decisions were reached as the content of its regulations that is most disturbing.

Although certainty is impossible, it appears that CMS's attempt to restrict the availability of PMDs was based primarily on cost considerations. It is uncertain whether CMS undertook a thoroughgoing analysis of the actual or potential utilization of these devices, of the indirect impact of their provision or denial, or of anything beyond the program's short-term desire to stem the escalation of costs. CMS's concerns are understandable and appropriate, but cost, unconnected to any meaningful effort to assess impact or to measure the extent of legitimate demand, should not be the sole driver of purportedly medical policy decisions.

NCD recommends that CMS plan and host a national conference or series of regional forums in select geographic locations in collaboration with national and state organizations and agencies serving people with disabilities. This would be part of an effort to obtain the fullest possible sense of the issues involved, with a view to fashioning a policy that truly makes sense for the twenty-first century, that recognizes the potential of technology and the aspirations of its users, and that does not force people with mobility impairments to make the choice between dependence, immobility,

and potential danger, on the one hand, and a situation very much akin to house arrest, on the other. Legislation was introduced into the 109th Congress to modify the harshness of CMS's interpretation of the law.⁶⁰ NCD recommends the adoption of this legislation.

National and Local Coverage Determinations

Within the framework of federal administrative law, the Medicare program operates through some procedures that are not found elsewhere. Among these, the National Coverage Determinations and the Local Coverage Determinations, through which it implements coverage rules, have few direct equivalents or parallels. Therefore, much of the law surrounding these programs cannot be predicted or influenced by precedents in the administrative law canon.

Until recently, promulgation of these coverage determinations was not subject to public comment, as may be the case with other regulations. Moreover, for reasons addressed in previous reports, the ability to appeal denials of service based on these coverage determinations was extremely difficult and rare.

In the context of recent reforms, the coverage determination process has become slightly more transparent, slightly more open to public and professional input, and slightly more accountable, but many problems remain. One of the central problems is when, whether, and to what extent CMS is required to develop a record of, or to show a sound medical, legal, or other basis for, a coverage determination. This is particularly critical when a coverage determination categorically bars a particular device or service without regard to the specifics of any individual case. This is especially necessary in cases in which, but for the coverage determination, that item or service would fall within normal coverage parameters.

Responding to comments on this issue in the *Federal Register*, CMS stated, "in the rare event that no evidence exists to support an LCD [Local Coverage Determination] or NCD [National Coverage Determination], we will either voluntarily withdraw the policy,

or request the ALJ [Administrative Law Judge] Board to strike down the applicable provision(s) of the policy, whichever is the more expeditious option.”⁶¹

NCD recommends that Congress hold oversight hearings into whether CMS consistently has adhered to this commitment. Furthermore, the Council recommends that Congress conduct a review of all coverage determinations, court and administrative tribunal filings, and other relevant sources to determine whether coverage determinations are being made or applied on the basis of reliable and verifiable evidence, or whether their origins and purposes continue to be shrouded in secrecy.

The Medicare Ombudsman

NCD commends CMS for establishing the post of Medicare Beneficiary Ombudsman. NCD appreciates the efforts made, such as the Open Door Forum (ODF) teleconferences, to enable the Ombudsman to speak directly with Medicare beneficiaries and advocates.⁶²

Though recognizing that the range of subjects that can be addressed in this way is limited, NCD urges that consideration be given to using the ODF approach, via telephonic and online communication, to solicit input on issues of particular concern to Medicare recipients with disabilities. Potential topics for such outreach are numerous and might usefully include the following: (1) the accessibility of Web-based materials provided or approved and sponsored by CMS (such as information on the Medicare Part D prescription drug plans available); (2) the accessibility of services and facilities paid for with Medicare funds; (3) the responsiveness of Medicare Managed Care Plans to the specialized practitioner, services, or facility needs of people with disabilities; (4) the adequacy of Medicare-funded posthospitalization home health services and skilled nursing facilities; (5) the availability of sign-language interpreters in Medicare-funded interactions; and (6) a host of other matters.

NCD recommends that the Medicare Ombudsman publish a notice in the *Federal Register* seeking input on disability-related topics that the Ombudsman should consider

and that, based on this input, appropriate ODFs be scheduled, publicized, and conducted.

During 2006, at the direction of the President, CMS began publishing what is called transparency information about various types of facilities, including ambulatory surgical centers receiving payment for services through Medicare.⁶³ The information is intended to help the public make more informed choices about health care and, as such, is laudable.

But as examples of things the Ombudsman might wish to pursue, NCD finds no indication that the transparency data included any information on the accessibility of these facilities, on their provision of auxiliary aids and services, or on their policies regarding accessible informed-consent documents, qualified sign-language interpreters, or other matters of pertinence and urgency for many people with disabilities, who make up a major component of the Medicare beneficiary population. Whether from the standpoint of a patient or a family member (for example, someone making a visit with a service dog) such matters may be as important to the choice of facility as is the other information posted online.

Similar issues arise in connection with Medicare's initiative, launched through its Senior Risk Reduction Demonstration in 2006,⁶⁴ to assess the applicability of various health-promotion and disease-prevention strategies in the Medicare population. By reference to the senior risk-reduction program, Medicare appears to omit beneficiaries with disabilities under the age of 65 from focused participation in this important demonstration. Equally, their omission appears largely to foreclose the investigation of strategies to reach this audience with the education and information needed for health promotion and risk reduction. In doing so, it precludes the agency from learning about specific issues facing such health-promotion efforts with this segment of the population.

CMS's failure to take an inclusive approach might well be something else the Ombudsman could pursue. Because of this apparent failure, potentially significant savings opportunities achieved through the implementation of effective risk-reduction

strategies for people with disabilities could be lost or delayed. If it is true, as the Medicaid data cited above suggest, that beneficiaries with disabilities are responsible for higher per capita costs than are other beneficiaries, then it should be worth investigating whether risk-reduction and health-promotion efforts conducted with this segment of the population might not have high leverage value.

Accordingly, NCD recommends that the Centers for Disease Control and Prevention and CMS, in their design, implementation, and evaluation of all future risk-reduction and health-promotion demonstrations with Medicare beneficiaries, ensure that beneficiaries under the age of 65, including people with a wide range of all disabilities, be recruited and enabled to participate fully in the demonstration and that estimates of potential health benefits and cost savings be developed based on this inclusive approach.

Mental Health Issues

People with mental illness or people who have had mental illness in the past are no different from anyone else. Yet, our laws, attitudes, and treatment practices combine to create issues that are not shared by the population at large or even by other subgroups of people with disabilities. For this reason, a number of these distinct issues, including discriminatory insurance coverage and punitive incarceration, are addressed in the following subsections.

Mental Health Parity

No discussion of health care in this country today can proceed far without addressing the subject of insurance. For no group of Americans is this more an issue than for people with mental health treatment needs or concerns. Not only do they face the general problems of availability, affordability, portability, and scope that confront all people, as well as the risk of arbitrary denial of coverage on the basis of disability, but they also face the likelihood that even when insurance is available it will severely restrict reimbursement for or provision of mental health treatment. Some of these practices are

illegal in some areas; some are temporarily illegal throughout the nation; others, including a number of the most widely used ones, are not clearly unlawful anywhere.

In its final flurry of activity before adjournment in December 2006, Congress extended for one year the federal mental health parity bill that has been in existence, most recently via two one-year extensions, for the past decade.⁶⁵ While this is a positive step and a source of relief to many, it provides neither complete nor permanent parity in any sense. The legislation deals with the imposition of discriminatory payment caps and a number of other matters, but such issues as copayments, as well as overall questions relating to the denial of coverage based on mental illness or the alleged risk thereof, are left unaddressed.

Because the extension was for only one year, the 110th Congress will have to revisit this issue late in 2007. NCD recommends that permanent mental health parity legislation be adopted, barring any discrimination in benefits, copayments, premiums, or other terms and conditions based on mental illness or on the nature of the condition for which treatment is being sought. If the competitive marketplace could remedy this problem, as it has been given ample opportunity to do, a legislative solution might not be needed. But where, as here, stigma, marginalization, and fear appear to combine to thwart the potential for market-based remedies, no alternative strategy for providing coverage appears to exist.

It often is argued, largely without evidence, that requiring equal coverage for mental health treatment will drive up insurance costs, and in doing so, reduce affordability for all. But even if the proponents of this view could present persuasive evidence of its accuracy, their argument would still fail to consider the countervailing costs that result from our failure to provide equitable coverage for mental and physical health.

Leaving aside all economic and cost-shifting arguments, our current understanding of mental illness no longer supports the rationality of sharp distinctions between the body and the mind. We predominantly treat mental illness with pharmaceuticals that alter brain chemistry. By that therapeutic choice, we endorse the view that mental illness is

largely a biochemical phenomenon. Thus, it becomes indistinguishable from other biochemical phenomena that we call physical, simply by virtue of expressing itself in different ways and having different symptoms.

Traditional separation of the mental from the physical also breaks down because modern medicine tells us that physical symptoms can have psychological and emotional causes (most notably, stress), whereas so-called mental symptoms can have physical causes (such as depression). In light of the evidence from modern science, and the lack of real economic justification for perpetuation of coverage gaps, the only possible conclusion is that prejudice, ignorance, and fear are the true bases for current policy.

Recognizing the increasing nonviability of mental and physical coverage distinctions, a number of states have begun to enact their own mental health parity laws. The statute known as Timothy's Law, adopted in New York State late in 2006, is a good example of this trend. Unless the insurance industry is prepared to seek the invalidation of such state statutes through the courts, their number and variety, in the absence of national legislation, is likely to grow. Economic inefficiency, market distortion, and overall confusion are the inevitable results. Even if the insurance industry's opposition to parity results from its objection to further regulation on principle, the time for that objection has passed. The real question is whether the regulation will be national and uniform, or varied and state by state.

Prison Inmates with Mental Illness

Over the past two years, NCD's progress report has addressed concerns relating to the growing number of prison inmates with mental illness and the use of criminal detention facilities to hold juveniles with mental and emotional illnesses while they await more appropriate placement.

Exposés in the past year suggest that the problem is growing ever more serious and widespread. In terms of the lack of adequate medical care in prisons, the problem may be much the same for people with physically manifested illnesses as for those with

mentally manifested illnesses. But whereas it is unlikely that people have been sent to prison because of a physical disability, there is strong reason to believe that people have been and are being incarcerated predominantly or solely on account of mental or emotional illness. Many imprisoned people would not have engaged in the criminal behavior but for underlying causal illness, and many people might not be sent to prison upon conviction if appropriate, alternative treatment resources were available.

No one suggests that people who engage in criminal behavior should be excused of responsibility on account of the existence of underlying mental illness, but it would be equally foolish to suggest that prisons represent a sensible or cost-effective means to fill treatment vacuums in our society. Even in cases in which society's legitimate interest in punishment is strong, that interest may not be well served if mental illness limits the effectiveness of punishment in altering future behavior, or if the costs to the taxpayers are disproportionately high compared with other approaches that would protect society equally well.

The trouble is that in this era of compartmentalized government no one body is clearly identified as an authority to ask, let alone to begin authoritatively and comprehensively answering, these questions. For this reason, NCD recommends the appointment by the President of a high-level national commission to study the issues involved in imprisonment of people with mental illness, including (1) the extent to which enhanced community-based treatment services could reduce the incidence of criminality, imprisonment, and recidivism among people with mental illness; (2) the degree to which diversion of certain offenders from prison to treatment settings could be achieved without risk to public safety and without undermining the credibility of the criminal sanction; and (3) the amounts that federal, state, and local taxpayers might save as a result of such measures.

Veterans

No discussion of health and disability is complete without paying attention to America's growing number of wounded veterans.

The injured return from each of our nation's wars with different disabilities, different expectations, and different needs. Although data on the nature and extent of disability among today's returning veterans (those wounded physically and those wounded psychologically) are fragmentary, NCD has discovered little ground for confidence that the needed comprehensive, multiagency, integrated planning is taking place. Regarding what is required and what resources are needed, we can say that the immensity of the challenge is equaled only by the enormity of our responsibility to provide the highest quality of services and the fullest range of opportunities to those who have given up so much in service to the nation. NCD stands ready to be of all possible assistance to other government agencies and to appropriate nongovernmental entities in this crucial effort.

Recommendations

Recommendation 4.1: NCD recommends that Congress incorporate in any future Medicaid reform legislation provisions requiring each state, as an element of its approved state plan, to develop meaningful criteria for determining the return on investment of all expenditure increases, or expenditure cuts, contemplated in the state's Medicaid program.

Recommendation 4.2: NCD recommends that CMS augment its published data on managed care SNPs to indicate the extent to which such plans meet concerns often expressed by people with disabilities, including concerns about the range and availability of specialized practitioners and services, rights to continuity of service in established practitioner relationships, and similar matters. CMS should review the regulatory and advisory guidance it gives to Medicare Advantage plan providers and state Medicaid agencies in regard to these matters, with a view toward ensuring that the full scope of rights that exist under the law are effectively communicated to program administrators and service providers.

Recommendation 4.3: NCD recommends that Congress enact legislation creating a standing committee, including representatives of CBO, CMS, OMB, and the disability community, to monitor progress, develop forecasting tools, and assess alternative

assessment models to measure and predict the budgetary impact of rebalancing on the overall fiscal status of the Medicaid program.

Recommendation 4.4: NCD recommends that CMS create, in house or by competitive bidding, a national clearinghouse on consumer-controlled and self-directed human services programs.

Recommendation 4.5: NCD recommends that the highest levels of CMS and the IRS meet to identify the extent of the tax penalization of Medicaid budget holders and that the two agencies jointly develop and implement strategies for its prevention, including recommendations to Congress for legislative action, if necessary.

Recommendation 4.6: NCD recommends that CMS plan and host a national conference or a series of regional forums in select geographic locations in collaboration with national and state organizations and agencies serving people with disabilities. This would be part of an effort to obtain the fullest possible sense of the issues involved in Medicare's implementation of the in-the-home rule, with a view toward fashioning a policy that truly makes sense for the twenty-first century, that recognizes the potential of technology and the aspirations of its users, and that does not force people with mobility impairments to make the choice between dependence, immobility, and potential danger and a situation very much akin to house arrest.

Recommendation 4.7: NCD recommends that Congress hold oversight hearings into whether CMS consistently has adhered to its commitments regarding the reform of the national and local coverage determination processes, and furthermore, that Congress conduct a review of all coverage determinations, court and administrative tribunal filings, and other relevant sources to determine whether coverage determinations are being made or applied on the basis of reliable and verifiable evidence, or whether their origins and purposes continue to be shrouded in secrecy.

Recommendation 4.8: NCD recommends that the Medicare Ombudsman publish a notice in the *Federal Register* seeking input on disability-related topics that the

Ombudsman should consider, and that based on this input, appropriate ODFs be scheduled, publicized, and conducted.

Recommendation 4.9: NCD recommends that the Centers for Disease Control and Prevention and CMS, in their design, implementation, and evaluation of all future risk-reduction and health-promotion demonstrations with Medicare beneficiaries, ensure that beneficiaries under the age of 65, including people with a wide range of all disabilities, be recruited and enabled to participate fully in the demonstration, and that estimates of potential health benefits and cost savings be developed based on this inclusive approach.

Recommendation 4.10: NCD recommends that permanent mental health parity legislation be adopted, barring any discrimination in benefits, copayments, premiums, or other terms and conditions based on mental illness or on the nature of the condition for which treatment is being sought.

Recommendation 4.11: NCD recommends the appointment by the President of a high-level national commission to study the issues involved in imprisonment of people with mental illness, including (1) the extent to which enhanced community-based treatment services could reduce the incidence of criminality, imprisonment, and recidivism among people with mental illness; (2) the degree to which diversion of certain offenders from prison to treatment settings could be achieved without risk to public safety and without undermining the credibility of the criminal sanction; and (3) the amounts that federal, state, and local taxpayers might save as a result of such measures.

Chapter Five: Long-Term Services and Supports

Introduction

This chapter begins with an attempt to put the issue of long-term services and supports (LTSS) into context. It does this by addressing some of the definitional complexities surrounding efforts to address the subject. Citing NCD's three major related reports published between 2004 and 2006, the section notes how traditional demarcations between medical and personal services and how conventional programmatic categories that separate housing from transportation from personal assistance further complicate the effort to come to terms with long-term care.

Recognizing that some elements of the definition and some perspectives on the problem confronting society are widely understood and shared, the chapter then discusses the institutional bias in Medicaid and other human services programs that favors nursing home or other institutional settings to aging in place or living in one's own community and home. Because Medicaid is the largest source of funding for long-term services and supports in this country, the section offers a brief history of Medicaid to explain how the bias came about. It then discusses the strategies that have been used to incorporate greater flexibility into the funding formula and that have resulted in the emergence of important new options for home and community-based services and care. A number of these options are discussed, with an emphasis on recent changes in the law, including the enactment of Money Follows the Person (MFP), that reflect an awareness of the need to rebalance Medicaid expenditures in ways that will increase the resources for LTSS.

In a related vein, the chapter next discusses recent changes in the Older Americans Act that likewise reflect the growing policy consensus around home-based services and around consumer-controlled and cash-and-counseling models of service in a growing array of program settings.

Key changes in the law expanding the availability of cash and counseling are discussed next. Great hope attaches to these approaches, and NCD attempts to set forth some of the major reasons this model is generating so much interest.

Following this discussion, the chapter returns to the pressing questions surrounding private sector long-term-care insurance. Issues in the state partnership program are discussed, and recommendations are offered for a study of means to make such insurance more widely available.

Finally, building on the long-term-care insurance concept, the chapter directs attention to the highly innovative AmeriWell plan described in NCD's 2005 long-term services report. Further research into the potential of this model is recommended, based on its great potential for resolving many of the difficulties that have stymied other proposals.

Scope of the Concept

As NCD has indicated, the first and still key question in discussing the need for and the provision of long-term services and supports in this country is one of definition. Exactly what do long-term services entail and for whom are they intended?

Broadly speaking, long-term services include medical, income maintenance, residential, personal assistance, transportation, housing, and other services targeted to older people and to those people with disabilities who meet certain additional medical, income, or other criteria. Many of these issues are addressed by specific statutes and designated funding streams, but many also involve the complex interaction among service systems and funding streams. Still others fall between the service systems and remain substantially unaddressed.

Public policy debates over the funding of Social Security (as an income maintenance program), the costs of Medicare (as a health care program), or other specific programs and funding streams, while important, lose sight of the big picture. Their proper scope,

likely cost, and most effective design cannot be analyzed or even intelligently discussed in isolation.

NCD has been deeply engaged in understanding the scope and meaning of long-term services and supports for all Americans, including people with disabilities. In the past three years, the Council has produced three major reports addressing the subject from the standpoint not only of what specific community resources are required to meet long-term services needs, but also of what criteria constitute livable communities. These reports are *Livable Communities for Adults with Disabilities*,⁶⁶ *The State of 21st Century Long-Term Services and Supports: Financing and Systems Reform for Americans with Disabilities*,⁶⁷ and, most recently, the Council's October 2006 report *Creating Livable Communities*.⁶⁸

According to NCD's 2005 long-term services report,

NCD undertook research for this report because it has grown increasingly concerned about the (a) lack of a coherent national long-term services and supports (LTSS) public policy for all people with disabilities; (b) fragmented nature of service and support delivery systems, with uneven access and services provisions; and (c) LTSS costs of 22 percent or more of state budgets, which are fast becoming unsustainable.... no single federal program, federal agency, or congressional committee is charged with the responsibility for the management, funding, and oversight of LTSS; however, 23 federal agencies are actively involved in LTSS using the NCD definition.

As reflected in this report, NCD believes that America needs a coherent and comprehensive framework for its LTSS policies, programs, and funding.

The development of long-term services and supports (LTSS) comprehensive policy will define the future economic independence of Americans with disabilities. Changing demographic and economic trends, here and abroad, will demand that the United States retool its programmatic and financial infrastructure to protect and promote individual dignity and independence of all Americans with disabilities. The development of sustainable and affordable LTSS public policy for the 21st century—funded through a unique combination of individual contributions, innovative private sector assistance, and public

support—will provide a new security for Americans with disabilities to work and live independently.

Redressing the Institutional Bias

However much people may differ in their definitions or expectations of LTSS, virtually all who have studied the subject agree that a far larger proportion of such services than necessary is available only in nursing homes or other institutional settings. As a result, the number of people living in nursing homes rather than in their own homes and communities is widely recognized to be far greater than need be. In explaining this institutional bias in LTSS arrangements, one of the main factors is the role of Medicaid in the provision of funding for LTSS.

Medicaid and the Community

As part of a system for providing medical care for older people and people with disabilities who meet poverty guidelines, Medicaid included provisions for nursing home services where needed. Because beneficiaries would be deemed eligible for such services only if no longer able to live on their own, people needed to reach a level of severe medical need or frailty that would warrant institutional care. Of course, in numerous cases, people could have, and most often would have, preferred to receive services in their homes and communities, but by rejecting institutional care, they also forfeited any entitlement to Medicaid LTSS. A kind of catch-22 was created. If you were sick enough to be eligible for Medicaid, you needed to be in a nursing home. If you didn't need institutional care, you weren't sick enough to need these care services.

The history of Medicaid over the past 25 years is in part a history of efforts to broaden the range of home and community-based and home care services that are available to people outside of institutions, and to extend eligibility for such services to as many people as possible who need and can benefit from them.

Until the year 2000, this effort to reform Medicaid largely took the form of creating waiver programs through which states could secure funding and permission to deviate

from normal Medicaid requirements. Through such waivers, most notably home and community-based waiver services, and through the use of Sections 1115 and 1915 (c) of the Medicaid Act,⁶⁹ states were thus enabled to provide formerly institution-based services to children in their homes, to senior citizens, and to adults with disabilities in various circumstances.

Nothing in the law required a state to apply for or implement any such waivers. In 1999, however, this changed to some degree with the Supreme Court's landmark decision in *Olmstead v. L.C.*,⁷⁰ holding that unnecessary institutionalization is prohibited by the Americans with Disabilities Act. The Court laid down a three-pronged test to determine when involuntary institutionalization would be regarded as improper and indicated some of the factors that would go into assessments.

But without alternatives to nursing homes in the community and without resources for community living, a finding that institutionalization is illegal would have little impact. Accordingly, perhaps the most important result of the *Olmstead* decision was the development of coordinated state planning to (1) identify people who could return to or remain in the community and (2) develop the resources and assistance necessary for them to do so.

Opinions about the effectiveness of *Olmstead* implementation vary widely, as have the implementation strategies adopted in different states. What is not disputed is that the vast majority of Medicaid LTSS funding (most recently estimated at 73 percent⁷¹) continues to go to institutional rather than home-based care; that Medicaid represents the single largest source of public funding for LTSS (most recently estimated at 45 percent of a \$137 billion annual commitment⁷²); and that continued primary reliance on waivers as a means to divert funds from institutional to community-based services burdens efforts to redress the balance in numerous and complex ways.

Money Follows the Person

In the past two years, two major developments have occurred under Medicaid that could contribute significantly to the redirection of funds into the provision of decentralized, community-based, even consumer-controlled Medicaid LTSS. One of these, the elimination of waiver requirements for cash-and-counseling programs under the Medicaid home health care service category, will be discussed in the Cash-and-Counseling section below. The other, MFP, is a historic step toward breaking down Medicaid's institutional bias.

Adopted under the Deficit Reduction Act of 2005 (DRA), which was signed into law on February 8, 2006,⁷³ MFP creates a competitive program of grants to states for use in providing expanded home and community-based services to Medicaid recipients. Unlike standard Medicaid, no matching funds are required. Moreover, eligibility for home and community-based services (amounting to LTSS) is not predicated on a person's ability to meet the level-of-care needs that would justify nursing home admission. In some cases, an inability to perform two or more activities of daily living could trigger eligibility for these services. This means that MFP is a preventive program, rather than just an alternative to nursing home care.

Other features of MFP have positive implications for flexibility and for breaking down the either-or dichotomies, between needing and not needing services, and between medical and personal care, that have characterized Medicaid throughout its history.

MFP is a demonstration, limited in the number of people it can reach. Although its use of incentive funding should encourage states to participate, and although states will need to submit comprehensive plans to win funding, receipt of funds by itself is no guarantee that states will make significant progress in redressing the institutional balance. States will need to coordinate a number of options, policies, and funding streams to achieve the goals of MFP.

One important feature of the program is that it creates a framework for immediate action and for achieving longer-term goals. In this connection, the Centers for Medicare and Medicaid Services (CMS), the federal agency that administers and oversees Medicaid, is expected to release rebalancing criteria for use by state grantees in evaluating the long-term success of their programs. It is expected that these criteria will provide for the establishment of specific numerical or monetary goals for use in assessing the movement of people and funds out of institutions and back into the community.

NCD is confident that federal recognition of the need for deinstitutionalization is widely diffused and likely to be enduring. But given the complexity of the issues and programmatic interactions involved, a variety of decisions, including but not limited to budgetary decisions, can affect MFP and related initiatives in unintended and often unforeseen ways. For example, as noted by commentators, decisions that encourage states to make further use of Medicaid managed care could have implications for MFP, depending on how and whether this service was incorporated under the managed care umbrella.

NCD takes no position on whether and how Medicaid managed care should be employed. What NCD does emphasize, however, is that small, demonstration state-grant programs like MFP are hugely vulnerable and hugely important. To ensure that all decisions effecting MFP are made consciously and intentionally, NCD recommends that CMS convene an advisory panel of advocates, Medicaid recipients, state officials, home health care providers, and other appropriate stakeholders to (1) closely monitor the operation of the fledgling program, (2) identify issues arising at the state level or because of actual or impending federal action, and (3) advise the Administration on a real-time basis of implications and outcomes that might not otherwise be apparent but that need to be considered before final decisions are made.

In this connection, NCD renews its call for enactment of what must be considered an important piece of companion legislation to MFP. NCD recommends reintroduction and enactment of the Medicaid Community Attendant Services and Supports Act (MiCASSA), which has been offered in each of the past several Congresses.

The Older Americans Act

Since its inception, the Older Americans Act (OAA), a small, far less well-known program than Medicaid, has maintained a greater focus on providing services to people in their homes and communities. Although not targeted to people with disabilities as such, its relevance arises from the convergence of disability and age. More specifically, its relevance arises from its role in helping to prevent unnecessary institutionalization, a role that if successful will include among those benefited a significant proportion of older people with disabilities.

Paralleling aspects of both MFP and cash and counseling, the recent amendments to the OAA create the Choices for Independence (CFI) demonstration project.⁷⁴ Under this program, states will be eligible to receive grants to establish demonstration programs that give OAA services recipients unprecedented opportunities to manage their own budgets and to determine the nature and sources of the services and care they need. Although not involving the literal diversion of funds from nursing home to home-based services, CFI, by giving people more control over their services, is likely to contribute powerfully to people's ability to remain in their own homes. If people can get what they individually need, instead of a narrowly predetermined list of services that people in their situations generally are expected to need, their sense of autonomy and real options are likely to be significantly greater. Nursing homes can become truly a last resort.

The full details of the CFI demonstration will not be determined until the Department of Health and Human Services (HHS) issues implementing regulations. NCD recommends that, in its implementation and oversight of the OAA, HHS endeavor to maximize the value of the demonstration by collecting all reasonably available data concerning the benefits accruing to participants and the savings achieved by states as a result of consumer choice and that the department attempt to measure the level of nursing home costs avoided or deferred by virtue of the program. HHS should collect and disseminate technical assistance materials including best practices to assist all states in developing similar programs.

Cash and Counseling

The notion of self-directed care has attracted great interest and been the subject of experimentation under the Medicaid program. As the key component of self-directed care, cash and counseling allows Medicaid recipients to exercise control over their own budgets, deciding on the range of goods and services they need, selecting providers, and either dispersing funds directly or through a case manager or other intermediary.

Cash and counseling exemplifies the thin line between traditional medical services and other LTSS. As an element of the Medicaid program, its discussion could have been included in Chapter Four on Health. Because most of the services involved—that is, those services that people choose for themselves—do not fall within the domain of traditional medical services and are not provided by physicians (though they may in some instances require medical authorization or justification), cash and counseling is addressed here as LTSS.

Until now, cash-and-counseling demonstrations under Medicaid have been authorized and carried out under the waiver provisions of the law. This means that, once again, specific CMS approval was required, separate administration and funding were established, and the program operated as an exception to standard Medicaid practice. Pursuant to the DRA,⁷⁵ cash-and-counseling programs can now be operated by states as part of their regular Medicaid program, without the need for a waiver from CMS.

To be sure, freedom from waiver requirements means that certain standard Medicaid provisions that could be eliminated by waiver continue to apply. For example, recipients of the new service need to be eligible for home health services under the state's Medicaid plan. But on balance, the ability to forgo the waiver process would seem to outweigh the requirements of regular Medicaid, making this provision a positive step in the direction of greater availability and use of cash-and-counseling strategies.

Although data are preliminary, indications from cash-and-counseling projects conducted around the country thus far suggest they represent an important step forward in public

health policy. These preliminary data suggest that they hold out the potential for improving consumer satisfaction and autonomy as well as enhancing health outcomes.⁷⁶

Understandable concerns have been expressed that cash and counseling could cost more than traditional Medicaid. Obviously, these questions will play a large role in any systematic analysis done by CMS or in any meta-analyses of small studies. NCD recommends that, in evaluating the cost implications of cash and counseling, HHS and Congress should consider the fact that ordinary comparisons of per capita beneficiary costs cannot take into account or assign a monetary value to all of the values underlying greater beneficiary self-determination or all of the benefits resulting from heightened autonomy.

Long-Term-Care Insurance

Existing Models

The DRA contains amendments to the State Qualified Long-Term-Care Insurance Partnership Program.⁷⁷ Under this program, participating states essentially make a deal with citizens. If the citizens buy certain long-term-care insurance policies, the state will exempt from asset-limitation tests for Medicaid eligibility the amounts of money received as benefits under such policies. Apart from toughening the look-back provisions and lengthening the look-back period for establishing Medicaid eligibility, it is not clear whether the DRA has taken major steps in the area of long-term-care insurance. In NCD's view, much more could be done to encourage the purchase of and to enhance the availability of long-term-care insurance.

NCD recommends that Congress establish a national commission, including consumers, experts, regulators and legislators, insurance industry representatives, and other interested parties, to comprehensively review the potential means by which long-term-care insurance, including coverage for home and community-based services and care, could be made more widely, if not universally, available. If qualifying coverage under the state partnership programs does not make adequate provision for home-

based LTSS (which according to AARP should include transportation, nutrition, and housing), such insurance could have the perverse consequence of working against the trends and values discussed above and could push people into institutional care for the sake of coverage in many of the same ways that Medicaid has traditionally done.

The AmeriWell Plan

NCD's report *The State of 21st Century Long-term Services and Supports*⁷⁸ proposes a remarkable new model for the provision and funding of long-term-care and LTSS for all Americans. The model would respond to the traditional population of retirees whose needs and circumstances have garnered the bulk of attention in the LTSS discussion. While addressing their needs in a way that de-couples LTSS from Medicaid or Medicare, and thereby reduces the tensions and ambiguities surrounding the definition of health care, the AmeriWell plan addresses the long-term-care needs of people prevented by significant disabilities from pursuing gainful work. Within the course of one generation, the plan dramatically reduce actuarial estimates of the costs to the taxpayers of several types of dependency.

The key to the AmeriWell concept is the AmeriWell account, funded at birth for every American through a combination of public and private sources, allowed to grow through the processes of safe investment and compounding, available to expand the pool of capital available to this country for investment and economic growth, and ultimately available to meet the LTSS needs of people when they are no longer able to work.

A proposal of this magnitude will require extended public discussion and education around the LTSS problem. To that end, NCD recommends that the long-term-care insurance study commission recommended above be tasked more broadly to study the AmeriWell proposal and make a full report to Congress and the Administration on what would be involved in bringing it into existence.

Recommendations

Recommendation 5.1: NCD recommends that CMS convene an advisory panel to (1) closely monitor the operation of the fledgling MFP program, (2) identify issues arising at the state level or because of actual or impending federal action, and (3) advise the Administration on a real-time basis of implications and outcomes that might not otherwise be apparent but that need to be considered before final decisions are made.

Recommendation 5.2: NCD recommends reintroduction and enactment of MiCASSA.

Recommendation 5.3: NCD recommends that, in its implementation and oversight of the OAA, HHS endeavor to maximize the value of the demonstration by collecting all reasonably available data concerning the benefits accruing to participants and the savings achieved by states as a result of consumer choice and that the department attempt to measure the level of nursing home costs avoided or deferred by virtue of the program.

Recommendation 5.4: NCD recommends that, in evaluating the cost implications of cash and counseling, HHS and Congress consider the fact that ordinary comparisons of per capita beneficiary costs cannot take into account or assign a monetary value to all of the values underlying greater beneficiary self-determination or all of the benefits resulting from heightened autonomy.

Recommendation 5.5: NCD recommends that Congress establish a national commission to comprehensively review the potential means by which long-term-care insurance, including coverage for home and community-based services and care, could be made more widely, if not universally, available.

Recommendation 5.6: NCD recommends that the long-term-care insurance study commission (see Recommendation 5.5) be tasked more broadly to study the AmeriWell proposal and make a full report to Congress and the Administration on what would be involved in bringing the program into existence.

Chapter Six: Children and Youth

Introduction

A chapter dealing with youth necessarily differs from the other chapters in this report. Though such a chapter should address specific laws and regulations, successes and failures, reports and budgets, it must also address questions of leadership development. Even more, it must find a way to capture the voices of youth, as they identify their issues and priorities, and as they learn and express anew the challenges of life in their own words and their own way.

In this light, the chapter begins with a discussion of NCD's Youth Advisory Committee. It then proceeds to describe the National Youth Leadership Network. While offering specifics respecting the activities of both, the chapter attempts to convey a sense of their more intangible, longer-term goals, and attempts to convey a sense of the issues and concerns expressed by youth themselves.

The chapter commends White House efforts to direct attention and resources to the needs of youth, expressing the hope that these efforts are inclusive.

The chapter next considers foster care. A major forthcoming NCD study should provide comprehensive and valuable data for assessing the effectiveness of current policies and programs, and should offer insights into areas in need of reform.

The chapter's final section addresses resources for transition and for youth employment, noting the existence of several valuable resources and suggesting ways that their relevance to the needs of youth with disabilities can be more fully ensured.

The Youth Advisory Committee

NCD is especially proud of the work of its Youth Advisory Committee (YAC) over the years. The YAC has created a forum in which youth from all backgrounds and all parts

of the country can develop leadership skills, identify issues of concern to them, engage in outreach on behalf of a variety of goals and concerns, and provide input through NCD into the development of national disability policy.

In 2006, the YAC expanded the scope of its work, holding its 2006 Next Generation Roundtable.⁷⁹ At this event, members of the YAC, together with additional invited youth participants, raised and discussed the issues of greatest concern to them. Issues related to employment and to the experiences and demands of leadership emerged as particularly fruitful topics.

It is not possible to capture the richness of the discussions or the vibrant voices of the participants in this report. Those wishing to learn more about the Roundtable are urged to visit the NCD Web site and review the summaries, evaluations, and other materials generated.⁸⁰

The Roundtable was held in conjunction with NCD's annual celebration of the anniversary of the signing of the Americans with Disabilities Act. Combining these two events afforded an opportunity for YAC and NCD members to become acquainted, and exposed future leaders to the key history that still animates and forms the backdrop for many of their efforts. NCD is greatly benefited by the input and energy that its members and staff received from the YAC members and guests.

On the basis of its experience with the YAC, NCD recommends that all federal agencies engaged in youth-related policymaking or program administration take measures to obtain input and feedback from the children and youth who are the objects and intended beneficiaries of their efforts.

The National Youth Leadership Network

NCD commends the continuing work of the National Youth Leadership Network (NYLN).⁸¹ Currently funded by a consortium of federal agencies, NCD is proud to have been a supporter of the NYLN over the years.

Open to youth between the ages 16 and 28, NYLN has introduced many talented future leaders to public policy issues and has witnessed the participation of numerous members and alumni in a variety of posts and on a variety of state and local boards.⁸²

Examination of a recent issue of the NYLN newsletter reflects the broad range of leadership development, education, and other functions it serves. Articles include profiles of candidates with disabilities for elective office, an account of study abroad for students with disabilities, and other features designed to build skills, foster confidence, and widen horizons.⁸³

White House Conference

NCD commends the White House for hosting the White House Conference on Helping America's Youth⁸⁴ and particularly for holding regional conferences designed to bring the effort to local communities and to spotlight local initiatives and partnerships that are making a difference. NCD is confident that many worthy models will be highlighted through this process.

NCD is hopeful that a stronger connection can be forged between these efforts and the President's New Freedom Initiative. Many of the issues faced by young people are the same, whether or not they are people with disabilities. But many other issues are different, or at least made more complex by the presence of a disability, and by the different interactions with a variety of programs and institutions, and most of all by the different attitudes.

Attention to youth development such as that accorded by the White House through these conferences is priceless. That attention is inclusive and certainly does take youth with disabilities fully into account, but it should more consciously and more expressly do so. Therefore, NCD recommends that if the White House continues this form of outreach to the youth, families, and communities of America, then efforts should be included to remind the nation of the many ways in which children and youth with

disabilities are affected by the way programs are designed and implemented, and should emphasize the values of inclusiveness that we all share.

Foster Care

NCD has long maintained a high degree of concern for children with disabilities in the foster care system, and this subject has been addressed in recent progress reports. In light of the serious difficulties facing the foster care system nationwide,⁸⁵ and in light of the probability that children with disabilities make up a larger proportion of the foster care population than of the childhood population as a whole, NCD has been understandably concerned about whether child-finding services, case management, individualized services, abuse and neglect prevention, long-term placement, funding, and other variables are operating in effective and coordinated ways.

Now, NCD has commissioned a major study of the issues. Expected to be completed by the fall of 2007, this study will examine demographic data, information on available services, and the nature of existing laws to create as full a picture as possible of the foster care population of children with disabilities, of existing resources, of legal provisions, and of any needed reforms. NCD expects that this study will contribute significantly to the formulation of public policy in the foster care area.

Transition and Employment

One of the issues of concern to youth themselves and to a variety of service systems on their behalf is that of transition.⁸⁶ In that light, NCD commends the work of the Federal Partners in Transition Workgroup, of which the Council is a part. NCD appreciates the supportive role played by workgroup member agencies in organizing the 2006 Roundtable. NCD recommends that the workgroup expand its role and develop plans for bringing the resources of each member agency to bear more effectively in addressing and solving the problems that hinder seamless transition from school to work or to adult services.

In a related connection, the major statute structuring our governmental participation in job placement, worker training, and employment development is the Workforce Investment Act of 1998 (WIA).⁸⁷ Although the future of WIA is uncertain, because of delays in its reauthorization, it continues in effect pending revisions.

One of WIA's major premises is that local communities and workforce development partnerships should play a leading role in defining needs and identifying and preparing workers. In this connection, the act requires that resources be devoted to youth development and that local boards use a competitive bidding process to identify and select providers of youth services.

To assist in this identification process, the Department of Labor Employment and Training Administration has developed the "WIA Youth Request For Proposal (RFP) Guide."⁸⁸ NCD hopes that this guide—and all similar resources developed to help WIA partners meet their obligations to youth—will reflect the presence of youth with disabilities among the youth population to be served, will identify the needs of this population, and will emphasize the means by which service providers can best meet these needs.

Accordingly, NCD recommends that all technical assistance materials developed to facilitate implementation of the WIA be reviewed by the sponsoring agency. This review should ensure that in dealing with youth transition, training, or placement issues these materials reflect the needs of youth with disabilities among the targeted population.

Recommendations

Recommendation 6.1: NCD recommends that all federal agencies engaged in youth-related policymaking or program administration take measures to obtain input and feedback from the children and youth who are the objects and intended beneficiaries of their efforts.

Recommendation 6.2: NCD recommends that if the White House continues this form of outreach to the children, families, and communities of America, efforts should be included to remind the nation of the many ways in which children and youth with disabilities are affected by the way programs are designed and implemented, and should emphasize the values of inclusiveness that we all share.

Recommendation 6.3: NCD recommends that the Federal Partners in Transition Workgroup expand its role and develop plans for bringing the resources of each member agency to bear more effectively in addressing and solving the problems that hinder seamless transition from school to work or to adult services for many youth with disabilities.

Recommendation 6.4: NCD recommends that all technical assistance materials developed to facilitate implementation of the WIA be reviewed by the sponsoring agency to ensure that in dealing with youth transition, training, or placement issues these materials reflect the existence and needs of youth with disabilities among the population being addressed.

Chapter Seven: Employment

Introduction

The year 2007 promises to be a watershed year for employment policy. A major NCD report on the subject, including several issue briefs, will be published.⁸⁹ Another landmark NCD report dealing with federal employment programs in the broader context of financial incentives in the lives of people with disabilities also will be published.⁹⁰ Finally, the long-awaited reauthorization of the Workforce Investment Act of 1998 (WIA), including the vocational rehabilitation (VR) system, is likely to take place.

These watershed events unfold against an increasingly ominous backdrop, however. Research findings indicate that, after peaking in 1994, the percentage of adults with disabilities who are employed has fallen steadily.⁹¹ Moreover, although stimulation of mainstream participation in society through employment was one of the primary objectives of President Bush's New Freedom Initiative, the negative trajectory, which began in the mid-1990s, has continued through this decade.

Consistent with the centrality of employment to the destinies and aspirations of all Americans, NCD has maintained a keen awareness of, and has paid close attention to, the subject of employment over the years, including in major reports⁹² and in analyses of various dimensions of the issue in each of its annual status reports. NCD is obliged by statute to address employment in its annual reports to the President and Congress, but that obligation has been only the starting point for the Council's involvement and concern.

Because 2007 will witness important input to the employment policy discussion, this report will not attempt to address the full range of issues that will be covered in greater depth elsewhere. Instead, it will attempt to highlight the historical and cultural context in which a number of the key issues and barriers to employment will present themselves. Attention also is directed to some of the pressing decisions society must make for those barriers to be surmounted.

In that light, the chapter begins with a discussion of the changing role of employment in the economy and the rapidly changing nature of employer expectations and labor market demands. It raises questions about whether our approach to fostering employment relationships takes full account of all that employers want and need today. The chapter proceeds to a consideration of other systemic changes in the labor market, such as the changing role of fringe benefits and the decline of single-employer careers, with a view to initiating discussion of their implications for our approach to the stubborn persistence of high unemployment among people with disabilities who are willing and able to work.

Turning to the specifics that are likely to dominate policymaking and discussion this year, the chapter addresses the core problem of work disincentives. After reviewing the nature of the problem, the chapter discusses dramatic proposals for reform that NCD believes hold significant promise.

Owing to the emphasis currently placed on education and outreach to employers, the chapter next addresses questions concerning the impact of these efforts. While appreciating the timeliness and accuracy of the information conveyed, NCD suggests that better data are needed on what kinds of marketing efforts work and why.

In connection with the alarming data concerning the decline in workers with disabilities in Federal Government employment, the chapter applauds the concern already shown about this issue and suggests specific questions and sources of data for fully analyzing and responding to the problem.⁹³

Finally, the chapter discusses two lesser-known employment and small business programs, suggesting that their role and relevance needs to be reassessed in light of contemporary conditions and needs.

The Changing Nature of Employment

The Ticking Clock

Few Americans can doubt the psychological primacy of work in the establishment of self-worth and the preservation of pride and dignity. In our culture, work and identity are closely linked. But where society to varying degrees has accepted a responsibility for access to some of the basic building blocks of a good life—education, food, housing, and emergency medical care—our attitude toward employment is more ambivalent. Although national policy, as embodied in the Humphrey-Hawkins Act, commits the nation to full employment, we continue to rely largely on the marketplace, and on the skill and initiative of workers coupled with the needs and self-interest of employers, to bring that result about.

We operate a large number of programs designed to assist in the fostering of employment relationships, including significant programs targeted specifically at the training and placement of individuals with disabilities. Yet, despite considerable effort and investment, data consistently show an employment rate for working-age Americans with disabilities of less than one-half that for the population as a whole. At the same time, other data show lower incomes when people with disabilities do work and generally higher levels of poverty for this segment of the population.

Equally disheartening, available data indicate that, far from steady progress, our efforts, both in the private sector where we have little direct control and in the public sector where we have much, are headed in the wrong direction.

There was a time when society believed that people with disabilities could not work. Indeed, to a large degree, a presumptive inability to work constitutes the basis for the status or the characterization of being “disabled.” However well intentioned it may originally have been, this attitude, which still pervades much of our public policy, resulted in the substitution of dependency for productivity. Today, as pressure on public resources mounts, as critical baby-boomer-replacement labor shortages loom, and as

the proportion of working-to-nonworking Americans falls, we can less and less afford this waste of human potential.

The time may be closer than any of us care to acknowledge when public resources or attitudes no longer will be able or willing to sustain high levels of dependency. Viable strategies for replacing dependency with opportunities for productive employment are urgently needed.

Changing Demands

NCD's forthcoming employment report is expected to use a framework that divides issues and strategies into a supply-side and demand-side format. This approach is welcome, because it echoes much of the thinking and terminology currently used in economic policy discussions, and because it creates a useful framework for organizing the multitude of issues, institutions, and variables that must be taken into account when fashioning solutions. Yet the range of issues that must be considered is daunting and increasingly complex.

Worker Flexibility

In anticipation of the employment report, NCD believes that existing employer-education and worker-training efforts continue to rely on assumptions that may be increasingly out of step with the realities of the contemporary labor market. For instance, casual examination of a number of federal and business-sponsored education initiatives reveals an emphasis on the loyalty, productivity, and dependability of workers with disabilities, and on the fact that the cost and difficulty of accommodations are frequently overestimated. All this is well-documented and eminently worth emphasizing, but much of it may miss the point. Even a cursory examination of any major newspaper's job ads suggests that neither employers nor employees expect or demand a high degree of loyalty in terms of tenure or other traditional measures. What growing numbers of employers are beginning to seek and expect from employees are flexibility and adaptability, in terms of skills, expectations, deployments, assignments, and functions.

We have done a good job in propounding principles of workforce flexibility in terms of work hours, telecommuting, and other conditions of work, but we have yet to adequately address the perplexing questions of how the training and marketing of workers with disabilities can respond to, let alone turn to advantage, the likely labor shortage and other labor market trends over the next decade.

The traditions of job development and placement for workers with disabilities, which emphasize the practice of job analysis and the identification of technology that will facilitate the effective performance of a given job, are as admirable as ever, but sadly, they also may be relics of a bygone age. Beyond responding more quickly to the evolving skill requirements of employers, we also must respond to the fact that it is mind-set, skill set, and attitudes—defined in more ways than ever before—that increasingly embody what the corporate environment demands today.

It is likely that the WIA reauthorization has advanced too far for this report, or for the two NCD reports noted above, to directly affect its content. Nevertheless, such new realities as the ever-increasing rate at which job duties and work technology shift require that we take a whole new approach to the role of what were traditionally called postemployment services in VR and to the ways that we support and nurture the employment relationship once established, from the standpoint of job retention and upward mobility. The new realities suggest that rapid-response technological support, and intensive lifelong worker training tightly integrated into the VR system, have become indispensable elements of employment policy.

Outsourcing

In a related sense, NCD has not been successful in finding evidence of the impact of outsourcing and rapid expansions and contractions of workforces on the employment of people with disabilities. Nor has NCD found evidence of in-depth discussions among policymakers regarding implications of these labor market trends for the placement and tenure of workers with disabilities. Once again, while the rhetoric of stability, reliability, and the like hark back to the post–World War II era of career employment, the realities

of today's labor market have become all the more fluid and unstable. Much the same could be said of part-time work, with its implications for people stringing together often unrelated jobs in an effort to make a satisfactory living. Nothing in the current Rehabilitation Act or in what NCD has heard in the discussion of its reauthorization gives confidence that these issues have been understood or adequately addressed.

Fringe Benefits of Employment

One of the major problems facing our society is the decline of fringe benefits of employment, most notably the decline of employer-sponsored health insurance. While the consequences of this trend for society as a whole are widely known, its specific impact on workers with disabilities and their families has not been so fully aired.

For a variety of reasons not pertinent here, courts consistently have declined to apply antidiscrimination laws to employer-provided health insurance. Paradoxically, as employer provision of insurance decreases, the problems faced by workers with disabilities become much more acute, since for them, the ordinary problems associated with finding alternative coverage are compounded.

This issue will be discussed further in the Work Incentives section below. Whether from the standpoint of health care, retirement savings, job tenure, or any of a number of other traditional fringe benefits and social-contract expectations, the assumptions underlying our arrangements for helping people with disabilities to enter or retain work are still overwhelmingly dominated by the vision of a world that simply no longer exists, a world in which the contractor is rapidly eclipsing the permanent employee. Until efforts are made to address the question of whether and how the assets traditionally associated with employment can be replaced, it will continue to be difficult to deal effectively with the employment situation for this segment of our population.

Asset Development

Perhaps nothing is so deeply ingrained in the American psyche as the belief that with hard work anything is possible. Part and parcel of that belief, and lying at the core of our

job development strategy for individuals with disabilities, is the notion that careers begun with entry-level work can progress to great heights.

Yet there is mounting reason to fear that, inspiring individual success stories notwithstanding, the historic link between entry-level employment and upward mobility may be broken. Largely on the basis of our belief in this connection, as mediated by the drive and ability of the individual, our policies have been predicated on the juxtaposition of dependency and work. Demonstrated ability to work has led to the reduction and elimination of benefits. The rate of reduction has been steep (hence the term “benefit cliff”).⁹⁴ The rate of benefit decline greatly exceeded the rate of replacement through earnings, savings, benefits, and investments. But that was all right because, in time, upward mobility made up for the difference.

Strategies and solutions must be sought through vigorous debate and deliberation. Among the issues and questions that should be addressed are the following: What does it mean for disability employment policy if entry-level work no longer leads to upward mobility, if wages no longer carry the same prospects as they did in previous generations? What does it mean for the ways in which people will ever achieve self-sufficiency? What does it bode for the relationship between wages and benefits? What role should intensive, lifelong education and training play in the VR arena?

Related Entities

Part of the problem with employment policies is the sheer range and number of agencies, programs, and nongovernmental entities involved. This problematic complexity is all the more the case regarding programs for people with disabilities, because employment policies for this sector involve not merely mainstream employment programs but also, potentially, a number of specialized programs. Sorting out who should be involved in any reform or systemic experiments, and devising mechanisms for coordinating their actions, timing, and decisionmaking, may present more severe problems than conceptualizing the experiments. As noted by NCD, no mechanisms

currently exist for costing or assessing proposed models, or for carrying principles of accountability beyond three- to five-year timelines.

As demonstrated by the issue briefs accompanying NCD's forthcoming employment report, the problem is further compounded by the intimate connections between employment and education, housing and transportation.

Segmentation of the Population

Any attempt to discuss the workforce of people with disabilities is doomed to imprecision, because the circumstances and characteristics of people making up this population are so diverse. Policies need to be responsive to these differences. Approaches that would help young people establish themselves when transitioning from school to work are not the same as those that will prove efficacious in enabling senior employees who have been out of work after the onset of a disability to return to productive positions.

NCD has noted that the work opportunity tax credit⁹⁵ could be more effective if it included a provision to provide incentives not merely to new hires but also to certain employees returning to work following long periods of disability leave, especially when returning to different departments or positions or under probationary arrangements. Such rehires, particularly of workers who have begun receiving Social Security Disability Insurance (SSDI) benefits, potentially could be enhanced by provisions that would subsidize employers for providing health insurance to returning workers, such as those included in the Medicare Modernization Act of 2003.⁹⁶ Such provisions might well yield savings to the SSDI trust fund, as well as increased return to employment. But such provisions would play little role in bringing new workers into the labor force.

As will be elaborated in our discussion of experiments and demonstration projects below, the importance of a nuanced approach that tailors the strategy to the specific subgroups of workers sought as employees cannot be overstated. Through the Workforce Investment Boards established under the WIA and through other means,

public policy has begun to recognize the necessity of involving employers in the job training and VR and placement processes at every point. That demand-side awareness has been accompanied by a supply-side emphasis that too often has focused only on the nature of the disability. Additional attention should be given to the available policy levers based on experience, age, established relationships, and other demographic and organizational factors.

Against the backdrop of the six major issues discussed in this subsection, this chapter next turns to the immediate contexts in which these issues are being discussed and debated, and to the immediate opportunities for experimentation and change.

Work Incentives

The Problem

Perhaps no element of the employment dilemma has received more attention than that of work incentives, or as they are more aptly called, work disincentives. These are embodied in such benefit programs as Supplemental Security Income (SSI) and SSDI. From the first enactment of the SSDI Trial Work Period provision in 1980 to the Ticket to Work and Work Incentives Improvement Act of 1999 as amended, to myriad regulatory tweaking and experiments (including most recently in 2006 the renaming of a major protection and advocacy program to emphasize its focus on Work Incentives Planning and Assistance),⁹⁷ the effort to reduce the destructive impact of work incentives has been ongoing. But alas, by all evidence, it has been largely unsuccessful.

There are three relatively undisputed problems with all our work incentives (or to put it more precisely, with all our anti-disincentive provisions). These are as follows:

- Their complexity and uncertainty, exacerbated by the lack of sufficient expertise in benefits counseling and advisement, by the lack of certainty or predictability in how they will be applied by different agencies or programs to varying individual fact patterns, and by the highly technical requirements surrounding compliance and the avoidance of penalties.

- Their failure, even when properly used and fully understood, to meet the subsistence needs of beneficiaries. This failure is exemplified by low rates of utilization (fewer than 3,000 people are currently operating under a plan for achieving self-support [PASS]), by the reduction of cash benefits at rates that make the effective rate of pay from employment far lower than the minimum wage in many instances, by limitations on the amounts and purposes for which savings can be sheltered that substantially prevents their use for most self-sufficiency goals, and by the lack of coordination with non-Social Security assistance programs, which potentially results in decreased benefits in such other programs that offset the benefits of the work incentives.
- Their failure, even if they permit the retention of health insurance for a number of years after entering work, to include any guarantee of the permanence of such coverage if private insurance is not obtained, or of the swift reinstatement of coverage if private insurance previously obtained is lost.

Current Experiments

Although uncoordinated and not centrally reported or evaluated by common criteria, a number of experimental efforts have been mounted, and others proposed, to mitigate the work disincentives problem. In essence, they all have the same basic premise that graduating the loss of benefits—so that it occurs less steeply, over more time, and with better opportunities for reinstatement under specified conditions—will encourage and enable more people to work. These initiatives include the established, permanent work incentives under the Social Security Act, Medicaid buy-in programs, beneficiary counseling and benefits advisement programs, and the Disability Program Navigator initiative in the workforce development system, as well as a number of small experimental programs, including several work incentive demonstrations, most notably the Youth Transition Demonstration program, operated by the Social Security Administration.⁹⁸ Perhaps best known among all the attempts to remove disincentives to work are the health insurance–related provisions of the Ticket to Work program, which are designed to allow retention of Medicare or Medicaid benefits for a number of years

after entry into employment. A number of other demonstrations, all based on variations of the same basic concepts, have been proposed in the past year.⁹⁹

At the same time, policy initiatives originating in the poverty and welfare sectors have had limited impact in the disability sphere. Such measures as the individual development account, though not administratively integrated with PASS and not targeted specifically to people with disabilities (but rather to low-income people, a group that includes many people with disabilities), have been available to some labor market entrants or returnees with disabilities.

Although broad conclusions are hard to draw and comparisons among demonstration programs or program types are difficult to make, the impression seems inescapable that, thus far, all these programs have had, and are likely to have, little if any effect. Data on how long people receive benefits and how many people leave the SSI and SSDI benefit rolls tell the depressing story. As most recently documented by the National Disability Institute, those who leave the rolls number in the single digits.¹⁰⁰ Given the erosion in the labor market noted above, it is unlikely that any of the existing approaches to eliminating work disincentives can have a statistically significant effect on improving those outcomes.

The Proposed Solution

Public policy never emerges or exists in a vacuum. Proposals, no matter how sensible or self-evident, are inevitably mediated by politics and emotion. The analytical framework used by policymakers in evaluating proposals, the priorities that decisionmakers uphold, and the analytical methods they employ go a long way toward creating the political and emotional climate.

As this relates to the universally shared goal of moving people with disabilities from the benefit rolls and into the competitive workforce, the current situation argues for a bold initiative that may require an enormous attitudinal change but that has a high likelihood

of yielding enormous benefits to society, in terms of both increased employment and reduced public expenditure over the next generation.

In its forthcoming financial incentives report, NCD will recommend total elimination of work disincentives on an experimental basis for a period of 5 to 10 years, so that benefits recipients can work, earn, and save without fear or restriction, and without fear of health insurance or other benefits loss. Thereafter, so long as employment continued, benefits would be phased out over a period of time so as to not undermine the economic value of work.¹⁰¹

Perhaps more important than the recommendations or the proposed methodology for carrying them out is the economic analysis the study provides. Using conservative assumptions and established actuarial methods, the analysis shows that with even modest growth over present levels in the number of people leaving the benefits rolls, the experiment will return large financial savings to the taxpayers over the period of time that beneficiaries otherwise would be expected to remain on the rolls. Moreover, if implemented as proposed, even the administrative savings likely to result from eliminating the need to minutely track beneficiaries' income and expenses on a monthly basis would substantially offset the increased benefit costs, even if fewer beneficiaries than expected were enabled to permanently leave the benefit rolls. Economically and socially, the program is a win-win proposition. Accordingly, NCD recommends that Congress hold hearings on the proposals set forth in the financial incentives study report and that the necessary enabling legislation be enacted.

NCD appreciates that time and further explanation will be required for these proposals to become clear to all stakeholders and urges all those interested in this crucial matter to study the findings carefully. NCD knows that economics alone cannot determine the outcome and that even those who recognize the economic soundness of the proposal may balk, for emotional or political reasons, at the idea of allowing people to work, save, and obtain upward mobility with the help of the public purse. We can only hope that the powerful economic realities, the intractability of the problem, the widely accepted need for reform, and the initially limited nature of the experiment will combine to overcome

these misgivings. Wisely or unwisely, our nation subsidizes many people to do many things. We do so because we believe it is in the greater interest of the nation. NCD believes that the evidence will show that few investments can have a greater and more demonstrable or objective return than the one here proposed.

Employer Education

The proposed solutions in the previous section represent a classic illustration of supply-side economics, in that they liberate an unprecedented supply of good workers. By itself, this will do nothing to relieve employers of the range of fears and misconceptions that surely have prevented, and may continue to prevent, all too many from taking full advantage of the productive potential of workers with disabilities.

As discussed in the Work Incentives section above, attention must be paid to addressing the needs of employers today, not employers of the 1950s. Beyond that, enduring stereotypes and fears remain to be addressed, in whatever era they present themselves. Numerous outreach efforts, including several significant ones in the past year¹⁰² have endeavored to do just this, but they have suffered from one serious limitation. By and large, this limitation is related to a lack of full understanding of why myths, fears, and stereotypes about people with disabilities continue to persist among employers.¹⁰³ More documentary evidence is needed about the kinds of employer education and outreach strategies and experiences that are most effective in enduringly overcoming these problems and limitations.

For this reason, NCD recommends that the Department of Labor's Office of Disability Employment Policy (ODEP) undertake a systematic study of all employer education efforts in recent years. ODEP is urged to systematically assess which techniques have been most successful. Correspondingly, this systematic study should obtain employer and disability community input into which outreach techniques have worked.

Federal Government Employment

Among the many statistics on the employment of people with disabilities, few are as surprising as those of federal employment. The Equal Employment Opportunity Commission (EEOC) is among those that have noted and addressed sharp declines, so much so that by 2005 the percentage of federal employees with significant disabilities, which had peaked in 1994, had slid back to 1984 levels.¹⁰⁴ Following a meeting in June to gain the views of a variety of stakeholders regarding the reasons for this decline,¹⁰⁵ EEOC launched its Leadership for Employment of Americans with Disabilities initiative in October.¹⁰⁶

Since enactment of the Rehabilitation Act of 1973 it has been understood as a matter of law, and NCD believes as a matter of consensus, that the Federal Government should be a leader in the employment of people with disabilities. Hence, when the overall national decline in employment for Americans with disabilities is confirmed and compounded by a perhaps even more precipitous decline in the public sector, this becomes a matter of great concern. The decline is important for two reasons. First, it sounds an alarm that must be heeded. Second, although public and private sector employment differ in many ways, the striking parallels in the declines may shed light on both, if the federal situation can be explored and used as a laboratory to investigate causes and remedies.

The EEOC has undertaken a major education campaign as well as other steps to remind and assist federal agencies in this area. The Commission has sought input from a wide range of stakeholders and knowledgeable parties. NCD believes that additional measures are urgently needed.

A number of federal sources should be able to shed light on potential causes and solutions. From the published information, it is not clear whether EEOC specifically consulted each of these sources, or what input and advice they offered, if consulted. First, the Office of Personnel Management (OPM) should be asked for any information it may have on job applicants with disabilities, under both standard entrance pathways

and under the specialized hiring authority available. If such information is not centrally available, OPM should institute measures to obtain it.

Second, inasmuch as the data reveal a significant attrition rate for employees with significant disabilities, detailed exit (or in this case post-exit) interviews with retiring or resigning employees might shed light on their experience. Numerous channels exist for soliciting voluntary, nonindividually identifiable input from such former employees.

Third, to the extent that technology has become a key link in the accessibility and the performance of all jobs, two key technology-related resources should be able to evaluate technology's role in the employment of federal employees with disabilities. The first of these is the Computer Electronic Accommodations Program (CAP) of the Department of Defense. This program provides technology-related job analyses and recommendations for a large number of federal agencies and their workforces. It seems that CAP's input concerning issues encountered in this work, including issues bearing on the ability and willingness of managers to seek and implement technology-based accommodations, could yield valuable insight into the present situation.

The second key source of information on the intersection between technology and the federal workforce should be the agencies and officials with responsibility for implementing and monitoring Section 508 of the Federal Rehabilitation Act.¹⁰⁷ As discussed in Chapter Eleven of this year's report, Section 508, if it is working properly, should enhance the employment, tenure, and mobility of federal employees with various disabilities, through its information technology accessibility requirements.

Fourth, a final but indispensable source of information must be the Department of Justice. The Department's Civil Rights Division (CRD) should undertake an in-depth review of civil service and civil rights law with a view toward identifying what, if any, material provisions, practices, oversight, or enforcement standards have changed since 1994. Major changes have occurred in the overall government personnel system over that period of time, and it would be likely for such changes to have had an unforeseen and unrecognized impact on the recruitment and retention of workers with disabilities.

Using all of these resources and any others that may have relevant information to convey, NCD recommends that the EEOC undertake a comprehensive examination of the issues raised by the disheartening statistical data and make a report to the President, Congress, and the public, setting forth major impediments to employment and proposed solutions to steadily raise levels of employment and monitor upward mobility. This report should address exempt and nonexempt employees, temporary and permanent civil service positions, the federal executive service, and appointive positions subject to Senate confirmation.

Other Specialized Programs

Two programs with their origins in the 1930s have been in the news during 2006, and NCD believes the time may be right for a reappraisal of these programs in light of changing conditions and needs. A Senate hearing publicized in the spring of 2006 drew attention to excessive executive pay and perks among managers of several agencies operating under the Javits-Wagner-O'Day (JWOD) program.¹⁰⁸ At the same time, renewed attention has been directed to the relevance and impact of the Randolph-Sheppard Vending Facility (RSVF) program.

These programs have been the subject of considerable controversy over the years. On the one hand, they are not in keeping with the emphasis on integrated, competitive mainstream employment that has generally defined policy over the past 30 years. On the other hand, they offer employment, training, and in some cases entrepreneurial opportunities to people who might not otherwise have had these opportunities.

NCD is not in a position to express opinions at this time concerning how or whether these programs should be redesigned. But the Council does believe that the complexities noted above present an opportunity for a thorough review of these programs to determine whether they continue to meet their objectives in a cost-effective manner, whether they provide employment and business opportunities to people who would not otherwise be likely to obtain them, and whether they are doing all that is reasonably possible to maximize the growth and potential of participants. Accordingly,

NCD recommends that a study of the JWOD and RSVF programs should be undertaken by a congressionally appointed commission, including representatives of the Department of Education (within which at least three units are involved), the Committee on Purchase (AbilityOne), the Department of Labor, and organizations representing people with disabilities within and outside of the two programs.

Recommendations

Recommendation 7.1: NCD recommends that Congress hold hearings on the proposals set forth in NCD's financial incentives report and that the necessary legislation be enacted to facilitate a 10-year demonstration designed to put Social Security benefit recipients back to work as they and the nation desire.

Recommendation 7.2: NCD recommends that the Department of Labor's ODEP undertake a systematic study of all employer education efforts undertaken in recent years. ODEP is urged to systematically assess which techniques have been most successful. Correspondingly, this systematic study should aim to obtain employer and disability community input into which outreach techniques have worked.

Recommendation 7.3: NCD recommends that the EEOC undertake a comprehensive examination of the issues raised by the disheartening federal employment data on people with disabilities and submit a report to the President, Congress, and the public, setting forth major causes and proposed solutions to steadily raise levels of employment and monitor upward mobility.

Recommendation 7.4: NCD recommends that a study of the JWOD and RSVF programs be undertaken by a congressionally appointed commission, including representatives of the Department of Education (within which at least three units are involved), the Committee on Purchase, the Department of Labor, and organizations representing people with disabilities within and outside of the two programs.

Chapter Eight: Welfare Reform

Introduction

This chapter discusses the reauthorization of the nation's welfare reform law, reiterating concerns that NCD has noted before regarding the status of people with disabilities who remain on the rolls and whose needs the welfare reform process appears largely unable to meet. Gaps in services are discussed with a view toward identifying strategies that could increase the ability of many of these people to find and retain employment.

The chapter considers several issues in the administration of Temporary Assistance to Needy Families (TANF) and related programs that pose issues for accessibility and participation by people with disabilities.

The chapter then raises concerns relating to the relative lack of asset development strategies in the law. Fear is expressed that shrinking the welfare rolls has been the easy part of what needs to be a two-part effort to assist former beneficiaries, including those with disabilities who face barriers to the establishment of conventional career paths, in securing better and more stable circumstances. Asset development represents the increasingly indispensable companion to job placement. A study into the status and well-being of former recipients with disabilities is recommended to clarify the role that asset development might play.

Finally, the chapter endorses financial education and financial literacy as elements that should be included in the TANF program, noting the importance of accessibility and culturally sensitive outreach if these resources are to be effective in achieving their intended goals.

The Law

In early 2006, as part of the Deficit Reduction Act, the Personal Responsibility and Work Opportunity Reconciliation Act of 1996 (PRWORA), our nation's welfare reform law, was

reauthorized.¹⁰⁹ Before reauthorization, during several short-term, temporary extensions, debate had focused on the nature of work requirements that states would have to meet. Some argued for greater flexibility in the range of activities that would count toward these work requirements, whereas others argued for stricter definitions and for an increase in the mandatory number of work hours required per week of each program participant.

Ironically, it was states' success in cutting their welfare rolls that gave rise to some of the most heated debate. Under the original law, states that succeeded in cutting the number of beneficiaries by more than 50 percent were allowed greater flexibility in meeting and defining work requirements for their remaining beneficiaries. Many states were so successful in meeting these numerical goals that they were left free to impose minimal work requirements on those who remained on the welfare rolls.

NCD has been able to locate no data on the proportion of people leaving the welfare rolls who were people with disabilities or parents of minor children with disabilities. Nor is it known whether the proportion of recipients with disabilities leaving the rolls is comparable to that of recipients without disabilities. What is clear, as reported in NCD's progress reports over the past two years, is that those remaining on the rolls include a significant percentage of people with disabilities.

In our recent progress reports and in other position papers and testimony, NCD has expressed concern that work requirements need to be defined broadly enough to include the kinds of specialized training that many recipients with disabilities need to enter the labor market with any hope of job acquisition or job stability. Regrettably, the changes made in work requirements by the reauthorization do not reflect a full appreciation of these concerns. For example, in extending the work requirements to the parents or guardians of children who are beneficiaries, the law does not consider the specialized childcare needs that many of these children with disabilities are likely to face. Likewise, in making no allowances for specialized training or for creating and strengthening mandatory links between welfare, vocational rehabilitation (VR), and benefits counseling programs, the new law continues to operate largely on a vision of all

welfare recipients as people who need to be forced to work and monitored while they work. NCD believes that most recipients with disabilities would welcome the opportunity to work and could do so if given the specialized assistance and supports of training, child care, transportation assistance, and assistive technology (AT) that they need.

NCD is not aware whether final rules implementing the PRWORA reauthorization had been published by the end of 2006, but the interim final rule, released on June 28, 2006, appears to contain no enhancements to the previous, inadequate provisions bearing upon these needs. NCD is disappointed that the new law does not address the concerns or suggestions that the Council has made. NCD believes that if requirements for better coordination with the VR system and Social Security programs, for evaluation of possible disability and disability-related training needs, and for the greater availability of accessible transportation, specialized child care, AT, health insurance, and reasonable accommodations in employment had been added to the law, the number of people who could permanently leave the welfare rolls for self-sufficiency through employment would prove far greater than may prove to be the case under the current provisions.

NCD continues to hope that improvements can be made, and the Council renews its offer to work with the Administration for Children and Families, the Office of Family Assistance, and other components of the Department of Health and Human Services (HHS) in an effort to devise an appropriate and coordinated approach.

To achieve the necessary coordination and continuity in services, NCD recommends that the Secretary of HHS convene an interagency committee designed to comprehensively identify the barriers to work faced by welfare recipients with disabilities and tasked with developing solutions for these problems that will enable these people to leave the rolls for gainful employment within the legally allowable time.

Problems in Program Administration

NCD remains concerned with some of the methods reportedly used by states and localities to administer TANF, the Food Stamp program, and other programs. Some of these methods may inadvertently but seriously interfere with the ability of people with disabilities to participate in and benefit from these programs.

From the provision of services in inaccessible buildings (including those in locations not served by public transit) and print-only application and reporting forms or non-sign-language-interpreted personal interviews, to program identification cards that are inaccessible to or unusable by people with visual or cognitive disabilities, numerous practices appear to exist that pose barriers to program participation by people with various disabilities. NCD accepts that most of these barriers are quite unintentional, but their effects can be as harmful as if they were deliberate.

NCD is concerned by the failure of the reauthorization or of the draft implementing regulations to include provisions requiring accessibility in the design and administration of the federally funded welfare and related programs at state and local levels. To document the extent of these problems and create awareness of the need for greater care in program administration, NCD recommends that the Secretary of HHS commission a survey of present and former welfare recipients with disabilities to identify the nature and extent of exclusion from benefits, from job training programs, and from other opportunities and resources resulting from inaccessibility in the design or operation of programs, policies, and procedures or in the selection of activity locations.

Asset Development

Asset development, designed to help people translate their income into access to financial and tangible assets, represents a critical component of any effort to improve the economic well-being of many people with disabilities, as well as all welfare recipients with and without disabilities. For this reason, one of the features of PRWORA that NCD most strongly endorsed was its provisions dealing with individual development

accounts (IDAs).¹¹⁰ IDAs constitute one of the major asset development strategies currently in use for low-income people. They allow benefits recipients to save money that would ordinarily exceed program income or resource limitations, provide for matching funds that leverage the value of money saved from earnings, and target accrued funds for certain asset-related purposes. NCD hoped that this part of the welfare reform program would be enhanced by the reauthorizing legislation. In this preference, NCD seeks to look beyond the possibility of entry-level employment to the broader and longer-term question of how economic self-sufficiency and upward mobility are to be achieved. Reductions in welfare caseloads alone, while desirable, cannot define the success of welfare reform. It is what happens to the former recipients afterward with which we must ultimately be concerned.

Unfortunately, the TANF reauthorization does not deal with serious problems previously noted by the Council in the design of the TANF IDA program. Among permissible target expenditures for TANF accumulations, three items are recognized: education, homeownership, and small business startup or growth. These are all highly laudable items, but they fail to recognize several considerations. For example, for many people with disabilities, acquisition of AT may be a prerequisite to any gainful work, whether of the employed or self-employed variety, or home modifications may be a prerequisite to homeownership. It is not clear why a capital asset, such as an accessible motor vehicle (like a van with a wheelchair lift), should be a proper IDA goal when used for self-employment but not when intended for use to travel to and from a paying job.

NCD recommends that the rules governing all IDA programs, including those operating under the TANF program and those established under the assets to financial independence (AFI) program, be revised (1) to eliminate the distinctions between small business and employment as they relate to capital assets needed by people with disabilities to work and (2) to recognize, through flexibility in asset limits, that accessibility often raises the cost of homeownership.

Financial Education

Financial education has been an integral element of many IDA and other asset development programs. NCD regards these financial education programs as vitally important, but cautions that for people with disabilities program accessibility is crucial to their success.

In this connection, NCD commends the Federal Deposit Insurance Corporation (FDIC) for its efforts to adapt its Money Smart financial literacy curriculum for use by people who are blind. FDIC has made the program available in Braille, and has taken steps, such as the addition of textual material to explain charts, to make the material more accessible to users with visual impairments.

NCD also congratulates the Internal Revenue Service's Wage and Investment Division's Stakeholder Partnerships, Education, and Communication (SPEC) program for its sustained efforts to incorporate access to financial education into the work of its Volunteer Income Tax Assistance sites around the country.

In the waning days of the 109th Congress, Senator Akaka of Hawaii introduced the TANF Economic and Financial Education Promotion Act of 2006.¹¹¹ This legislation would require states to provide economic and financial education to parents and certain other individuals in the program, and would provide that such training count toward fulfillment of the beneficiaries' work requirement. While taking no position on the particular legislation, NCD recommends that HHS take all possible measures to incorporate financial education and financial literacy training into the TANF program and that this be done in ways that ensure full participation to recipients with disabilities.

Recommendations

Recommendation 8.1: NCD recommends that the Secretary of HHS convene an interagency committee designed to comprehensively identify the barriers to work faced by welfare recipients with disabilities and tasked with developing solutions for these

problems that will enable these people to leave the rolls for gainful employment within the legally allowable time.

Recommendation 8.2: NCD recommends that the Secretary of HHS commission a survey of present and former welfare recipients with disabilities to identify the nature and extent of exclusion from benefits, from job training programs, and from other opportunities and resources resulting from inaccessibility in the design or operation of programs, policies, and procedures or in the selection of activity locations.

Recommendation 8.3: NCD recommends that the rules governing all IDA programs, including those operating under the TANF program and those established under the AFI program, be revised (1) to eliminate the distinctions between small business and employment as they relate to capital assets needed by people with disabilities to work and (2) to recognize, through flexibility in asset limits, that accessibility often raises the cost of homeownership.

Recommendation 8.4: NCD recommends that HHS take all possible measures to incorporate financial education and financial literacy training into the TANF program and that this be done in ways that ensure full participation to recipients with disabilities.

Chapter Nine: Housing

Introduction

This chapter addresses issues relating to the supply, affordability, and accessibility of housing for people with disabilities, including people seeking to remain in or return to the community in this era of deinstitutionalization. The chapter seeks to draw out the commonalities and the differences in the issues facing people with disabilities and issues facing all Americans, particularly people of limited means, in the current housing environment. The chapter addresses these issues in light of the turbulence that has affected the housing market since our last report.

The chapter opens with a discussion of affordable housing, analyzing the role of the low-income housing tax credit and the various housing voucher subsidy programs in the affordability equation. The chapter next turns to civil rights, examining the adequacy of procedures to monitor previously achieved civil rights settlements, and the nature of current reasonable accommodations enforcement litigation in the housing area. The Civil Rights section concludes with a discussion of the application of the newly enacted Money Follows the Person (MFP) provisions of the Medicaid law to housing as an integrally related community resource.

In light of our nation's efforts to mobilize tax law and other incentives on behalf of environmental-protection and energy-conservation goals, the chapter next explores whether any of the strategies used might be applied to the goals of housing accessibility.

The chapter considers the connections that current policy requires to be forged among housing, transportation, and health policy, discussing ways that housing and transportation planning have been brought together and identifying tools that are needed to make such collaborations and joint planning processes more effective.

In its last section, the chapter returns to the familiar theme of barriers to homeownership facing Americans with disabilities. In light of the sober realizations that in the past year have undermined many of our assumptions about how homeownership programs are working for all Americans, the section proposes some new approaches, including tax-based and asset-accumulation strategies, to increase homeownership for Americans with disabilities.

Affordable Housing

One area of likely congressional activity in the 110th Congress is that of housing affordability. From several standpoints, the growing unaffordability of housing has emerged as a national crisis. Housing has become more of an issue and now consumes more time and financial resources of average Americans than ever before. This is manifest in many ways, including the growing inability of public employees or private sector support workers to find housing in the municipalities in which they work (and whose infrastructures they often service); the increasing distances Americans must travel between their place of work and locales where they can find affordable housing; and the predatory lending practices that have blossomed as people resorted to ever-more desperate measures in their efforts to fulfill the American dream of homeownership.

It is likely, as the problems worsen, become more widely known, and more complex, that the Administration and Congress will redouble their efforts to provide effective solutions. What is of great concern to NCD in this connection is that accessibility, which the Council believes to be an essential component of affordability for Americans with disabilities, not be overlooked in the discussion and not be shunted to the side in the urge for a swift response.

Few areas of public policy involve as many different programs, funding streams, and rules as housing. A review of how accessibility and affordability intersect in the design of these programs goes well beyond the scope of this status report. Nevertheless, a few illustrations of what could be done should suffice to remind policymakers of the

importance of accessibility and to suggest feasible and fiscally responsible ways in which accessibility can be taken into account—and in doing so, far from delaying this result, actually can contribute to the affordability of housing for all.

The Low-Income Housing Tax Credit

The Low-Income Housing Tax Credit (LIHTC)¹¹² is an important provision of the Internal Revenue Code (IRC), and one of the most prominent examples of what is known as targeted tax expenditure, meaning the creation of market-based tax incentives to encourage private sector entities or private individuals to engage in activities that are deemed to advance public policy goals.

The LIHTC allows states to provide tax credits to those who build and operate rental housing. Many requirements must be met to qualify for the credit, but unlike other tax provisions, credits are awarded in specified amounts before developers raise or spend money for the projects.

One recent estimate indicates that up to 50 percent of rental units built in this country may receive financial help through the LIHTC.¹¹³ Controversy surrounds this and other features of the LIHTC. To some, its major role is proof of the need for it; to others, it reduces the rental housing supply by supplanting private sector investment. NCD has no basis for entering into such debates, but the Council does believe that the credit could and should be far more effective in stimulating the building of accessible housing.

Nothing in the current law prevents states from using their LIHTC allocations to stimulate the production of accessible, rental housing. Indeed, at least two states are reported to have done exactly this, one by creating preferences for projects that incorporate accessibility, and one by requiring the inclusion of accessibility in approved plans.

NCD recommends that Congress amend the LIHTC and other related provisions of the IRC to require that all housing receiving tax credits or that all housing otherwise

subsidized under the tax system through the use of tax-favored public activity bonds be required to comply with the same accessibility standards currently applicable under federal civil rights laws to housing built or supported through direct federal subsidies.

No credible basis exists for believing that such a requirement would materially increase the cost of new housing or significantly reduce its supply. To the contrary, so far as cost is concerned, it is likely that accessibility requirements would result in substantial net savings to the public, and to the private developers, over reasonably foreseeable time frames. Because the housing was financed with LIHTC funds, once it is built, it is not exempt from fair housing laws. By incorporating accessibility from the outset, developers and investors avoid the risk of costly retrofitting or damage awards arising from inaccessibility.

Housing Voucher Programs

Under Section 8, the Federal Government operates a number of targeted voucher programs that subsidize rents for specified groups of people, in either private or public housing. Vouchers also play a role in some homeownership initiatives.

While the subtypes of Section 8 programs are complex, they do have certain important features in common. They are all available for use on behalf of individuals with disabilities, either because people with disabilities are found among other eligible or targeted groups such as older people or people with low incomes, or because the vouchers specifically target people with disabilities. Among the programs that target people with disabilities, there also are variations in terms of how and how much the targeting is specified to be done, whether a percentage of vouchers or a percentage of dollars can or must be used for people with disabilities, and related matters.

Advocates have long been concerned that the Department of Housing and Urban Development (HUD) may lack adequate means to track the actual use of the vouchers it issues. Hence, HUD may not be in a position to ensure that vouchers are being used on

behalf of people with disabilities to the extent contemplated in enabling legislation and appropriations bills.

Accordingly, NCD recommends that HUD undertake a comprehensive review of all existing voucher and other direct financial assistance programs, whether for construction and renovation, rental assistance, or homeownership enhancement. This review should comprehensively identify the potential of these programs to specifically address the housing needs of people with disabilities, determine the extent to which the Department currently is able to monitor the effectiveness of their use for this intended purpose, and create improved means to ensure that funds and authorizations targeted to housing for people with disabilities will be used fully and effectively for that purpose.

A related issue is that of accessibility. Because housing built with federal financial assistance is subject to the accessibility requirements of Section 504, the Fair Housing Act, and the Americans with Disabilities Act (ADA), whether such housing is built specifically for people with disabilities or not, there no longer can be any justification for federal housing assistance to be used in ways that do not support accessibility. No construction or renovation, rent subsidization, or homeownership encouragement should take place with federal funds around property that is not accessible within the meaning of the law.

In this light, it would be useful for HUD to review the entire range of its existing subsidy and direct financial assistance programs to verify that accessibility requirements are fully incorporated into the governing regulations for each, and to ensure that adequate means exist for monitoring compliance with these requirements and for acting on complaints of violation.

Once again, any short-term cost increases will be quickly offset by verifiable and demonstrable savings. Even within the Section 8 program itself, heightened accessibility will result in a greater availability of appropriate units for individuals with disabilities, and this should translate into a lower cost to the subsidy programs for meeting the housing

needs of these individuals. Likewise, pressure on local public housing agencies should be reduced over time, with positive results for their financial picture as well.

NCD notes that accessibility is not a mysterious or complicated concept, whether discussed in terms of the requirements applicable to a particular house or apartment or in terms of the percentage of units in a given development to which accessibility requirements apply. Indeed, in some of the HUD civil rights enforcement actions discussed in the next section, the clarity and stability of the applicable design guidelines go far in explaining why vindication of these key values was so readily possible and so highly necessary.

Civil Rights

Voluntary Compliance Agreements

In last year's progress report, NCD commended HUD for its work in entering into voluntary compliance agreements (VCAs) with public housing agencies around the country. Through these agreements, it was possible for the Federal Government and local agencies to work cooperatively in the identification and resolution of civil rights compliance issues and to avoid costly and time-consuming litigation.

NCD believes that while such agreements serve many objectives, their ultimate value depends on their long-term implementation and on their effect on housing agency practices. For this reason, NCD remains concerned about whether and how HUD plans to monitor implementation of VCAs over time to ensure their continuing effectiveness.

NCD recommends that HUD include in its standard auditing practices randomized and unannounced annual reviews of public housing authority (PHA) compliance with VCAs. These reviews should identify instances in which implementation may have lapsed and motivate PHAs to maintain the high standards contemplated in the agreements.

To the degree that HUD has entered into judicial consent decrees in settlement of cases involving PHAs or other entities, NCD recommends that these be audited on a regular basis to ensure full compliance.

Reasonable Accommodations

A number of important enforcement actions were launched by HUD during 2006. Several of these hold out the potential for important clarifications and extension of civil rights protections under the law.¹¹⁴ Once again, it is critical for HUD to develop means for ensuring the successful execution of the outcomes decreed and agreed to in these cases. Reliance upon complainants, complainants' counsel, or third parties to monitor implementation is insufficient.

It would help if HUD would develop case-finding policies on an annual basis, utilizing the kinds of complaints filed during the preceding year and the kinds of settlements reached as primary sources of input on the issues to be emphasized. NCD recommends that HUD create an advisory panel composed of fair housing advocates and people with disabilities to advise it on key emerging issues in the fair housing arena.

Money Follows the Person

In Chapter Four, Health Care, and Chapter Five, Long-Term Services and Supports, one of the most important developments of 2006 was discussed—the MFP provision. As an innovation in the Medicaid program, MFP is thought of mainly in terms of its effects on the provision of health care in general, and home-based, personal-assistance, and attendant services in particular. On one level this is true, but the fundamental point to remember about MFP, in both its technical and philosophical senses, is that without integration of housing policy and resources into its planning and implementation, MFP will have little impact or potential to meet its goals.

To understand the ways in which housing policy fits into the MFP framework, it may be useful to look back on the implementation by states of the U.S. Supreme Court's

Olmstead decisions over the past seven years. In the aftermath of *Olmstead*, which is the legal basis for the use of the ADA to free people from unnecessary institutionalization and to assist them in remaining in or returning to their homes and communities, states were required to develop *Olmstead* plans. Without provisions for making housing accessible and available, for linking the timing of its availability with the timing of release from institutions, and for coordinating funding sources, it was clear that the desire to live in the community would have relatively little meaning. This experience with *Olmstead* should serve as an important precedent for MFP.

NCD is not in a position to comment on the applications submitted by states for MFP funds. As such, the precise means used to achieve coordinated housing and health care policies by each successful applicant are not yet known. In its July 26, 2006, announcement of the first round (2007) of MFP demonstration grants to states, the Centers for Medicare and Medicaid Services (CMS) indicated that extra points would be awarded for plans that included housing. As CMS put it, “the advancement of home and community-based long-term-care services requires increased community housing options.”¹¹⁵

NCD expects that, because of the indispensability of housing in any effort to meet MFP’s goal of rebalancing the distribution of resources between institutional and home and community-based services, successful applications included housing. But beyond the award of extra points, NCD believes that CMS, in its administration of MFP funds, needs to go further. Accordingly, NCD recommends that in subsequent rounds of MFP demonstration funding, CMS, as the funding agency, require all applications to include detailed information on how adequate housing options will be identified and modified, where necessary, and how they will be funded.

Energy and Transportation

The Energy Precedent

In recent progress reports, NCD has offered a number of proposals to increase the proportion of America's housing stock that is accessible. Believing that widespread accessibility is necessary if the housing barriers facing America's citizens with disabilities are to be successfully addressed, NCD has long regarded this goal as key. NCD's recommendations, which are reiterated here, include making a home's accessibility status a mandatory disclosure item under the Real Estate Settlement Procedures Act; requiring accessibility or at least "visitability" in all newly constructed or substantially renovated residential properties; and incorporating other measures. Several efforts undertaken in recent years to reduce energy utilization in American homes suggest powerful precedents for use on behalf of accessibility.

A significant contribution of direct and tax expenditure has been used to encourage homeowners to make their property more energy efficient. Among these are tax credits for certain home modifications designed to conserve energy, state and local-level building code changes that favor less use of energy resources, and a number of other resources and incentives on behalf of the economic, environmental, and health benefits of energy conservation and environmental cleanup. The benefits to society of increased home accessibility are also great. If the measures just noted, as well as others not mentioned here, can effectively reduce America's use of fossil fuels, NCD wonders whether they might not be equally valuable in reducing the waste of economic and human resources that exclusion arising from inaccessibility continues to cause.

Some of the techniques, such as tax credits and planning priorities, currently brought to bear on behalf of environmental consciousness will prove applicable in this field, while others will prove less relevant. NCD recommends that Congress instruct HUD to conduct a detailed study of whether and how each of the incentives and strategies currently used to encourage the creation of a greener nation could be adapted for use in creating a more accessible nation as well.

Transportation

As policymakers struggle to come to terms with the new relationship between housing and the health care system, they must simultaneously address housing's increasingly pivotal connection to transportation. Again, the deinstitutionalization movement offers the best window into this relationship. If people are trapped in their homes, whether those homes are their own homes in the community or institutions and congregate care settings, the promise of *Olmstead* and MFP becomes illusory. This is why NCD has observed that, from a practical standpoint, the inability to drive may be among the most serious disabilities in America today, interfering as it does with almost every major life activity, including getting an education, going to work, obtaining health care, and participating in social, community, religious, and family life.

How we go about linking housing and transportation policy and resources constitutes one of the key questions for the organization of our society in the first half of the twenty-first century. As it relates to people with disabilities, this effort begins with the inclusion of housing and transportation agencies in the *Olmstead* planning process. The awareness is also reflected in New Freedom Initiative programs pursued under the Human Services Transportation Coordination umbrella. NCD appreciates the incentives that have been put in place to encourage and support coordinated cross-program and cross-agency planning, but the Council is concerned about the relative lack of data regarding the impact of these efforts. There is also an apparent lack of data concerning the effects of such joint-planning processes on the quality, availability, and cost of housing or transportation.

NCD believes that methods to establish accountability and document evidence-based outcomes present new and unique issues when applied to multiagency programs and cross-agency planning processes. Accountability tools do not yet exist for outcomes and programs that are the joint responsibility of numerous and separate agencies and programs. In circumstances in which no one agency, no one program, and no one preordained outcome is at issue, as in the interconnected development of transportation and housing policy on behalf of a better quality of life for people with disabilities, what

evaluative measures can be applied that provide meaningful data for policymakers or that highlight needed improvements? What apparently has been accomplished so far is the creation of settings in which agencies interact and then create reports that display the efforts of each participating service system side by side. But we have yet to develop organic planning processes that hold one system accountable for the effects of its decisions on the other, or that provide reliable means that go beyond merely signing off on anticipated effects and instead ensure that they are taken fully onboard. Today, no planning process or budget strategy exists for rewarding a transit system that targets service to areas where high-density housing could be built more cheaply. Likewise, no mechanisms exist for rewarding those who choose to build housing in areas that can more conveniently or less expensively be served by public transit compared with other areas that, from the construction costs standpoint, are no more expensive to choose.

The interests of people with disabilities and of America's senior citizens are drawing closer together. It may be time to recognize that the interests of these two groups are converging with the interests of environmental health and energy conservation to form a new triumvirate.

As a starting point in addressing these issues, NCD recommends that the Office of Management and Budget (OMB), the Congressional Budget Office (CBO), and the Government Accounting Standards Board (GASB) form a joint commission to study and develop a means for "scoring" (that is, for analyzing the cost and benefit implications of) multiagency and cross-program initiatives and planning efforts. Absent concerted thinking and work in this evolving area of policy, well-intentioned government efforts are more likely to operate at cross-purposes than to combine to contribute to a desired outcome.

Homeownership

In a number of reports, including recent annual progress reports, NCD has lamented the ownership gap facing Americans with disabilities. As discussed in detail in NCD's 2003–04 progress report, while our leaders rightly proclaim pride in record high

homeownership levels, rates of homeownership among people with disabilities have remained far lower. Moreover, though homeownership rates had been rising across the board for most cultural, ethnic, and economic groups, they had not risen appreciably for Americans with disabilities.

The Subprime Crisis

NCD has reviewed many obvious and some potential causes for the subprime crisis and has urged policymakers to analyze and address the subject. But since our last report, the sanguine picture of homeownership in America has altered dramatically. Whereas until recently the upward curve of homeownership was perceived to have no sinister components, the recent subprime mortgage crisis has alerted us to some of the financial stresses and to many of the predatory lending practices that have contributed to the apparently steady rise in the homeownership rate.

What the subprime fiasco has already made clear is that the arrangements for bringing the American dream to working people and others of moderate income have not been satisfactory. Before the upheavals in the real estate market are over, new creditworthiness standards will be established, new disclosure requirements will be made, and other fundamental changes will take place in the way Americans buy and sell homes. What better occasion than the redesign of the system to take into account all those who are excluded? How should credit-reporting practices or creditworthiness standards treat Supplemental Security Income (SSI) or Social Security Disability Insurance benefits? What procedures should be required to ensure that existing disclosure standards are met for buyers or sellers with sensory or cognitive disabilities? These are but a few of the questions that naturally emerge in anything approaching a thorough effort to figure out how homeownership in America can be a reliable and meaningful option for all.

Asset Accumulation

Individual Development Accounts

Whether the review of lending practices is undertaken inclusively or not, the problem of how to amass a down payment will continue to represent an enormous barrier for people who rely on needs-based or means-tested social programs for any part of their income or health care. Even vehicles such as the individual development account (IDA) that allow the sheltering of resources for approved purposes, including home purchase, limit the amount of such accumulation, currently \$10,000—far too little to meet down-payment needs in the current market, or in any market setting in which deceptively low teaser promotions are to be avoided.

Accordingly, NCD believes current limitations on the amounts of earnings that can be saved for homeownership, and limits on the time period within which savings can be built up, are too restrictive to allow for achievement of the goal of homeownership by most IDA participants. Therefore, in the forthcoming reauthorization of IDA legislation, NCD recommends that Congress provide that, if the sums in question are actually and strictly used for home-buying purposes, limitations on the amounts that can be aggregated for first-time home purchase through IDAs be eliminated and that limitations on the time frames in which funds can be saved also be eliminated.

Plans for Achieving Self-Support

For people with disabilities, IDA is not yet a common self-help vehicle. Far more common for people with disabilities, particularly low-income individuals receiving SSI, are a number of work-incentive provisions including the plan for achieving self-support (PASS).

PASS, unlike IDA, is designed to permit the accumulation of assets for self-sufficiency-related activities, including the purchase of work-related assistive technology, training and education, and related costs. All are subject to Social Security Administration

approval and to fairly rigorous accounting and tracking, but homeownership is not included.

While recognizing that homeownership is not readily possible without employment or some other regular source of income, the Council also recognizes that for people who do obtain employment the lack of a down payment often represents a significant barrier. If people utilizing any of the existing work incentives were allowed, as an adjunct to these, to maintain and build homeownership accounts, the down-payment barrier could be overcome in responsible and prudent ways by many people.

For this reason, NCD recommends that Congress authorize the creation of a homeownership accounts demonstration, modeled on PASS, for SSI recipients and for people with disabilities receiving cash or in-kind benefits under other needs-based and asset-limited federal and state programs. For those individuals eligible to participate in both IDA and PASS programs, NCD recommends that Congress establish mechanisms for pooling the resources of the two account types to obtain maximum leverage and benefit.

In any consideration of homeownership and people with disabilities, another fundamental anomaly has to be considered. When people who already own their own homes become eligible for needs-based assistance because of changes in life circumstances or increased need, means ordinarily exist for the retention of their homes, or at least of the right to live in them. Yet for people who become benefits recipients before reaching this position, the possibilities are substantially foreclosed. In this light, it is especially important to create ways for all benefits recipients to have the same life opportunities, especially people who are willing and eager to work and save in order to make their dream a reality.

Tax Considerations

Few areas of daily life are more powerfully or more visibly influenced by tax law than homeownership. But the tax law operates in complex ways, ways that advantage some

homebuyers but disadvantage and exclude others. People who can already afford a down payment receive the benefit of mortgage interest deductibility, whereas those who cannot afford the costs of entry receive no assistance in getting over the threshold. For people with disabilities, low income coupled with the implications of needs-based programs (including those that provide otherwise unavailable health insurance) may present all but insurmountable difficulties. If it is the goal of the tax system to reward those who already own homes, then little can be done about this problem through the tax law. But if it is the goal of tax policy to encourage and broaden homeownership, then potentially a great deal can be done.

Among the range of well-recognized principles of tax law and administration, a number of alternatives seem well-suited to this objective. They include extending the LIHTC, allowing carryover as a means to generate capital for down payment, and providing advance deductibility for mortgage interest. NCD recommends that HUD and the Internal Revenue Service establish a joint commission to study the various methods and report to Congress within one year on the homeownership potential and federal revenue implications of each.

Recommendations

Recommendation 9.1: NCD recommends that Congress amend the LIHTC and other provisions of the IRC to require that all housing receiving tax credits, or all housing otherwise subsidized under the tax system through the use of tax-favored public activity bonds, be required to comply with the same accessibility standards currently applicable under federal civil rights laws to housing built or supported through direct federal subsidies.

Recommendation 9.2: NCD recommends that HUD undertake a comprehensive review of all existing voucher and other direct financial assistance programs, whether for construction and renovation, rental assistance, or homeownership enhancement. This review should comprehensively identify the potential of these programs to specifically address the housing needs of people with disabilities, determine the extent

to which the Department currently is able to monitor the effectiveness of their use for this intended purpose, and create improved means for ensuring that funds and authorizations targeted to housing for people with disabilities will be used fully and effectively for that purpose.

Recommendation 9.3: NCD recommends that HUD include in its standard auditing practices randomized and unannounced annual reviews of PHA compliance with VCAs. These reviews should identify instances in which implementation may have lapsed and motivate these local housing agencies to maintain the high standards contemplated in the agreements.

Recommendation 9.4: NCD recommends that HUD create an advisory panel composed of fair housing advocates and people with disabilities to advise it on key emerging issues in the fair housing arena.

Recommendation 9.5: NCD recommends that in subsequent rounds of MFP demonstration funding, CMS require all applications to include detailed information on how adequate housing options will be identified and modified, where necessary, and how they will be funded.

Recommendation 9.6: NCD recommends that Congress instruct HUD to conduct a detailed study of whether and how each of the incentives and strategies currently used to encourage the creation of a greener nation could be adapted for use in creating a more accessible nation as well.

Recommendation 9.7: NCD recommends that the OMB, the CBO, and the GASB form a joint commission to study and develop a means for “scoring” (that is, for analyzing the cost and benefit implications of) multiagency and cross-program initiatives and planning efforts.

Recommendation 9.8: NCD recommends that, in the forthcoming reauthorization of the IDA legislation, Congress provide that, if the sums in question are actually and

strictly used for home-buying purposes, limitations on the amounts that can be aggregated for first-time home purchase through IDAs be eliminated and that limitations on the time frames in which funds can be saved also be eliminated. Congress should create a homeownership accounts demonstration, modeled on PASS, for SSI recipients and people with disabilities receiving cash or in-kind benefits under other needs-based and asset-limited federal and state programs.

Chapter Ten: Transportation

Introduction

This chapter begins with a discussion of United We Ride (UWR), one of the major local and regional transportation initiatives undertaken pursuant to the Administration's human services transportation coordination and improvement efforts. Existence of this effort reflects the growing awareness of a new class of disability: transportation-disadvantage. The section discusses organization and recent developments in the UWR program, and makes three suggestions for its enhancement. These suggestions include recommendations dealing with how its accomplishments can be made most tangible and recommendations bearing on federal legislation that may be needed to maximize the potential for coordination among federally funded transportation service providers.

Another important transportation initiative, not specifically targeted toward people with disabilities but potentially of great importance to many, is the job access and reverse commute program. This program is aimed at facilitating transportation to and from work for variously transportation-disadvantaged people. Given the importance of such transportation as a link in the chain of employment, the section addresses ways in which the program could be made maximally responsive and accessible to workers with disabilities.

Turning to civil rights in transit, the chapter discusses the positive role of the Department of Justice (DOJ) in a recent Detroit public transit case. Noting how issues under the Americans with Disabilities Act (ADA) have evolved from matters of equipment design to issues of maintenance, program accessibility, and the fairness of transit-agency policies and procedures, NCD urges DOJ to maintain active oversight of local transit system accessibility and to incorporate this emerging set of issues into its monitoring and oversight.

The chapter next describes the ongoing development of ADA passenger vessel guidelines. Encouraging the Department of Transportation (DOT) to complete its work

on its part of these guidelines, the section once again notes the growing role of procedure and policy in the enforcement of the ADA, and also notes the complexities created by the need for specific guidelines, such as those for cruise ships, to cover various unique environments.

In the final major section on air travel, cutbacks in the availability of the aviation consumer protection hotline are noted and reasons why such cutbacks should be reversed are set forth. NCD urges DOT and the Transportation Security Administration (TSA) to complete work on key guidelines relating to such matters as screening practices for use with people who are deaf, accessibility of self-service airport ticket machines and other kiosks, and accessibility of airline Web sites.

United We Ride

Pursuant to President Bush's 2004 Executive Order on human services transportation coordination,¹¹⁶ the Federal Interagency Coordinating Council on Access and Mobility (CCAM) was established. One of CCAM's chief projects is the UWR initiative. UWR, like the overall human services transportation coordination effort, reflects an emerging awareness of a new form of disability. This new disability, while not rising to the level of legal recognition or civil rights protection, nevertheless represents one of the most restrictive sources of isolation, dependency, and underachievement in America today. This new disability includes people who can be described as "transportation-disadvantaged," such as older Americans, individuals with lower incomes, and people with disabilities.

We commonly think of transportation-disadvantaged people as those who are unable to drive, but the category extends to people who cannot afford to drive, people who could drive with assistive technology devices but cannot obtain them, and people who would use mass transit if it were available and accessible.

Although CCAM has not undertaken systematic research into the costs of transportation disadvantage, anecdotal accounts suggest that the costs are high and of three sorts.

First, hidden opportunity costs often result from reduced or forfeited access to employment and education. Second, there are the also largely invisible economic costs of dependency, in terms of time lost from work by friends or family members who must provide transportation services to those who lack this autonomy. Society has recognized similar issues in such areas as the provision of home-based care by family members or friends, but its applicability in the transportation arena has been little discussed. The third and final cost, which is more widely recognized, is potentially enormous. In areas from delayed provision of health care services and failure to obtain preventive services, to premature institutionalization of people who otherwise could, and would prefer to, remain in their homes, lack of access to transportation may play a major role.

Significant developments in the program during 2005–06 are reflected in a new UWR progress report.¹¹⁷ NCD commends the CCAM for a number of key achievements, including its role in increasing from 5 to 40 the number of states with human services transportation coordinating councils, the provision of planning and implementation grants, and the development and dissemination of training and technical assistance activities. NCD appreciates the opportunity to participate in the work of the CCAM and looks forward to further cooperative and collaborative efforts in the coming years.

NCD believes that major opportunities exist to enhance the work, sharpen the focus, and leverage the benefits of human services transportation coordination efforts. In this connection, the Council wishes to address three points.

Accountability Measures

NCD commends the CCAM for including accountability among its major goals and believes that achievement of this goal could be heightened by clarification of a number of policy points. It would be helpful, for example, to ask grantees and their partners to establish distinctive goals and priorities that distinguish such objectives as providing better service to existing riders from providing service to additional or new riders. Additionally, subjective measures of customer satisfaction should be supported by

objective measures such as frequency of getting where one needs to go, reliability of schedules and trip duration estimates, convenience of service in terms of its categorization of door-to-door or fixed-route service, scheduled versus on-demand service, and other variables.

It is not nor should it be CCAM's role to make decisions for local communities about how to address these variables; however, from the standpoint of accountability and program evaluation, it would be reasonable to expect grantees and partners to establish their own baselines against which program outcomes can be objectively and comparatively measured.

Identification of Partners

The latest UWR progress report does not attempt to describe the likely diversity of partners involved in various state and local transportation efforts. Nor does it specifically name the 25 national organizations comprising the National Consortium on Human Service Transportation. The report lacks any specific indication that these transportation efforts are linked with closely related key policy initiatives, such as deinstitutionalization efforts like those under *Olmstead* or under the "rebalancing" provisions of the Money Follows the Person program (discussed in Chapter Five). Similarly, the report does not indicate whether the CCAM has conducted its coordination efforts to the extent of incorporating transportation planning into funding decisions made by other federal agencies in areas ranging from housing to health care.

Accordingly, NCD recommends that the CCAM develop procedures to ensure that federal departments and agencies participating in its deliberations incorporate transportation-access considerations into their own planning and decisionmaking and ensure that their contractors and grantees will consider transportation in all relevant planning and implementation activities.

Needed Legislation

At least twice in the UWR report, the possible need for enabling legislation is addressed. The first involves cost-sharing. The CCAM makes clear its support for cost-sharing, and the very terms it uses suggest that legislation is needed to make the process easier and more understandable. The report states, “[w]here statutorily permitted that standard cost allocation principles for transportation be developed and endorsed by Federal human service and transportation agencies.” Put another way, there may be instances in which federal law does not otherwise permit cost allocations among federal programs, and even if the law does permit such cost allocations, the methods would have to be developed and endorsed by the various federal human services and transportation agencies. Under these circumstances, it is hardly surprising that most grantees and partners are uncertain about cost-sharing initiatives.

In this light, NCD recommends that the CCAM, in conjunction with the Office of Management and Budget (OMB), propose specific legislation to Congress designed to facilitate cost-sharing among federally funded participants in the human services transportation sector.

NCD joins the CCAM in recommending enactment of authorizing legislation to permit the development of unified or single-system transportation demonstration projects in which a consolidated federal funding stream would be used to meet the total mobility needs of transportation-disadvantaged populations. NCD cautions that this needs to be done in a way that avoids the inadvertent creation of barriers to cooperation between human services and other transportation providers.

Job Access Program

For many years, the time spent by Americans driving and the distances traveled between home and work have been increasing. While this is a mere nuisance for many, it dramatizes the growing connection between access to transportation and access to employment.

Our nation's transportation policy has come to recognize two key changes in the distribution of population relative to the location of jobs. These changes are, first, that many people who cannot drive, whether on account of disability, low income, or both, are increasingly limited in their employment opportunities as a result. Second, existing mass transit systems, designed as they were to bring people into and out of the downtown sections of major cities, cannot be relied on to transport workers to and from the spread-out, low-density, suburban work environments and business corridors that increasingly represent the locale for job creation and economic activity.

The Job Access and Reverse Commute (JARC) program is operated by the Federal Transit Administration (FTA), under the authority of the Safe, Accountable, Flexible, Efficient Transportation Equity Act—A Legacy for Users of 2005.¹¹⁸ JARC embodies a national concern to help redress these problems.

A report to congressional requesters issued by the U.S. Government Accountability Office in November 2006 outlines major recent changes in the JARC program, particularly those dealing with the formula for allocating funds among states.¹¹⁹ This report describes a number of oversight issues. What goes unaddressed in the report is the degree to which JARC does, can, or should attempt to meet the specific job-related transportation access needs of people with disabilities.

NCD believes that the JARC program could and should take a number of steps to ensure maximum inclusion of people with disabilities. To determine whether programs are taking these steps, NCD recommends that the FTA undertake a study of its own regulations and of the accessibility practices of transportation service providers. This study should include (1) the extent of requirements for vehicles to meet accessibility standards, (2) the nature and targeting of publicity regarding the programs, (3) the degree of involvement of disability-oriented organizations in planning processes, and (4) other factors. If the study determines a low level of accessibility, a minimal degree of outreach, or a lower utilization of JARC resources by workers with disabilities than might be expected, then FTA should take steps to correct the process to ensure that JARC is as available as possible to those who want to work.

Urban and Regional Mass Transit

One vital link in our transportation system is the public bus, light rail, subway, and commuter rail systems that serve many metropolitan areas. These systems are major modes of transportation for employed people in a number of major cities, including our nation's capital. In recent years, the importance of mass transit for people with disabilities has grown, as ADA compliance and other factors have led existing systems to become more accessible. Until recently, efforts to increase mass transit accessibility have focused on equipment design requirements associated with vehicle procurement.

But, now, issues require new monitoring and enforcement strategies. In that regard, the Detroit bus case, discussed in last year's NCD progress report, bears further attention. NCD commended the Department of Justice (DOJ) for its intervention in this case and for its recognition that vehicle maintenance, service, and a variety of transit-agency policies and procedures may play as decisive a role as equipment design standards do in determining the real accessibility of transit systems.

NCD commends DOJ for its intervention and positive, sustained role in the Detroit case. For that role to be fully effective, however, it must accomplish two things. First, it must result in long-term compliance with the terms of the settlement and in levels of passenger service that are consistent with the goals of the agreement. Second, it must serve as a template for proactive monitoring of transit system practices and procedures around the country.

DOJ's involvement in the Detroit case began with its intervention in a case initiated by private parties. In other cities, although the problems may be as severe, private individuals may not always be in a position to pursue the matter. For this reason, NCD recommends that DOJ formalize procedures for routine patterns-and-practices monitoring of ongoing compliance by local mass transit systems with ADA requirements. Such matters as maintenance, scheduling, deployment of accessible vehicles, operator training, making of stop announcements, accessibility of Web sites,

complaint-handling practices, and a variety of other matters should be included in these routine audits.

Passenger Vessel and Cruise Ship Accessibility Guidelines

In the wake of the Supreme Court's 2005 *Spector* decision,¹²⁰ holding that foreign-flag cruise ships operating in U.S. ports are covered by the ADA, efforts to develop cruise ship accessibility guidelines have gained new impetus. The process has been a long and laborious one, involving the Access Board, DOT, and DOJ. This process reflects the intersection of a number of issues, including divided jurisdiction among government oversight agencies, technical design issues pertaining uniquely to the application of accessibility principles to ships, and issues relating to the practices and procedures of cruise ship operators.

DOT is expected to issue a notice of proposed rulemaking (NPRM) early in 2007 covering many of the nonarchitectural matters. In view of the few lawsuits filed and the considerable number of anecdotal reports concerning practices ranging from denial of passage after money had been accepted, to refusal to accommodate service animals, to insistence on a companion paid for by the passenger with a disability, NCD believes such guidelines can provide important benefits to consumers and much-needed clarity and stability to the cruise ship industry.

Accordingly, NCD recommends that DOT issue its NPRM as quickly as possible and that the Department expedite the process of comment solicitation and review, so that final regulations may be promulgated at the earliest possible date. Meanwhile, NCD urges DOT to make clear, by appropriate *Federal Register* notice, that its pending ADA cruise ship regulations do not preempt the application of state civil rights laws to practices that (1) occur within the confines of the state and (2) would be actionable if committed by the proprietors of other transportation modalities.

Air Travel

Aviation Consumer Hotline

In 2003, DOT established an Air Carrier Access Act (ACAA) hotline. Operating 24 hours a day, this hotline created an opportunity for air travelers facing disability-related problems with carriers to seek real-time assistance from knowledgeable duty officers. NCD received reports that the availability of the hotline offered a real-time method to resolve many disputes. As such, NCD believes that the hotline benefited passengers with disabilities, TSA staff, airport employees, and air carrier personnel.

On October 1, 2006, the hotline ceased to operate in real-time. Since then, the hotline has been staffed only during business hours (eastern time) on weekdays, and as of this writing, callers are told by recorded message to leave their names and numbers so that their calls can be returned.

Air travel and the time people spend in airports are not limited to business hours. Moreover, only DOT has the authority, and in many cases the knowledge, to adjudicate ACAA disputes. If airport screening and other terminal personnel and flight crews were not subject to such constant and rapid turnover, institutional awareness on the part of covered entities concerning the requirements of the ACAA would be greater. If the air travel environment were not so stressful and hurried, misunderstandings and disputes might be less of a hazard. But under the circumstances that air travelers, regulators, and the aircraft industry confront today, curtailment of the hotline is problematic from the standpoint of passengers and the industry alike.

On the basis of informal conversations with air travelers with disabilities, NCD believes that the hotline's existence and potential usefulness are not widely known. Hence, it could well be that minimal usage reflects not a lack of need but a lack of information on the part of potential users.

NCD recommends that DOT revisit its decision to curtail the hours of its hotline and that it work with the industry and consumers to promote the existence and function of the

hotline to travelers with disabilities and to the agencies and companies that may also benefit from the resolution or avoidance of disability-related disagreements.

TSA Guidelines

In late 2006, DOT announced its adoption of the ADA Accessibility Guidelines, as revised by the Access Board.¹²¹ NCD commends the Department for this step, but because air travel issues are largely governed by the ACAA, this decision on the part of DOT is likely to have little impact on air transportation. Other matters currently on the agenda of the Department's TSA are described below and hold considerable promise for easing air travel for people with disabilities. These matters should be pursued energetically.

Guidelines for Accommodating Travelers Who Have Hearing Impairments

In early 2006, the TSA sought public comments on proposed guidelines for accommodating travelers who are deaf, hard of hearing, or deaf-blind in the security screening process. These guidelines are important for two reasons. First, they should serve to improve accessibility of travel and reduce screening problems for many passengers with disabilities. Second, by applying the ACAA to the screening process itself, they embody at an important new level TSA's recognition that security and equal access are fully compatible and, indeed, are complementary.

As extended, the comment period for these proposed guidelines was due to expire June 24, 2006. To NCD's knowledge, the TSA has not taken further action pursuant to the receipt of those comments. NCD recommends that the TSA immediately announce the status of the accommodation guideline, and state its intentions with regard to the promulgation of the guideline. If changes are necessary, NCD stands ready to work with the TSA in perfecting the guideline.

Self-Service Kiosks

In May 2006, NCD issued “NCD Position Paper on Access to Airline Self-service Kiosk Systems.”¹²² This paper reviews the applicable law and technology, and makes a powerful case for action by DOT to require that self-service airport kiosks be made accessible.

The economic and practical arguments favoring accessibility have been set forth in detail in the kiosk paper and NCD’s last two annual progress reports. To NCD’s knowledge, no one has put forth any sound reason—technical, legal, or economic—why kiosks couldn’t and shouldn’t be accessible. Nor was the technology unknown or untried at the time when the build-out of current self-service airport technology began.

In a 2004 NPRM,¹²³ DOT indicated its belief that kiosks owned and operated by air carriers (as well as Web sites operated by them for ticketing and information) were subject to the ACAA. While NCD endorses DOT’s view, it does not follow that ACAA jurisdiction precludes a role for any other statute, such as the ADA or even state laws.

Airport buildings, where kiosks are located, are public facilities subject to Title II of the ADA if owned or operated by public agencies, such as airport authorities or municipal governments. And such terminals are public accommodations within the meaning of Title III of the ADA if owned or operated by private entities, including the parent companies of air carriers.

With each passing day of inaction, DOT gives carriers and other parties increased opportunity to use the growing size of the self-service kiosk’s installed base as an argument against the costs of retrofitting. With each day that passes, the build-out of this generation of machines draws nearer to completion.

NCD urgently recommends that DOT indicate its legal authority to move under both applicable laws (the ADA and the ACAA) and announce an expedited timetable for completion of the regulatory process. This action should result in meaningful accessibility in the increasingly self-service world of the modern airport for all

passengers with disabilities, including passengers who are blind or who for other reasons cannot access touch screens.

Airline Web Sites

In November 2004, DOT issued an NPRM in connection with its planned updating of the ACAA regulations.¹²⁴ Among other matters, the NPRM undertook consideration of the adoption of rules requiring that airline Web sites be accessible to customers with disabilities.

As discussed in last year's report, DOT has failed to move forward and failed to indicate whether, and if so what, public comment was received. To the best of the Council's knowledge, since issuance of the proposed rule, DOT never addressed the subject in any formal or regulatory setting.

NCD reiterates its recommendation that the Secretary of Transportation forthrightly and unequivocally state the Department's position regarding its legal authority to require Web site accessibility and its intentions with regard to the issue, whether in the context of the 2004 NPRM or otherwise. If DOT lacks the authority to mandate this equality, NCD recommends Congress enact legislation that will enable the Department to make the promises of the ACAA a reality.

Recommendations

Recommendation 10.1: NCD recommends that the CCAM develop procedures to ensure that federal departments and agencies participating in CCAM's work incorporate transportation-access considerations into their own planning and decisionmaking and to ensure that their contractors and grantees will consider transportation in all relevant planning and implementation.

Recommendation 10.2: NCD recommends that the CCAM, in conjunction with OMB, propose specific legislation to Congress designed to facilitate cost-sharing among federally funded participants in the human services transportation sector.

Recommendation 10.3: NCD recommends enactment of authorizing legislation to permit the development of unified or single-system transportation demonstration projects in which a consolidated federal funding stream would be used to meet the total mobility needs of transportation-disadvantaged populations.

Recommendation 10.4: NCD recommends that the FTA undertake a study of its own regulations and of the accessibility practices of human services transportation service providers.

Recommendation 10.5: NCD recommends that DOJ formalize procedures for routine patterns-and-practices monitoring of the ongoing compliance by local mass transit systems with the requirements of the ADA.

Recommendation 10.6: NCD recommends that DOT issue its cruise ship NPRM as quickly as possible and that the department expedite the process of comment solicitation and review, so that final regulations may be promulgated at the earliest possible date.

Recommendation 10.7: NCD recommends that DOT revisit its decision to curtail the hours of its consumer hotline and that it works with the industry and consumers on a campaign to promote the existence and function of the hotline.

Recommendation 10.8: NCD recommends that the TSA immediately announce the status of the proposed accommodation guideline for the security screening of deaf airline passengers and state its intentions with regard to the promulgation of the guideline.

Recommendation 10.9: NCD recommends that DOT indicate its legal authority to move under both applicable laws (the ADA and the ACAA) and announce an expedited timetable for completion of the regulatory process. This action should result in meaningful accessibility in the increasingly self-service world of the modern airport for all passengers with disabilities, including passengers who are blind or who for other reasons cannot access touch screens.

Recommendation 10.10: NCD recommends that the Secretary of Transportation state the Department's position regarding its legal authority to require airline Web site accessibility and its intentions with regard to the issue, whether in the context of its existing 2004 NPRM or otherwise.

Chapter Eleven: Assistive Technology and Telecommunications

Introduction

This chapter highlights several issues related to assistive technology (AT) and to access to our nation's communications networks.

The chapter begins with a discussion and lengthy quote from NCD's December 2006 technology report. The chapter provides a review of recently published research findings concerning the persistence and extent of the digital divide to illustrate some of the problems and concerns discussed in the report.

In connection with specific policy contexts in which opportunities for heightened communications access exist, the chapter then discusses the pending revision of regulations governing the two key civil rights provisions: Section 255 of the Communications Act and Section 508 of the Rehabilitation Act. A number of procedural and substantive issues surrounding the content of the new guidelines and concerning oversight and implementation of these laws by federal administrative agencies are considered.

Next, the chapter reviews a number of access-related issues falling under the jurisdiction of the Federal Communications Commission (FCC), including issues concerning relay services and closed captioning, suggesting strategies for rationalizing and improving practice and policy in the oversight of these areas.

The chapter then discusses developments under the Assistive Technology Act that promise heightened coordination in the delivery of services and the development of programs under the Act.

Finally, a recommendation for using the tax law to promote the development of accessibly and universally designed technology and services is presented.

NCD's *Over The Horizon* Report

In December 2006, NCD issued a comprehensive report, *Over the Horizon: Potential Impact of Emerging Trends in Information and Communication Technology on Disability Policy and Practice*.¹²⁵ This report draws together the major trends in technology today and identifies both the positive implications and the risks posed to access for people with disabilities. Speaking of the concerns and issues, the report states:

Many of the same technological advances that show great promise of improved accessibility, however, also have the potential to create new barriers for people with disabilities. The following are some emerging technology trends that are causing accessibility problems.

Devices will continue to get more complex to operate before they get simpler. This is already a problem for mainstream users, but even more of a problem for individuals with cognitive disabilities and people who have cognitive decline due to aging.

Increased use of digital controls (e.g., push buttons used in combination with displays, touch screens, etc.) is creating problems for individuals with blindness, cognitive and other disabilities.

The shrinking size of products is creating problems for people with physical and visual disabilities.

The trend toward closed systems, for digital rights management or security reasons, is preventing individuals from adapting devices to make them accessible, or from attaching assistive technology so they can access the devices.

Increasing use of automated self-service devices, especially in unattended locations, is posing problems for some, and absolute barriers for others.

The decrease of face-to-face interaction, and increase in e-business, e-government, e-learning, e-shopping, etc., is resulting in a growing portion of our everyday world and services becoming inaccessible to those who are unable to access these Internet-based places and services.

In addition, the incorporation of new technologies into products is causing products to advance beyond current accessibility techniques and strategies. The rapid churn of mainstream technologies, that is, the rapid replacement of one product by another, is so fast that assistive technology developers cannot keep pace. Even versions of mainstream technologies that happen to be accessible to a particular group can quickly churn back out of the marketplace. To complicate the situation further, the convergence of functions is accompanied by a divergence of implementation. That is, products increasingly perform multiple functions that were previously performed by separate devices, but these “converged” products are using different (and often incompatible) standards or methods to perform the functions. This can have a negative effect on interoperability between AT and mainstream technology where standards and requirements are often weak or nonexistent. Thus, without action, the gap between the mainstream technology products being introduced and the assistive technologies necessary to make them accessible will increase, as will the numbers of technologies for which no accessibility adaptations are available.

This summary lays out a formidable array of problems, but in view of the opportunities and benefits that are at stake, they are problems that can and must be overcome. To all those of good will who share a desire to ensure technological access and equality (even if they do not necessarily have the personal experience or technological knowledge to understand the problem in each case) a careful reading of this report, including especially the principles it sets forth for overcoming these barriers, is recommended.

The Digital Divide

A powerful illustration of the access problem and its consequences can be gleaned through a recent review of several surveys. Since a 2002 National Telecommunications Information Administration report announced that the digital divide had closed, the very term “digital divide” has become anachronistic in the minds of many. Yet a detailed report published in September 2006 by the University of Montana’s Research and Training Center (RTC) on Disability in Rural Communities shows that the digital divide is still very real, and with the increasing centrality of the Internet in our lives, that it is growing ever-more profound in its implications.¹²⁶ The RTC report studied several sources of survey data. Though their methodologies differed, their results pointed to the

existence of a significant gap between computer use and Internet access for people with and people without disabilities. Broadly speaking, it appeared that the rate of access for people with disabilities may be only about half that for the general population.

In attempting to account for these discrepancies, one factor cited by the review was the low rates of employment among people with disabilities. This could account for some of the disparity, because many people use computers and have Internet access at work. Likewise, if income and education levels were controlled for, it is possible that the disparities would have been less pronounced. But to say that people may have lesser access to the Internet because of unemployment and poverty is to say something akin to higher death rates can be explained by poor health.

NCD believes that the processes at work are circular and mutually reinforcing. Lesser education, lower incomes, and higher unemployment contribute to digital isolation, but among the factors contributing in turn to these, the serious problem of the inaccessibility of much mainstream technology, as described in *Over the Horizon*, surely plays a major role. A generation ago this was not an independent variable of great significance. But today it has joined all the familiar problems as a source of exclusion and a breeding ground for frustration and despair.

Bringing people with disabilities fully into the technological mainstream has emerged as one of the chief arbiters of equal opportunity and full participation in our society. No serious commitment to equality, such as that embodied in the President's New Freedom Initiative, can hope to succeed unless this dimension is addressed.

For this reason, NCD believes that an intensive effort to achieve equal access to electronic communication, resources, and environments is vital. NCD recommends that Congress create a national panel, with representatives drawn from government, industry, and the disability community, tasked with identifying and recommending specific measures to overcome barriers, such as the barriers described in the NCD report. The remainder of this chapter will focus on a number of the key barriers and the

most viable solutions that can be implemented quickly and that would have the greatest value in bringing about increased access and participation.

Nondiscrimination

To some, the notion that telecommunications inaccessibility can be a form of discrimination may initially be jarring or implausible. After all, how can the host of decisions made by a broad range of public and private entities, based on a tangle of laws and regulations, and motivated largely by the perceived interests of the economy as a whole and of certain businesses in particular, involve or amount to discrimination? The answer depends on one's definition. If you believe that discrimination can only occur intentionally, that it can only take place when a decision is made for the specific purpose of excluding people with disabilities, without regard to any other consequences, then no, most decisions about technology and telecommunications are not discriminatory. But that is not what the law says.

As early as in its 2001 paper *The Accessible Future* NCD made the case that decisions made with indifference to their negative consequences for people with disabilities, under circumstances in which the existence of inclusive alternatives is known and in which these alternatives are not costly or impractical, are discriminatory. When such indifference is manifested in the face of laws specifying a higher standard of care, the inference of discrimination becomes even stronger.

In its December 2006 paper, *The Need for Federal Legislation and Regulation Prohibiting Telecommunications and Information Services Discrimination*,¹²⁷ NCD assessed many of the strategies that would be most effective in bringing about equal access to the high-speed digital, wireless, Web 2.0 and related environments. These strategies include better enforcement of existing laws, promulgation of clear standards and design principles, and development of strategies to help the competitive marketplace to correct for its failure to achieve accessibility. Additional strategies include economically rewarding service providers, software developers, and equipment manufacturers who incorporate accessibility into their products and services through

adherence to principles of universal design (UD) and through support for interoperability with AT.

These strategies, which should be made operational by the national panel recommended in the previous section, are embedded in existing law. With that in mind, let us turn to some current legislative and regulatory initiatives through which their application can be understood and advanced.

Specific Issues

Access Board Update of Section 255 and Section 508 Regulations

Section 255 of the Telecommunications Act¹²⁸ and Section 508 of the Rehabilitation Act¹²⁹ are two of the bulwark provisions bearing on telecommunications and information technology accessibility. Both embody the principles just described. Section 255 requires that telecommunications services and equipment (including “customer premises equipment”) be accessible to and usable by all people, including people with disabilities, to the extent that it is “readily achievable” to do so. Section 508 attempts to harness the Federal Government’s enormous buying power in the service of accessibility. It requires that electronic and information technology (E&IT) purchased by the government for its own use be accessible to users with disabilities unless one of several exceptions apply, including that making it accessible would constitute an “undue burden.”

The meaning of these requirements is not always self-evident, and both statutes provided for the establishment of government-industry-consumer committees under the auspices of the Access Board to draft guidelines and standards. Both processes were duly completed, and the standards were adopted, in the case of 255 by the FCC, and in the case of 508 by the Department of Justice (DOJ) and the General Services Administration.

In its annual progress reports over the past four years, NCD has tracked the progress and implementation of these statutes and has carefully reviewed the effectiveness of these guidelines. That effort has obliged the Council to note repeatedly what it regarded as serious deficiencies in enforcement and oversight of both laws.

Against this backdrop, and recognizing the rapid evolution of technology, NCD noted with great interest the announcement in mid-2006 of the creation by the Access Board of the Telecommunications and Electronic and Information Technology Access Advisory Committee (TEITAAC)¹³⁰ to revise the guidelines for both laws. NCD understands that none of the guidelines recommended by the TEITAAC, or indeed by the Access Board, will have the force of law until adopted by the FCC in the case of 255 and by DOJ in regard to 508. NCD is confident that well-thought-out recommendations that responsibly address the serious problems associated with both laws will be hard for those implementing agencies to ignore or disregard.

Therefore, NCD believes that this revision process has the potential to remedy many of the administrative and enforcement problems affecting the two laws, but the Council is also concerned that the revisions could result in serious weakening of these vital protections.

Does One Size Fit All?

NCD's first overriding concern is that the effort to create a single set of guidelines, while desirable from the standpoint of clarity and simplicity, could obscure key differences between the two laws, including distinctions in how responsibility for enforcement is allocated and on whether the "readily achievable" or the "undue burden" standard is used. Accordingly, NCD recommends to the Access Board that while avoiding unnecessary duplication and including as much shared material as possible, the revised guidelines being developed by the TEITAAC treat Sections 255 and 508 separately, as their differing requirements, procedural elements, and oversight and enforcement mechanisms require.

Section 255 Guidelines

Not all that needs to be done to strengthen and vindicate Section 255 can be done by the TEITAAC. A number of key issues fall outside its sphere of responsibility. But the Committee can take a number of steps.

First, by way of documentation requirements, the Committee needs to do two things. The first is to define the documentation of accessibility features as a key element of those features. However it may be that a particular feature or function is accessible, if knowledge of that fact and of how to use it are not conveniently and widely available to users, the net effect may be the same as if the capability did not exist at all.

But documentation in the context of Section 255 has another meaning as well. Thus, the second key element of documentation relates to the need to track companies' efforts to make their products and services more accessible. If a company is going to claim that accessibility, UD, or interoperability with AT is not "readily achievable" in connection with a particular device, system, or function, then it is at least reasonable to ask that the company asserting this defense be able to present evidence of the efforts it has made, the research it has done, and the outreach it has undertaken to achieve the desired results.

The goal is threefold: (1) to discover those rare cases of bad faith in which the claim of "not readily achievable" is glibly made but no serious efforts to achieve accessibility were ever undertaken; (2) to reveal cases in which a firm acting in good faith was mistaken or misinformed about the capabilities of existing technology or design; and (3) to qualify UD research expenditures for the expanded research and development tax credit proposed below.

Section 508 Guidelines

In connection with Section 508 guidelines, there is also much the TEITAAC can do. Once again, perhaps its greatest contribution can be in the area of documentation. Consistent with the underlying statute and with the scope of its responsibility, the

committee should clarify how and when federal agencies must document the reasons for their inability to procure compliant equipment or services. The statute provides a number of circumstances in which full compliance is not required, including circumstances in which compliance would represent an undue burden and situations in which accessible products simply do not exist. No one suggests that the TEITAAC can or should modify these exceptions and defenses. But it can and should ensure the integrity of the process by requiring, as the statute clearly contemplates, more transparent, standardized, and available explanations by procuring agencies whenever any applicable exceptions are brought into play.

The goal is to identify situations of mistake or misinformation and to focus attention on products and services for which achievement of accessibility remains a problem.

A second key step the TEITAAC can take with respect to Section 508 is to reverse the exceptions added to the requirements by its predecessor advisory committee, the EITAAC. For example, in exempting “back office” equipment from the requirements of the law,¹³¹ the original EITAAC’s action had the unintended effect of denying accessibility, and potentially employment opportunities, to some number of federal workers or job applicants with disabilities. Nothing in Section 508 indicated an intention to draw a distinction between covered and noncovered employees based on whether they did their work in the front or the back office.

The third step the TEITAAC can take to strengthen Section 508 is to clarify whether the information created, stored, and transmitted by the technology, or only the technology itself, needs to be accessible. This is particularly important with respect to the role of the public.

Section 508 extends beyond federal employees to include members of the public who are permitted or required to use federally owned E&IT for various transactions or interactions. But exactly what this means remains unclear in several respects. Take for example the case of an executive branch Web site required to be accessible under the law. For example, assuming that people with disabilities are able to find and download

video clips from a covered Web site, does the law also require that accessible versions of the content (for example, audio or text versions, or captioned versions of videos) be accessible? Similarly, if a member of the public uses an information terminal machine or point-of-sale machine such as a postal service stamp machine or a machine that issues forms, do the documents emanating from such machines need to include any accessibility features? Finally, if the computers and printers on which federal employees prepare sensitive personal communications with citizens are required to be accessible to and usable by those workers, does it follow that the documents or other materials produced by them need to be accessible as well?

One way the TEITAAC can help federal agencies answer these questions is by strengthening its guidance concerning the planning provisions of the law. The statute requires that agencies develop plans for alternate methods of making information accessible when E&IT cannot be made accessible. By emphasizing the importance of developing these plans, the line of demarcation between what is required to be made accessible and what is not can be more clearly analyzed and understood.

The TEITAAC needs to consider all these questions. NCD recommends that the TEITAAC seek the broadest possible range of input in answering the inseparable policy and technical questions that will so heavily influence the impact of Sections 255 and 508 in the years to come.

FCC Implementation of Section 255 Recommendations

In terms of implementing the recommendations made by the TEITAAC, and in terms of actions that are solely within its own jurisdiction, the FCC can do many critical things. NCD's annual reports over the past four years have articulated many of these actions and have urged the FCC to take action, but despite the Commission's admirable and energetic pursuit of equal access for people with disabilities under other laws, its extreme passivity in regard to Section 255 remains inexplicable and disheartening.

Regulatory Categories

Over the years, the FCC has continued to redefine various telecommunications technologies and services in ways that remove them from the coverage of Section 255 altogether. Section 255 covers “telecommunications” services and equipment. But by defining almost all Internet-based services and Internet-enabled devices as “information technology” or services, the Commission has steadily narrowed the scope of 255, leaving it to cover only those residual, dial-up, analog, and other traditional services that are increasingly marginal in our high-speed, online world.

As discussed in last year’s progress report, congressional enactments ratifying these FCC policies, together with a major Supreme Court ruling on the subject, appeared to give these regulatory decisions the force of law. NCD came to believe that the question was left open whether, even if it wanted to, the FCC could restore civil rights protections under Section 255. NCD therefore urged the FCC to work with Congress to restore the necessary protections, and considerable effort has been made by the advocacy community to incorporate civil rights safeguards in pending broadband legislation.

To NCD’s knowledge, the FCC has not reached out to Congress in connection with this matter. Nevertheless, apart from what Congress does or does not do, a number of regulatory initiatives emanating from the Commission during 2006 strongly suggest that it does believe itself to have considerably more authority in relevant areas than many had supposed. Accordingly, NCD no longer believes that the FCC lacks authority to cover many of the newer Internet-based, broadband, high-speed, and wireless services under the civil rights protections of Section 255. Nor does NCD think that the FCC regards itself as lacking the statutory authority to protect the civil rights of people with disabilities in cyberspace.

For more detailed information, consult the two NCD papers noted earlier in this chapter. Although prepared to take the initiative by extending a number of legal requirements, including the levying of certain taxes or fees, to the supposedly deregulated realm for Internet-based information services, the Commission has remained strangely reluctant

to extend disability rights protections, especially any arising under Section 255 to this domain. Yet, through a number of pathways, NCD is confident that it has the legal power and the responsibility to do so.

NCD several times has urged the FCC to issue an authoritative statement regarding its interpretation of its authority under existing law to extend civil rights protections to the Internet and to the IP-based (Internet Protocol) services and technologies involved. NCD renews its strong recommendation that the FCC issue a statement regarding its authority to apply Section 255 to so-called information services, and if the Commission determines that it lacks statutory authority to do so, then to consult Congress for the necessary legislative authorization. NCD stands ready to work with the Commission to define the changes that would yield the greatest benefit to people with disabilities in terms of education, employment, commerce, and access to government, and to work with the Commission in devising approaches that would maximize the incentives to industry of incorporating accessibility and UD into its product and service offerings.

Monitoring

NCD can find no evidence in FCC publications or dockets that the Commission is undertaking any effort under Section 255 to determine the level of telecommunications accessibility, to identify positive or negative trends, or to address problem areas. Judging from anecdotal reports, even the list of companies' Section 255 contact officers that the FCC requires be maintained is inaccurate and out-of-date. NCD has found no indication that the Commission has made any effort to get companies to update or verify the accuracy of the contact information on this list.

With respect to monitoring, the Commission appears to believe that the complaint process will meet this need. NCD emphatically disagrees. As explained in last year's progress report, isolated consumers are in no position to negotiate on terms of equality with large telecommunications companies, and in particular, such consumers are in no position to refute company claims regarding what is and what is not possible.

For this reason, returning to the question of documentation, NCD recommends that the FCC notify all Section 255 complainants of their right to have a review by the Commission of the respondent company's claims of fact, including statements regarding the efforts it has made to achieve accessibility and the reasons it could not be done. Isolated civilian petitioners cannot be expected to evaluate such claims on their own. Nor should they be required to go through the complex process of filing formal complaints to invoke the Commission in resolving disputes.

Access Board and DOJ Implementation of Section 508 Recommendations

In terms of the recommendations noted above, and in terms of administrative actions within the discretion of DOJ, a number of important things can be done to ensure the integrity of Section 508. The Access Board should adopt and forward to DOJ for approval the TEITAC recommendations noted above, and, unlike the apparent case with the revised ADAAG (discussed in Chapter Two), DOJ, after seeking and reviewing comments, should adopt the revised 508 guidelines into law, reject them, or amend them. Under no circumstances should it leave them to languish unattended.

A related area of concern, noted in previous progress reports, is the biennial reports to Congress by DOJ specified in the statute. These reports have not been forthcoming for a number of years. NCD therefore urges DOJ to announce its intentions and timetables regarding the preparation of these required reports. NCD further urges DOJ, in the event the Department feels that its other heavy responsibilities prevent it from carrying out this function in a timely manner, to ask the President to request that Congress transfer the responsibility to another appropriate federal entity.

Relay Services

There was a time when references to relay services could be abbreviated as TRS because of their applicability to telecommunications relay services. Because of the proliferation of new methods for delivering captioning, real-time signing, and other

modalities, the *T* in TRS is increasingly inadequate to capture the dynamic range of possibilities and developments.

Any attempt to come to terms with the current potential for risks confronting video relay services (VRS), real-time captioning, and related services requires disentanglement of a number of intersecting technologies and several applicable laws. Not only Section 255 but also the ADA, the Communications Act, and various state statutes and programs are implicated in the discussion. Two confounding issues need to be addressed.

Funding

Mechanisms exist for funding traditional TRS services, as well as for funding teletypewriters and other specialized equipment that people with hearing, speech, or other telephone-access disabilities use. As new Internet-based equipment and services have become available, and as new subpopulations have been enabled to benefit from speech- or voice-carryover, from redundant audio and visual presentations, and from other techniques, questions of how these devices and services should be funded, as well as for whom they should be provided, have become increasingly important.

NCD believes that the current Universal Service Fund (USF) should be made available for use in supporting VRS. State-based equipment distribution programs should be broadened to address the technology needs of people with a wide variety of telecommunications disabilities and should be available to subsidize all devices designed to overcome such disabilities.

Various means exist to bring about the most flexible utilization of funds. Debate has raged this year about extending USF fees to Internet-based telephony, with a view toward increasing funds available to define and accomplish our nation's traditional commitment to universal telephone access. NCD takes no position on whether a per-line surcharge or a percentage-of-bill approach should be used, but we do believe that no sound policy basis exists for taxing one form of telephone communication but not another. The attraction of VoIP (voice over Internet protocol) is sufficiently great to

ensure that the development of the technology will not be hindered by the addition of the USF fee.

What NCD believes necessary is a broad-based consideration of the funding mechanisms that currently exist, or that need to be created, to ensure that present and emerging relay technologies will be supported and made available. Therefore, NCD recommends that the FCC initiate a rulemaking proceeding to solicit the broadest possible input concerning existing and potential funding streams, with a view toward drafting regulations or making legislative proposals designed to ensure that resources will keep up with technology in this key area.

Jurisdiction

With the Telecommunications Act administered primarily by the FCC, with ADA responsibility (including ADA Titles II and III responsibility for payphone accessibility) divided between DOJ and the FCC, and with state laws playing the major role in determining what specialized telephone-access equipment (and for what classes of users) will be subsidized, it is no wonder that a comprehensive overview of the video access question remains elusive. Depending on whether computers, cable or satellite television, high-speed wire or wireless, cable- or phone company-provided technology or services are involved, different laws with differing regulatory structures will apply. Therefore, NCD recommends that as part of the rulemaking proceeding recommended above the FCC seek input about rationalizing jurisdiction and ensuring the necessary interagency coordination.

Closed-Captioning

In connection with the requirements for provision of closed-captioning of television programming, the FCC has been aggressive in its efforts to ensure that timetables for closed-captioning would be established, understood, and met. The applicable regulations do contain provisions allowing program creators to petition for waivers under

various hardship conditions, but consistent with the ADA standards, they must show that captioning would constitute an undue burden.

A decision released in mid-September, as amplified and spotlighted by a letter of concern written by Representative Markey shortly thereafter,¹³² has thrown this long-standing FCC commitment into doubt and raised concerns that the FCC may be in the process of unilaterally carving out new and far-reaching exceptions to the captioning requirement. The Markey letter expressed concern regarding the secrecy surrounding the review of waiver requests.

NCD has not been able to determine whether Representative Markey's letter was answered. In view of the concerns expressed, however, NCD believes it would be prudent for the Commission to reaffirm the established legal standards for reviewing closed-captioning waiver requests. The Commission should establish procedures to ensure that the review of such requests takes place in an open environment, through official publication and posting, and with opportunity for public comment before a request can be granted.

E-9-1-1 Access

On November 15, the Commission held an E-9-1-1 Disability Access Summit to bring together government, industry, experts, and advocates to gather critical input on needs, barriers, and possible solutions related to accessing the 9-1-1 system.¹³³ The Commission provided Web casting of this summit, which allowed for great participation of stakeholders.

On December 15, the Commission issued an order extending by one year, to January 1, 2008, the deadline for VRS providers to become compatible with the 9-1-1 system. NCD is not aware of what conclusions the Commission has drawn from the summit or how it will affect Commission policies, or whether the VRS decision was influenced by anything that took place at the summit. However, NCD commends the FCC for coordinating the summit to address possible solutions to improved access.

NCD anticipates many positive outcomes from the summit. NCD urges the FCC and potentially other agencies to expand the use of inclusive and interactive strategies such as this subject-based summit. These technology-based venues expand involvement for people with disabilities in the public policy decisionmaking process and allow them to have a voice in issues that so profoundly affect their lives.

The Assistive Technology Act

In 2006, there was a major reorganization of the three technical assistance programs operating under the AT Act: (1) statewide AT programs, (2) the Protection and Advocacy for Assistive Technology Program, and (3) the Access to Telework Financial Loan Program. These three programs have been combined to form the National Assistive Technology Technical Assistance Partnership (NATTAP), under the auspices of the Department of Education's Rehabilitation Services Administration. These technical assistance projects reflect the broad scope of AT Act activities.

NCD commends the opportunities for coordination and for information and resource sharing that this partnership makes possible. NCD understands that a NATTAP conference, bringing together all AT Act constituencies, is slated for the spring of 2007. NCD commends this effort and hopes that it will result in significant capacity building throughout the nation.

Tax Provisions

It comes as little surprise that the leaders of our nation regard tax law as a primary vehicle for the achievement of a wide variety of economic and even social goals. Rare in the public policy discussions of this decade is a subject or problem that has not been deemed amenable to tax-based intervention. Given the economic realities that surround the development and dissemination of AT and of accessible information and communication technology and services, NCD believes that the tax code can play a significant role in the advancement of AT and UD as well.

NCD has made tax-related technology recommendations in previous reports. With the recent reauthorization of the research and development (R&D) tax credit¹³⁴ (now the research and experimentation credit), NCD recognizes the potential applicability of that provision to AT and UD product and service development efforts by businesses. To ensure that such an application of the R&D credit would be equitable and administered with integrity, NCD recommends that Congress create a joint Internal Revenue Service (IRS) and Access Board committee, modeled on those used in the Section 255 and 508 contexts, to develop guidelines for determining the activities that would qualify for the AT and UD R&D credit and to specify the documentation that will be required to demonstrate such qualification.

Recommendations

Recommendation 11.1: NCD recommends that Congress create a national panel, with representatives drawn from government, industry, and the disability community, tasked with identifying and recommending specific measures to overcome barriers, such as the barriers described in the 2006 NCD report, *Over the Horizon*.

Recommendation 11.2: NCD recommends to the Access Board that, while avoiding unnecessary duplication and including as much shared material as possible, the revised guidelines being developed by the TEITAC treat Sections 255 and 508 separately, as their differing requirements, procedural elements, and oversight and enforcement mechanisms require.

Recommendation 11.3: NCD recommends that the TEITAC seek the broadest possible range of input in answering the inseparable policy and technical questions that will so heavily influence the impact of Sections 255 and 508 in the years to come.

Recommendation 11.4: NCD reiterates its strong recommendation that the FCC issue a statement regarding its authority to apply Section 255 to what are denominated as deregulated information services, and NCD further recommends that if the Commission

determines that it lacks statutory authority to do so, that the Commission then reach out to Congress for the necessary legislative authorization.

Recommendation 11.5: NCD recommends DOJ announce its intentions and timetables regarding the preparation of required Section 508 reports to Congress, and NCD further urges DOJ, in the event the Department feels that its other heavy responsibilities prevent it from carrying out this function in a timely manner, to ask the President to ask Congress to transfer the responsibility to another appropriate federal entity.

Recommendation 11.6: NCD recommends that the FCC initiate a rulemaking proceeding to solicit the broadest possible input concerning existing and potential funding streams, with a view toward drafting regulations or making legislative proposals designed to ensure that resources will keep up with technology in this key area.

Recommendation 11.7: NCD recommends that the FCC reaffirm the established legal standards for reviewing closed-captioning waiver requests and that it establish procedures to ensure that the review of such requests takes place in an open environment, with official publication and posting, and with opportunity for public comment before a request can be granted.

Recommendation 11.8: NCD urges the FCC and potentially other agencies to expand the use of inclusive and interactive strategies such as a subject-based summit, and to expand the use of techniques such as Web casting, as tools to involve people with disabilities as fully as possible in the public policy decisions that so profoundly affect their lives.

Recommendation 11.9: NCD recommends that Congress create a joint IRS and Access Board committee to develop guidelines to determine the activities that would qualify for the AT and R&D tax credit and to specify the documentation that will be required to demonstrate such qualification.

Chapter Twelve: International Affairs

Introduction

This chapter deals with a number of developments occurring in the international arena during 2006 that are of particular importance to disability policy in this country and in the world. The chapter begins with a discussion of the historic U.N. Convention on the Rights of Persons with Disabilities. It then discusses international efforts to respond to communications accessibility and efforts by the Organization of American States (OAS) to harness the expertise of groups working in the area of disability policy. Following this, the chapter discusses the work of the U.S. Department of State to address disability-related concerns. Finally, the chapter deals with interconnected legal and technology design issues that have arisen in the implementation of accessibility standards in recent years.

The U.N. Convention

In December 2006, the U.N. General Assembly adopted the Convention on the Rights of Persons with Disabilities.¹³⁵ The treaty was opened for signature by member nations beginning in March 2007 and will come into effect once ratified by 20 countries.

The treaty is comprehensive, dealing with matters ranging from the right to life to health care, employment, participation, nondiscrimination, and other access and equality goals. For those interested in gaining a fuller sense of all the Convention's provisions, previous NCD papers and statements marking the development of the Convention, explaining its provisions, and clarifying potential misunderstandings regarding its terms and implications are recommended.

To many, the decision by the United States to not sign the U.N. Convention is disappointing. NCD has made clear its belief that the United States should sign, and more important, has outlined its reasons for this belief.¹³⁶ Several points about the post-Convention world are worth addressing. In this regard, although the United States will

not be a signatory to the treaty, American experience and American law contributed significantly to its development and final form. As noted in last year's NCD progress report, numerous briefings on American approaches and American law were prepared for the committee drafting the Convention. The impact of American law, and even more powerfully, the impact of America's example can be felt in the words and the spirit of the Convention. NCD hopes and believes that once the Convention goes into effect experience will, in the course of time, calm the fears and suspicions currently shadowing it.

Global Initiative

The International Day of Disabled Persons (IDDP), observed in December, has a chosen theme or issue each year, and those involved seek to increase awareness and to galvanize effort around it. The issue chosen in 2006, for what came to be known as e-Accessibility Day, was access to technology and, in particular, to the Internet.¹³⁷

In connection with this observance, several elements of primary importance emerged. By selecting technology and communications access as its theme, this year's IDDP drew attention to the international nature of communications access for people with disabilities. The international nature and implications of the Internet—in terms of regulation, language, censorship, technology standards, costs, encryption, and other matters—have been long and widely discussed. Now the status of people with disabilities, as an element of these discussions, has been raised to a previously unprecedented level of awareness.

Time will tell what will be the long-term effects of the IDDP. At the very least, it is safe to say that, to the extent nations rely on technology for their economic development or for the conduct of their institutions, they must be more aware than ever that failure to incorporate people with disabilities into the development of these communications infrastructures carries with it a substantial long-term cost.

The Organization of American States

NCD commends the work of the OAS in its adoption of the Inter-American Convention on the Elimination of All Forms of Discrimination Against Persons with Disabilities, and on its efforts to implement that Convention. Specifically, NCD notes the organization's outreach efforts in requesting input from civil-society organizations that work on issues related to people with disabilities.¹³⁸ The OAS has invited comments from such agencies in connection with the work of creating the initial documentation involved in establishing the Committee for the Elimination of All Forms of Discrimination Against Persons with Disabilities provided for in the Convention.

NCD believes that regional efforts of this kind can prove valuable in responding to the economic and social conditions in this hemisphere. NCD recommends that the Department of State, the U.S. Agency for International Development (USAID), and other Federal Government entities and partners involved in multinational, hemispheric, and regional development efforts do all in their power to encourage and facilitate the participation of U.S. nonprofit, private sector, voluntary, and faith-based organizations in the work of the new committee. NCD recommends that the United States explore ways to encourage similar regionally based efforts and to support such efforts with culturally sensitive technical assistance resources.

Involving People with Disabilities In Policymaking

In 2004, the Department of State and USAID established the Advisory Committee on Persons with Disabilities to advise both agencies on issues of concern to people with disabilities in the development and implementation of American foreign policy. NCD has commended this effort and appreciates the efforts made to further expand the process, including the holding of public meetings.¹³⁹

NCD is eager to learn more about how this process has worked and, subject to applicable principles of confidentiality, to gain some sense of how this advisory committee has contributed to foreign policy decisions or practices. To derive possible

lessons from the process, NCD recommends that the sponsoring agencies issue a report indicating their views on how and how well the Advisory Committee has assisted them, and setting forth such views as the agencies or the committee members may have on how this advisory process can be made more effective and can be extended to the foreign policy-related activities of other federal entities, including the Department of Commerce, the U.S. Trade Representative, Immigration and Customs Enforcement, and other agencies.

Trade and Commerce

Two years ago, in the *Spector* case,¹⁴⁰ the Supreme Court ruled that the Americans with Disabilities Act applied to foreign cruise ships operated into and out of American ports. This decision represents one of many illustrations of the ways in which national and international law are affecting and complicating the design of products and services. No longer can a foreign-flag cruise line, designing and building its ships far from the United States, ignore U.S. accessibility design requirements, that is, if the vessel is to serve U.S. customers.

Many other illustrations of this type of interaction can be found. For example, televisions sold in this country must comply with the legal requirements for inclusion of closed-caption decoder chips, no matter where the television is manufactured. Electronic and information technology purchased by federal agencies for their own use must comply with the accessibility requirements of Section 508 of the Rehabilitation Act, even if some of the components were manufactured or assembled abroad. Telephones sold in the United States must comply with the accessibility requirements of Section 255 of the Telecommunications Act, regardless of where they were manufactured.

Similar issues are now arising in the area of services. For instance, many companies required to have teletypewriter (TTY) options available as part of their customer service programs now outsource that customer service to various foreign nations. Anecdotal reports suggest that questions have arisen regarding the sufficiency of TTY or other auxiliary aids and services in many of these customer service operations.

The range of issues presented in the devices and services realms is broad. Among the questions requiring systematic evaluation and answers are those such as which U.S. laws apply and how overseas entities can reliably learn about them, or what redress is available for Americans when outsourced or out-of-country network services do not comply with the law. Accordingly, NCD recommends that the President appoint a blue-ribbon national commission, with the Department of State as the lead agency. This commission should review the range of situations in which accessibility requirements may come into play in the administration of foreign assistance or the management of international trade. The commission should make recommendations for the clarification of responsibilities, rights, and sources of authoritative information and assistance to resolve all issues that may arise in connection with outsourced services provided by entities covered by the ADA.

Recommendations

Recommendation 12.1: NCD recommends that the Department of State, USAID, and other Federal Government entities and partners involved in multinational, hemispheric, and regional development efforts do all in their power to encourage and facilitate the participation of U.S. nonprofit, private sector, voluntary, and faith-based organizations in the work of the new committee. NCD recommends that the United States explore ways to encourage similar regionally based efforts and to support such efforts with culturally sensitive technical assistance resources.

Recommendation 12.2: NCD recommends that the sponsoring agencies, the Department of State and USAID, issue a report indicating their views on how and how well the advisory committee has assisted them. This report should set forth such views as the agencies or the committee members may have on how this advisory process can be made more effective and on how it can be extended to the foreign policy–related activities of other federal entities, including the Department of Commerce, the U.S. Trade Representative, Immigration and Customs Enforcement, and other agencies.

Recommendation 12.3: NCD recommends that the President appoint a blue-ribbon national commission, with the Department of State as the lead agency. This commission should review the range of situations in which accessibility requirements may come into play in the administration of foreign assistance or the management of international trade. The commission should make recommendations for the clarification of responsibilities, rights, and sources of authoritative information and assistance to resolve all issues that may arise.

Chapter Thirteen: Homeland Security

Introduction

In the past five years the term “homeland security” has changed from an abstract concept to one with multiple meanings that depend on how it is applied to everyday life circumstances. We came to understand homeland security in relation to the risk of terrorism. Then we came to recognize that natural disasters, too, such as those resulting from hurricanes, came within the homeland security domain. Most recently, there has been yet a further expansion of the concept, as we have come to know that pandemic disease also needs to be seen as a threat to our homeland security. And the time may be near when long-term climate change will take its place along with the others in the growing pantheon of concerns.

This chapter addresses a number of issues and developments from 2006 that highlight the specific ways in which homeland security affects the lives of people with disabilities. Emergency preparedness and communication, disaster relief, and other elements of homeland security are critical issues in all our lives, but for people with disabilities, they frequently present different issues and have varying effects than may at first be apparent.

The chapter examines the litigation that resulted in an agreement by the Federal Government to provide accessible trailers to displaced Gulf Coast residents. It also recommends ways that litigation to achieve such basic access rights can be avoided in the future.

Beyond disaster relief, the chapter addresses issues surrounding the inclusion of people with disabilities in the rebuilding process, and recounts some of the observations of organizations that have been involved in consortium relief and renewal efforts.

To create a context for full discussion of the issues and to assess their relative impact, the chapter describes the scope of interwoven issues involved in the effort to restore normal life.

Finally, the chapter reviews recent Federal Communications Commission (FCC) enforcement action in the area of emergency broadcast communications and makes suggestions for methods to ensure that television stations across the country comply with crucial standards for information accessibility in times of emergency.

Accessible Trailers

For many survivors of Hurricanes Katrina and Rita, the need to live in temporary housing has gone on longer than they could have imagined. For many, return to a permanent home still is not imminent, and for many, a Federal Emergency Management Agency (FEMA) trailer provides the only option for them to return to their home areas while waiting for permanent housing to be built or rehabilitated.

For many people with disabilities, the privations of living in a trailer have been exacerbated by accessibility problems. A federal class action lawsuit, settled in September 2006,¹⁴¹ provided documentation of the problem and established procedures for its remedy.

NCD commends FEMA and the Department of Homeland Security (DHS) for undertaking the task to identify and meet the accessibility needs of evacuees and temporary housing tenants. To prevent such situations from recurring, however, NCD recommends that FEMA and DHS develop plans for anticipating and preparing to meet disability-related needs in other postdisaster activities and settings. It should not take a lawsuit to bring such issues to the attention of federal authorities and to bring about action. With the proper planning and outreach to the disability community, NCD is confident that such delays in responding to serious needs will not recur.

The Rebuilding Process

If we have learned anything in the past few years, it is that decisions about the nature of disaster relief measures and about the resources to be provided must be made before the disaster occurs. Whether from the standpoint of prevention, or from the perspective of damage limitation and hastened recovery, we have learned that preparedness is key to our efforts. In January 2006, in the wake of the Gulf Coast tragedy, the then chair of NCD wrote:

As we forge ahead with recovery and reconstruction in the aftermath of Hurricanes Katrina and Rita, we have the opportunity and the duty as a nation to establish facilities and communities that are fully accessible to all without the barriers that currently divide the landscape into a patchwork of islands of access for people with disabilities.

The National Council on Disability urges those who are rebuilding communities and restoring lives to include people with disabilities in all stages of disaster relief, future disaster preparedness, and recovery and reconstruction operations. We have a critical opportunity to learn from our mistakes.¹⁴²

To create procedures and planning infrastructures that will facilitate the participation of people with disabilities, NCD has continued to support legislation such as the bipartisan Emergency Preparedness and Response for Individuals with Disabilities Act of 2006,¹⁴³ and has endorsed the creation of state, regional, and local planning processes and coalitions that are inclusive, both in their membership and in the scope of their concerns.

In this connection, NCD was heartened to learn about the American Red Cross's outreach efforts, undertaken during the summer of 2006, to recruit and train people with relevant expertise to assist it in working with people with disabilities in disaster planning and relief efforts.¹⁴⁴

NCD also was pleased to learn of the participation of the National Disability Rights Network (NDRN) in the Katrina Aid Today initiative, a nine-organization consortium

sponsored by FEMA. Reviewing the conditions faced by hurricane survivors one year after the devastation, NDRN was clear in its observations that far more than physical accessibility is required if life is to regain any coherence.¹⁴⁵

The Scope of the Problem

For all disaster survivors, a complex combination of issues must be faced. These include economic, residency, interpersonal, health, employment, and community issues.

For survivors with disabilities, the issues are the same in nature but often different in degree and complexity. Life may have been organized around numerous fragile arrangements, involving specialized assistance, scarce resources, and coordinated activities and interventions, leaving little margin for error. Often a break in the chain, like a chance event such as the failure of a personal assistance provider to show up as scheduled, or a paratransit ride to arrive on schedule, or an appointment to be kept in a timely manner, can throw numerous other and contingent details into chaos. When the underpinnings of a community have been so fractured, when people have been scattered and resources either destroyed or totally reoriented, the situation, including its psychological implications, can become bleak. At a time when case management, inclusion and self-management may be more necessary than ever before, the resources to be managed and coordinated may be in unprecedented short supply.

With all manner of recovery efforts believed to be slow and in disarray, the issues faced by people with disabilities (including those who had disabilities before the disaster and those who have acquired their disabilities since) may best be understood as an intensified or crystallized version of the challenges facing entire communities. In the end, our success and capacities must be judged by our ability to address the basic needs for sustenance, security, and community of all whose lives are uprooted by disaster.

NCD recommends that DHS in collaboration with other key federal agencies convene a national conference on disaster relief, reconstruction, and assistance for people with

disabilities. At this conference, the groups involved in disaster relief and recovery work can share lessons and experience, members and representatives of the disability community can share their experiences and needs, and government officials and policymakers can enter into the sort of dialog that can result in the formulation of sound policies and programs.

Emergency Communications

On November 21, 2006, the FCC levied a fine of \$12,000 on WTTG, a Washington, DC, metro-area television station, and entered into a consent decree settling a complaint against the station for failing to make emergency information visually available to people with hearing impairments during a thunderstorm/tornado alert in 2004.¹⁴⁶ NCD commends the FCC for its vigorous enforcement of the law in this case, and congratulates the television station for the commitments embodied in the consent decree. In particular, NCD appreciates the station's commitment to distribute its visual information presentation policies to all employees every six months, and to incorporate this policy in the training of new employees.

While NCD is confident that WTTG will succeed in meeting these high standards over time, the problem remains that for timely and effective communication of emergency information to take place, hundreds of television stations and their staffs must be aware of and have the capability and the commitment to adhere to the key standards that have been developed. Given the risks of failure, success is vital, but monitoring is difficult or impossible.

Therefore, NCD recommends that the FCC require television stations to periodically report on their plans and resources for making emergency information accessible, and that accessibility be formally incorporated into a wide variety of emergency broadcast system tests and other simulation exercises.

The responsibility in this area should not be vested solely in the FCC. A December 2006 Congressional Research Service (CRS) report details legislation on emergency

communications enacted since September 11.¹⁴⁷ One of the major areas of concern has been the availability and performance of emergency alert systems (EAS). Because Congress is likely to revisit the subject of EAS each year, ample opportunity should arise for Congress to include specific provisions regarding, or at least to reflect consciousness of, the need for people with disabilities to be taken into account in all EAS discussions.

Recommendations

Recommendation 13.1: NCD recommends that FEMA and DHS develop plans for anticipating and meeting disability-related needs in other postdisaster activities and settings, so that lawsuits never again will be required to achieve basic accessibility.

Recommendation 13.2: NCD recommends that DHS in collaboration with other key federal agencies convene a national conference on disaster relief, reconstruction, and assistance for people with disabilities, at which the groups involved in disaster relief and recovery work can share lessons and experience, members and representatives of the disability community can share their experiences and needs, and government officials and policymakers can enter into the sort of dialog that alone will result in the formulation of sound policies and programs.

Recommendation 13.3: NCD recommends that the FCC require television stations to report periodically on their plans and resources for making emergency information accessible, and that accessibility be formally incorporated into a wide variety of emergency broadcast system tests and other simulation exercises. Congress should reflect an awareness of the needs of people with disabilities in its forthcoming review of emergency alert systems.

Appendix A: Mission of the National Council on Disability

Overview and Purpose

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

Specific Duties

The current statutory mandate of NCD includes the following:

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

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

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

- 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 education, transportation, emergency preparedness, international disability rights, employment, foster youth with disabilities, vocational rehabilitation, livable communities, and crime victims with disabilities.

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.

Endnotes

¹ <http://www.gao.gov/new.items/d051.pdf>.

² Martin Gould, “A User’s Perspective on Federal Disability Data,” paper presented before the American Statistical Association, National Council on Disability (August 17, 2006), http://www.ncd.gov/newsroom/testimony/2006/gould_08-06.htm.

³ ACS Content Test Evaluation Report on Disability (January 2007), http://www.census.gov/acs/wwwAdvMeth/content.test/P4_Disability.pdf.

⁴ For example, 109th Congress, H.R. 6258 (The Americans with Disabilities Act Restoration Act of 2006).

⁵ For a discussion of planned employment-related research see *NCD Bulletin* (March 2006), <http://www.ncd.gov/newsroom/bulletins/2006/b0306.htm>; “Same Struggle, Different Difference: Civil Rights Policy Forum,” Forum Summary Paper, NCD (March 29, 2005), http://www.ncd.gov/newsroom/publications/2005/forum_summary.htm; “Righting the ADA,” NCD (December 1, 2004), http://www.ncd.gov/newsroom/publications/2004/righting_ada.htm.

⁶ NCD letter to the Chair of the House Judiciary Committee’s Subcommittee on the Constitution in connection with its ADA oversight hearing (September 20, 2006), http://www.ncd.gov/newsroom/correspondence/2006/chabot_09-20-06.htm.

⁷ “Righting the ADA,” *supra* note 4; see also Nancy Lee Jones, “The Americans with Disabilities Act (ADA): The Definition of Disability,” Congressional Research Service, CRS Order Code RL 33304 (March 9, 2006).

⁸ See Nancy Lee Jones, “Americans with Disabilities Act.”

⁹ See “Righting the ADA,” *supra* note 4.

¹⁰ Compare *Garrett v. Board of Regents, University of Alabama*, 531 US 356 (2001) with *Tennessee v. Lane*, 541 US 509 (2004).

¹¹ 109th Congress, S. 3823 Sec. 4.

¹² *Creating Livable Communities* (Washington, DC: NCD, October 31, 2006), http://www.ncd.gov/newsroom/publications/2006/livable_communities.htm.

¹³ See *Disability Rights Online News*, Issue 14 (August 2006), <http://www.usdoj.gov/crt/ada/newsltr0806.htm>.

¹⁴ For example, *United States v. AMC Entertainment, Inc.* (government brief), <http://www.usdoj.gov/crt/ada/briefs/amcptaubr.doc> (government’s brief); see also *United States v. National Amusements, Inc.* (No. 00-12568) (January 9, 2006), <http://www.ada.gov/national.htm>.

¹⁵ *University of Iowa School of Law, Disability Law and Policy E-Newsletter* 3, no. 23 (December 1, 2006), <http://disability2.law.uiowa.edu/bbs/showthreaded.php/Cat/0/Number/1479/an/0/page/0/#Post1479>.

¹⁶ “When the Americans with Disabilities Act Goes Online: Application of the ADA to the Internet,” NCD (2003), <http://www.ncd.gov/newsroom/publications/2003/adainternet.htm>.

¹⁷ *United States v. TicketMaster* (settlement agreement, December 22, 2005), *Disability Rights Online News*, Issue 11 (February 2006), <http://usdoj.gov/crt/ada/newsltr0206.htm>.

¹⁸ *PGA Tour v. Martin*, 532 US 661 (2001).

¹⁹ *American Council of the Blind v. O’Neill* (Civil Action 02-0864 (JR), F. Supp. 2d D.D.C., (November 28, 2006), <http://www.dc.uscourts.gov/opinions/>.

²⁰ This is one of many cost estimates issued by stakeholders. We have found no items in the press purporting to place a dollar value on the benefits or current costs of inaccessibility.

²¹ NCD has discovered no persuasive analysis of how “undue burden” defenses mounted by the Federal Government should be evaluated. To the suggestion that the size and budget of the agency should be primary factors, the counterargument has been made that agency budgets are within the control of Congress. If a court were to assess damages against a federal agency, such as the Treasury, for civil rights violations or for wrongful death in a tort action, or if the court were to order remedial action as it did here, the agency would not be able to avoid liability or responsibility by claiming that Congress had not appropriated the necessary funds.

²² “NCD Statement: Voluntary Voting System Guidelines” (June 23, 2006), http://www.ncd.gov/newsroom/publications/2006/voluntary_voting.htm.

²³ “Justice Department Sues New York State over Voting Rights” (March 1, 2006), http://www.usdoj.gov/opa/pr/2006/March/06_crt_108.html.

²⁴ P.L. 109-246.

²⁵ NCD letter to the Chair and Ranking Minority Member, Senate Committee on the Judiciary (July 27, 2006), http://www.ncd.gov/newsroom/correspondence/2006/specter_07-27-06.htm.

²⁶ “The Civil Rights of Institutionalized Persons Act: Has it Fulfilled its Promise?” NCD (August 8, 2005), <http://www.ncd.gov/newsroom/publications/2005/personsact.htm>.

²⁷ NCD letter to the Honorable Tom Davis, Chair, House Committee on Government Reform (June 30, 2006), http://www.ncd.gov/newsroom/correspondence/2006/davis_06-30-06.htm.

²⁸ P.L. 108-446 (The Individuals With Disabilities Education Improvement Act of 2004).

²⁹ *Federal Register* (August 14, 2006), <http://idea.ed.gov>.

³⁰ See letter of John H. Hager, Assistant Secretary of Education, announcing release of IDEA Part B regulations and noting public comment process, *Justice For All Archives*, Article No. 2885 (August 18, 2006), <http://www.jfanow.org/jfanow/index.php?mode=A&id=2885>.

³¹ See “States Await Special Education Testing Rule,” *Education Week* (December 14, 2005). As indicated in NCD’s 2005 status report, the Department of Education was expected to revise this rule on a permanent basis. NCD has been unable to determine the Department’s decisions in this regard.

³² The OSERS IDEA resources Web page, <http://www.ed.gov/policy/speced/guid/idea/idea2004.html>; see generally, Richard N. Apling and Nancy Lee Jones, “Individuals with Disabilities Education Act (IDEA): Analysis of Changes Made by P.L. 108-446,” Congressional Research Service, CRS Order Code RL 32716 (January 5, 2005).

³³ “Questions and Answers on Serving Children with Disabilities Placed by Their Parents at Private Schools,” <http://www.ed.gov/policy/speced/guid/idea/idea2004.html>.

³⁴ 34 CFRIEND Sec. 300.172.

³⁵ “Over the Horizon: Potential Impact of Emerging Trends in Information and Communication Technology on Disability Policy and Practice,” NCD (December 26, 2006), http://www.ncd.gov/newsroom/publications/2006/emerging_trends.htm; see also “The Need for Federal Legislation and Regulation Prohibiting Telecommunications and Information Services Discrimination,” NCD (December 28, 2006), <http://www.ncd.gov/newsroom/publications/2006/discrimination.htm>.

³⁶ “Students with Mental Retardation Make Gains in the Classroom,” *Justice For All Archives*, Article No. 2924 (October 5, 2006), <http://www.jfanow.org/jfanow/index.php?mode=A&id=2924>.

³⁷ *Winkelman v. Parma City School District*, F. 3d (6th Cir. 2006), on appeal to the U.S. Supreme Court, No. 05-983.

³⁸ “NCD Speaks Out on Supreme Court *Winkelman v. Parma City School District* Case,” NCD News Release No. 07531 (February 26, 2007), <http://www.ncd.gov/newsroom/news/2007/r07-531.htm>.

³⁹ Compare *Golin v. Allenby*, F. 3d (No. 04-15900, 9th Cir. 2005).

⁴⁰ See <http://www.ed.gov/policy/highered/guid/secletter/0603011.html>. Despite several accounts seeming to characterize this as a new provision, teacher loan forgiveness has existed in the law previously.

⁴¹ “Principles for the Reauthorization of No Child Left Behind,” Consortium for Citizens with Disabilities, Education Task Force, *Justice For All Archives*, Article No. 2913 (September 2006), <http://www.jfanow.org/jfanow/index.php?mode=A&id=2913>.

⁴² Dave Reynolds, “Teachers, and Parents Support School Board’s Inclusion Plan,” *Inclusion Daily Express* (December 6, 2006), <http://www.inclusiondaily.com/archives/06/12/06/120606flinced.htm>; see also Rhonda J. Miller, “Board Hunts for \$17 Million; District Wants Students with Disabilities in Regular Classroom,” *South Florida Sun-Sentinel* (December 7, 2006).

⁴³ *United States v. University of Chicago* (settlement agreement July 17, 2006), *Disability Rights Online News*, Issue 15 (October 2006), <http://www.usdoj.gov/crt/ada/newsltr1006.htm>.

⁴⁴ Jodi S. Cohen, "University of Chicago Deal is Part of Crackdown by U.S.," *Chicago Tribune* (September 8, 2006), *Justice For All Archives*, Article No. 2896, <http://www.jfanow.org/jfanow/index.php?mode=a&id=2896>.

⁴⁵ *Ibid.*

⁴⁶ Compare, "Using the Medicaid and Medicare Work Incentives to Retain a Funding Source for Assistive Technology and Other Key Service" (Fall 2006), <http://www.nls.org/av/late-fall06.htm>, with "Strategies to Help States Address Increased Expenditures During Economic Downturns," U.S. Government Accountability Office, GAO-07-97 (October 18, 2006).

⁴⁷ "CMS News: Effort to Combat Medicaid Fraud and Abuse Launched," *Justice For All Archives*, Article No. 2846 (July 19, 2006), <http://www.jfanow.org/jfanow/index.php?mode=A&id=2846>.

⁴⁸ "Final Report of the National Medicaid Commission" (December 29, 2006), <http://aspe.hhs.gov/medicaid/>. For a variety of articles and analyses of the work of the national Medicaid commission, see <http://www.aapd.com/News/commission/indexmedcomm.php>. One member of the commission voted against its managed care recommendations, noting there was no evidence to demonstrate that managed care of beneficiaries with disabilities is less costly. NCD believes that only if controlled research is done, involving matched pairs of people with similar medical histories, diagnoses, access to care, and care needs, can the economic case for managed care be proved or refuted. A Commonwealth Fund report cited in the November 30, 2006, *Kaiser Daily Health Policy Report* concludes that per capita costs for people in Medicare managed care actually exceed those for beneficiaries in fee-for-service plans. See "Federal Government's Costs for Medicare Beneficiaries Enrolled in Managed Care Plans 12.4 Percent Greater Than for Those in Fee-For-Service Plans, According to Study," http://www.kaisernetwork.org/daily_reports (requires log-in to access).

⁴⁹ See "Improving Access to Integrated Care for Beneficiaries Who Are Dually Eligible for Medicare and Medicaid," CMS Release, *Justice For All Archives*, Article No. 2856 (July 27, 2006), <http://www.jfanow.org/jfanow/index.php?mode=A&id=2856>.

⁵⁰ *Supra* note 47.

⁵¹ P.L. 109-171, Sec. 6071.

⁵² "Money Follows the Person—One State's Data," *Info. Bulletin* no. 109 (May 15, 2006), <http://www.stevegoldada.com>.

⁵³ See review of work done by demographers at the University of California-San Francisco, Andrew Schwartz, "School of Nursing Stat Mavens Make Numbers Tell the Truth" (June 15, 2006), <http://pub.ucsf.edu/today/cache/feature/200606149.html>.

⁵⁴ See “Change is Happening: Look at FY 2005 MA Expenditures,” *Info. Bulletin* no. 117 (July 6, 2006), <http://www.stevegoldada.com>.

⁵⁵ *Supra* note 50, Sec. 6087. For background information on cash and counseling, visit <http://www.cashandcounseling.org>.

⁵⁶ *Ibid.*

⁵⁷ NCD is not familiar in detail with the work of the Cash and Counseling National Program Office at the Boston College School of Social Work, but the Council does not suggest duplication of any ongoing work being done by this project.

⁵⁸ “Important Changes to Wheelchair Coverage Policy—Access Concerns Remain,” Item Coalition, Medicare Action Alert, *Justice for All Archives*, Article No. 2966 (November 10, 2006), <http://www.jfanow.org/jfanow/index.php?mode=A&id=2966> (including summary of recent developments in CMS-powered mobility rules).

⁵⁹ *Ibid.*

⁶⁰ 109th Congress, S. 3677.

⁶¹ *Federal Register* 68 Fed. Reg. 63691 at 63699.

⁶² For example, “Medicare Prescription Drug Benefit: 2007 Annual Coordinated Election Period,” CMS Open Door Forum Announcement, *Justice for All Archives*, Article No. 2962 (November 8, 2006), <http://www.jfanow.org/jfanow/index.php?mode=A&id=2962>.

⁶³ See <http://www.cms.hhs.gov/HealthCareConInit/>.

⁶⁴ “Medicare Seeks Proposals for Senior Risk Reduction Demonstration,” *Medicare News*, CMS Office of Media Affairs (August 21, 2006), <http://www.cms.hhs.gov/apps/media/press/release.asp?counter=1949>.

⁶⁵ The Tax Relief and Health Care Act of 2006, P.L. 109-432, Sec. 115 (parity extended for one year).

⁶⁶ *Livable Communities for Adults with Disabilities* (Washington, DC: NCD, December 2, 2004), <http://www.ncd.gov/newsroom/publications/2004/Livablecommunities.htm>.

⁶⁷ “The State of 21st Century Long-Term Services and Supports: Financing and Systems Reform for Americans with Disabilities,” NCD (December 15, 2005), http://www.ncd.gov/newsroom/publications/2005/longterm_services.htm.

⁶⁸ *Creating Livable Communities* (Washington, DC: NCD, October 31, 2006), http://www.ncd.gov/newsroom/publications/2006/livable_communities.htm; compare “The Social Security Administration’s Efforts to Promote Employment for People with Disabilities: New Solutions for Old Problems,” NCD (November 30, 2005), <http://www.ncd.gov/newsroom/publications/2005/ssa-promoteemployment.htm>.

⁶⁹ These two provisions created the waiver programs under which states could seek federal approval to deviate from otherwise-applicable Medicaid rules.

⁷⁰ *Olmstead v. L.C.*, 527 US 581 (1999).

⁷¹ *Supra* note 52.

⁷² *Supra* note 47.

⁷³ *Supra* note 50.

⁷⁴ P.L. 109-365, Secs. 408-409 (Older Americans Act Amendments of 2006).

⁷⁵ P.L. 109-171, Sec. 6087.

⁷⁶ Supported by a public-private partnership of Department of Health and Human Services (HHS) and Robert Wood Johnson Foundation funds, the Cash and Counseling program is being formally evaluated. According to the Cash and Counseling National Program Office at Boston College, Mathematica Policy Research Inc. found positive initial results before expansion of the program in 2006.

⁷⁷ P.L. 109-171, Sec. 6021.

⁷⁸ *Supra* note 66.

⁷⁹ "Overview: The Next Generation Roundtable 2006," Youth Advisory Council of the National Council on Disability (July 2006), http://www.ncd.gov/newsroom/advisory/youth/yac_roundtable.htm.

⁸⁰ *Ibid.*

⁸¹ <http://www.nyl.n.org>.

⁸² *Ibid.*

⁸³ See Fall 2006 Newsletter, *Ibid.*

⁸⁴ See <http://www.helpingamericasyouth.gov>.

⁸⁵ For example, Wendy Koch, "No State Fully Compliant with Child-welfare Standards," *USA Today* (January 18, 2006) (citing DHHS findings).

⁸⁶ In many different words, this is a recurrent theme emerging from all the youth forums and discussions mentioned above.

⁸⁷ P.L. 105-220.

⁸⁸ Go to www.doleta.gov/youth_services/rfpguide.cfm to find DOL's WIA Youth Request for Proposal (RFP) Guide. Other Department of Labor efforts by the Office of Disability Employment Policy (ODEP), such as support for youth employment mentoring efforts, also deserve commendation. See "First Ever Conference on Mentoring Youth with Disabilities," ODEP Announcement, *Justice For All Archives*, Article No. 2822 (June 19, 2006), <http://www.jfanow.org/jfanow/index.php?mode=A&id=2822>.

⁸⁹ Approximately a dozen NCD employment issue briefs are being developed in connection with the forthcoming employment report.

⁹⁰ NCD Financial Incentives Study (forthcoming in fall 2007).

⁹¹ For a broad overview of the data, go to <http://www.aapd-dc.org/index.php>; see also Kris Maher, "Disabled Face Scarcer Jobs, Data Show," *Wall Street Journal* (October 5, 2005) (citing findings from Cornell research).

⁹² *Supra* note 88.

⁹³ For example, “Announcement of EEOC Public Meeting on Employment in the Federal Government,” *Justice For All Archives*, Article No. 2824 (June 28, 2006), <http://www.jfanow.org/jfanow/index.php?mode=A&id=2824>.

⁹⁴ Allen Jensen and Robert Silverstein, “Policy Proposals for Improving SSDI, SSI and Medicaid Work Incentives,” *Justice For All Archives*, Article No. 2744 (April 4, 2006), <http://www.jfanow.org/jfanow/index.php?mode=A&id=2744>.

⁹⁵ Internal Revenue Code (IRC) Sec. 51.

⁹⁶ P.L. 108-173.

⁹⁷ “Social Security—Work Incentives Planning and Assistance Program (SSA) Work Incentives Planning and Assistance (WIPA) Program,” Social Security Administration, *Justice For All Archives*, Article No. 2791 (May 2006), <http://www.jfanow.org/jfanow/index.php?mode=A&id=2791>.

⁹⁸ For an excellent overview of work incentive provisions, see Edwin J. Lopez-Soto and James R. Sheldon Jr., eds., *Benefit Times Management for Working People with Disabilities: An Advocate’s Manual* (Rochester, NY: Empire Justice Center, rev. ed. 2007), <http://www.nls.org/tocplanr.htm>.

⁹⁹ “Issue Brief: The Basics of the National Council on Disability’s Social Security Report: The Social Security Administration’s Efforts to Promote Employment for People with Disabilities: New Solutions for Old Problems,” NCD (2005), <http://www.ncd.gov/newsroom/publications/2005/ssa-promoteemployment.htm>; see also “A Disability System for the 21st Century,” Social Security Advisory Board (September 2006), <http://www.ssab.gov/documents/disability-system-21st.pdf>; compare, 109th Congress: H.R. 276.

¹⁰⁰ *Supra* note 89.

¹⁰¹ *Ibid.*

¹⁰² “Announcement of Scholarship Program for College Students with Disabilities” (a project of the Washington Center for Internships and Academic Seminars and the Department of Labor’s ODEP, designed to “help increase employment for students with disabilities through an academic internship program”), *Justice For All Archives*, Article No. 2839 (July 5, 2006), <http://www.jfanow.org/jfanow/index.php?mode=A&id=2839>; see also “ODEP Announces Cooperative Agreement for Research Consortium to Design Methodology and Conduct Case Studies: Employment of Individuals with Disabilities: Department Announces Cooperative Agreement for Research Consortium to Design Methodology and Conduct Case Studies” (ODEP announcement of availability of funding for a cooperative agreement “for a Research Consortium to develop a standard design methodology and conduct case study research to identify ways in which an organization’s structures, values, policies and day-to-day practices, facilitate the employment of people with disabilities”), *Justice For All Archives*, Article No. 2785 (May 13, 2006), <http://www.jfanow.org/jfanow/index.php?mode=A&id=2785>; also, “Announcement of Cornell University’s Rehabilitation Research and Training Center on Employment Policy for Persons with Disabilities, and the American Association of People with Disabilities’ (AAPAID), and Georgetown Law School’s

Workplace Flexibility 2010 Forum: Workers with Disabilities: The Role of Workplace Flexibility, A Forum on Policy and Practice,” *Justice For All Archives*, Article No. 2960 (November 13, 2006), <http://www.jfanow.org/jfanow/index.php?mode=A&id=2960>.

¹⁰³ Precisely because we understand that employer attitudes represent the greatest barrier to employment, the failure of research to address the persistence of negative attitudes represents a major gap in our knowledge. After years of technical assistance, employer education and outreach, and even the positive experience of so many companies, we know little about what works and why, and we have little data on the cost-effectiveness or instrumentality of current advocacy and education techniques compared with others that might be used or compared or in concert with aggressive enforcement of the law.

¹⁰⁴ See “EEOC Moves to Stem Decline in Disabled Workforce,” *Justice For All Archives*, Article No. 2927, (October 6, 2006), <http://www.jfanow.org/jfanow/index.php?mode=A&id=2927>.

¹⁰⁵ *Supra* note 92.

¹⁰⁶ *Supra* note 103.

¹⁰⁷ Principally, these would be the General Services Administration (GSA), the Department of Justice (DOJ), the Office of Management and Budget (OMB), and, ultimately, pursuant to a congressional research request, the Government Accountability Office (GAO).

¹⁰⁸ See “Letter from NISH [National Industries for the Severely Handicapped]” (responding to charges regarding mismanagement in the Javits-Wagner-O’Day program made in the press and at a Senate Health, Education, Labor and Pensions Committee hearing), *Justice For All Archives*, Article No. 2728 (March 12, 2006), <http://www.jfanow.org/jfanow/index.php?mode=a&id=2728>; see also Bryan Denson, Jeff Kosseff, and Les Zaitz, “Congress Aims to Fix Job Program for Disabled” (reviewing developments in the controversy over the program) (November 27, 2006), <http://www.newhousenews.com/archive/denson112706.html>.

¹⁰⁹ P.L. 104-193.

¹¹⁰ The IDA provisions of the new law, if not the old.

¹¹¹ 109th Congress, S. 3863.

¹¹² IRC Sec. 42.

¹¹³ “The Low-Income Housing Tax Credit: A Framework for Evaluation,” Congressional Research Service, CRS Order Code RL 33904 (March 7, 2007).

¹¹⁴ For example, *Three Rivers Center for Independent Living v. the Pittsburgh Housing Authority* (settlement agreement, November 20, 2006); see <http://www.stevegoldada.com/stevegoldada/archive.php?mode=A&id=185;&sort=D>; see also “Reasonable Accommodations and Federally-Funded Housing,” (August 21, 2006), <http://www.stevegoldada.com/stevegoldada/archive.php?mode=A&id=171;&sort=D>; see generally, “Information on the Roles of HUD, Public Housing Agencies, Capital Markets,

and Service Organizations,” U.S. Government Accountability Office, GAO-06-419T (February 15, 2006).

¹¹⁵ See “Program Announcement: Money Follows the Person Rebalancing Demonstration,” CMS (July 26, 2006), http://www.cms.hhs.gov/NewFreedomInitiative/downloads/MFP_2007_Announcement.pdf.

¹¹⁶ For an update on human services transportation programs under the reauthorized federal transportation legislation, see “FTA Publishes Draft Circulars for Human Service Programs,” *Justice For All Archives*, Article No. 2902 (September 11, 2006), <http://www.jfanow.org/jfanow/index.php?mode=A&id=2902>; see generally, United We Ride, <http://www.unitedweride.gov>.

¹¹⁷ “Progress Report: Implementation of Executive Order 13330, February 2005–February 2007,” United We Ride (February 2007), http://www.unitedweride.gov/UWRProgress_report2005-20072_2_07.doc. This report includes an update and overview of the work of the Federal Interagency Coordinating Council on Access and Mobility.

¹¹⁸ P.L. 109-59.

¹¹⁹ “Federal Transit Administration: Progress Made in Implementing Changes to the Job Access Program, but Evaluation and Oversight Processes Need Improvement,” U.S. Government Accountability Office GAO-07-43 (November 17, 2006); see also “Getting To Work: The Need for Reliable and Accessible Transportation Employment,” Issue Brief No. 8, National Council on Disability (forthcoming).

¹²⁰ *Spector et al. v. Norwegian Cruise Line Ltd.*, US (2005), No. 03-1338, <http://www.admiraltylawguide.com/supct/Spector.pdf>.

¹²¹ *Supra* note 14.

¹²² “NCD Position Paper on Access to Airline Self-Service Kiosk Systems,” NCD (May 17, 2006), <http://www.ncd.gov/newsroom/publications/2006/kiosk.htm>.

¹²³ 69 *Federal Register* 64363-64395 (November 4, 2004) (this NPRM covers a broad range of updates to 14 CFRIEND Part 382, the regulations implementing the ACAA).

¹²⁴ *Ibid.*

¹²⁵ *Supra* note 34.

¹²⁶ “Disability and the Digital Divide: Comparing Surveys with Disability Data,” RTC Rural Institute, University of Montana (June 2006), <http://rtc.ruralinstitute.umt.edu/telcom/divide.htm>.

¹²⁷ *Supra* note 34.

¹²⁸ 47 U.S.C. Sec. 255; 36 CFRIEND Part 1193.

¹²⁹ 29 U.S.C. Sec. 794d; 36 CFRIEND Part 1194.

¹³⁰ Revisions of the governing regulations are expected to be proposed during 2007.

¹³¹ 65 *Federal Register* 80,500 at 80,504 (December 21, 2000) (preamble to the Access Board's Final Rule implementing Sec. 508).

¹³² FCC Consumer and Government Affairs Bureau (CGB), DA No. 06-1802 (September 11, 2006), http://fjallfoss.fcc.gov/edocs_public/attachmatch/DA-06-1802A1.pdf.

¹³³ The FCC E-9-1-1 summit on November 15, or the applications for waivers.

¹³⁴ IRC Sec. 41.

¹³⁵ "NCD Commends Adoption of UN Convention on the Rights of People with Disabilities," NCD (December 18, 2006), <http://www.ncd.gov/newsroom/news/2006/r06-527.htm>.

¹³⁶ "Update on the UN Convention on the Rights of People with Disabilities," NCD (April 17, 2006), http://www.ncd.gov/newsroom/publications/2006/un_convention.htm.

¹³⁷ "UN Celebration of International Day of Disabled Persons," *Justice For All Archives*, Article No. 2986 (December 11, 2006), <http://www.jfanow.org/jfanow/index.php?mode=A&id=2986>.

¹³⁸ See "Opportunity for Disability Groups Internationally" (letter from the Committee on Juridical and Political Affairs [CAJP] of the OAS [Organization of American States] Permanent Council, requesting that civil society organizations working on issues related to people with disabilities submit their comments and recommendations with respect to the establishment of the Committee provided for in the Inter-American Convention on the Elimination of All Forms of Discrimination against Persons with Disabilities), *Justice For All Archives*, Article No. 2963 (November 8, 2006), <http://www.jfanow.org/jfanow/index.php?mode=A&id=2963>.

¹³⁹ See "U.S. Department of State and U.S. Agency for International Development Announcement," Meeting of Advisory Committee on Persons with Disabilities, Article No. 2757, *Justice For All Archives* (April 21, 2006), <http://www.jfanow.org/jfanow/index.php?mode=A&id=2757>.

¹⁴⁰ *Supra* note 119.

¹⁴¹ *Brou v. FEMA* (No. 06-0838, E.D.La. 2006), <http://www.fema.gov/plan/prepare/specialplans.shtm>.

¹⁴² "Involve People with Disabilities in Relief Plans: Let's Learn From Our Mistakes Before the Next Disaster Strikes" (statement by NCD Chair Lex Frieden), *Justice For All Archives*, Article No. 2668 (January 9, 2006), <http://www.jfanow.org/jfanow/index.php?mode=A&id=2668>.

¹⁴³ 109th Congress, H.R. 4704/S. 2124.

¹⁴⁴ "American Red Cross Wants Your Input on Emergency Preparedness: Tell Us What You Think, Provide Input into Emergency Preparedness Education for People with Disabilities" (announcement of a joint American Red CROSS and COULDC [Centers for Disease Control and Prevention] effort to gather information on a number of emergency preparedness and response-related issues including preparedness involving people

with disabilities), *Justice For All Archives*, Article No. 2810 (June 9, 2006), <http://www.jfanow.org/jfanow/index.php?mode=A&id=2810>.

¹⁴⁵ “One Year Later, People with Disabilities Still Left in Wake of Hurricane Katrina,” National Disability Rights Network (August 28, 2006), <http://www.napas.org/media/pr/060828.htm>.

¹⁴⁶ “In the Matter of WTTG-TV,” FCC press release, *Justice For All Archives*, Article No. 2971 (November 21, 2006), <http://www.jfanow.org/jfanow/index.php?mode=A&id=2971>.

¹⁴⁷ “Emergency Communications Legislation, 2002-2006: Implications for the 110th Congress,” Congressional Research Service, CRS Order Code RL 33747 (December 14, 2006).