National
Disability Policy:
A Progress Report

December 2003–December 2004

National Council on Disability
November 17, 2005

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

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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

November 17, 2005

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

Dear Mr. President:

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

The report covers the period from December 2003 through December 2004. It reviews federal policy activities by issue areas, notes input by other federal agencies on their progress where it has occurred, and makes further recommendations, where necessary, primarily to the executive and legislative branches of the Federal Government.

As indicated in the report, NCD has observed examples of progress in disability policy and the broader policy arena. Among these are the efforts made by the Transportation Security Administration (TSA) to ensure that the concerns of people with disabilities are taken into account in the formulation of security and screening procedures, as well as the continuing efforts by the TSA to reach out to the disability community and to take its views into consideration. As another example, the Department of Education (DOE) issued a request for public comment as part of the process of writing implementing regulations for the Individuals with Disabilities Education Act (IDEA), including focus groups to obtain stakeholder and public input. NCD believes this outreach will result in useful and broad-based input.

Under NCD's statutory mission, examination of the status of disability policy discloses that incremental progress made in some areas is clouded by other major barriers and challenges that continue to block paths available to the general population. Gaps in necessary services and supports remain to the extent that, as stated in NCD's 2003 progress report, far too many Americans with disabilities are undereducated and unemployed.

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

Sincerely,

Lex Frieden

Lex Frieden, Chairperson

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

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Executive Summary

This introductory section sets the stage for the subject matter covered in the following chapters. The introduction identifies major trends and overarching issues that are valuable in organizing information and creating a framework for the discussion of complex issues.

The body of the report begins with Chapter 1 on disability statistics and research. Research and statistics increasingly lie at the heart of public policy and represent the chief source of data on which policy is based. The chapter discusses the increasingly important links between the accuracy and completeness of research and statistical data, and the formulation of evidence-based program and expenditure policy.

Section (a) addresses the role of the Census in creating an understanding of disability and its implications for policy in our nation. Section (b) addresses new areas in which statistical data is becoming a predominant source of evidence-based policy. Section (c) considers some potentially important groups that may fall through the cracks of current data collection efforts. Section (d) discusses the choices that are made as they relate to the kinds of information collected.

Chapter 2 covers civil rights. It addresses substantive civil rights issues along with the interagency relationships necessary to bring about effective implementation of the law.

The chapter begins with the Americans with Disabilities Act of 1990 (ADA), addressing the current context created by court decisions, legislative proposals, and Executive Branch actions. It then discusses National Council on Disability's (NCD's) work on ADA, summarizing some of the Council's key findings and recommendations, including its support for the ADA Restoration Act.

Section (b) of the chapter concerns itself with planning and coordination issues, including the budgeting process, involved in enforcement of disability rights laws. With efforts to contain federal spending likely to grow more intense, NCD highlights the importance of addressing these issues as soon as possible.

Section (c) deals with voting rights. It addresses developments and issues under both ADA and the Help America Vote Act (HAVA). Commending several major initiatives of 2004, the section emphasizes the need for continued attention and coordination among the several agencies involved in HAVA implementation. Section (c) further counsels that, even in a nonelection year, loss of focus or momentum would be dangerous.

Section (d) reiterates the need for hate crimes legislation to protect vulnerable people with disabilities from opportunistic or prejudice-based violence, much as laws already protect racial and ethnic minorities.

Section (e) addresses the need for legislation barring the improper use of genetic information. It reviews some of the concerns underlying the need for genetic nondiscrimination legislation and identifies two areas in which interactions between genetic information and privacy laws warrant further action.

Chapter 3 examines recent developments in education, emphasizing issues concerning integration of the new Individuals with Disabilities Education Act into the framework of the No Child Left Behind Act. The chapter also addresses developments in higher education related to students with disabilities.

Chapter 4 deals with health care issues. Individuals have varying health care needs and look to different practitioners or payment sources, but no one is unaffected by the challenges facing our health care system. The chapter filters some of the most timely health policy issues through the experiences of Americans with disabilities.

Section (a) deals with the issue of the uninsured. It explores its dimensions and suggests that application of various proposed solutions to people with disabilities requires careful attention and analysis.

Section (b) concerns itself with Social Security reform. It points out ways in which the Social Security system affects many people with disabilities whose situations or numbers are not reflected in the current public debate.

Section (c) considers the proposed National Health Information Infrastructure (NHII) with a view to incorporating, at an early point, issues of concern to people with disabilities into the NHII planning process. NCD addresses a range of issues that are critical to an effective and inclusive system.

The chapter next confronts the Medicaid program as it stands on the threshold of great change. The section draws out some of the main implications for people with disabilities, of major structural changes in the program, and of Medicaid's role in helping to reduce work disincentives for beneficiaries with disabilities.

The next section probes issues arising under the Medicare program devolving from implementation of the Medicare Modernization Act. The section also raises concerns about the ability of Medicare to contribute to the return to work of beneficiaries, as it is expected to do under several laws.

The recent controversy over the Medicare standard for availability of powered wheelchairs is also discussed, both from the standpoint of the light it sheds on the relationship between cost-driven and medically based decision making and from the standpoint of new procedures recently adopted for increasing public input into program design. Finally, the chapter reviews the growth and implications of consumer-directed health care as it relates to people with disabilities.

Chapter 5 addresses long-term services and supports. Section (a) begins with a discussion of the definition of long-term services and supports (LTSS) in the context of income replacement, health care, and community-based services. Clear and widely accepted definitions of the concept of LTSS are needed before effective planning or forecasting can take place.

Section (b) discusses the major NCD study on this subject, which is expected to be released in winter 2005. Based on key issues explored by that study, it raises additional questions about how reasonable expectations for LTSS can be set and about the role of federalism in the allocation of responsibility in this area.

Section (c) provides further background for the emerging national discussion of LTSS by describing the situation of people with disabilities under age 65 and by describing some of the issues that affect them in the design of LTSS.

Recognizing the potential importance of private sector partners in any solution to the LTSS needs of our country, the chapter discusses the role of long-term care insurance and recommends finding strategies for expanding its role.

Chapter 6 deals with issues of special relevance to youth. Section (a) discusses some of the issues arising from the intersection between the juvenile justice and mental health systems, noting disturbing evidence of the increased warehousing role of juvenile detention facilities. Section (b) addresses needs and gaps in current adoption incentives and in neglect and abuse data reporting. Section (c) addresses the work of NCD's Youth Advisory Committee (YAC). Finally, Section (d) directs attention to new issues emerging in connection with the provision of school-to-adult life transition services.

Chapter 7 is about employment. Despite a long history of bipartisan commitment to programs designed to enhance employment among people with disabilities, unemployment among adults with disabilities remains unacceptably high.

NCD commends the significant efforts being made by a number of federal agencies and programs to develop strategies for getting recipients of Social Security program benefits and others with disabilities back to work. A number of these efforts are discussed in this chapter. But NCD also believes that new and dramatic approaches will be needed for the problem of unemployment among people with disabilities to be materially and durably reduced. Some suggestions along these lines are also discussed.

In this connection, the chapter reviews a number of work incentive programs undertaken in recent years, discusses some of the procedural and evaluation issues involved in their use, and explores the origins and current viability of a number of the basic assumptions underlying work-incentive efforts.

Next, the chapter addresses issues arising in connection with the forthcoming reauthorization of the Workforce Investment Act. This discussion covers issues arising under the mainstream career-development and labor-market programs charged with serving people with disabilities on a full and equal basis, and issues facing the specialized system of vocational rehabilitation for people with disabilities that exists alongside of and in partnership with general programs.

Finally, the chapter explores the implications for disability employment projects of a range of issues presented by changes in society, in the labor market, and in the expectations of employers and government. It raises key questions that must be answered if the efficacy of our career development services is to be strengthened.

Chapter 8 of the report draws attention to welfare. The legal framework for welfare reform has not changed in the past year. Thus, NCD believes that the detailed recommendations set forth in both our 2002 and 2003 status reports continue to apply to the reauthorization of the nation's welfare law.

The chapter points up the prevalence of people with disabilities among the welfare-recipient population and suggests issues bearing on achieving successful employment outcomes.

Although transportation is referenced in a number of other chapters, Chapter 9 deals with the subject in its own right. Section (a) addresses accessibility-related issues in transportation security; Section (b) deals with developments under the Air Carrier Access Act; Section (c) reviews developments in local and regional transportation policy during 2004; and Section (d) looks forward to possible enactment of a new national transportation bill in 2005.

Chapter 10 considers housing. NCD continued to address concerns relating to the coherence and organization of federal civil rights enforcement, the adequacy and sufficiency of funding and staffing in key program areas, and the extent to which long-term planning and goal-setting in the housing area have taken the needs and concerns of citizens with disabilities into account. Section (a) deals with civil rights enforcement and policy. Section (b) deals with the place of people with disabilities in housing goal-setting and planning. Section (c) addresses key linkages that underlie the role and importance of adequate housing. Section (d) reviews a number of innovative strategies for improving the housing situation for people with disabilities.

Chapter 11 considers a variety of issues related to technology and telecommunications, reviewing in a number of areas how key decisions, including seemingly unrelated ones, will have a profound impact on the lives of people with disabilities.

The chapter begins with a discussion of the reenactment of the Assistive Technology Act and discusses some of the benefits of that program. The chapter goes on to consider the broad range of technology initiatives undertaken by the government, arguing for their importance and urging that they be maintained intact until the results of major ongoing research are published.

Taking NCD's universal design report as its point of departure, the chapter next considers the role of federal policy and programs in supporting universal design practices. A study of how this could be done more effectively is recommended.

We next consider developments during 2004 in the implementation of the accessibility requirements of Section 508 of the Rehabilitation Act, making recommendations for enhanced monitoring, discussing impacts of the law going well beyond its actual jurisdiction, and suggesting ways that outcomes research can be done in a technological environment.

The remainder of the chapter addresses a constellation of increasingly important access and civil rights issues falling within the domain of the Federal Communications Commission. These include enforcement of Section 255 of the Communications Act, technological and economic challenges facing closed-captioning and telecommunications relay services, the role of accessibility in the e-rate program, and the implications for civil rights and accessibility requirements of the above to Voice over Internet Protocol (VoIP) communications.

Chapter 12 turns to international issues. The chapter begins with a discussion in Section (a) of the growing convergence between domestic and international issues. Section (b) deals with U.S. foreign aid practices, and Section (c) addresses developments surrounding the pending U.N. Convention on the Rights of People with Disabilities.

Chapter 13, the final chapter, represents the newest addition to the subjects considered by NCD's annual status report: homeland security. Section (a) reviews developments during the past year, commending the Executive Order issued in connection with emergency preparedness and people with disabilities. Section (b) goes on to express concerns about the possible inadequacy of existing legal provisions to ensure that critical electronic information resources will be available in emergencies to all people with disabilities on a real-time basis. Section (c) reviews the importance of including people with disabilities in emergency planning, especially in emergency planning that is specifically undertaken with them in mind. Section (d) deals with the host of issues confronted in harmonizing and standardizing the accessibility and related practices of the numerous agencies making up the homeland security system.

Finally, Section (e) reflects on other dimensions of civil rights enforcement in a system composed of so many diverse organizations and traditions, noting that a major report on this subject was issued by NCD in early 2005.

Introduction

Each year, as required by law [1], NCD submits to the President and Congress a status report, summarizing major developments affecting the lives of people with disabilities in the preceding year and highlighting issues likely to emerge in the year to come. Key topics include issues of concern to all people with disabilities (such as housing, health care, transportation, technology, and homeland security) and issues of concern to people at every stage of the life cycle (from education and youth to employment and long-term services).

As the range and complexity of issues have grown, NCD has wrestled with how best to help readers gain an overview for dealing with a dense and detailed body of what to many may be unfamiliar information and issues. To do this, the Council has, in recent years, endeavored to introduce its report with a discussion of major overarching trends and unifying themes that should help readers organize the material in the chapters to come. This year, as in past years, NCD has identified several important and recurrent themes that need to be addressed. Discussion of the three most important and timely themes follows.

(a) Program Design for a New Century

Our nation faces the process of structuring and financing domestic programs, including programs with particular significance for people with disabilities, in a new and rapidly changing environment. It is an environment rich with hope for the opportunities that innovation, attitudinal change, and technology hold out. But it is also an environment beset by anxiety and challenge, as the limitations of available resources in the face of growing expectations and needs become all the more inescapable and ominous.

In programs for people with disabilities, such as special education and vocational rehabilitation, the need for innovative program design has been recognized, but the means for carrying it out remain matters of debate. How tightly should these programs be tied, in procedures or expectations, to their mainstream counterparts—No Child Left Behind in the case of education and the Workforce Investment Act in the case of employment? How literally can the expectations of these mainstream programs be carried over, and how are the potentially varying resource demands of such expectations to be understood and met?

By the same token, many programs are not designed with people with disabilities specifically in mind, but they have a disproportionately large impact on their lives. Health insurance programs, including Medicaid and Medicare, are prime examples. As debate over the reform and restructuring of these programs proceeds, how can the effects of proposed changes on beneficiaries with disabilities (which may often be quite different and quite surprising) best be identified and taken into account?

Similarly, the interests and destinies of Americans with disabilities are frequently implicated and significantly affected by decisions made with little or no awareness of this group's unique concerns, in areas that at first seem to have little or no special connection to their lives. For example, in policy areas ranging from telecommunications (in which issues of accessibility of equipment and services are central to the ability of people with disabilities to participate in mainstream society) to long-term services and supports (in which the range of services people may need belies any traditional notion about the boundaries between medical and social programs), most discussion and debate fail to acknowledge, let alone understand, the significant ways that the decisions made will impact the lives and hopes of more than 50 million Americans. How are these issues and concerns to be incorporated into the public debate?

Without coherent and consistent notions of the role people with disabilities are expected to play in society and without clear recognition that real-life issues can no longer be addressed through the lens of a single program or the jurisdiction of any one agency, these overarching questions are likely to go unanswered or to receive only ad hoc and fragmentary answers on an unpredictable, case-by-case basis.

The new era in program concept and design will take many forms. New program models; new definitions of services themselves and of target populations and stakeholder groups; new allocations of responsibility and authority among federal, state, and private sector partners (including end-users and consumers); and new criteria for measuring program outcomes and success—all of these can be seen to one degree or another in virtually every major piece of legislation discussed in this report. All such changes may have implications for various subgroups of Americans, of course. Few subgroups are as large as that of people with disabilities, though, and few are as certain to be affected by almost every program development, whether expressly aimed at them or not.

In the chapters that follow, numerous examples of this are encountered, including the effects of Census data collection techniques on our understanding of who people with disabilities are (Chapter 1); the impact of proposed Medicaid restructuring on the key low-incidence services so crucial to many beneficiaries with disabilities (Chapter 4); the implications for access to employment of how the Federal Communications Commission (FCC) decides to regulate new VoIP communications services (Chapter 11); and the ways that several recent trends have combined to make the juvenile detention system a default treatment venue for children and youth with mental and emotional disabilities (Chapter 6).

Consistent with its mission, NCD has traditionally sought to provide decision makers with key background information, perspective, and human dimensions to assist them in reaching their decisions. While the Council continues to offer its balanced recommendations and informed views in numerous legislative, regulatory, and judicial contexts and through a variety of issue briefs, white papers, research reports, and testimony presentations, we recognize that the torrent of issues makes it impractical for us or any small advisory body to weigh in on a timely basis in all instances where our data and views might prove valuable. What we fundamentally urge, therefore, is the development of mechanisms for ensuring that, whether the ultimate decisions are made in a manner that best serves the interests of people with disabilities or that subordinates those interests to larger or more pressing concerns, they are at least made with the fullest possible consciousness of the interests and implications at stake.

Illustrations of this need are evident in every chapter of this report. Solutions require new partnerships in fashioning policy and identifying relevant stakeholders; that is, partnerships in planning similar to those increasingly being used to deliver program services to citizens, customers, and consumers.

(b) Program Evaluation

1. Evidence-Based Practice

As program models and goals change to accommodate new values, new notions of federalism, and new fiscal realities, so too must the ways we evaluate programs evolve and grow. Evidence-based criteria in the evaluation of programs and evidence-based practices in their design and implementation have justly become watchwords of this new environment.

But identifying an evidentiary, research-driven basis for many programs and activities can be difficult, controversial, and time-consuming. If childhood nutrition influences health in adulthood, how many years would be required to establish the efficacy of children's nutrition programs? If the benefits of a good education are accrued over the course of a lifetime, when is the proper time for evaluating the impact of investment in education, let alone for assessing the comparative merits of various educational techniques about which experts and practitioners disagree?

To a great extent, the nature and significance of evidence remains a function of baseline performance and basic expectations for a program, how important the perceived outcome is, and a host of other contextual factors. For instance, in applying per capita expenditure levels to the work of vocational development programs (as might be done through the use of the Office of Management and Budget's (OMB) Job Training Efficiency Common Measures program) (see Chapter 7), what role should be accorded to the specialized needs of particular subgroups of job seekers? For people with disabilities who may need assistive technology to access data or even to get to and from interviews or work locations or who may need specialized training services to perform their jobs, what scope should mainstream program evaluation standards accord to these accommodation needs and costs? How should the level of these costs be evaluated, how should their extent be measured, and how should the costs of accommodations be allocated among the parties to the employment relationship? Finally, how should small reductions in unemployment be regarded for a population group that begins from a much higher and intractable baseline of joblessness than the population at large?

NCD is frankly concerned, as illustrations drawn from this report demonstrate, that broad-based decisions about programs' value and effectiveness are being made without adequate knowledge of, or attention to, such variables. What constitutes acceptable outcomes can sometimes be measured on per capita cost or other aggregate numerical bases but must, at other times, be measured by the impact of program services and goals on the lives of individuals.

Again, in addressing the question of how evaluation and outcome measurement can flexibly, but rigorously, be applied to programs and services that affect people with disabilities as part of a larger target population, NCD does not contend that programs can or even should always be designed to maximize the achievement of successful outcomes by people with disabilities. The Council does insist, though, that if programs are to be evaluated in ways that create barriers to successful outcomes by people with disabilities (such as through the use of per capita cost measures that do not take the costs of necessary accommodations into account) or if program outcomes for individuals are to be subordinated to other worthy or larger priorities (as on occasion they must be), this subordination be done knowingly and consciously, not accidentally or as a casual byproduct of other decisions.

As our nation prepares to enter into a major debate over the restructuring of Medicaid, such questions become particularly pertinent. What is the relative priority to be accorded to the individualization that may be necessary to ensure the preservation of every individual life? How are the demands for standardized evaluation techniques, evidence-based validation of program modalities and treatments, encouragement of state innovation, and restriction of spiraling costs to be reconciled? For people with disabilities—who often depend for their quality of life, if not in many cases for life itself, on services and supports that have traditionally been considered optional and of little value in relation to their cost—the answers to these questions are of inestimable importance.

Whatever the answers, the trend NCD observes is for the evidentiary standards of practice and the outcome standards for evaluation to be centralized and formalized. If formal evaluation processes are to be increasingly demanded in order to qualify treatments and devices for coverage, how will the low-incidence but high-impact interventions needed by people with disabilities be ensured a place anywhere near the front of the evaluation queue? If an extended time frame is required for the evaluation of a practice or treatment that has strong practitioner and professional support but little empirical data behind it, how will the practice be handled pending the completion of controlled research that meets prescribed methodological standards? Will it be covered based on practitioner experience and belief, or will it be withdrawn because of the lack of supporting clinical validation? And if particular modalities, such as sensory access or mobility technology, yield measurable improvements in the quality of life for their users but don't result in any changes that would be regarded as medical in nature, will they be eligible for coverage?

NCD appreciates the need to ensure that public resources are wisely and efficiently used, but the Council continues to be concerned that, unless the processes for creating official and governing standards of practice and criteria for outcomes are inclusive, the results will too often omit or inadvertently harm people with disabilities.

2. Accountability

Perhaps no single word is heard more often in the discussion of domestic policy today than accountability. Problems with accountability as it is often discussed relate to the difficulty of grasping or tracking the cross-program nature of many outcomes. An example (discussed in Chapter 4) illustrates the twofold problem this creates. The Medicare program has engaged in a process of changing the standards for which beneficiaries are eligible to obtain powered wheelchairs and other powered mobility devices. It is widely believed that these changes will result in significant curtailment of access through Medicare (including, therefore, access for recipients of Social Security Disability Insurance to their health care through Medicare) to these devices. What is the range of consequences that accountability and outcomes measurement will encompass? Put another way, what are the medical outcomes of these changes, and are there other outcomes that, although not traditionally considered medical in nature, need to be considered as part of the powered-mobility proposal review process?

For example, many people believe the new rule will result in loss of employment for some people with disabilities who use powered mobility devices to get to and from work as well as in their homes (but who would be ineligible to receive them under the new Medicare standard). Should the Centers for Medicare and Medicaid Services (CMS) be required to assess the extent of this risk before implementing the new eligibility requirements? If the new rule does result in job losses, should vocational programs suffer in their accountability ratings as a result? Where does accountability end? What responsibility does accountability impose on one agency or program for the effects its self-referential decisions have upon the success and resources of another?

Current evaluation procedures and outcome measurement criteria derive from two principal sources: the Government Performance and Results Act (GPRA) and the OMB's Performance Assessment Rating Tool (PART) Performance Measurements Program (used for rating programs in the federal budget). Neither GPRA nor PART currently lends itself to this kind of cross-program, interagency outcomes analysis. NCD believes this must change before accountability can be meaningfully assessed or applied.

Perhaps nowhere is the meaning of accountability more critically at issue than in the area of civil rights. Although various statistical, caseload, case-processing time, complaint outcome, and other measures can be used to assess the administrative efficiency of civil rights programs, fundamental questions about the value of civil rights enforcement do not lend themselves to any conventional outcome measures or cost accounting. While administrative efficiency and internal controls are key, only in the extent to which civil rights compliance and resultant equal opportunity are increased can programs' value ultimately be measured.

NCD believes that vigilant civil rights enforcement is an indispensable component of any balanced effort to achieve equality of opportunity in society. But if statistical evidence were needed to justify this belief, one would be hard-pressed to produce it. Evidence of the costs of compliance to industry and government can readily be produced, but comparable data demonstrating the value of a just society or tracking the impact of vigorous enforcement on public attitudes and behavior over time is hard to define, let alone to collect. Yet the incredible complexities surrounding efforts to demonstrate the benefits of a just society, and the likely impossibility of ever proving them with statistics, does not make the critical importance of promoting a just society any less meaningful or urgent.

NCD enthusiastically supports the goal of extending accountability to as many programs and sectors as possible. But the Council is concerned about two features of this effort. First, the Council is concerned with the increasing tendency on the part of some in Congress and the Executive Branch to equate the dollar costs of compliance or participation with burdensomeness or ineffectiveness. While NCD believes that the costs of compliance with all laws should be minimized, the Council also strongly believes that emphasis on the dollar costs to government and business of compliance is premature, unless accompanied by reciprocal attempts to ascertain the costs of noncompliance for individuals and for society as a whole. No statistic collected by government would recognize as a cost of nonenforcement the amount of money not earned by a person with a disability who does not get a job because of discrimination. There is no mechanism for measuring the dollar, let alone the human, benefits of civil rights compliance or for readily comparing those benefits with dollar costs. Yet all too often discussion and debate about how much compliance costs seem to end with the furnishing of cost data by those entities in a position to collect it.

Cost savings to some, without the fullest possible inquiry into the related cost benefits and losses to others, cannot represent a sufficient approach to outcomes measurement in civil rights or in any area of traditional public concern.

NCD's second concern regarding accountability is the shrinkage of options by which citizens with disabilities can hold government and its private sector partners accountable for misapplication, error, or even discriminatory implementation of the law. Along a broad front, virtually every major program reauthorization enacted by the last Congress and every major proposal by the administration contains some curtailment of the means available to individuals for seeking redress. Most notable among these are provisions of the Individuals with Disabilities Education Improvement Act (discussed in Chapter 3) that create the possibility, under an as yet imprecisely defined legal standard, for parents who appeal against special education decisions made in connection with their children to be held financially liable for the potential attorneys' fees of their school districts. NCD has already heard several anecdotal reports of dissatisfied parents being told by school administrators, “If you lose, you pay.”

While recognizing and respecting the widely held view that in many settings the pendulum has swung too far in the direction of individuals’ ability to intervene in expert decisions or to thwart program administration, NCD believes that accountability must be a two-way street. While federal and state oversight have always been and should remain the chief guarantors of program effectiveness and integrity, history teaches that individual self-advocacy has served not only as a spur to effective oversight but also as the source of some of our most important programmatic innovations.

Assuming the best intentions in the world, administrators may often have as much difficulty as recipients understanding the inordinately complex and technical nature of many laws. Serious and potentially harmful errors in their interpretation and administration are inevitable. Yet, against this backdrop and at the very time when we are seeking to give consumers increased control over their own lives in a variety of program settings and relationships, it would be sad indeed if we simultaneously witness systematic efforts to limit the ability of consumers to protect their growing rights.

(c) Coordination

In light of the concerns about cross-program accountability noted previously, it is extremely gratifying and reassuring to note that President Bush’s New Freedom Initiative (NFI) recognizes the interconnection of programs and subjects. The creation of issue-specific task forces and interagency committees and working groups, the issuance under the NFI rubric of multiagency reports, and a variety of other measures reflect this awareness.

In 2004, NCD published *Livable Communities for Adults with Disabilities* [2]. This report vividly shows how a variety of programs must work together efficiently to achieve a high quality of life for intended beneficiaries. As NCD’s work and common experience make clear, it is no longer possible to look at housing in isolation from transportation, at employment separately from health care, or at income supports in old age apart from long-term services and noncash supports. The challenge is to shape this growing awareness into processes that will fulfill the promise of coordinated planning and programming.

In part, the need is to develop accountability measures that reflect the full extent of program impacts and possibilities. But there is also an increasing need to develop planning, budgeting, analytical, and scoring methodologies that anticipate interactions and that take them into account from the very beginning. Without such intelligent design, programs are likely to continue to work at cross-purposes, to counteract each other in foreseeable or unforeseeable ways, or to create a patchwork of inconsistency and complexity impenetrable to anyone who does not devote full time to understanding the complexities.

NCD does not underestimate the difficulties associated with such efforts. Throughout this report, readers will encounter these difficulties in illustrations of inconsistency or even conflict among programs, and in instances in which the recognition of the need for coordination was sincere but achievement of the goal was largely lacking. Broadly speaking, as these examples show, the methods for implementing this next vital step in effective planning and budgeting are yet to be devised or put in place. It remains the unmet challenge, but the unique opportunity, of the NFI to demonstrate that government can act coherently, effectively, and constructively with its limited resources to build livable communities and to honor productive lives.

Each of the following chapters provides recommendations that flow from the data collected; the Council believes that these recommendations are responsive to the issues raised and to the resources available. The recommendations are also collected in a section at the end of the report. While recognizing that not all of them can be adopted, the Council believes that all will contribute to informed discussion and to the wisest and most inclusive decisions in the year to come. NCD stands ready, as it has for the past 20 years, to be of all possible help and support in these efforts.

Chapter One—Disability Statistics and Research

Introduction

Statistics increasingly lie at the heart of public policy and represent the chief source of data on which policy is based. No longer can anecdotes or emotions suffice to guide programs and expenditures. In this era of growing insistence on evidence-based data, the accuracy and completeness of our statistics thus become more important than ever.

In few areas of public policy are the demographic and other data collection issues more complex than in the area of disability. This chapter will examine the complexity and importance of some of these issues.

Section (a) addresses the role of the Census in creating our understanding of the nature and extent of disability, and in fashioning our response. Section (b) addresses new areas where statistical data is becoming a predominant source of evidence-based policy. Section (c) considers some potentially important groups that may fall through the cracks of current statistics-gathering efforts. Finally, Section (d) discusses the importance of the information we collect, as well as about whom we collect it.

(a) The Extent of Disability

The importance of the U.S. Census conducted every 10 years (the Decennial Census) and its interim and subsidiary surveys—including the Current Population Survey (CPS) and the American Community Survey (ACS)—is well known. The Census determines the allocation of seats in the House of Representatives among (and in some cases within) the states; it governs numerous funding formulas used in distributing federal funds; and it plays a large role in defining many of the issues and problems our nation faces. One need only look at the current debate over Social Security reform to see the way statistical projections of revenue, expenses, and population drive our perception of and response to problems.

One important goal of Census data collection is to determine the size of various subgroups of the population. This includes people with disabilities, whose numbers, employment and economic status, educational attainments, and health status are all vitally important questions. But while some groups may be difficult to find and count, no population subgroup presents the definitional complexities that characterize the population of Americans with disabilities.

NCD has long and carefully documented the importance and the strengths and weaknesses of our efforts to obtain accurate data on people with disabilities. Through our annual status reports and through such studies as our January 2004 report *Improving Federal Disability Data* [3], NCD has provided detailed commentary and strong and continuing support for improved data collection. Those concerned with these issues are urged to study this paper in depth. For the moment though, it is important to look forward to the 2010 Decennial Census, which holds out the opportunity for improving on our past efforts.

In this connection, NCD is concerned about both the content of disability-related questions and the procedure for validating these questions and arranging for their inclusion in the short-form household survey questions and the long-form follow-up interviews. Recognizing that time is limited, even at this midpoint in the 10-year Census cycle, NCD reiterates its commitment to work with the Bureau of the Census, the Bureau of Labor Statistics, and other key partners in field-testing appropriate and useful question formulations.

Broadly speaking, so far as the content of recommended questions is concerned, NCD believes that previous versions have suffered from two fundamental weaknesses. First, they have left the assessment of disability too much to the subjective responses of answerers. Second, the approaches taken have overstated and oversimplified the correlation between disability and work.

Changes in the nature of work, together with advances in technology and evolution in attitudes, have made it possible for more people with disabilities than ever to work. Any serious effort to use employment status as a marker for disability, therefore, requires attention not merely to the functional limitations posed by a physical or mental condition but to the barriers of design, transportation, disincentives, and attitudes that may combine to limit options and prevent successful outcomes. Hence, as part of our effort to understand the links between disability and the painful persistence of high levels of unemployment or underemployment, our inquiries must include an effort to obtain some sense of respondents' understanding of what factors have contributed to their failure to obtain or retain employment, and of what factors most influence their efforts and expectations in this regard.

To help clarify the relationships among physical or mental function, intervening societal variables, individual employment, and health or educational status, and to help reduce the subjectivity inherent in the disability data collection process, NCD recommends that the Interagency Committee on Disability Research (ICDR) undertake an intensive assessment of the feasibility of applying the principles and organization underlying the World Health Organization's International Classification of Functioning, Disability and Health (ICF) to the formulation of Census questions [4].

In this connection, NCD also recommends that Congress adopt legislation requiring the Census Bureau to determine to the best of its ability, and to report to Congress the estimated number of persons with disabilities in our nation, together with the methodology used for arriving at that number.

(b) New Uses of Statistics

More and more, our evidence-based policy environment seeks and uses objective performance data to evaluate the impact of a variety of measures and programs. To a large degree, this objective data is statistical in nature. Moreover, in terms of planning, the objectives of many major initiatives are being expressed in statistical and numerical terms. From the savings expected to result from the National Health Information Infrastructure (NHII) discussed in Chapter 4, to the health improvements anticipated under CDC's Healthy People 2010 initiative, to the energy savings predicted by those who favor a two-month extension of daylight savings time, proposals and policies are judged by objective statistical results.

Existing data collection techniques are being reviewed (as in the current discussions of reauthorization of the Workforce Investment Act), and new instruments and categories of data are being created (as in the tracking mechanisms put in place for educational reform or that will be used to measure the savings accrued under the NHII). A crucial issue in all these cases is that the potential for differences in the ways programs affect people with disabilities must be taken into account. It is possible that programs that yield aggregate statistical or outcome gains may not always do so for people with disabilities. It is equally possible that initiatives that do not demonstrate large-scale benefit or cost-effectiveness may have a significant impact on the lives of various subgroups, including people with disabilities. Finally, evaluative criteria used to measure program impact or program value cannot always be the same for people with disabilities as for people without disabilities. For example, one would not expect the per capita costs of successful long-term job placements to necessarily be the same for people with disabilities as for other people, any more than one would expect them to be identical for well-educated computer professionals and non-English-speaking manual workers.

Sophisticated approaches to the design of measurement strategies and tools will be needed across a broad spectrum of programs to capture and understand the key nuances and distinctions. To give a graphic example, no one would expect the per operator technical assistance call volume or call time for operators receiving TTY calls to be the same as for operators receiving voice calls. Yet, unless recognition of such distinctions were factored into the evaluation of an information and referral (I&R) service, the existence of such differences, let alone their significance, would be lost under the weight of undifferentiated, aggregated numbers.

In this light, NCD recommends that OMB incorporate measures for identifying disability-related variables in its review of all management data practices and procedures and of all data-collection instruments. OMB should not endorse or utilize data-collection instruments or program-review criteria that fail to take these variables into account. OMB should adopt methods for determining when such impacts are most likely to occur and, if they occur, when they are most capable of either skewing or being obscured by aggregate data.

(c) Reporting Requirements

Each year, seemingly countless numbers of agencies and programs submit their statutorily required reports to Congress. In light of our findings in the child-maltreatment area—that required state data was not being systematically collected or forwarded to Congress (Chapter 6)—NCD recommends that the Government Accountability Office (GAO) conduct a broad-based study of statutorily required agency, program, GPRA, and other periodic reports submitted to Congress. This study should examine the extent to which statutorily required data or other information pertinent to programs and policies affecting people with disabilities is being collected, analyzed, and made available to Congress for its consideration and use. GAO should, of course, be free to utilize such sampling techniques as it believes adequate in reaching reliable determinations on these points.

NCD recognizes that a number of existing reporting requirements may prove unrealistic, outmoded, or unduly expensive. In these cases, the Council expects that Congress will reevaluate the requirements in the light of current resources and today's informational needs.

(d) Scoring

The FY 2006 budget proposals submitted by the President to Congress will result in painful and austere decisions. Many programs, including programs of importance and concern to people with disabilities, are certain to undergo cuts or even be eliminated. Administration recommendations on what programs should be cut or abolished will hinge in part on what are known as PART (Performance Assessment Rating Tool) ratings. These are the scores or evaluations assigned to each program by the OMB.

Without regard to any particular program, NCD believes that the process of PART scoring has taken on sufficient importance to warrant discussion and attention. Congress, in most cases, will rightly defer to OMB's considered judgment of the relative merit of various programs in its deliberations over budgets and authorizing legislation. For this reason, NCD regards it as vitally important for Congress and the public to have the fullest possible understanding of both how the ratings process is conducted and the assumptions and goals underlying the ratings.

NCD's particular concerns—which the Council has addressed before in the context of Congressional Budget Office (CBO) scoring [5] and the application of "undue burden" and similar standards under civil rights legislation—remain simple and straightforward. Do the criteria used fully reflect the impact of the program on the lives of the individuals to be served? Do those criteria take full account of the cross-program, intergovernmental, and long-term costs and benefits of programs? And do the methods and criteria used consider the opportunity costs that would result from elimination of the program or service?

To ensure that the criteria and methods used to evaluate programs are fully consistent with the goals of Congress in establishing the program or service, and to create the opportunity for public input into the processes by which the value of competing priorities are assessed, NCD recommends that GAO undertake a study of the PART system with a view to determining the way it reflects and balances the range of human, administrative, and other considerations that effective management and fidelity to program goals must take into account.

Recommendations

Recommendation 1.1: NCD recommends that the Interagency Committee on Disability Research undertake an intensive assessment of the feasibility of applying the principles and organization underlying the World Health Organization's International Classification of Functioning, Disability and Health to the formulation of Census questions.

Recommendation 1.2: NCD recommends that Congress adopt legislation requiring the Census Bureau to determine, to the best of its ability, and to report to Congress the estimated number of people with disabilities in our nation, together with the methodology used for arriving at that number.

Recommendation 1.3: NCD recommends that OMB incorporate measures for identifying disability-related variables in its review of all management data practices and procedures, and in its review of all data-collection instruments.

Recommendation 1.4: NCD recommends that the GAO conduct a broad-based study of statutorily required agency, program, GPRA, and other periodic reports submitted to Congress. This study should examine the extent to which statutorily required data and other information of pertinence to programs and policies affecting people with disabilities are being collected, analyzed, and made available to Congress for its consideration and use.

Recommendation 1.5: NCD recommends that GAO undertake a study of the PART system with a view to determining the way it reflects and balances the range of human, administrative, and other considerations that effective management and fidelity to program goals must take into account.

Chapter Two—Civil Rights

Introduction

Chapter 2 addresses key civil rights issues in light of developments during 2004. It addresses them substantively, as well as in terms of the procedures and interagency relationships necessary to bring about effective implementation and advancement of the law.

The chapter begins with the Americans with Disabilities Act of 1990 (ADA). It addresses the current context of court decisions about the law and discusses means for capitalizing on the *Tennessee v. Lane* decision. It then discusses NCD's work on ADA, summarizing some of the Council's key findings and recommendations, including its support for the ADA Restoration Act. The chapter then considers the oversight role Congress can play in reviewing the proposed legislation and more broadly in reviewing the progress of ADA. Particular attention is paid to the authority and responsibility that continue to rest with Congress, even after the courts have asserted such a large role in interpreting ADA.

Finally, the ADA section discusses Executive Branch activities relating to updating ADA. These include the revision of the ADA Accessibility Guidelines and a number of other pressing issues not covered by the guidelines but of great importance to many of the law's constituencies.

Section (b) of the chapter deals with planning and coordination issues, including the budgeting process involved in effective and coordinated enforcement of disability rights laws. With efforts to contain federal spending likely to grow more intense and imperative, anticipation of these issues and development of methods for maximizing resources and for performing evidence-based assessments of existing policies and priorities need to be developed while there is still time.

Section (c) deals with voting rights. It addresses developments and issues under both ADA and the Help America Vote Act (HAVA). Commending several major initiatives of 2004, the section emphasizes the need for continued attention and coordination among the several agencies involved in HAVA implementation and counsels that, even in a nonelection year, loss of focus or momentum would be dangerous.

Section (d) reiterates the need for hate crimes legislation to protect vulnerable people with disabilities from opportunistic or prejudice-based violence, much as laws already protect racial and ethnic minorities. The section recommends positive congressional action on pending legislation on this subject.

Section (e) addresses the need for legislation barring the improper use of genetic information. It reviews some of the concerns underlying the need for genetic nondiscrimination legislation, recommends adoption of legislation introduced into the last Congress, and identifies two areas in which interactions between genetic information and other privacy laws warrant executive Executive Branch investigation and action.

(a) The Americans with Disabilities Act

1. The Supreme Court's Landmark *Lane* Decision

In cases decided over the past five years, the Supreme Court has interpreted and applied the Americans with Disabilities Act. These cases are discussed in detail in NCD's series of issue briefs titled *Righting the ADA* [6]. The issues are brought fully up to date in NCD's major *Righting the ADA* report of December 2004 [7].

For the most part, these cases have been decided in ways that NCD and much of the disability community regard as violating the intent of Congress in adopting the ADA [8]. Several of the decisions interpreted ADA as a whole and are applicable to all of its three major titles of employment, state and local government, and public accommodations. Most notable among these would be the three decisions known as the *Sutton* trilogy, which held that whether an individual has a disability must be determined after the application of "mitigating measures" [9]. Other decisions specifically related to Title I, employment. Most notable among these is the *Garrett* decision, which held that Congress lacked constitutional power to authorize suits by private individuals against state governments seeking money damages for disability-based employment discrimination [10]. By the end of 2003, Title II of ADA, dealing with state and local government, had emerged as the least interpreted and least narrowed of the three major titles.

It was against this backdrop that the disability community watched the Supreme Court oral argument in January 2004 and awaited the Court's decision in the case of *Tennessee v. Lane.* The facts of this case have been so widely reported and discussed as to need no repetition here. Because the defendant State of Tennessee conceded that the inaccessibility of the courthouse was a violation of ADA [11], the legal issue in the case could be narrowly and clearly focused on whether the statute was constitutional in authorizing suits by citizens against states. Thus, Tennessee contended not that it had complied with the law, but that the suit seeking to enforce the law and punish its violation could not be brought. The state argued that this suit was barred by recent Supreme Court decisions holding that the Fourteenth Amendment prevented suits by private citizens against states to enforce a number of federal laws. ADA, Tennessee argued, should be added to that list.

The plaintiffs, on the other hand, contended that in light of the central role of access to the courts in any definition of citizenship or in any notion of full participation, the history of discrimination brought to Congress's attention when it enacted ADA provided ample constitutional justification for the law and the enforcement mechanisms it contained [12]. Moreover, the plaintiffs contended that without the right of citizens to enforce the law, including by suit, no effective means for protecting many key civil rights would exist.

By a 5-4 margin, the Supreme Court ruled that Title II's application was constitutional and that the lawsuit could be brought and decided on its merits [13]. Reflecting its crucial awareness of the importance of access to the courts, the decision stated the following:

"Like Title I, Title II seeks to enforce the Fourteenth Amendment's prohibition on irrational disability discrimination. But it also seeks to enforce a variety of other basic constitutional guarantees, including some, like the right of access to the courts here at issue, infringements of which are subject to heightened judicial scrutiny. Congress enacted Title II against a backdrop of pervasive unequal treatment of people with disabilities in the administration of state services and programs, including systematic deprivations of fundamental rights. With respect to the particular services at issue, Congress learned that many individuals, in many States, were being excluded from courthouses and court proceedings by reason of their disabilities. Congress's chosen remedy for the pattern of exclusion and discrimination at issue, Title II's requirement of program accessibility, is congruent and proportional to its object of enforcing the right of access to the courts.

"This duty to accommodate is perfectly consistent with the well-established due process principle that, within the limits of practicability, a State must afford to all individuals a meaningful opportunity to be heard in its courts.

"Ordinary considerations of cost and convenience alone cannot justify a State's failure to provide individuals with a meaningful right of access to the courts."

As with so many far-reaching Supreme Court rulings, the real meaning of the *Lane* decision may take some years to unfold. Of course, the decision prevented a dramatic further closing of the courts to people with disabilities in the most literal sense of the word. But time and further cases will be required before we can know whether the Court will apply these access rights to a broader range of state and local government services, facilities, and programs, or whether it will restrict this role for Title II enforcement to a narrow range of settings (like courthouse access) deemed particularly central to equality and citizenship.

NCD commends the Supreme Court for its enlightened and careful analysis in the *Tennessee v. Lane* case. In light of the narrow margin of victory, the uniquely compelling facts underlying the case, and the special scrutiny long extended to access to the courts, the Council also recognizes that much work and reinforcement will be needed if the *Lane* decision is to take its enduring place in the annals of civil rights. For the moment though, it may be worth noting that the decision was issued 50 years to the day after the Supreme Court announced its *Brown v. Board of Education* ruling, regarded by many as the seminal court decision of the 20th century.

NCD believes there is much the disability community, Congress, and other interested citizens can do to help ensure that *Lane* lives up to its highest potential. Therefore, the chapter turns next to some strategies for preserving and revitalizing the civil rights values enshrined in ADA.

2. The ADA Restoration Act

NCD has proposed the ADA Restoration Act [14] as a means for correcting what our analysis concludes are the serious and unwarranted losses of civil rights protection for people with disabilities resulting from the succession of Supreme Court decisions noted previously. NCD's proposals do not come lightly, but are supported by exhaustive analysis of the nature, rationale, and impact of judicial decisions interpreting and applying ADA. In its report *Righting the ADA*, released December 1, 2004, NCD analyzes each of the key legal controversies the Supreme Court and the lower courts has addressed [15]. While recognizing that Congress cannot alter the Supreme Court's constitutional decisions, many of the most pressing issues reflect only judicial interpretations of the statute that can be modified by Congress.

This annual status report is not the place to detail the findings of the *Righting the ADA* report or the proposals contained in the recommended legislation. NCD urges all those with an interest in this subject, or who recognize the importance to the future of our nation of its efforts to fully include people with disabilities in mainstream society, to review the report in depth. We believe that people of goodwill will find its recommendations sensible and balanced, carefully designed in accordance with the original intent of Congress, and capable of achieving the goals of ADA in a manner that both maximizes the opportunities for inclusion of people with disabilities and reflects the rightful desire of all to prevent undue financial and other burdens from falling on individuals, businesses, or other entities and institutions.

Therefore, NCD recommends that the 109th Congress include among its highest domestic priorities the holding of public hearings on the proposed ADA Restoration Act legislation. In approaching these oversight and legislative hearings, NCD urges that Congress proceed with several key points in mind. First, Americans with disabilities have reason to feel alienated from and fearful about the law's ability to protect their rights. Second, people with disabilities note the repeated introduction in Congress of the ADA Notification Act that, by imposing notice requirements before the filing of suits under ADA, would treat ADA claimants differently from people seeking to assert their rights under any other federal law [16]. Third, people with disabilities note language in Supreme Court opinions suggesting a belief among some of the justices that disability discrimination is rational [17]. And fourth, people with disabilities recall that the Supreme Court has applied principles of statutory interpretation to ADA that are at variance with those normally used in other civil rights contexts, which the court adopts and abandons without explanation, but in ways that seem to indicate their selective use to bring about negative results. [18]

There is yet another matter that NCD urges in Congress's consideration of these hearings. Beyond the suspicion of double standards, one-of-a-kind ad hoc legal reasoning, judicial hostility, and result-oriented decision making, there are two problems with the Supreme Court's decisions that cannot be overlooked. First, the decisions are consistent in expressing concerns for the impact of ADA on the costs or other burdens and responsibilities faced by private, state, or local governmental entities [19]. Absent from the decisions, however, is any parallel concern for the impact of the rulings on the lives of Americans with disabilities or any effort even to assess that impact. Put another way, there is little attempt to place a value on opportunity costs borne by large numbers of individuals with disabilities or to balance these costs with the financial costs to government or the private sector. There is no recognition of the admittedly complex, finely crafted set of assessments developed by ADA to ensure that just such balancing takes place.

Let us examine one important case in this light. In *Murphy v. United Parcel Service*, the Supreme Court ruled that employees with diabetes were not entitled to reasonable accommodations (such as specifically timed breaks to take insulin) because their blood sugar could be controlled by medication [20]. Such medication was a mitigating measure, and with it taken into account, these workers failed to meet the law's definition of disability, because no major life activity was substantially limited by their physical condition. It can be argued that if these workers are not covered by ADA, the impact of the decision on them is beyond the scope of the Court's inquiry. After all, the decision was jurisdictional, and how can the impact on people who simply fall outside the jurisdictional category be part of the record or the discussion?

But whether covered by the law or not, the fact remains that some of these workers may continue to need reasonable accommodations, and some are going to be unable to control their blood sugar and insulin levels adequately with drugs, and some are going to have insurance that doesn't cover the needed pharmaceuticals. How many people have lost jobs or have failed to obtain or been refused jobs because employers, freed from any obligation under ADA, simply decided that in a labor market with more applicants than jobs, they might just as well not bother hiring someone with diabetes who might prove more complex or expensive to manage or insure?

One would have thought or hoped that the U.S. Supreme Court, which has shown itself willing to speculate about financial or other harms to business or government going well beyond the record in many of the cases before it, would pause to recognize the utility, if not the imperative, of at least acknowledging the consequences of its rulings for the vulnerable and isolated individuals whose destinies are at issue in those cases. The Supreme Court had every right to hold that the law does not cover them, but NCD believes it owes the American people some acknowledgment of their existence and some awareness of the likely harm that will befall many.

NCD also looks forward to working with Congress to identify key facts and myths, and to helping distinguish the products of data and experience from those of misunderstanding and fear, as well as, more important, to emphasizing the potential of hope. For example, a number of states have adopted definitions of disability that are broader than ADA's definition, as narrowed by the courts [21]. Many of these definitions dispense with the requirement of a showing of "substantial limitation" in a major life activity, and some do not look to the potential availability of "mitigating measures," regarding these mitigating measures as relevant not to the definition of disability but to the question of what accommodations or services would be appropriate.

What is important about these alternative definitions is what has and what has not happened in the states that have adopted them. NCD is unable to find a shred of empirical data or even credible anecdotes suggesting that use of these alternative, far less restrictive definitions has resulted in increased expenses, additional demands, or any other burdens or impositions on small business. Any claims that broadening of the ADA definition would give rise to such risks must carry a burden of proof in light of the evidence of absence of any such consequences in a number of states.

Another issue NCD hopes to assist Congress in fully addressing is the way the role of the courts and the balance of power among the branches of government have been changing since ADA was written. Through the use of the Commerce Clause of the Constitution [22] and, as noted above, the Eleventh and Fourteenth Amendments, the Supreme Court has shown itself willing to declare congressionally enacted civil rights laws unconstitutional. Under these circumstances, Congress must not lose sight of the prerogatives and responsibilities it retains, including its right and responsibility to review and react to judicial determinations of what Congress itself meant to do or say in various statutes. Even if Congress were to determine that it was entirely satisfied with the Supreme Court's ADA jurisprudence, that determination should come after a full and public review of what the Court has done.

A related concern involves the often-used term "judicial activism." Throughout the recent campaign, President Bush insisted strongly that appointed judges, however wise and well intentioned, should not make decisions best left to the people through their elected representatives. In the case of ADA, the analytical tools the Supreme Court has adopted have led to a situation in which in many instances judges are called on, with little guidance from anywhere, to decide whether a given physical or mental impairment does or does not limit a major life activity and, if so, whether the limitation is substantial. As documented in the Council's *Righting the ADA* report, the Supreme Court has not been consistent or clear in its definition of "substantial limitation" or even in its identification of which "major life activity" is relevant in each situation. As a result, there is uncertainty today as to whether working, in its own right, is regarded by the Court as a major life activity.

Judges also have little guidance on what, if any, nexus needs to exist between a major life activity and the tasks of the job. The situation is, in short, impossibly confused, leaving employees, employers, and parties to various other relationships and transactions dangerously uncertain and unnecessarily fearful. Uncertainty in the law is never good for anyone—not business, government, or the individual and family. The costs of uncertainty are difficult to measure, but surely they are as or more worthy of concern than the costs of compliance.

At the moment, it is enough to say that Congress will find fertile opportunity for rebalancing the law, for taking into account a host of legal and technological developments of the past 15 years, and for clarifying expectations and responsibilities across society by taking up the findings and recommendations of NCD's report.

3. The Americans With Disabilities Act Accessibility Guidelines

A. Guidelines Revision

The Americans with Disabilities Act Accessibility Guidelines (ADAAG), promulgated by the U.S. Department of Justice (DOJ) in 1992, represent the principle regulatory guidance for interpreting ADA [23]. The ADA statute contemplated that the guidelines would be updated from time to time. The process of updating the guidelines began in 2004 with the issuance on July 23 of proposed new and revised guidelines by the Architectural and Transportation Barriers Compliance Board (Access Board) [24].

The proposals issued by the Access Board will not necessarily become law, however. Ultimately, the final guidelines will be those adopted by DOJ. As its opening step in the process, the Department issued an advance notice of proposed rulemaking (ANPRM) seeking public comment on, and examples of, cost-benefit data bearing on ADA [25]. The comment period ended January 28, 2005. Thereafter, following review of the comments and of the Access Board's proposals, DOJ issued a notice of proposed rulemaking (NPRM) and extension of comment period until May 31, 2005, setting forth its proposed final guidelines and providing opportunity (typically between 60 and 120 days) for public input before the revised guidelines become final.

NCD commends the Access Board for its work in updating the guidelines. In particular, NCD appreciates the clarification of legal requirements that should result from inclusion in this edition of the guidelines of subjects and facilities covered by ADA but not previously referenced by ADAAG. Among these requirements are children's playgrounds, public rights of way, correctional facilities, and recreational facilities [26]. Accordingly, NCD recommends that coverage for these important facilities and services be retained in the final DOJ guidelines.

Pending the issuance of the NPRM, NCD will not make detailed comments on the Access Board's proposals at this time. The Council does, however, believe that legal developments involving ADA during 2004 give rise to an urgent need for certain matters to be covered. These matters are not required by the statute to be addressed, so they are not included in the Access

Board's revised ADAAG proposals; but they are issues that have been brought to the fore by court decisions and by changes in technology in recent years.

B. Needed Update

First and perhaps foremost among subjects the DOJ must address, whether through ADAAG or by other means, is the issue of the applicability of ADA to the Internet. In September 2004, in the case of *Access Now v. Southwest Airlines*, the U.S. Court of Appeals for the Eleventh Circuit dismissed the appeal from a lower court decision [27]. The district court had concluded that the Web site of Southwest Airlines was not covered by Title III of ADA and therefore did not need to be accessible. This ruling by the Court of Appeals has been widely misunderstood, but that very misunderstanding, together with the reasons for it, demonstrate why action by DOJ is greatly needed by potential plaintiffs and defendants alike. NCD commends DOJ for the amicus briefs it has filed in several cutting-edge Internet-related ADA cases [28], but more needs to be done to clarify the law.

Although the effect of the Court of Appeals action in the Southwest Airlines case was to let the lower court judgment against accessibility stand, in fact the Court of Appeals did not affirm or endorse the judgment of the lower court. It simply dismissed the appeal from that judgment, principally on the ground that the issues sought to be raised in the appeal could not properly be considered by the appeals court because they had not been raised before the lower court first.

Thus, key questions of ADA jurisdiction and statutory interpretation were left open. Most important among these is the question of whether airline Web sites or related electronic and information technology (E&IT) such as ticketing machines, baggage weighing machines, and other such modalities are governed by ADA at all or by the Air Carrier Access Act (ACAA) [29]. As discussed in Chapter 10, the Department of Transportation believes that the ACAA is the controlling statute; it has issued an NPRM that would establish accessibility requirements for airline Web sites.

The Eleventh Circuit never considered the role of the ACAA. But regardless of which statute controls the situation, a second key problem has to do with issues the plaintiffs did try, but were unsuccessful in, raising. This is the nexus theory of ADA applicability to private sector Web sites. In essence, the nexus theory, which a number of courts have endorsed [30], holds that if there is a sufficient connection or nexus between the Web site and activities conducted at a "place" of public accommodations, then Title III of the ADA requires that the Web site, as an extension of the place of public accommodations, be accessible, even though Title III may not generally apply to Web sites.

Through the ADAAG update process or by other means, DOJ needs to provide guidance to business and the public as to its views regarding the viability of the nexus theory and as to, if nexus is the proper test to be applied, what standards determine when a sufficient nexus exists to trigger application of ADA to the commercial Web site. Leaving the matter wholly to case-by-case determination cannot serve the interests of predictability or effective Web design. With some courts embracing nexus, others completely denying the applicability of ADA to the Web under any circumstances, and still others accepting that ADA covers the commercial Web without need of establishing a nexus, failure by DOJ to authoritatively address this issue can only lead to uncertainty and chaos.

4. Other Issues

Experience with ADA over the past year has suggested a number of other areas in which DOJ may wish to address emerging questions or problems of interagency coordination in the law's interpretation.

A. Service Animals

One of the great advances wrought by ADA is the establishment of a clear right, not dependent on varying state laws, to use and be accompanied by service animals in places of public accommodation [31]. Recently however, attempts to expand the definition of service animals under other laws have created the potential for confusion.

In 2003, the Department of Transportation (DOT) issued a new and expanded definition of service animals [32]. This definition was promulgated under the ACAA and is the basis for determining what service or companion animals will be allowed to accompany people on commercial air flights and in airports. The trouble is that because this definition was established under the authority of a different statute than ADA, and applies only in places where ACAA takes precedence over ADA, a traveler who is allowed to take a companion animal on an airplane may arrive at her destination only to find she is not allowed to bring the same animal into her hotel room at journey's end. Great confusion and real danger to the person and to the animal can result.

In this connection, anecdotal information reaching NCD indicates that many people believe that a physician's prescription of a service animal is enough to qualify the animal as a service animal entitled to admission to places of public accommodation. While it is not clear where this erroneous belief comes from, it may have something to do with confusion between the provisions of ADA and the requirements of other laws. For instance, the Internal Revenue Code (IRC) allows service animal costs to be deducted as medical expenses but does not use the ADA definition [33].

It may be argued that since the ACAA and the IRC are not administered by DOJ, the Department lacks authority to provide clarification or coordination of statutes that it does not enforce. But DOJ can and should take the lead in developing joint issuances with the coordinate agencies involved so that confusion can be avoided and continuity in the understanding and application of the law can be maximized.

Apart from coordination between ADA and other statutes, concern is warranted over whether the procedures and standards adopted by the various federal agencies with concurrent jurisdiction over ADA reflect a high degree of consistency and coherence. While some variation is inevitable in how agencies interpret and apply the law, NCD recommends that DOJ should undertake a comprehensive assessment of ADA requirements, monitoring, and administration as understood and practiced by all federal agencies with relevant jurisdiction. If DOJ determines that excessive variation or inconsistency exists, it should seek to develop means for creating greater predictability and uniformity.

B. Availability of Legal Assistance

In January 2004, DOJ entered into a settlement with an upstate New York attorney whose failure to provide a sign-language interpreter in a domestic relations divorce case for consultations with his client who was deaf constituted a violation of ADA [34]. Discussions with people with disabilities, including but not limited to people with hearing impairments, have yielded concerns regarding whether people with various disabilities are finding availability of legal representation artificially constricted by the unwillingness of attorneys to take them on as clients.

NCD recommends that DOJ undertake an inquiry into this question, and that it develop and disseminate such targeted technical assistance (TA) resources as may be appropriate to remind the legal profession of its obligations in the client-acceptance, auxiliary services, office accessibility, and related areas.

C. Privacy and Confidentiality

In areas from health information to credit histories, individual privacy and data confidentiality are becoming matters of ever-growing concern and increasing legal magnitude. As the crime of identity theft has reached epidemic proportions, the significance of these issues and the consequences when standards are breached have become much more far-reaching and profound.

Many of the entities called on to guard privacy rights and adhere to confidentiality requirements in their dealings with people are also subject to ADA. The question of the interplay between its requirements and the requirements of other laws needs to be systematically addressed. Last year’s status report discussed the implications of informed consent and related requirements of the Health Insurance Portability and Accountability Act (HIPAA) for information access by people with sensory or other disabilities. As new and self-contained legal formulations—such as the new law governing access to credit reports (effective December 1, 2004)—come into play [35], it has become increasingly clear that a comprehensive review of these legal interrelationships between ADA and other privacy laws is greatly needed.

If a credit report is available to a person with visual impairment only in standard print, then, by definition (because the services of a third party are required in order to read it), confidentiality is impossible. If key oral information in a medical examination, including securing consent, requires the intervention of a sign-language interpreter in communication between practitioner and patient with a hearing impairment, confidentiality cannot be ensured.

How and whether ADA has anything to say about resolving these matters and about what is required represent important dimensions of the application of these and future laws to the lives of people with disabilities. Put simply, DOJ needs to determine whether the “effective communication” requirements of ADA are violated when people with disabilities are compelled to waive their privacy rights conferred under other laws because of the inaccessibility of personal information or because information is communicated inappropriately.

NCD recommends that DOJ develop procedures for anticipating issues arising under other laws but that impact ADA and procedures for working proactively with other agencies to develop strategies and approaches that answer key questions and provide necessary guidance.

(b) Federal Funding for Civil Rights Enforcement

The U.S. Commission on Civil Rights has regularly tracked federal spending on civil rights over the past 10 years, most recently in its report *Federal Funding for Civil Rights Enforcement: 2005* [36]. While this report documents greater support for some civil rights programs than for others, it reflects a firm and steady commitment by the Administration and Congress to the work of the Disability Rights Section of DOJ’s Civil Rights Division. But as all domestic spending comes under pressure in the effort to control federal spending, it is readily foreseeable that this, as well as other civil rights enforcement and outreach programs maintained by a variety of government agencies, may face stagnation or reductions in the resources available to do their work. On the eve of this new era of scarcity, efforts at coordination, planning, and priority setting will be required if the efficacy of civil rights programs is to be maintained.

NCD believes that such an effort must begin with two steps. First, procedures must be developed for maximizing effective coordination among agencies and programs in the information-collection, case-referral, rulemaking, and technical assistance–public outreach spheres. Existing planning processes, such as those carried out by each agency under GPRA, established intergovernmental review and coordination processes and other budget and program coordination activities carried out by OMB. While valuable, these activities do not necessarily ensure continuity and consistency in the interpretation and enforcement of major civil and disability rights laws.

The second, closely related step is to undertake serious planning for future levels and allocation of civil rights funding and other enforcement resources. What are the next steps for federal funding of civil rights enforcement? Where do we need to go? Are there optimal staffing ratios of personnel to caseloads, personnel to inquiries, or personnel to technical assistance commitments? What is the best allocation of resources among the potentially competing goals of public education, guidance development, public outreach, enforcement and other priorities? Among agencies with overlapping jurisdictions, what methods exist for determining the most effective allocation of resources, and what strategies exist for sharing of resources to leverage them as much as possible?

NCD does not presume to know the answers to these questions, but the Council believes it is critically important for them to be addressed thoughtfully and at the highest levels. NCD recommends that the administration appoint by Executive Order a high level commission to examine, beyond mere numbers and statistics, the effectiveness of current civil rights practices and relationships, to develop evidence-based tools for evaluating the relative efficacy of varying priorities and expenditure patterns, and to recommend overarching funding and administrative strategies to ensure effective cross-agency planning and monitoring efforts in the future.

(c) Voting

Voting was uppermost in the minds of many Americans during 2004. For voters with disabilities, it was a year of important milestones on the path to what the Assistant Attorney General for Civil Rights has justly called participation in democracy [37].

Developments occurring in 2004 can be divided into two groups. The first group relates directly to the integrity and accessibility of the voting process in 2004. The second group set the stage for full implementation of HAVA, which begins January 1, 2006.

Regarding developments pertaining to the recent elections, in February 2004 DOJ issued the ADA Checklist for Polling Places [38]. NCD commends DOJ for publication of this resource and believes it provided and consolidated important information and guidance on many issues faced in the various settings where polling takes place.

As valuable as the checklist was, it necessarily took only ADA as its point of departure, because HAVA was not yet in effect. Thus, the checklist had comparatively little guidance to offer about the nonphysical barriers to voting, such as inaccessible voting machines that many voters with cognitive, sensory, or other disabilities continue to confront. The coming challenge will include creating the synergy between ADA and HAVA that will bring about the greatest overall benefit.

Because of the dual or potentially overlapping jurisdiction created by HAVA, developments under that statute are also of great importance. In this connection, NCD congratulates the federal Election Assistance Commission (EAC) for its issuance, in conjunction with the National Institute on Standards and Technology (NIST) in April 2004, of the report *Improving the Usability and Accessibility of Voting Systems and Products* [39]. Without standards as to what constitutes accessibility in the design and operation of voting systems, the challenge of promulgating and implementing voting accessibility requirements cannot be effectively met. For this reason, the EAC-NIST report, mandated by Section 243 of HAVA, represents an important marker on the path to achieving the goal of at least one accessible voting machine per polling place by 2006.

Although the 2006 elections may seem a long way off, efforts to effectuate the new law by then must proceed every day, without loss of focus or resources. As is so often the case with major initiatives and crucial concerns, jurisdiction is divided among a number of federal agencies, including, in this case, the EAC, the Department of Health and Human Services (HHS), and DOJ. Congress, through the appropriations process, will also continue to play a key role, as will state and local elections officials around the country.

Beyond noting its concerns and urging continued focus and attention, NCD has no new recommendations to make at this time.

(d) Hate Crimes

NCD continues to believe that our law needs to do more to recognize and respond to the problem of crimes against people with disabilities. As detailed in annual status reports over the past several years, NCD believes that prejudice of the sort eligible for enhanced punishment is a factor in many offenses against people with disabilities. For this reason, the Council has continued to advocate for inclusion of disability in federal hate crimes legislation.

NCD supports the Local Law Enforcement Hate Crimes Prevention Act of 2004 (H.R.4204; see also S.966), which was introduced with 178 cosponsors in April and referred to the House Judiciary Committee's Subcommittee on Crime, Terrorism and Homeland Security

NCD recommends that this legislation, or other legislation embodying similar protections for crime victims and vulnerable people with disabilities, be reintroduced and passed in the 109th Congress.

(e) Genetic Discrimination

NCD has repeatedly expressed serious concerns regarding the misuse of genetic information, including in each of the last three annual status reports. While valuing and supporting the enormous potential of genetic testing and treatment to identify health problems and improve treatments, NCD also recognizes that unrestricted access to genetic information by employers, insurers, landlords, or others can result in the making of crucial decisions about people's lives on the basis of factors that ought to play no part in critical access to employment, insurance, or housing.

NCD therefore recommends that the 109th Congress make the adoption of genetic nondiscrimination legislation a top domestic, health care reform and human rights priority.

Pending congressional action, NCD urges the following two measures upon the Administration. First, the Attorney General should determine whether genetic decision making in the employment context ever constitutes a violation of ADA. To the extent that an employer declines to hire an otherwise qualified individual because of a genetic characteristic or predisposition of such person, the refusal to hire is generally not limited to a single or specific job. The refusal would, logically, apply regardless of the job being applied for. Arguably, this constitutes discrimination under the “regarded as” test of Title I of ADA [40].

NCD recommends that DOJ issue an opinion as quickly as possible regarding whether it considers refusal to hire on genetic grounds a violation of ADA and, if it does determine that such practices violate the law, that it immediately proceed, in cooperation with the Equal Employment Opportunity Commission (EEOC), to enforce the employment discrimination provisions of Title I of ADA accordingly.

NCD also recommends that the Secretary of Health and Human Services determine whether personal genetic information is covered by the privacy standards implemented pursuant to the Health Insurance Portability and Accountability Act of 1996 (HIPAA) regulations, implementation of which came into force in 2003. If, as the Council believes may be the case, genetic information should come under HIPAA protections, then HHS should move quickly to implement appropriate safeguards. Opportunities for protecting personal genetic information will also emerge in the design of the National Health Information Infrastructure (discussed in Chapter 4).

Recommendations

Recommendation 2.1: NCD recommends that the 109th Congress hold public hearings on the proposed ADA Restoration Act legislation and adopt its major recommendations.

Recommendation 2.2: NCD recommends that issues and guidelines proposed by the Access Board for inclusion in the revised ADA Accessibility Guidelines be retained in the final guidelines that DOJ adopts.

Recommendation 2.3: NCD recommends that DOJ should undertake a comprehensive assessment of ADA requirements, monitoring, and administration as understood and practiced by all federal agencies with relevant jurisdiction.

Recommendation 2.4: NCD recommends that DOJ undertake an inquiry into the issues of the availability of attorney services to people with disabilities where effective communication or other accessibility issues must be addressed in order to ensure an effective attorney-client relationship.

Recommendation 2.5: NCD recommends that DOJ develop procedures for anticipating issues arising under other laws but that impact ADA, and procedures for working proactively with other agencies to develop strategies and approaches that answer the key questions and provide the necessary guidance in such areas as privacy and confidentiality of personal information.

Recommendation 2.6: NCD recommends that the administration appoint, by Executive Order, a high-level commission to examine, beyond mere numbers and statistics, the effectiveness of current civil rights practices and relationships; to develop evidence-based tools for evaluating the relative efficacy of varying priorities and expenditure patterns; and to recommend overarching funding and administrative strategies to ensure effective cross-agency efforts in the future.

Recommendation 2.7: NCD recommends that legislation on hate crimes currently before Congress, or other legislation embodying similar protections for crime victims and vulnerable people with disabilities, be reintroduced and passed in the 109th Congress.

Recommendation 2.8: NCD recommends the 109th Congress make the adoption of genetic nondiscrimination legislation a top domestic, health care reform, and human rights priority.

Recommendation 2.9: NCD recommends that DOJ issue an opinion as quickly as possible regarding whether it regards refusal by employers to hire on genetic grounds to be a violation of ADA and, if it does determine that such practices violate the law, that it immediately proceed, in cooperation with the Equal Employment Opportunity Commission (EEOC), to enforce the employment discrimination provisions of Title I of ADA accordingly.

Chapter Three—Education

Introduction

This chapter will examine recent developments and current opportunities in the integration of the No Child Left Behind Act (NCLB) and the special education system, as recently revised by the Individuals with Disabilities Education Act (IDEA) amendments of 2004 [41]. After reviewing the regulatory environment in which key decisions are now being developed, major sources of guidance in formulating and implementing special education programs will be examined. These include NCLB; the findings of ongoing NCD oversight, including the Council's 2004 paper on improving educational outcomes [42]; and the new directions and initiatives embodied in the reauthorized IDEA.

The report will next discuss issues raised by NCD and other observers that have not been addressed either by IDEA or NCLB and its implementing regulations. Finally, the chapter will address developments in higher education as they relate to the aspirations and opportunities for students with disabilities.

(a) Current Context

1. The Legal Framework

On December 3, 2004, President Bush signed the IDEA amendments into law. This bill, at least two years in the making, reauthorizes and significantly amends the Individuals with Disabilities Education Act of 1997 [43].

Implementation of the law will proceed during the course of this year. The Department of Education (DOE) has issued a request for public comment as part of the process of writing implementing regulations [44], and the Department will hold focus groups in order to obtain stakeholder and public input [45].

NCD commends DOE for this participatory and inclusive process. NCD believes this outreach will result in useful and broad-based input, and NCD stands ready to be of all possible assistance to the Department as it goes about its work.

The work of implementing the new IDEA poses unusual challenges. Not only must a complex and far-reaching piece of legislation be interpreted and applied under requirements that place a premium on the least amount of regulation needed to apply the law [46], but the law must be interpreted and applied so as to maximize its consistency and coordination with NCLB, including under circumstances in which the absence of cross-referencing or the potential for contradiction makes this more difficult.

2. Individualization and Testing

When NCLB was enacted, one of its main premises was that federal involvement in education was too process-oriented and not sufficiently outcome-driven. Thus, NCLB concentrated on making improved student and school performance (measured primarily by academic outcomes) the chief goal of federal policy and the chief criterion for determining program outcomes and success. Under NCLB, schools and school districts are required to demonstrate adequate yearly progress (AYP) as measured by test scores, and all students are expected to participate and to have their test results counted in aggregate outcomes.

While it would be hard to find anyone who disagreed with the goals of annual improvements in school performance for all students, including students with disabilities, major issues surround full incorporation of the NCLB methods and standards into special education. Often, students with disabilities need to be assessed by alternative techniques, provided with reasonable accommodations, or learn in different ways that necessitate modifications to the standard curriculum. Variables such as these render test results noncomparable and nonstandard.

Beyond the technical, statistical, and equity issues involved, broader philosophical chasms had to be crossed as well. Deeply embedded in the philosophy of special education was the notion of individualization. This is the notion that students needed individualized approaches and goals, and that in many instances their progress needed to be judged by the achievement of the individual's goals and by the overcoming of the individual's obstacles, not by some universally applicable set of norms and numbers. These views, together with the relatively small number of students involved, made inclusion of students with disabilities in universal testing a difficult process.

Schools and school systems are now being judged by their levels of year-on-year improvement. Fears appear to be widespread among mainstream educators that inclusion of all students with disabilities in standardized testing could lower their schools' aggregate scores and thus put them at a disadvantage compared to other schools.

To respond to all these concerns, various measures have been adopted. These include clarification of how and when alternate assessments can be used, particularly for students with intellectual disabilities, within the framework of states' accountability requirements [47].

3. The New Idea

The new IDEA seeks to achieve congruence with NCLB in a number of ways. A detailed analysis of the changes wrought in IDEA by the new law, as well as a discussion of many of the relationships between IDEA and NCLB, can be found in a Congressional Research Service (CRS) report, which was released on January 5, 2005 [48].

Against this backdrop, and at this unique crossroads in the history of inclusive education in our nation, NCD wishes to examine some of the provisions of the new law as they bear upon existing practices and identified needs.

(b) Major Goals of Reform

1. NCD's Long-Term Concerns

In its recent paper "Improving Educational Outcomes for Students with Disabilities" [49], NCD continued the history of attention and concern for educational issues that has marked its work over the years. In this paper, NCD identified a number of key outcome goals that need to be addressed and achieved if educational opportunities and achievements for students with disabilities are to reach equality with those of other students. These goals included reducing the high school dropout rate for students with disabilities; increasing the proportion of nondropouts who leave school with academic diplomas as opposed to certificates of attendance; operationalizing high standards in terms both of expectations and outcomes for students with disabilities; finding and applying evidence-based research and practices and converting them into educational practices and techniques; and ensuring the availability of highly qualified special education teachers.

NCD believes these outcome-oriented goals to be strongly supportive of the principles of NCLB. To provide the infrastructure necessary to achieve these goals, NCD has also addressed IDEA reauthorization issues in its annual status reports of the past two years. In these reports, the Council has been particularly concerned with disciplinary standards, federal funding levels, individualized education program (IEP) content and implementation, and parental involvement.

Perhaps most of all, NCD has been concerned with monitoring and enforcement of the law. In light of GAO research indicating that failure by schools to implement services called for in students' IEPs represents a major problem [50], NCD has been greatly concerned that any and all reforms address the ongoing need for monitoring and enforcement, which the Council has long believed could be done without increasing paperwork or other noninstructional burdens on school systems and personnel.

Not all of these issues can be resolved solely within the framework of IDEA. Nevertheless, to the extent that the new statute provides important new baselines for thinking about them, NCD would like to review some of the ways the new law addresses these issues. The Council would also like to make recommendations to DOE for ways that its current regulatory review can contribute most effectively to achieving the goals of a quality education and steadily improving outcomes for all students.

2. The New Law

A. Teacher Qualifications

NCD is encouraged by the unequivocal support shown in the new IDEA for the premise that special education teachers, including those teaching core academic subjects, must meet the high professional standards applicable to creation of a pool of "highly qualified" teachers for all students [51]. NCD is concerned about two issues, however. First, the high expectations the law has for special education teachers will require resources for training and likely for salaries to make the extra training and formal education possible. NCD recommends that DOE immediately undertake a study to determine whether currently available resources, provided through IDEA grants or from other sources, are adequate to train the required number of highly qualified teachers and other key personnel.

If additional resources are found to be needed to meet statutory goals, then the Administration, in conjunction with Congress, should begin consideration of how the necessary resources can be developed. This must be done before shortfalls in qualified personnel become an acute problem under the new law.

NCD's second concern is the implications of mainstreaming for teacher training and qualifications. As important as it is for special education teachers, consultants, and paraprofessionals to be highly qualified, the likelihood is that a growing percentage of students with disabilities will receive more and more of their educational services in mainstreamed classroom settings that constitute the least restrictive environment (LRE) suitable for their education. Concern seems warranted therefore that, although these mainstream classroom teachers will be highly qualified in the subject matter areas they teach, their knowledge of evidence-based techniques for maximizing educational benefit for students with disabilities may, for lack of training or appropriate support, not always be at optimal levels.

Such matters as reasonable accommodations, assistive technologies, and related services may not always be self-evident or have been included in teacher training. Yet, in many instances, such resources and expertise can represent the difference in a student's ability to fully participate and benefit in the classroom.

To help students respond effectively, classroom teachers also deserve all possible support in addressing the needs of their students with disabilities and in marshaling the resources that can do so much toward achieving core goals. In the absence of these resources, it is not surprising that all too many dedicated teachers and administrators may fear and oppose inclusive education rather than embracing it.

NCD recommends that the DOE accord particular attention to this issue in its implementation of the new IDEA.

B. Dropout and Graduation Rates

Any attempt to assess the possible impact of the reauthorized IDEA on high school dropout rates and diploma graduation is complicated by the fact that NCLB does not yet apply to secondary schools. Accordingly, its framework is not available for addressing issues in the high school years.

NCD continues to believe that transitional services can play a critical role in establishing the basis for satisfactory postschool placements, activities, and outcomes. The new law includes a number of provisions designed to strengthen transition services, and on the whole it appears to contemplate a heightened emphasis on transition to postsecondary education [52]. But without any overarching interagency system for compelling secondary and postsecondary educational institutions and vocational rehabilitation (VR) agencies to work cooperatively and effectively, NCD is concerned that this heightened emphasis may not have the results for which all would hope.

NCD continues to believe, as it has suggested in prior reports, that until a system of joint and shared accountability is established that includes all those with responsibility for postsecondary school transition, progress is likely to fall far short of what is needed. Accordingly, NCD recommends that DOE—which houses all of the major educational, vocational training, and vocational education programs involved—work with DOL and with HHS (whose stewardship of health insurance programs is highly pertinent here) in developing an approach to transition that will provide the oversight, coordination, and shared accountability needed for the chronic barriers in this area to be overcome.

C. Evidence-Based Research and Practice

As it has been a central principle of NCLB, now it is also a fundamental tenet of IDEA that evidence-based practices must be developed and used. This means there must be testing, validation, and use of methods and techniques that are demonstrated to have value in facilitating the educational process, in enhancing the quality of assessment tools available, in evaluating the appropriateness of various goals and standards, and, above all, in contributing to improved student performance and better outcomes. Although many variables arise in developing and implementing evidence-based strategies, NCD is pleased to note the marshaling of research under the new law in the National Institute for Education Science (NIES) [53]. The specialized center created within NIES should be able to spearhead, support, and disseminate important research.

NCD is nonetheless concerned that powerful and effective practices may sometimes be difficult to validate by experimental means or that the research necessary to validate them could take considerable amounts of time or involve considerable cost in some cases. No one suggests that habitual use or widespread acceptance of a practice or measurement criterion should indefinitely substitute for scientific confirmation of its utility. But until the necessary data can be developed, replicated, and validated, considerable scope and deference should be accorded to the experience of special education professionals and to the techniques which they believe to be most effective.

D. Student Discipline

One of the issues that received most public attention during the development of the IDEA amendments was that of discipline. Under the contentious and difficult circumstances of the debate, NCD appreciates the effort and care that went into crafting the final legislation. Key to any balancing of the goals of education and order is the recognition, which the bill preserves, that disruptive, dangerous, or illegal behavior can in some instances be a consequence or aspect of a disability, while in other situations it will occur independently of this element. For that reason, NCD commends retention of the “manifestation determination” as a prerequisite to any disciplinary action [54]. NCD also notes with appreciation the bill’s incorporation of the principle that even in those cases in which alternative interim placements are found to be warranted, educational services must continue to be provided [55].

However, NCD is concerned with the way in which the manifestation determination will be made and with the nature of the alternative educational services and settings to be provided. NCD recommends that in its application of the manifestation-determination concept, DOE recognize that the connections between frustration and alienation on the one hand and aggressive behavior on the other may not always be so direct as to be obvious and may not be tracked in textbooks or diagnostic manuals. It is easy to imagine how inability to participate, exclusion, possible mistreatment by fellow students, and lack of a full sense of being able to communicate and learn can lead to frustrations that, while not to be condoned, are all too likely to boil over if not addressed.

DOE and the schools must remain sensitive to the antecedent events and the chain of causation leading to any single incident or outcome. This is not to suggest in any way that bad behavior should be excused. It is only to say that there may exist various means for dealing with it and for preventing its recurrence.

Accordingly, NCD recommends that as part of the manifestation determination, DOE require that school districts address the likelihood of recurrence and the means available for reducing or eliminating such risk.

One reason why enlightened application of manifestation determination is so important is that alternative placements may often fail to fulfill all elements of a student's IEP. This is likely to occur not because of any willful desire on the part of officials to reduce the scope of services but simply because of the difficulty of quickly or efficiently replicating the intricate patterns of relationships and the services and resources that may have been developed and put in place to achieve the goals of a particular IEP.

E. Parental Involvement and Due Process

NCLB and IDEA use a variety of means to maximize parental involvement in the education of their children. Our commitment to local control of education is in large measure reflected in this commitment.

But one of the ways IDEA has traditionally sought to ensure parental involvement has become increasingly controversial and, in the view of some, counterproductive in recent years. This method is the range of due process and procedural rights, including the right to complain or even to litigate against school districts that the law accorded to parents who believed that schools were failing to adequately address the special education needs of their children. In particular, criticism has been directed at the role of lawyers in the process, based on the belief that their involvement has become an impediment to a smoothly running and effective educational process or a cause of conflict where none might otherwise exist.

NCD has addressed the issues raised by these concerns in what is believed to be a balanced fashion in a number of previous reports. While the Council recognizes that isolated examples can be found of all the evils feared or alleged by critics, NCD has remained concerned that in most instances of disagreement between schools and parents, parents lack the knowledge or resources to effectively counter professional opinions. All they have is the most intimate and extensive knowledge of their children, and that is something of which the law takes little formal cognizance.

As with student discipline, NCD recognizes that the provisions of the new law bearing upon due process, attorney fees, and related matters reflect the best efforts and extended labors of many people. Thus, our concern is not to revisit Congress's deliberations or decisions but to suggest to DOE some issues likely to arise in its outreach to the public during the implementation process.

In this connection, NCD is particularly concerned about how and by whom the notion of a "frivolous," "unreasonable," or "without foundation" complaint will be defined [56]. This matters greatly, because the law includes provision for school district attorney fees to be levied against a parent's attorney or even against the parent if a complaint is found to fall into any of these categories [57].

It is easy to see how this threat could have a profoundly chilling effect on the assertion of meritorious claims. Many are the cases that have been thrown or laughed out of court at successive levels of the judicial process, only to be taken seriously by the Supreme Court or to ignite productive public discussion of matters that were not previously of concern.

For these reasons, it is vital that DOE define the circumstances under which such reverse fee awards are possible in a way that does not intimidate good faith claims solely because they are mistaken. To do this, NCD recommends that DOE require clear and convincing evidence of malice, bad faith, vindictiveness, or some other impermissible motive (that is, a purpose other than achieving the services being requested) before these sanctions can be brought to bear.

This is particularly important because (except during what is called the resolution phase) there are no limits on the funds school districts can spend on legal counsel and no restrictions on the ability of districts to drag out or prolong the process and otherwise to proceed in a way that is designed to exhaust even a determined parent [58].

F. Accessibility of Instructional Materials

NCD commends Congress for the inclusion of requirements for the accessibility of instructional materials [59]. NCD further commends DOE for its leadership in developing the consensus standards that made this requirement possible.

But one thing that concerns NCD in this instance is the learning curve that many school administrators, instructional personnel, and procurement officials may need to go through to fully understand the meaning of this requirement, to be aware of the options for meeting it, or to know what to do when no suitable solution is available. Accordingly, NCD recommends that DOE make certain that schools are advised of the sources of technical assistance, including the ADA Disability and Information Technology Technical Assistance Centers, for meeting these important objectives. In cases in which inaccessible instructional materials are nonetheless acquired or used, schools should be expected to show that they have pursued all available means for locating and securing accessible ones.

In addition to such technical assistance as may be necessary to ensure effective implementation of this important new equal opportunity, DOE should take measures to emphasize the substance of the accessibility requirement. In this regard, NCD recommends that the regulations make schools accountable for achieving the goals of accessibility by alternative means when the technology for achieving it does not exist. Specifically, NCD therefore recommends that school systems be required to develop plans for how the informational and instructional content of all media will be made available to all students, if the technology cannot be made accessible.

G. Full Funding

NCD wishes to commend Congress for the commitment, evident through its deliberations on the IDEA amendments, to steadily increase the level of federal participation in the funding of special education [60]. NCD has long advocated such an increase.

The Council is concerned that the projected rate of increase may come to be seen by some as a de facto ceiling, rather than as a floor, for federal financial participation. NCD recommends that DOE make clear that in its evaluation and assessment of progress in achieving the educational reform goals now embodied in IDEA, the Department and other key policymakers will be alert to situations in which lack of resources inhibits the attainment of key objectives. No one suggests that money can or should be a substitute for commitment and creativity, but neither can it be irrelevant to them.

(c) Monitoring

In December 2004, less than a month after the IDEA amendments were signed into law, the settlement of a nearly 10-year-old Pennsylvania special education class action lawsuit was announced [61]. This suit involved allegations of significant and systemic failures on the part of a major state to afford students with disabilities mainstream educational opportunities in regular classrooms, and it resulted in the commitment by the state to make significant changes.

Beyond the specifics of the *Gaskin* case, its scope and outcome suggest that major problems still exist in the implementation of IDEA. The timing of the settlement, coming as it does so close to the adoption of the IDEA amendments, inevitably leads to questions regarding how monitoring and enforcement will be handled under the new law.

NCD’s reports over the years have documented concern that vigorous federal monitoring and enforcement are essential to the effectiveness of IDEA. But the new law, while making clear that monitoring is an important state responsibility [62], does not emphasize federal monitoring or oversight as a primary technique for assuring achievement of program goals. In fact, it appears that the framers of the new law to some degree regard monitoring as a potential enemy to achievement of program goals, associating it in many instances with paperwork requirements and procedural demands unrelated to individual student or overall school performance.

In this connection, the new law includes provision for a four-year, 15-state pilot project designed to waive many recordkeeping, documentation, and procedural requirements [63]. NCD supports all experiments and pilot demonstration projects that have the potential to provide an evidentiary basis for educational policy reform. But for the pilot to be as informative and authoritative as possible, great care must be devoted to its design, especially to the selection of data to be collected and to the establishment of baselines against which change can be measured.

NCD is reasonably confident that minimization or elimination of administrative burdens could reduce the costs of special education, but the impact of these measures on the educational experiences and outcomes of students with disabilities are matters of equal concern. Unfortunately, some of these effects may be more difficult to determine, or may not even become apparent until after the four-year study has been completed.

In developing the details of these pilot projects, NCD recommends that DOE ensure that it can capture sufficient information about the services actually provided and the outcomes achieved to allow it to assess the broadest range of effects and implications.

(d) Additional Concerns

A number of pressing issues are not addressed by the IDEA amendments but bear crucially on the interaction between IDEA and NCLB.

1. Inaccessibility of Transfer Schools

Under the terms of NCLB, multiyear failure by schools to achieve AYP can result in their students being afforded the opportunity to transfer to other, better performing schools. Neither NCLB nor the new IDEA in any way indicates how this opportunity is to be accorded to students with disabilities when the transferee school is not fully accessible or is in some other way unsuitable for their continued education or attendance.

NCD would not argue that students without disabilities should be denied the right to attend a better school because some of their fellow students with disabilities cannot attend it too. But the situation does raise great concern and calls for some anticipation of resources or measures to ensure that in such circumstances students with disabilities will not be left behind.

2. Accessibility of Tutoring or Other Enrichment Services

Short of transferring students out of underperforming schools, NCLB provides a number of interim resources and strategies to help schools improve their performance. Regrettably, although it is likely that students with disabilities will suffer as much as other students from the systemic problems of poorly performing schools, the law appears to provide little guidance on how the availability of these enrichment strategies on equal terms will be ensured to these students.

The problem is complicated because many of the services in question will be provided to students based on the status and overall performance of their schools rather than on the basis of the students' particular needs. Assessments of individualized need have traditionally formed the basis for most special education services. If these extra services are to be provided within the special education framework, will this traditional structure have to be accommodated? Will such services and resources have to be included in and meet the requirements for being part of the students' IEPs?

Whatever the administrative format, it will be necessary that the same principles of accessibility as apply to standard school curriculum and services be maintained in these added service areas. NCD recommends that the DOE clarify how equity to students with disabilities will be ensured in the provision of extra services to NCLB-failing schools.

3. Rural Districts

A 2004 GAO report identified serious unmet problems with the implementation of NCLB in rural communities [64]. Concern is warranted over whether these problems—relating to such matters as lack of resources, low-density of population, and related issues—might not also arise under IDEA and might not arise in even more serious form.

Initial commentaries on and reviews of the IDEA amendments do not indicate that the new law has anticipated or addressed these issues. Accordingly, NCD recommends that DOE undertake, as part of its nationwide gathering of input, to ascertain whether rural districts and populations are likely to be put at a disadvantage under the new law; if so, the Department should develop proactive strategies for dealing with these problems.

(e) Higher Education

1. The Higher Education Act

Students with disabilities are concerned with and influenced by the range and nature of financial aid programs available, by the accessibility of facilities and resources at the schools they attend, by the employment opportunities available at and through colleges and universities, and, of course, by the research and writing that academic institutions and scholars do. Students with disabilities are also affected by the nature of teacher training programs operated at various universities.

In connection with the reauthorization by Congress of the Higher Education Act (HEA) [65], the initial point worth noting is that mainstream programs have as much of an impact on the lives and careers of students with disabilities as more specialized and narrowly targeted programs do. In connection with HEA, examples of this impact are numerous and lead to a number of recommendations. NCD recommends that student financial aid programs be designed to incorporate sufficient flexibility to benefit students with disabilities to the same extent as they are intended to benefit other students. For instance, limitations on the duration of enrollment or requirements as to the minimum number of per-semester or per-quarter credits can become a hardship if mechanically applied. Such requirements should be subject to modification for students with disabilities who are obliged to take fewer courses and need a longer time to complete their studies.

Similarly, all programs should clearly recognize and support the availability of funds for needed assistive technology, personal assistants, or other resources necessary for attendance and successful performance. Consideration should also be given to the possibility of providing for additional funding within existing formulas to cover extraordinary expenses such as these, which were not considered when the legislation was being devised but which are necessary for the full participation of students with disabilities.

It is widely reported that the Administration will seek major changes in the Pell grant program. NCD expresses no opinion on whether or how Pell grants should be restructured; however, the Council underscores the need for awareness that whatever is done will affect students with disabilities and may do so in ways that are not necessarily obvious or intended. These potential impacts must be studied and considered.

In light of HEA's role in supporting preservice teacher training programs, special attention should be paid not only to the training and preparation of special education teachers but also to preparing mainstream teachers with the added knowledge of special education resources and issues they will need.

2. The Tax Code

Just as tax policy has come to play a larger and larger role in economic policy, and is coming to play a heightened role in medical care (through health savings accounts and related strategies) [66], so tax policy is becoming more important in the area of higher education. Measures adopted over recent years—such as the Hope and Lifetime Learning credits [67], Coverdell education savings accounts [68], and Section 529 tuition programs—have all increased the role of the tax system in the funding of higher education.

Beneath the general questions of whether and how well these provisions have made higher education possible for people who would otherwise have been unable to afford it or more available to those who would have had difficulties obtaining it, issues of particular significance to people with disabilities emerge. The particular questions that arise in this regard relate to whether these provisions have the flexibility to be of use to these students and their families. By and large, these tax code provisions are rigid in the amount of money that can be sheltered for use in higher education, and they are restricted in the range of expenses they can be used to meet and in the time periods over which they can be used. As it considers possible restructuring of the tax law, Congress may wish to consider changes that would allow additional funds and broader uses, as well as more flexible time periods in connection with the aggregation and expenditure of these funds.

Recommendations

Recommendation 3.1: NCD recommends that the Department of Education immediately undertake a study to determine whether currently available resources, provided through IDEA grants or from other sources, are adequate to train the required number of highly qualified teachers and other key personnel.

Recommendation 3.2: NCD recommends that DOE accord particular attention to the issue of training and support for mainstream teachers in its implementation of the new IDEA.

Recommendation 3.3: NCD recommends that DOE—which houses all of the major educational, vocational training, and vocational education programs involved—work with DOL and HHS in developing an approach to transition that will provide the oversight, coordination, and shared accountability needed to overcome the chronic barriers faced in this area.

Recommendation 3.4: NCD recommends, in its application of the manifestation-determination concept, that DOE recognize that the connections between frustration and alienation on the one hand and aggressive behavior on the other may not always be so direct as to be obvious and may not be tracked in textbooks or diagnostic manuals.

Recommendation 3.5: NCD recommends that DOE require evidence of malice, bad faith, vindictiveness, or some other impermissible motive before the provisions of the law allowing for attorney fee awards against parents or their attorneys can be brought to bear.

Recommendation 3.6: NCD recommends that DOE make certain that schools are advised of the sources of technical assistance, including ADA Disability Business Technical Assistance and IT Centers, for meeting these important instructional-media accessibility objectives.

Recommendation 3.7: NCD recommends that DOE make clear that in its evaluation and assessment of progress in achieving the educational reform goals now embodied in IDEA, it will be alert to situations in which lack of resources inhibits the attainment of key objectives.

Recommendation 3.8: NCD recommends that DOE ensure that it can capture sufficient information about the services actually provided and the outcomes achieved under the pilot programs to allow it to assess the broadest range of effects and implications.

Recommendation 3.9: NCD recommends that DOE clarify how equity to students with disabilities in the provision of extra services to NCLB-failing schools and their students will be ensured.

Recommendation 3.10: NCD recommends that DOE, as part of its nationwide gathering of input, ascertain whether rural districts and populations are likely to be put at a disadvantage under the new law; if so, the Department should develop proactive strategies for dealing with these problems.

Recommendation 3.11: NCD recommends that student financial aid programs be designed to incorporate sufficient flexibility to benefit students with disabilities to the same extent as they are intended to benefit other students.

Chapter Four—Health Care

Introduction

No American is unaffected by the nature, cost, or definition of health care, but we know that different groups within our population are affected in different ways. There are different sources of insurance depending on age, with Medicare of primary concern to retired Americans and employer-sponsored plans constituting the chief source of coverage for people employed by major companies. Differences exist in the kinds of benefits and the range of specialties that people need. And, as all agree, there are serious problems challenging our health care system, as well as numerous explanations for the causes of these problems and plentiful proposals for their solution.

While most Americans vary in their health care needs and concerns, many of the current health policy debates have unique implications for people with disabilities. Many of the proposed strategies and solutions will influence this population in ways that are not always highlighted in the public debate.

This chapter will filter some of the most timely current health policy issues and proposals through the lives and experiences of Americans with disabilities. Section (a) deals with the issue of the uninsured, exploring its dimensions and suggesting that application of various proposed solutions to people with disabilities requires careful attention and analysis.

Section (b) concerns itself with Social Security reform. It points out ways in which the Social Security system affects many people with disabilities whose situations are not widely represented or often recognized in the current public debate over the system's future and reform.

Section (c) considers the proposed National Health Information Infrastructure (NHII). Echoing concerns expressed in last year's status report regarding the need for accessibility and privacy, the section discusses issues surrounding information processing and access that are pertinent to people with disabilities. The section also seeks to define information broadly enough to include not only the contents of records but the variety of technologies and devices used to generate medical findings and data. Finally, the section seeks to incorporate discussions of disability into NHII planning at an early enough point to allow for this to be done in a seamless and effective way.

Section (d) confronts the Medicaid program as it stands on the threshold of great change. Building upon themes expressed in last year's report, the section deals with such matters as the implications of structural changes in the program for people with disabilities, and it reiterates concerns about the ability of the program to meet its goals in helping to reduce work disincentives for beneficiaries with disabilities.

Section (e) discusses the Medicare program. It probes a number of concerns arising from the implementation of the Medicare Modernization Act [69] and likewise asks questions about the ability of the program to contribute to the employment of beneficiaries. The recent controversy over the definition and availability of powered wheelchairs is also discussed, both from the standpoint of the relationship between cost-driven and medically based decision making and from the standpoint of new procedures recently adopted for increasing public input into program design.

Finally, section (f) reviews the growth and implications of consumer-directed health care as it relates to people with disabilities. Traditional service delivery notions and modern ideas of consumer control may on occasion come into conflict, but exciting potential is seen to exist in the new approaches.

(a) Health Insurance

1. Scope of the Problem

Increasingly in our nation, access to health insurance represents the point of entry for access to health care. For this reason, almost all proposals for dealing with gaps in the availability of medical services and care begin with the premise that health insurance in some form needs to be made more widely available. From those who favor "single payer" to those who would abolish all government involvement in the provision or regulation of health insurance, reliance on insurance is a central tenet.

In this light, the persistence of a large population of uninsured people in our country emerges as a major and growing concern. Detailed testimony provided to Congress in early 2004 by the Congressional Budget Office (CBO) [70] provided detailed information on the extent of uninsurance, and a House hearing on March 2004 [71] provided a variety of expert analyses and recommendations concerning how the problem might be alleviated.

Recent legislation now working its way through the health care and tax systems, including the creation of health savings accounts (HSAs) [72], has sought to address the insurance problem by stimulating employer-sponsored or individually or group-purchased coverage in the private sector.

Two findings emerge at this point. First, the number of uninsured Americans has been rising over the last years. Second, costs of health care in general, and health insurance in particular, are growing at a faster rate than gross domestic product (GDP) and are hence likely to consume a larger proportion of GDP in the coming years. According to one estimate provided by CBO, health care costs by 2050 could represent as large a share of GDP as the entire federal budget does today [73].

These findings and forecasts have the most serious implications for our nation. But hidden beneath them are issues and implications that may make the problems even more severe, and the solutions more elusive, for Americans with disabilities.

2. People With Disabilities in the Health Insurance Discussion

Federal agency data on health insurance coverage, as most recently collected and analyzed by CBO, takes great pains to identify demographic trends hidden in the data. Thus, fortunately, valuable data exists on the prevalence of uninsurance by ethnic group status, by age, by family income, and in relation to other variables. Surprisingly, however, the extent of the problem among people with disabilities has not been probed by Congress in any detail.

Many people with disabilities are covered by Medicare or Medicaid. The impact on them of proposed reforms in these programs will be discussed below. For those people with disabilities whose coverage must come through the private sector, the likelihood is that high rates of uninsurance prevail.

This conclusion derives from the fact that people with disabilities are statistically more likely than others to have many of the characteristics associated with other uninsured populations. They are less likely to be employed and tend to have lower incomes and less formal education than other Americans, both of which predict lower levels of insurance coverage. If one adds to these the cumulative effects of such factors as preexisting condition exclusions, possible "adverse selection" practices [74], and demographic data such as the association of disability with age, the situation grows even more troubling.

What becomes clear is that no serious effort to address the availability, affordability, and adequacy of health insurance in our nation is likely to prove comprehensive or effective unless it takes our citizens with disabilities fully into account. For example, it is expected that one feature of the President's 2005 proposals to make health insurance more affordable and available will be the creation of greater opportunities for small businesses and perhaps other groups to affiliate in the purchase of group insurance. Logically, it is believed that the greater buying power this will afford such purchasers will enable them to exercise greater leverage in the marketplace in demanding and obtaining coverage, better coverage, or lower cost coverage. But how will these proposals recognize and deal with the presence of people with disabilities among the employees or dependents to be covered?

3. Special Issues for People with Disabilities

NCD does not presume at this early stage to suggest how these issues should be addressed. Our purpose here is to remind all parties to the discussion and all stakeholders in the outcome that the actual, potential, or imagined costs of providing coverage to people with disabilities can and must influence the economic calculations that take place in the marketplace. What combination of experience-based or community-based rating systems is to be used in determining premium rates? Will the buyers or sellers of the new group insurance be permitted to exclude particular individuals, specific diagnoses, or identifiable future risk factors from coverage?

Another illustration of the need to include people with disabilities in the conversation can be seen in the use of tax-based approaches to health-insurance affordability. Measures such as HSAs are intended to encourage people to take control of some of their own health care spending. This is based on the premise that with such responsibility will come a desire to control those costs as prudently as possible.

To encourage such prudence, HSAs reward people who keep their health spending below the level of their deductibles by allowing them to retain and aggregate some of their unspent funds. These opportunities should benefit people with disabilities along with everyone else. But without attention to a number of additional factors, just the opposite may prove to be the case.

We offer one illustration of how this negative result could occur. Let us suppose that a low-income individual with a disability establishes an HSA and manages over the course of several years to aggregate $3,000 in unspent, self-contributed funds. How is this $3,000 in HSA savings treated for purposes of means-tested income and resource eligibility under a variety of other federal benefit and service programs? Similarly, how are the tax benefits to be delivered to people who, by reason of large impairment-related work expenses, are left with less taxable income than can be absorbed by the HSA benefit?

Again, our purpose here is not to suggest how these and other disability-specific issues should be addressed. It is only to suggest that many people with disabilities will be affected by the reforms to insurance that are adopted and that the issues confronting people with disabilities, complex as they may be, must be acknowledged before they can be addressed.

(b) Social Security Reform and Health

Social Security, long-term services and supports, and Medicare and Medicaid represent a group of closely related and converging policy areas. Historically, NCD has recognized the need for coordination among them but has addressed them as distinct policy areas. Thus, each service has been governed by its own statutes, assigned to its own implementing agencies, and paid for with its own funding streams and budgets. The task of thinking about these vast programs in the dynamic ways they relate to and affect each other is a daunting one, to say the least. It may be that we do not yet have the analytical tools or the frame of reference for doing our thinking and planning in this way. Accordingly, we need to recognize that income support (Social Security), health care (including Medicare and Medicaid), and long-term services and supports (including programs from nursing home services to community-based transportation, housing, or personal assistance) represent a continuum. None can be designed, evaluated, or even predicted without reference to its key interactions with the others.

We believe two points are especially important in this regard. First, the discussion over how and at what levels Social Security should be funded and whether personal accounts should be added to the system must not lose sight of the fact that many younger people with disabilities receive benefits under Social Security. Not so often thought about as recipients over age 65, these beneficiaries are people under the age of 65 forced to leave work before normal retirement age due to disability. They are recipients of income replacement through the Social Security Disability Insurance (SSDI) program.

Calculation of benefit levels cannot be fully done unless the benefit levels, private earnings, and potential for other resources of this group of beneficiaries are taken into account. Likewise, the impact on people with disabilities of personal retirement accounts or other program changes under Social Security may be quite different than for other people. For example, many of these prematurely retired younger workers will not have any earnings out of which to fund personal accounts. They may be paying nothing into Social Security at all. If their potential benefits from Social Security have been reduced on the assumption that invested funds will compensate for this by growing at historical rates, then the inability of these workers to participate in such accounts presents significant issues that must be examined.

Our second consideration in the Social Security reform discussion relates to the mix of services and funds that people with disabilities receive through the combination of long-term services, health care, and income-support programs. As we move toward increased consumer participation in health care, the mix of cash and services that people receive is likely to change. If the tenets underlying the ownership society prove as valid and productive as all hope, cash that people can use to purchase their own services is likely to play a greater role—some of it in subsidy, some of it in savings. Direct third-party services paid for by others are therefore likely to play a correspondingly smaller role.

We have very little experience or data concerning the health needs and profiles of people with long-term disabilities entering into their senior years. We do know that among the population at large, disabilities of all kinds increase in frequency with age for people over 65.

The cost implications of disabilities for people over age 65 must be part of any broad-based Social Security reform effort. We cannot fully evaluate the appropriateness of any particular Social Security benefit level without sound projections regarding these costs. Such projections are difficult. They are made still more difficult by the likelihood that their nature and amount will differ among people with long-term disabilities and people with late-onset disabilities. And these estimates are rendered even more difficult by the possibility that the mix of cash and services that go into meeting needs of older people with disabilities will be altered by new emphases on asset accumulation and consumer self-direction.

The urgency of reform may not leave sufficient time to answer all these questions. Considerable research may be required. But the lack of complete data should not prevent us from candidly acknowledging the uncertainty and building into reform models the resources and flexibility necessary to address the research agenda and to implement its established findings.

(c) The National Health Information Infrastructure

Spearheaded by HHS, the NHII represents a bold and broad-based effort to use modern electronic communications technology to improve the quality of health care outcomes, reduce health care costs, and empower health consumers, practitioners, researchers, and policymakers in a collaborative effort of enormous potential.

Since the November 2001 kickoff of the NHII in the report of the National Committee on Vital and Health Statistics to the Secretary of HHS [75], work has proceeded on a 10-year implementation strategy for the NHII. A fact sheet developed by HHS and available at its NHII Web site provides a good overview of this ambitious effort [76].

NCD subscribes enthusiastically to the goals of the NHII. The Council is determined to offer timely input to ensure that issues of concern to patients and families, practitioners, and researchers will be taken into consideration in the design and implementation of the initiative.

1. Privacy and Confidentiality

Throughout NHII documentation, respect for privacy and confidentiality of information and data are everywhere evident. The basis for this concern is not difficult to understand. Without such protections, both legal issues and public suspicion are inevitable. With these protections in place, the effort can better hope to attract the voluntary support, partnerships, and cooperation it will need for success.

Special attention is necessary if these protections are to fully benefit people with disabilities. Such attention is also necessary if people with disabilities are to have confidence in the initiative.

First and foremost among the issues of privacy and confidentiality is accessibility. All technologies, interfaces, and procedures used in the NHII must be designed with this in mind. The stakeholder communities involved in designing, pilot-testing, implementing, and evaluating all elements of the initiative must be selected in consideration of this necessity.

The NHII fact sheet lists a variety of stakeholders and partners from the public and private sectors, including medical consumers, clinicians and researchers, and people drawn from other sectors. NCD endorses this broad participation. Absent from the list, however, are people with disabilities and those with knowledge and experience in the information technology access field. People with disabilities will, of course, be included in all the other constituency groups, but their compelling interests in accessibility require a more explicit inclusion.

NCD is eager to work with HHS in identifying and marshaling the necessary resources. While this report is not the place for enumerating what accessibility will mean in the NHII context, a few basic principles deserve mention.

Accessibility means that all electronic information, whether public documents or personalized communications, be independently accessible by people with disabilities who use assistive technology (AT) to access computers. Demonstrated but flexible guidelines for such accessibility are available from a number of sources [77].

Accessibility also includes the availability of printed documents, including required informed consent forms, statutory notices, and others, in alternative formats and in versions that are written so as to be understood by a broad range of consumers, including to the greatest extent possible people with intellectual disabilities.

Accessibility requires that for documents needing explanation or discussion, or for other screening, consultative, or in-person interactions between health care practitioners and consumers, appropriate sign-language interpreters be available for people with hearing impairments. This means properly trained professionals, certified in interpreting, with knowledge of the subject area, and subject to all appropriate confidentiality requirements.

Accessibility means many other things, too. Here is not the place to detail them all, let alone to suggest how they will evolve as technology changes and as the NHII develops over the coming years. Once again, what is most important now is to ensure that the necessary outreach and attention to accessibility issues will be forthcoming at a point early enough in the NHII development process to ensure that the needed strategies, procedures, and technological designs can be incorporated into the planning process.

2. Medical Equipment

Medical equipment—including AT, durable medical equipment (DME), and other forms—should play an important role in the NHII definition of information technology, as it will undoubtedly play in the delivery of health care overall. Equipment will give readings, monitor test or treatment results, and generally serve as one of the key sources of information and data for all participants in the health care process.

For this reason, technology is itself a vital informational link in the NHII. And as a vital link, it must be accessible to and usable by people with disabilities.

Nor can a truly contemporary health care system incorporate all crucial sources of information or all key media for communicating information if it does not pay attention to the tests and apparatuses that yield this information. If a certain test cannot be performed because there is no safe and effective way of transferring an individual with a physical disability into and off of the apparatus, then the test for all practical purposes does not exist. The information it would and should have yielded becomes just as unavailable as if it were left out of a case record. The cause of the omission may be different, but the result is the same.

Medical equipment, including devices used in medical facilities and items utilized in people's homes, needs to be brought within the orbit of accessibility. NCD recommends that the NHII define relevant medical information broadly enough to include these vitally important links in the chain of data.

(d) Medicaid

The Medicaid program provides health insurance and care to some 53 million Americans [78]. As of FY 2002, an estimated 57 percent of its total costs were paid by the Federal Government. These ranged from a low of 50 percent in some states to a high of 76 percent in others [79]. Like Social Security, Medicaid is on the front burner for change and reform. It comes to this crossroads in its history carrying some painful baggage.

1. A Bad Year

The year 2004 was one of bad publicity for Medicaid. GAO raised major issues and problems relating to the program, including widespread use by states of questionable accounting techniques to improperly increase their federal reimbursement [80]. Studies also showed widespread use of cost-sharing in the related State Children's Health Insurance Program

(SCHIP) [81]. Such cost-sharing meant that poor children were subjected to co-payments, deductibles, or premium charges in 26 states under SCHIP.

Troubling as these revelations are, they likely reflect some of the real financial pressures states are experiencing in their efforts to keep up with rising Medicaid costs. To help combat these increases, Kaiser Commission and Families USA studies have tracked efforts by states to curtail Medicaid costs over the past three years [82].

While the methods used have varied, one recurrent approach involves the limitation or reduction of those Medicaid services that are optional [83]. Mandatory services cannot readily be reduced below minimum federal requirements, but optional services can be cut with little difficulty. This means that cuts can have a disproportionately large impact on people with disabilities, because many of the optional services are especially important to people with disabilities.

2. Current Context

Like Social Security, Medicaid stands on the brink of major restructuring and reforms. No one knows the precise recommendations the Administration will make. General agreement does exist that Administration proposals will seek to cap expenditure growth in the program and will attempt to give states more discretion in their use of funds and in program administration.

How these goals are achieved will hold great significance for people with disabilities. For this reason, NCD emphasizes the need for investigating these implications and for taking them fully into account in the formulation of new policy.

Several key concerns for people with disabilities can be mentioned. Cost containment efforts are likely to put further pressure on what are now optional services. Included among these are a number of services of particular importance to many people with disabilities, including speech-language pathology, audiology, vision services, and others. Concern must also be expressed regarding DME, which is already subject to what NCD believes to be severe restriction owing both to budget constraints and to procedures that many states have adopted.

3. Waivers

A related concern is the way in which waivers may be used. Under current law, home and community-based (HCB) waivers have been one of the key mechanisms for providing services in the home and the community. Such services are vital as an alternative to nursing homes or other forms of institutional care. They play a key role in the implementation of the *Olmstead* decision [84].

Any reform effort that modifies or expands waiver authority and gives the states greater authority to alter program rules must be developed with the *Olmstead* mandate centrally in mind. NCD favors expanded opportunities for experimentation and innovation at the state level. But such opportunities must not come at the cost of key emerging values and national policy priorities, particularly where, as with *Olmstead*, these priorities arise from a clear Supreme Court mandate.

Even under current conditions, major obstacles to increased use of HCB services are numerous. For example, a September 2004 survey of state direct-care workforce initiatives showed the persistence throughout the nation of major problems of worker recruitment and retention [85].

4. Other Issues

A number of issues have caused problems under existing law and should be addressed in the context of any broad-based reform initiatives. Two are particularly worth mentioning in this regard.

A. Medicaid Buy-In

Medicaid buy-in programs have allowed states to add new categories of recipients to Medicaid. Generally, they utilize cost-sharing and offer Medicaid coverage to people whose incomes or resources would ordinarily be just over the threshold for eligibility.

These programs have important potential to help people with disabilities return to work, because they ease the work disincentive problem that normally arises when people lose publicly funded health insurance as a result of earning income from work. For people who do not obtain comparable health coverage through their employment, the loss of medical coverage carries risks that many are afraid to take.

The Ticket to Work and Work Incentives Improvement Act of 1999 (TWWIIA) [86] has been a primary impetus for federal efforts to deal with this health-insurance and work-disincentives problem. As of the grant awards announced in March 2004, the Federal Government had awarded $57 million to 42 states and the District of Columbia for Medicaid infrastructure grants, designed to assist these states in enabling people with disabilities to return to work without losing critical health coverage [87].

Cutbacks or elimination of buy-in and of other expanded services can put this effort in jeopardy, and state cuts in various optional services may already have done so. Any reform effort must ensure that programs aimed at easing and fostering the transition of people with disabilities into competitive employment will not be weakened but will be supported and encouraged in every possible way.

B. Definitions

The subject of health insurance for employed people is important in another way, too. TWWIIA made clear our national commitment to use Medicaid and Medicare as tools to help people enter or remain in work. It was clearly Congress's intent, and it is a logical necessity, that these programs provide services to people who work outside the home. Yet, at the same time as we seek to use these insurance programs to assist people to enter and retain employment, the definitions used by these programs for a number of key health services presuppose or require in-home status as a condition for their availability.

An example is DME. There is no federal definition of DME in the Medicaid program, but many states use the Medicare definition [88]. That definition restricts DME to items used in the home (and thus has been construed to prevent payment for equipment intended for use outside the home). Because we have determined that Medicaid and Medicare should be used to support employed people, such restrictions seem counterproductive.

Efforts to reform the Medicaid program are motivated in part by the growing costs of the program. What could be more sensible than using this reform effort as an opportunity for maximizing the savings and revenues that transition from benefits to employment can yield?

(e) Medicare

The year 2004 was the first year of operation under the Medicare Modernization Act of 2003 (MMA) [89]. Much attention has naturally been focused on the implementation of the prescription drug provisions of this far-reaching new law. But at the same time, other major developments have been taking place that deserve attention and comment.

One development NCD would like to highlight is the controversy over powered wheelchairs or powered mobility devices, also known as assistive technology mobility devices (ATMDs) [90]. Concerned by steeply rising costs for ATMDs and by fraudulent activity on the part of certain suppliers [91], the Centers for Medicare and Medicaid Services (CMS) in late 2003 moved to revise the eligibility standards for which Medicare beneficiaries could receive ATMDs. This effort provoked considerable opposition from sectors of the consumer and supplier communities [92] and led to an ongoing dialog between CMS and affected communities over what the rules and standards should be.

CMS has undertaken a process to refine its standards, and the final shape of the ATMD policy is not yet decided. But the controversy illustrates some important points, which NCD believes Congress and the Administration should keep in mind in their further implementation of the MMA and in other Medicare-related legislation they may consider.

1. Cost-Driven Decision Making

Prevention and punishment of fraud is critical to the integrity of any program. Short of fraud, any major, intentional, or sustained violation of a program's rules must be a matter of concern. This said, it is unwise to predicate substantive decisions about eligibility for medical services on rising costs alone.

Apart from fraudulent activity, rapid increases in expenditures for ATMDs are widely regarded as having been a major factor in CMS's decision to modify or clarify its Medicare ATMD eligibility standards. In its 2003 annual status report, NCD discussed the lack of coordination between CMS's actions, announced in December 2003, and the report of the Presidential Task Force on ATMD, released just a few months before [93]. NCD noted the absence from that task force report of any indication of a national problem requiring rule changes or clarifications, and we noted the absence from CMS's own testimony published in the task force report of any indication of its intention to take the actions it shortly did.

With the passing of another year, NCD believes it has become increasingly clear that policy decisions or clarifications need to arise out of detailed analysis of needs, alternatives, and impacts. Only when these are fully done can determinations of whether costs are too high, adequate, or too low be made in a meaningful way. NCD has no basis for evaluating what level of funding should be available for ATMDs. But NCD does believe that questions of cost should never be confused with questions of medical necessity or functional effect.

2. Public Input

The public response to CMS's actions and that agency's reaction in turn also provide important lessons. NCD wishes to commend CMS for its receptivity to taking public comment into account in formulating final policies and rules. NCD believes the difficult events of the last year demonstrate the value of the new procedures put into effect for providing public input into national coverage decisions and other determinations made by CMS in administration of the Medicare program [94].

NCD recommends that CMS continue and expand the efforts it has made to involve the beneficiary community in Medicare policymaking. If only because issues of health, employment, and independent living converge in the lives of the individuals affected by CMS's decisions, such an approach is imperative if Medicare is to serve the interests of our nation.

(f) Consumer-Directed Services

Throughout this chapter we have highlighted programs and trends designed to increase the participation of individuals and families in health care decision making and even in health care funding. Demonstration projects undertaken in several programs around the country are currently testing and refining the potential for life accounts, cash and counseling, individual development accounts (IDAs), and other asset-accumulation programs, as well as other strategies to increase autonomy in a variety of settings [95].

NCD commends and encourages such efforts. However, we wish to remind policymakers that these efforts have implications that may not always be obvious but that are timely to discuss. Three are especially noteworthy here.

1. Scope of Services

There is a tension between traditional definitions of medical services and the values of consumer choice. If consumers of service are to be given increased discretion to choose, then not only the range of providers but the range of eligible services as well must offer the flexibility required to make such choice meaningful.

Education is a corollary to this. Experiments in consumer-directed health care must include efforts to identify and provide the kinds of informational resources, the media, and the delivery systems that will make consumers most effective in choosing providers and modalities for themselves.

2. The Costs of Mistakes

Any serious commitment to consumer choice necessarily implies the possibility of mistakes. As much as we provide educational and informational resources, even the best-informed individual can make the wrong choice.

Situations are likely to arise in which people will have utilized their available resources without obtaining the benefits expected. In cases in which serious unmet need still exists, the painful question must be confronted of whether and when additional support or resources should be offered, and how much autonomy shall be accorded in their use.

3. Means-Testing

Many people with disabilities are dependent on a variety of means-tested, needs-based programs. The asset-accumulation and self-directed services movement offer long-term hope that people will be able to escape poverty and end their reliance on means-tested programs. But in the meantime, there is a tension between means-testing and any program model that allows people to accumulate and control cash.

Current law tends to deal with the problem on a piecemeal basis, with very specific provisions indicating that one or another source of funds is exempt from income or resource limitations under one or another specific program. But these set-asides and exclusions are complex and often obscure.

As we move forward with individual empowerment and personal responsibility in publicly supported health care, NCD recommends that Congress and the Administration develop clear and overarching methods that will create predictability for people who need to understand how participation in the opportunities offered under one program may reduce benefits or entitlements under some other, often unrelated, program such as housing vouchers or food stamps.

Our government is committed to reducing the burdens and complexity of regulations for citizens and businesses. Initiatives such as the Regulatory Flexibility Act [96] and the Paperwork Reduction Act [97] illustrate this commitment. Yet, for a person with a disability trying to find out if a tax refund under the earned income tax credit (EITC) [98] will be counted as income or resources under any of a dozen needs-based programs, the regulatory complexity and level of uncertainty and fear remain as great and as impenetrable as they have ever been. It is time that regulatory simplification is brought to these programs and to the people struggling to move forward within their often conflicting parameters and rules.

Recommendations

Recommendation 4.1: NCD recommends that the NHII define medical information broadly enough to include the systems and devices that generate medical formation as well as the files and charts in which this information is stored and transmitted.

Recommendation 4.2: NCD recommends that CMS continue and expand the efforts it has made to involve the beneficiary community in Medicare policymaking.

Recommendation 4.3: NCD recommends that Congress and the Administration develop clear and overarching methods that will create predictability for people who need to understand how participation in the opportunities offered under asset-accumulation or self-directed services programs may impact benefits or entitlements under other programs.

Chapter Five—Long-Term Services and Supports

Introduction

This chapter addresses a concept that, although of increasing importance, remains ill-defined. Section (a) begins with a discussion of the definition of long-term services and supports (LTSS) in the context of income replacement, health care and community-based services. Clear and widely accepted definitions of LTSS are needed before effective planning or forecasting can take place.

Section (b) discusses the major NCD study on this subject. Based on key issues to be explored by that study, it raises additional questions about how reasonable expectations for LTSS can be set and about the role of federalism in the allocation of responsibility among the Federal Government, the states, and the private sector.

Section (c) puts the emerging national discussion of LTSS more fully into the framework of demographics by describing the place of people under age 65 in the process. It identifies some of the issues facing this population and urges this group, including workers forced to retire early due to disability and those receiving SSDI, not be overlooked.

Recognizing the potential importance of private sector partners in any solution to the LTSS needs of our country, section (d) discusses the role of long-term care insurance and recommends strategies for identifying means to expand that role.

(a) Definitions

Long-term services and supports are a relatively new area of public policy. In a comparatively short time, issues surrounding long-term services have become matters of concern to many policymakers and citizens.

But in discussing this subject we face a problem that is not encountered elsewhere. We do not have a consensus definition of what LTSS entails. While it touches on medical care, it is not about health. Although it involves income support, it is not Social Security. LTSS requires attention to the creation and preservation of livable communities, but it is not really within the domains of housing or transportation. LTSS overlaps and intersects all of these other services and systems, but it is not wholly within nor is it the primary responsibility of any of them.

As a relatively new area of public policy, LTSS requires new kinds of coordination and perhaps new kinds of thinking. We cannot estimate how much such services will cost or how those costs should be allocated until we have some notion of what the services should be. Perhaps more than in any other public policy sphere, the definition remains in flux and the scope of programs and services involved in long-term services remains open to discussion.

Among all the things we don’t know or haven’t decided, some are clear. We know that the need for LTSS is strongly correlated with advancing age and with disability. In regard to this connection, as the CBO put it in a 2004 study: “Preparing for the possible cost of future impairment and long-term care is a task that everyone faces as they age” [98].

Much of the research surrounding the costs of and the need for long-term services focuses on long-term care and has a medical or quasi-medical model in mind. The prominence of Medicaid, Medicare, and long-term care insurance in discussions of the funding of long-term services highlights this emphasis on a quasi-medical model. But many other funding streams and programs have to be taken into account.

A 2004 GAO report reflects the continuum of services and institutions involved in the provision of long-term care [99]. This report, on methods used by states to ensure consumer protection for residents of assisted living facilities, addresses an important element in the care continuum that is not part of the medical system. Beyond any level of care, though, are issues of housing, transportation, and community services that must be addressed in a coordinated fashion if the goal of independence is to be achieved and the scope of LTSS is to be effectively defined.

The role of many of these systems is illustrated by a 2004 CBO report on transportation and mobility for seniors [100]. As this report reminds us, one of the major limitations of disability associated with advancing age may be the loss of the ability to drive.

We probably all know people who have driven far longer than they should. While some may be in denial and some acting out of vanity, the painful truth is that for most people in America loss of the ability to drive a car is a serious blow to independence. For this reason, transportation is an element of LTSS. So is housing.

Interest in LTSS has grown considerably. We have sophisticated research tools for analyzing trends and projecting costs. Yet, without more consensus on fundamental concepts, our ability to use these tools, to do the necessary planning, and to identify needs for coordination are inevitably limited.

How many policymakers or budget forecasters can agree on the range of subjects and infrastructure systems that should be included in the discussion of LTSS? How many can agree on consistent cross-agency goals, such as maximizing person-centered and consumer-directed service models, in the design and oversight of these programs? How many can agree on whether and how the current costs of long-term care and other services and supports, including the costs of unnecessary institutionalization, should be measured?

As a basis for establishing the necessary common language and shared assumptions, NCD recommends that Congress and the President collaborate on a major national study designed to identify the proper scope of government involvement with LTSS, to define what services and needs are appropriately covered by the concept and to identify the ways in which reforms in health care, income support, and other related areas will affect the availability and demand for LTSS in the coming years.

(b) The NCD Study

To help formulate and answer some of the key questions around the nature of long-term services and the strategies for financing them, NCD has commissioned a major study of this subject [101]. Undertaken by the National Disability Institute of the National Cooperative Bank Development Center (NCBDC) in collaboration with a number of partners, such as the National Conference of State Legislatures (NCSL), this multifaceted research study was completed in mid-2005. Although it does not formally study the role of such resources as housing or transportation, it does involve a comprehensive review of resources, projections, and practices across the spectrum of what are traditionally regarded as long-term services. It aims at a comprehensive 21st century system for providing the necessary services.

An indication of the research's scope can be found in a list of the seven content areas studied in five selected states. These content areas are partnerships with the private sector; home care and personal assistance services; respite care and other family caregiver services; consumer-directed and -controlled services; residential alternatives to nursing home care; integration of disability and aging long-term care services and supports; and quality standards.

As the need to conduct this research in diverse states suggests, LTSS is not a concern of the Federal Government alone. For numerous reasons, substantial portions of the cost and growing discretion in how to meet those costs are likely to devolve upon state governments in coming years.

This involvement of states is already widely appreciated in certain areas. The role of state governments in nursing home services is widely understood, principally because of states' concerns to limit escalation of their Medicaid expenditures, including Medicaid-funded nursing home care. But the role of states in the management of other programs, including the licensing and regulation of assisted living facilities, seems less well known.

The role of the states matters for several reasons. Perhaps the most far-reaching of these requires the addition of a new question to our national dialog. That question is, "Should seniors and people under age 65 who need long-term services and care receive the same level of services, funded and administered in similar ways, all over the nation; if not, how much variation is feasible or appropriate?" With this new but central question in mind, let us turn to the current context for discussion of this set of concerns.

(c) The Current Context of Discussion

Discussions of long-term services and supports typically focus on senior citizens, whose numbers are rising dramatically, expected to double between 2000 and 2040, and to rise from about 12 percent to just over 20 percent of our population. While the size and variety of this population naturally command much of our attention, it should not be overlooked that fully one-third of people receiving long-term care services today are under the age of 65, including both adults and children [102]. Most of these are people with disabilities, and the issues that must be addressed in fashioning measures to address their needs and concerns are not always the same as those for older people.

One primary example of the differences relates to the role of educational opportunities and work incentives in the programs that serve these citizens. Other distinctive issues would involve the need for consumer-control mechanisms that reflect the differing needs, goals, interests, and capabilities of people throughout the life span.

Ironically, attention to the design of the long-term services system, for younger and older people alike, may diminish during 2005 because of intense national preoccupation with Social Security reform. As an income replacement and maintenance program for retirees and workers with disabilities, Social Security, including SSDI, plays a central role in the spectrum of long-term services and supports that this nation provides. But the nonincome replacement, often noncash, components of that service system, ranging from medical care to personal assistant services, are vitally important to the effectiveness of the income replacement. Unless these issues are considered in tandem as they affect individuals, and unless system planning is done according to a person-based model, possibilities for synergy will be lost and impact data will be fragmented and inadequate.

(d) The Private Sector

The private sector plays an important role in long-term services. On the medical side, most Medicare services have long been provided by private-sector health care practitioners under the traditional fee-for-services model. With increased reliance on managed care under MMA following its full implementation on January 1, 2006, the role of the private sector in the delivery of Medicare services will grow. More and more under the managed care system, care will be managed by private sector firms.

But the public-private partnership in long-term services extends far beyond its medical component. The growing use of consumer-controlled approaches in various service systems will result in more ownership of program resources by end-users and recipients themselves.

In relation to the various levels of service and support in residential options and personal assistance, one key partner is the private insurance sector. Long-term care insurance payments currently account for an estimated 5 percent of total national long-term care expenses, according to CBO data ([103] as cited from the Census Bureau's Survey of Income and Program Participation [SIPP]). CBO estimates that under our current model, this figure could rise to as much as 17 percent, but CBO also notes that this would still be far less than Medicaid's share of long-term care costs or the percentage paid by recipients out-of-pocket. Increased use of programs such as the long-term care (LTC) insurance–Medicaid partnership can help [104], but we have found no research suggesting that long-term care coverage can be expected to play a major role in the financing of long-term care.

As part of the discussion of Medicaid reform, which will be taking place this year in the shadow of the Social Security debate, means for enhancing awareness of the role of LTC insurance must be considered. Managed care has been adopted as a principal technique for reforming Medicare, and it may be that such approaches in the Medicaid and long-term services area could also prove of benefit and could help to balance the goals of cost control and quality service.

For LTC insurance to play a larger role in the financing of long-term services in the coming years, four things seemingly need to be done. First, employed people who can afford such coverage need to be educated as to its potential role. Second, the scope of coverage needs to be expanded, so that more than quasi-medical services and custodial care are covered. Currently, benefit payments under most policies are triggered by the insured's inability to perform two or more activities of daily living (ADLs) or instrumental activities of daily living (IADLs). Third, benefits for people who want to remain in their homes need to be more nearly comparable to benefits for nursing home or other institutional care than they presently are. And fourth, the cost of such insurance for those who cannot afford today's rates must be brought down.

Any discussion of the role of private insurance in long-term services and care presents some thorny issues. It has been suggested, for example, that one obstacle to private insurance's increased participation in the current system is incompatibility between private LTC insurance and Medicaid. Because Medicaid will pay nursing home care costs for people who have exhausted their resources, and because long-term care insurance, even if available, is unlikely to meet people's entire care and service cost needs, some may see little point in buying such insurance. Medicaid's potential stop-loss role, some say, is itself a disincentive to purchasing LTC insurance.

There is little doubt that if Medicaid were to relinquish its payer of last resort role (so that people could use private insurance and Medicaid in combination to meet their needs and maintain a higher standard of living), some people might try harder to obtain private sector coverage. But Medicaid's strict adherence to means-testing and its payer of last resort status are certainly not going to be eliminated in today's austere budgetary environment.

At the other end of the spectrum, if Medicaid were to make it more difficult for seniors to preserve their homes or to shelter any assets for passing on to their children, that too would probably cause more people to purchase LTC coverage, in the hope of avoiding the need for Medicaid. But it seems equally unlikely that Congress would adopt such a draconian approach to forcing people to obtain private coverage, especially because coverage is expensive and limited in the amounts it will pay for home and community-based services, and limited in the range of services and supports it will cover.

For people with disabilities, any effort to place greater reliance on private sector LTC insurance presents a number of additional issues. Rightly or wrongly, people with disabilities encounter denials of coverage or are deemed eligible only for the most expensive and most limited LTC coverage.

Insurer refusal to cover certain groups or types of people is known as adverse selection. Adverse selection on the basis of disability is, perhaps surprisingly, by and large not unlawful under federal antidiscrimination or civil rights laws such as ADA, especially if it is based on actuarial assessments or underwriting decisions [105]. For this reason, any attempt to increase the utilization of private insurance in the LTSS context must include strong protections against adverse selection. Once again, people with disabilities must not be overlooked or ignored in the gathering debate.

NCD believes that the private sector insurance market must be encouraged to play a larger role in the provision of traditional LTC and other elements comprising the LTSS continuum. NCD does not presume to know how this can best be brought about. For this reason, NCD recommends that Congress conduct extensive hearings into the current and potential role of private sector insurance in meeting the nation's need for LTSS, including the potential role of private insurance in meeting this need for people with disabilities.

Recommendations

Recommendation 5.1: NCD recommends that Congress and the President collaborate on a major national study designed to identify the proper scope of government involvement with LTSS, to define what services and needs are appropriately covered by the concept, and to identify the ways in which reforms in health care, income support, or other related areas will affect the availability and demand for LTSS in the coming years.

Recommendation 5.2: NCD recommends that Congress conduct extensive hearings into the current and potential role of private sector insurance in meeting the nation's need for LTSS, including the potential role of private insurance for meeting this need for people with disabilities.

Chapter Six—Children and Youth

Introduction

No age group exists in a vacuum. Every program and every trend in society affect youth, and programs designed with youth particularly in mind affect their families, communities, teachers, and future employers as well.

With these connections in mind, NCD has attempted to identify certain subjects and issues that are of primary concern to youth or that affect youth to a greater degree than they do other people. Section (a) of this chapter discusses some of the issues arising from the intersection between the juvenile justice and mental health systems. Section (b) addresses needs and gaps in current adoption incentives and in neglect and abuse data collection practices. Section (c) addresses the work and aspirations of NCD's Youth Advisory Council. Finally, section (d) addresses new issues emerging in connection with the provision of school-to-adult-life transition services.

(a) Incarceration

Awareness has grown over recent years about the extent to which the juvenile justice system has become responsible for dealing with youth who may suffer from emotional or mental illnesses. The needs of these youth for mental health services and other supportive and therapeutic interventions may be very different from what the courts and corrections systems, however well intentioned, are able to provide.

A report prepared for a bipartisan group of Senate and House members in July 2004 highlighted the particular dimension of this problem represented by pretrial incarceration of youth needing mental health services [106]. As the first national study of its kind, this report, which gathered its data directly from survey responses from juvenile detention facility administrators, contained profoundly disturbing findings. NCD recommends that anyone interested in this issue review this report carefully. In the meantime, NCD believes that discussion of the key issues raised is a necessary and long overdue prelude to fashioning effective solutions.

Essentially, the administrators told Congress that two-thirds of juvenile detention facilities are holding youth in custodial conditions, not because they have been accused or determined to have committed offenses (though some may have) but primarily, even in the case of those who are delinquent, because appropriate mental health services, placements, or even appointments are unavailable. The pervasiveness of detention used as an alternative to treatment for children as young as seven years of age is disturbing.

NCD recognizes that this situation has developed unnoticed over a number of years, and we are confident that all people of goodwill will be anxious to improve it. Children and youth with disabilities or who are at significant risk of developing disabilities should not be incarcerated solely because of a lack of treatment resources, any more than adults who have committed no crime should be.

Now that the problem has been recognized, NCD recommends that the 109th Congress hold hearings into the causes, extent, and most of all the potential solutions to this problem, and that the Administration make it a priority to ensure that effective and accountable measures are put in place for steadily reducing and eliminating the use of incarceration for nondelinquent children and youth deemed in need of mental health services. Particularly in this era in which punishment has become an increasingly important component of our justice system, juvenile detention is not and cannot be the default therapy provider for children in need of help.

(b) Child Welfare

As reflected in the scope of relevant federal regulations and funding programs, child welfare includes a number of areas. It includes foster care and adoption, programs for prevention and curtailment of neglect and abuse, data collection and record keeping, and related areas and concerns. A September 2004 Congressional Research Service (CRS) report on recent federal child welfare legislation presents an excellent overview of many of these programs, as well as of some of the current debates swirling around federal child welfare policy [107]. This report is recommended for those wishing to learn about this important topic in greater detail.

For purposes of this NCD status report, several issues warrant attention. These bear upon the ways current federal programs do and do not recognize the existence of children and youth with disabilities, and the ways these programs do or do not reflect awareness of the unique needs and issues facing many of these children.

1. Foster Care and Adoption

More and more in recent years, federal policy has sought to encourage the adoption of children in foster care who cannot be reunited with their birth families. Inclusion of federal financial incentives for states that achieve gains in the number of children adopted represents one strategy for achieving this goal [108]. In addition to per capita payments for states that exceed their baseline numbers, the law provides for bonus payments for successful placements of older children (those over nine) and of children with special needs (including children with disabilities) [109].

NCD is concerned to know how effective these incentives have been in stimulating the adoption of children with disabilities. Numerical data on adoptions, even when available, cannot necessarily answer the key questions.

To NCD’s knowledge, no current data-collection efforts focus on identifying the relative risk of family problems in homes including children with disabilities or the relationship of such problems to the unmet needs of such children. Moreover, data on the percentage of such children in need of permanent homes who actually achieve such placements would be extremely valuable, in itself and as a means of comparing the success of current efforts with the results achieved in work with other groups of children. Finally, data on outcomes achieved by children with disabilities who are adopted would shed considerable light on the adequacy of support services and technical assistance currently available to adoptive families.

The Department of Health and Human Services (HHS) maintains a major foster care and adoption reporting system, the Adoption and Foster Care Analysis and Reporting System (AFCARS). In 2003, HHS issued a request for comment on ways to improve AFCARS [110]. Additionally, in 2004 the Pew Commission on Children in Foster Care issued its recommendations for improving AFCARS [111]. NCD is not aware that either of these efforts specifically addresses issues concerning children with disabilities or analyzes the barriers presented by disability. For this reason, NCD recommends that HHS reopen its inquiry with a view to identifying the specific issues and experiences shaping the foster care and adoption processes for children with disabilities, so that key concerns may be incorporated in the AFCARS when it is revised.

For example, what would be the impact on adoption rates and success for these children of the earmarking of federal funds for needed home modifications or appropriate assistive technology? Given the role of these and other measures in the lives of children with disabilities generally, there is every reason to believe that heightened availability of home modifications or of AT through the child welfare system could make a substantial contribution to the options available to such children and to the supply of adoptive families who can reach out to these children.

In this connection, too, the child adoption tax credit was amended in 2002 to provide that in cases of special needs children with disabilities, adoptive families could claim the maximum credit of $10,000 whether or not they had actually incurred $10,000 in qualifying expenses [112]. Congress should evaluate the efficacy of this incentive provision. It might be the case, for example, that a refundable credit, allowing all qualifying expenses to be claimed, would do far more, perhaps even at less cost to the Treasury, to stimulate adoption of special needs children than the current version of the credit does.

2. Maltreatment, Abuse, and Neglect

As reauthorized by the Keeping Children and Families Safe Act of 2003 [113], the Child Abuse Prevention and Treatment Act (CAPTA) represents a key link in the federal effort to prevent, stop, and punish child abuse and to protect children against neglect and other forms of maltreatment. One need only consult the grim headlines to know that cases of child abuse in all its cruel forms are widespread. Because children are the most vulnerable sector of our population, the attention to and concern for this problem reflected in CAPTA, in the Family Violence Prevention Act, and in other laws and programs is of great importance.

No one knows the extent to which disability adds to the risk of neglect or abuse that children may face. Anecdotal evidence suggests that it does, and few could doubt that maltreatment in early life can contribute directly to the occurrence or severity of disability, through the effects of emotional or physical trauma. Recognizing the link between trauma and disability, the Individuals with Disabilities Education Act (IDEA) amendments of 2004 contain provisions for referral for early intervention services of children from families in which violence has occurred or children who have been the victims of or who have experienced other forms of family trauma [114].

Federal programs are increasingly responding to the problem of neglect and abuse by including provisions for combating these in their authorizing legislation. Another recent example of this is the Indian Child Protection and Family Violence Protection Act of 2004 [115], and further efforts can be expected as various programs are reauthorized and revised.

One key feature of any effort to identify and respond to a pervasive problem is information collection and reporting. The Administration on Children, Youth and Families (ACYF) is charged with the responsibility of submitting an annual report to Congress on child maltreatment. Information presented in December 2004 before the National Child Abuse and Neglect Data Systems directors by NCD reflected concern that problems with the undercollection and underreporting of required statistics may be hindering efforts by Congress and the Administration to fashion effective responses to this problem [116].

NCD recommends that all those with a concern for this issue consult its testimony. For the moment, it is important to note that not all states are providing the full scope of necessary data, including data on disability risk factors. In addition, CAPTA disability tables (based on state reported data) are not being fully incorporated into ACYF's annual report to Congress, as they should be.

Certainly, no one wishes to increase paperwork requirements borne by states, by local law enforcement or social services agencies, or by other entities. Nevertheless, because Congress has placed a high priority on gathering information concerning neglect and abuse, it is important that the role of disability and the impact of these problems on children with disabilities be adequately reflected in that data. Accordingly, NCD recommends that the Secretary of HHS review existing data collection requirements, data collection instruments, and reporting formats to ensure that all data called for under current law are collected, aggregated, and timely reported, and to determine, in those cases where such compliance might be difficult or costly, what strategies may be available for avoiding new administrative burdens while still achieving the substantive goals of policy and meeting the informational needs of Congress and the public.

(c) Youth Leadership

NCD is extremely proud of the existence and work of its Youth Advisory Committee (YAC). Those with an interest in the detailed operations and functions of this committee are urged to review published background material concerning its work [117]. For purposes of this status report, two points are particularly notable.

First, the existence of a body like the YAC provides NCD with invaluable grassroots input and feedback concerning the needs and concerns of a key constituency that may not have routine access to policymakers and that may lack means for expressing its concerns in ways that policymakers can take fully into account. NCD has long believed and reiterates now its belief that all agencies with responsibilities or concerns in areas of particular relevance to children and youth should seek means for incorporating the views and experience of this population group into their databases and frames of reference.

The second important point arising from the existence of the YAC is its role in developing leadership for the next generation. Although not necessarily a formal objective of the program, NCD is convinced that organized efforts to involve youth in policy development and deliberations will pay handsome dividends in terms of developing skills and awareness among participants and in engaging the energies and commitment of young people who will remain involved in community activities throughout their lives.

Once again, we believe that this model commends itself to a variety of other agencies and programs. To the extent that agencies and programs can enlist youth in, and inform youth about, what they do, foundations for citizenship and leadership are laid down for years and decades to come.

(d) New Transition Challenges

The recently reauthorized IDEA includes, as have earlier versions of the law, significant attention to transition services aimed at ensuring the most effective possible movement of students from secondary school to postsecondary education or other adult services settings [118]. The law's procedural requirements and provisions for vocational rehabilitation (VR) and education system collaboration all hold out great hope of ensuring that quality and timely services will be delivered to more students with disabilities, but concern exists whether these provisions and structures can reach youth who have dropped out or who are at high risk of dropping out prior to graduation or to other forms of school program completion. Given the increasing disparity in income and other life prospects between those who have and have not completed high school, identifying and reaching such youth among the population of children with disabilities must emerge as a matter of growing concern.

Existing transition program requirements largely presuppose that youth are receiving services in an educational setting. Interestingly in this regard, tax law provisions aimed at helping middle and working class families to defray the costs of education (and special education where not otherwise covered) focus almost exclusively on youth who are bound for college. These provisions include education or Coverdell IRAs, Hope and Lifetime Learning credits, and Section 529 tuition programs [119]. None of these salutary provisions appear to contemplate that youth who are not going on to college, especially youth with disabilities who may be alienated or at risk, may need similar support and resources in identifying and pursuing other life paths.

Thus, both for students who do complete secondary school but have no further educational goals and for those who may fall through the cracks and leave school prematurely, new models and mechanisms need to be explored and devised. NCD recommends that the Secretary of Education undertake a study to determine what proportion of students with disabilities who enter secondary school actually are in a position to benefit from existing transitional services and to develop strategies for identifying students with disabilities who are at risk for dropping out so that such children can be kept within the services network.

Recommendations

Recommendation 6.1: NCD recommends that the 109th Congress hold hearings into the causes, extent, and solutions to the problem of incarceration of children and youth in need of mental health services, and that the Administration make it a priority to ensure that effective and accountable measures are put in place for steadily reducing and eliminating the use of correctional system incarceration for nondelinquent children and youth deemed in need of mental health services.

Recommendation 6.2: NCD recommends that HHS reopen its inquiry with a view to identifying the specific issues and experiences shaping the foster care and adoption processes for children with disabilities, so that key concerns may be incorporated in the AFCARS when it is revised.

Recommendation 6.3: NCD recommends that the Secretary of HHS review existing child abuse and neglect data collection requirements, data collection instruments, and reporting formats to ensure that all information called for under current law is collected, aggregated, and timely reported, and to determine, in those cases where such compliance might be difficult or costly, what strategies may be available for avoiding new administrative burdens while still achieving the substantive goals of policy and meeting the informational needs of Congress and the public.

Recommendation 6.4: NCD recommends that the Secretary of Education undertake a study to determine what proportion of students with disabilities who enter secondary school actually are in a position to benefit from existing transitional services and to develop strategies for identifying students with disabilities who are at risk for dropping out so that such children can be kept within the services network.

Recommendation 6.5: NCD also recommends that Congress authorize the Secretary of the Treasury to initiate research to determine means by which the goals and benefits of current tax laws subsidizing and encouraging higher education could be effectively expanded so as to similarly support appropriate life goals outside the formal educational structure.

Chapter Seven—Employment

Introduction

For all Americans, employment is central to a productive and fulfilling life. It is for this reason among others that maximization of employment is a central goal of American economic policy.

Despite the unanimous support for enhanced employment opportunities for people with disabilities, and despite a long history of bipartisan commitment to programs designed to bring about this result, unemployment among adults with disabilities remains unacceptably high and stubbornly resistant to significant reduction. Estimates of the actual level of unemployment among the population of people with disabilities vary, depending on the definitions and research techniques used. Whatever the precise number, the disparity in life experience between Americans with and without disabilities may be greater in the area of employment than in any other sphere of life.

One element of the demographics of disability employment has been the growth over recent years in the number of people receiving SSDI [120]. This increase has added to the present and projected costs of the disability insurance (DI) program and to the projected costs of related Medicare health insurance coverage. It has also brought into sharp focus the fact that few people who begin receiving such benefits (under 2 percent [121]) have been able to return to unsubsidized gainful work.

Against this background, NCD commends the significant efforts being made by a number of federal agencies and programs to develop strategies for getting recipients and others with disabilities back to work. A number of these will be discussed in this chapter. At the same time, NCD believes that new and dramatic approaches will be needed for the problem of unemployment among people with disabilities to be materially and durably reduced. Some suggestions along these lines will also be discussed.

In terms of current efforts, this chapter will discuss a number of work incentive programs undertaken in recent years, including those operated by the Social Security Administration and those established under the Ticket to Work Act. It will seek to explore both the operation of these programs and some of the crucial assumptions underlying them.

Next, the chapter addresses issues arising in connection with the forthcoming reauthorization of the Workforce Improvement Act, including issues confronting the mainstream career development system and issues of particular concern to the VR system. Finally, the chapter will explore a range of issues presented by changes in society, in the labor market, and in the expectations and experience of workers, employers, and government. The chapter raises key questions that must be answered if the efficacy of our career development and specialized VR services are to be maintained and strengthened.

(a) Work Incentives

Through a number of statutory provisions [122], Congress has shown an awareness of the role of work disincentives in the existing income replacement and health care programs. The nature of these disincentives is no mystery. People risk losing, or fear they risk losing, benefits if they receive income. Because the significance of the loss, particularly when means-tested health insurance tied to income is endangered, is often much greater than the value of the income triggering the loss, and because health insurance may not be available or affordable in the private sector, the risk of returning to work is simply too great.

In broad terms, SSDI and Supplemental Security Income (SSI) are structured so that income, resources, or even evidence of the ability to work will ordinarily result in reduction or loss of income benefits and of health insurance. These programs, along with other programs ranging from housing subsidies to food stamps, vary in the details of how the disincentives work—in how long, at what rate, and with what exceptions.

To counter these disincentives, Congress has adopted a number of work incentives designed to reduce, delay, or otherwise soften the impact of these provisions. Under the Social Security programs (SSI and SSDI), these work incentive or antidisincentive features include the trial work period (TWP), impairment-related work expenses (IRWE), and plan for achieving self-support (PASS), to name some of the best known [123].

On balance, however, judging from the return-to-work statistics, it appears to be the conclusion of those who have studied the disincentives problem that these antidisincentive measures have had little impact on facilitating either exit from the SSDI or SSI rolls through return to work or in increasing overall levels of employment among people with disabilities.

The past year has witnessed the continuation and growth of a number of important efforts designed to better understand and improve the effectiveness and impact of the work incentives. A number of these are worthy of note.

1. SSA Demonstration Projects

The Social Security Administration (SSA) has been given a mandate by Congress [124] to conduct at least three types of work-incentive demonstration projects. These projects are designed to collect data on what works and to test various approaches to modifying the risk-reward equation faced by beneficiaries. Interestingly, in light of the growth of SSDI, the SSA's demonstration authority is not limited to current recipients but extends to experiments aimed at keeping people off the rolls in the first place as well.

Recently, the GAO issued a report indicating that SSA has not made full use of its demonstration projects authority [125]. Accordingly, NCD recommends that SSA review its current programs and plans to ensure that available resources and authority for innovative work-incentive projects are being utilized and documented to the fullest possible extent.

NCD joins in the expectation that current and planned demonstration projects will yield valuable data. Pending the collection and evaluation of findings and the making of recommendations, NCD notes that such demonstrations may fall short of their potential if they are not conducted in coordination with other ongoing efforts.

The demonstrations are based on the premise that changes in the pattern of incentives and disincentives can affect improvement in the return-to-work profile of the beneficiary population.

NCD is concerned that the findings may be compromised by parallel developments that enhance or impede the effects of changes in the risk-reward ratio. For example, in the case of SSI recipients receiving their health insurance through Medicaid, state actions beyond the control of SSA may influence the outcome of the demonstrations. For example, if a state chooses to eliminate or curtail Medicaid buy-in programs under which the working poor, including SSI recipients, can retain health insurance while working, the benefits of other changes in the equation (including changes that allow Medicaid to be retained) may be diminished.

The impact of seemingly unrelated programs, like state Medicaid funding and SSA demonstration projects, on one another illustrates the often baffling complexity but also the critical importance of comprehensive planning. That need, illustrated again and again in the interaction among programs and decisions, must be addressed, not only for initiatives to succeed, but for evidence-based policymaking to be truly possible.

Major related demonstration efforts include those being developed under the auspices of the Centers for Medicare and Medicaid Services (CMS). NCD commends CMS for its continued provision of Medicaid infrastructure grants to the states [126]. But even CMS does not control how the states, particularly if beset by budgetary crises and by potential cuts in federal Medicaid funding, will maintain or rethink their commitments to buy-in.

Along similar lines, the potential role of Section 1619 (b) of the Social Security Act [127] must be taken into account in designing work-incentive demonstrations and in selecting venues for conducting them. Section 1619 (b), an important but little known work incentive, allows Medicaid recipients to retain their benefits while earning income. This option is available only up to specified income levels, which vary by state according to formulas based on average medical costs in each state. Levels currently vary widely, from around $21,000 to over to $40,000. Because states have such differing Section 1619 (b) ceilings, the choice of states is likely to have an impact on the results of demonstrations involving SSI.

In addition, local labor market conditions must be factored into the design and site selection of demonstration pilot projects. If these variables are not taken into account, findings may be distorted. More seriously, the dangerous misimpression may go unchallenged that the impact of work-incentive programs can be evaluated in isolation from other important programmatic and economic variables.

The connections among programs suggest the need for close coordination between SSA and CMS in their administration of the Medicaid infrastructure, of real-choice and other consumer-directed experiments, and in other matters. If the benefits of demonstrations are to be maximized and if the implications of all these experiments are to be separated out for study and replication, such coordination must be made integral to the operation and design of all the programs.

Although NCD trusts that such coordination does take place on an ongoing basis, the Council is unaware of specific indications from either agency of how this is done or how the assumptions underlying each agency's experiments are influenced by the work of the other agencies or factored into their work.

In this connection, it should be noted that, until 1995, SSA was part of HHS [128], and CMS is housed in HHS. Although joint and coordinated planning might be easier if both agencies reported to the same Cabinet secretary and were part of the same department, close coordination should nevertheless be possible and is imperative.

2. TWWIIA

The Ticket to Work and Work Incentives Improvement Act of 1999 [129] represents another important variable in the work incentives concept. TWWIIA approaches incentives in two ways. First, it creates means for health insurance benefits to be maintained for substantial periods of time after entering employment and, in the case of Medicare, creates expedited procedures for regaining cash benefits if employment is lost.

But second, TWWIIA also pioneers another type of work incentive. It seeks to engage a new class of job placement and training organizations known as employment networks (ENs) and to pay them in a new way not based on fixed appropriation or on the number of people served. Instead, by using milestones and event-triggered payments, it seeks to reward the ENs for success in working with and placing ticket holders in employment.

Although still a relatively new program, Ticket to Work has thus far not brought about significant statistical results and has not attracted a large number of SSDI or SSI beneficiaries, according to available research [130].

Various factors have been cited as causes for the limited and disappointing impact of the program to date. These range from the insufficiency of EN-INCENTIVE payment levels to the complexity of the insurance maintenance procedures. It is not NCD's purpose here to evaluate the comparative significance of these or other causes, nor do we presume to suggest how the program could be improved. We do, however, wish to note the impossibility of reaching firm and reliable conclusions on these points without taking other related factors into account. Three such factors are noted and discussed as follows.

A. Powered Mobility Devices

At the very time that Medicare is being made more available through TWWIIA to people who return to work, the CMS has begun taking steps that may dramatically reduce the availability of mobility devices, such as powered wheelchairs work-returnee Medicare recipients [131]. We do not here suggest whether CMS's efforts in this regard are wise or unwise. We do suggest that it is the obligation of policymakers to find means for assessing the effect of these measures on the opportunities and outcomes for aspiring work-returnees. NCD is not aware that CMS has studied these implications or that their existence has been factored into assessments of the impact of TWWIIA.

B. In The Home Rule

Using the Medicare policy as a guide, many state Medicaid programs restrict the availability to beneficiaries of durable medical equipment (DME) to items used exclusively in the home [132]. Once again, it is not NCD's purpose here to evaluate this rule, either in Medicare or as applied to Medicaid, but it is essential that someone, somewhere, evaluate the implications of this rule for Medicaid and Medicare as employment support programs. If, by going out to work, people are denied access to items of DME that they need, either to work or to live independently, then the work-incentive potential of continued Medicare or Medicaid coverage is considerably undermined. NCD can find little evidence in the annals of policymaking that this question has ever been considered, seriously studied, or authoritatively answered.

C. Local and National Labor Market Conditions

TWWIIA had the misfortune of coming into full operation at a time of economic recession and slow job growth. While conditions in the labor market are widely understood, their exact impact is difficult to quantify or to study with rigorous evidence-based research techniques. NCD believes that a start on this could be made by comparing TWWIIA results across regions and states that had significantly different local labor market conditions during the early years of the program. Until or unless this is done, the impact of the TWWIIA work incentives and the efficacy of the ENs cannot be fully determined.

(b) The Workforce Improvement Act

The Workforce Improvement Act of 1998 (WIA) [133] was reauthorized in the first session of the 109th Congress. WIA includes many features of great importance to job seekers and jobholders with disabilities, including provisions to enhance participation in the mainstream workforce development system for people with disabilities and provisions governing the operation of the specialized programs of vocational rehabilitation for people with disabilities.

In February 2004, NCD conducted a major forum on employment issues at the First Annual Emerging Workforce Conference [134]. The conference and forum, coming as they did in conjunction with the consideration by Congress of WIA reauthorization, offered a major opportunity for the discussion of challenges, strategies, and results. This annual status report will not attempt to summarize the insights shared at the forum. We suggest that all interested people review the forum in detail. The sections that follow draw attention to issues that NCD believes will most significantly affect the role of WIA in the lives of people with disabilities over the coming years.

1. One-Stop Centers

The linchpin in the operation of the workforce development system created by WIA is the one-stop centers designed to centralize the delivery of the host of informational, assistance, training, referral, and other services available to job seekers under the various labor market development programs supported by federal law or federal funds.

A. Accessibility

If people with disabilities are to benefit fully from the services and resources of the one-stops, it is essential that these centers be physically and programmatically accessible to people with disabilities. Provisions of the existing law [135] require accessibility as defined by law and bar discrimination against people with disabilities, but many one-stop centers have not succeeded in making their premises, programs, and resources fully accessible and available to people with disabilities.

NCD commends, as we have done in past reports, the measures undertaken by the Department of Labor (DOL) to achieve one-stop center accessibility. The Council believes that more is required, and that the reauthorization currently making its way through Congress, though already well along [136], still offers significant opportunities for implementing these proposals.

Specifically, NCD recommends that the requirement for full programmatic and facilities accessibility be maintained and strengthened in the reauthorized law. To do this we recommend that federal financial support for one-stop centers, and for the local workforce investment boards (WIBs) that play so large a role in directing their activities, continue to be conditioned on the existence and implementation of an accessibility plan. This plan should contain measurable goals, time frames and methods (including funding sources and requirements) for achieving full accessibility over a reasonable period of time and for making steady improvement during the implementation period.

State-level plans should also be required and should address these issues from the standpoint of state financial participation, technical assistance, and quality monitoring. They should include detailed criteria for assessing whether equal access has been provided and for monitoring measurable progress toward that goal.

Broad input into the design of state-level and local accessibility plans may also be critical to their effectiveness and relevance. We should expect that procedures will be developed for obtaining and incorporating the views of people with disabilities as part of the planning process.

B. Accountability

The application of evidence-based standards to the workforce development system offers an important opportunity to make significant improvements in the ability of that system to serve all Americans, including workers with disabilities. But to achieve the levels of insight that evidence-based research makes possible, it is necessary to examine key factors that operate in different settings and to resist a simplistic, one-size-fits-all approach to cost-effectiveness measurement.

No one would suggest that the services offered or the per customer costs incurred by a one-stop center serving laid-off white-collar workers in a wealthy suburban community would or should be comparable to those found at a center serving immigrant, low-skilled, limited-English-proficiency manual workers in an impoverished inner-city neighborhood. For similar reasons, the resources required and the costs involved in serving individuals with disabilities cannot be identical to those involved with other population groups.

Accordingly, NCD recommends that before applying any mechanical cost-effectiveness formula to one-stops, Congress authorize the DOL to undertake and report detailed research concerning the predictable and appropriate levels of these costs. This report should also analyze the implications of varying degrees of one-stop center inaccessibility on the numbers of people with disabilities seeking their services, on the per capita costs of serving such people, and on the relationship between costs and outcomes.

Accountability also cannot rest on costs alone. Without detailed knowledge of program outcomes, the meaning of cost data cannot be analyzed. For job seekers with disabilities, this dimension of accountability involves two levels of information. First, outcome data must be systematically collected, in itself and in relation to program services and inputs. But second, and as important, outcomes for people with disabilities must be compared, so far as possible, with those results achieved by one-stop customers who do not have disabilities. Without this additional knowledge, the efficacy of one-stop outreach and inclusion efforts cannot be evaluated or understood.

C. The Navigator Program

NCD has expressed its support for the disability navigator program established to facilitate the identification and provision of appropriate services to one-stop center users with disabilities. We reiterate that commendation here.

The navigator program appears to rest on two assumptions. One, that the mix of mainstream and specialized services required for vocational success by people with disabilities involves complexities, relationships, and technologies that one-stop staff cannot routinely be expected to know about. Accordingly, it is the job of the navigators, stationed at one-stops, to help other one-stop staff and service recipients identify and access the specialized services needed to supplement and round out what the one-stops can provide or locate.

The second premise behind the navigator program, closely related to the first, is that lack of timely information about the range of available services and how to access them is itself a major barrier both to the ability of one-stops to serve individuals with disabilities and to the prospects for vocational success through the one-stops of those individuals with disabilities who seek their services and assistance.

NCD believes that both these assumptions are plausible, and we expect that ongoing research into the navigator program will demonstrate measurable results in both these respects. But, once more, we believe that efforts to structure or study the navigator pilot projects, if carried out in isolation, are likely to yield confusing results.

Navigators have a heavy responsibility. They must be knowledgeable about specialized resources for job seekers with disabilities and about the interface of those resources with mainstream opportunities. And they must be effective at communicating this information to individuals and colleagues. But it is additionally necessary that they remain closely familiar with mainstream resources and evolving labor market trends. It is invaluable if a navigator can advise the one-stop on how to make its computerized databases accessible. But if in the process, the navigator cannot remain fully up to date on what the databases on those computers contain, are used for, and can be expected to accomplish, then accessibility may only take the job seeker halfway to the employment goal.

Numerous strategies exist for fostering the effective interaction between navigators and other one-stop personnel. State and WIB plans need to emphasize the importance of sustained cross-fertilization, and Congress should include requirements that these plans be specific as to the means for doing so.

2. Vocational Rehabilitation

The federal-state vocational rehabilitation (VR) system for people with disabilities is in many ways a paradoxical system. Operating under the authority of Title IV of WIA [137], it exists and operates alongside the mainstream workforce development system. It is charged at once with being a primary and specialized resource for individuals with disabilities and at the same time with being a vital and cooperative partner in a number of efforts in which its role is coordinate, sometimes subordinate, to that of other programs and entities. Further complexity is introduced by the fact that VR's often contradictory roles must be developed and played out within the framework of a federal-state system that superimposes on the program a complicated allocation of authority between the Federal Government and the states.

The complex conditions under which the VR program operates are mirrored in the ambivalence of many advocates. While few advocacy organizations have been on record over the past decade voicing unqualified support for the results achieved by VR or for the methods used, these same critics have defended the system vigorously against attempts to abolish it and merge its functions and resources totally into the mainstream system. This question of whether and how to preserve the VR system played an important role in the deliberations surrounding its reauthorization, as part of the WIA structure, in 1998 [138].

As another reauthorization approaches, all indications are that, while changes in the funding formulas for VR may further reduce its resources, the VR system will remain largely intact.

At such a moment, with its survival ensured and with the system perhaps able to turn its attention once again to the future, it may be time to address areas in which current law and practice could be effectively updated to take full account of changing labor market conditions and customer profiles and needs. To stimulate thought on these important points, several ideas and suggestions are offered in the paragraphs that follow.

A. Tension Between Goals

Even within the framework of its operation as a primary service system, VR faces severe challenges as to its mission and methods. There was a time, perhaps until as recently as the 1992 reauthorization, when the primary objective of the VR system was to obtain full-time employment for its clients. Other outcomes and objectives, while permissible and technically countable as successful case outcomes in certain instances, were not a major focus of the program and do not appear to have been encouraged by custom or by federal regulations. The famous Status 26 competitive employment case-closure outcome was the grail of VR services, even if not so frequently achieved as all would hope.

In the last several reauthorizations of the Rehabilitation Act, the goals and methods of the program have been successively broadened to reflect more attention to self-employment and small business development, to countenance other employment outcomes than full-time employment (such as part-time or supported employment), and even to accord more weight to other life goals in addition to employment [139]. At the same time, the range of people and the kinds of disabilities served have grown, with increasing awareness and attention to the existence and circumstances of people with intellectual disabilities and with increasing attention on behalf of all target populations to assistive technology (AT).

It may be that we are at a crossroads where the imperative of employment as traditionally defined is coming into increasing conflict with the changing realities and expectations of the labor market and the modern consumer. For example, in developing an individualized plan of employment (IPE), the VR consumer is still expected to formulate a career, or at least job, goal. But what meaning does this have in a society in which job tenure is growing shorter and shorter, and in which the average worker will have several distinct careers over the course of a working life? Might it not make more sense to think through how the development of marketable and refreshable skill sets could be operationalized and incorporated into the program?

B. Job Tenure

Our current VR system, though updated many times since initial adoption of the current law in 1973, retains a structure that presupposes long-term job tenure with a single employer. This is evidenced in several core elements of the program, including the permissibility of case closure after only 60 days of employment; the fact that initial intake and eligibility-determination services continue to play a larger role in the program than postemployment or follow-along services do; and the fact that job retention and upward mobility services, while permissible, have not achieved the position of prominence that, in an aging workforce, one might expect they would.

As important as the historic mission of VR is, could it be that in the economy of 2005, preventing workers with disabilities from losing their jobs or leaving the workforce in the first place has as much or more leverage value as helping new labor market entrants or returning workers to get their first jobs?

NCD does not offer answers to these questions here. But these and similar questions must be discussed if the VR system is to remain vital and cost-effective in today's rapidly changing society. So far as NCD is aware, current data collection programs, approved by OMB under the Paperwork Reduction Act and consistent with applicable privacy regulations, do not address some of the fundamental demographic and attitudinal issues that need to be considered in determining how VR needs to be positioned and how effective it can be.

For example, among demographic issues, we do not know what percentage of unemployed people with disabilities has ever been employed in the past. Such information would be crucial to determining whether our current allocation of resources between job preparation or entry and postemployment or job-retention services is optimal. Similarly, we are aware of little data concerning the statistical links between the provision of specific services, such as AT or rehabilitation engineering, and successful case outcomes. If people receiving AT devices and services have demonstrably better outcome profiles, does this indicate that such services should be augmented or does it reflect some selection criteria that result in these services going disproportionately to people with greater prospects for success? Such matters need to be assessed.

Similarly, in more subjective areas, we do not have reliable information on what proportion of self-identified, successfully employed individuals with disabilities obtained relevant training, placement assistance, transportation assistance, or AT from the VR system, compared with how many obtained their jobs with the help of other resources or methods. Among self-assessed or objectively defined successfully employed people with disabilities, what do those who report substantial involvement with or help from VR regard as having been the key services or resources they received? Among people who obtained employment following extensive VR involvement but who do not regard VR as having played a major positive role in these outcomes, what changes would they recommend to make the program more effective?

Research aimed at gathering such information and feedback is eminently feasible, and should be undertaken urgently as part of the basis for further discussion. Meanwhile, features of the rapidly changing labor market must always be kept uppermost in mind.

C. Timeliness of Services

Whatever the goals and priorities of the VR system, timeliness and speed of response are more important to the economy and to employers than they have ever been before. No comprehensive data is known to exist on the relationship between existing procedural requirements and the timeliness of services and responses. This issue may be particularly crucial at this time, when a majority of state VR programs are operating under orders of selection.

As discussed in last year’s status report, order of selection [140] is a provision of the law that allows states to delay or withhold the provision of many services to some otherwise eligible individuals when state program resources do not allow the meeting of all valid requests for service. As a result, people deemed to have the least significant disabilities may be denied services or be placed on waiting lists for service, which can result in substantial delays.

As serious as such delays may be for people entering the labor market, their implications in postemployment situations, in which job retention may hang in the balance, are even more severe. Congress and the Administration need to know the extent of such delays or service denials, and what effects they are having on real people.

(c) The Eroding Job Base

1. Job Quality

As the recent presidential campaign clearly demonstrated, job growth and unemployment are critical numbers in the political arena. While Americans hope the recent upward trend in employment will continue, few are prepared to forecast rosy times ahead for those with limited educations, low skills, or poor self-marketing capabilities. For people without superior technical, professional, interpersonal, or other skills, wages are unlikely to rise faster than the cost of living and may indeed continue to fall behind.

At the same time, the pattern of fringe benefits American workers can expect from their employment is also changing rapidly. Traditional rewards for a lifetime of service, such as defined-benefit company pensions or employer-paid health insurance are likely to continue growing less and less common.

2. The Older Worker

Older workers are likewise becoming a subject of growing importance. Their status partakes of several key elements, ranging from the higher costs they typically represent to employers, on the one hand, to the higher levels of experience and commitment they bring to their jobs, on the other. Needs and methods of training as well as a higher incidence of disabilities are also key issues that emerge in considering the status of these workers. Keeping more older workers in the workforce longer entails costs. Encouraging them to leave the workforce carries other costs.

The issues and complexities surrounding the older worker were touched upon in Chapter 5 and are addressed only briefly in this chapter. A more in-depth discussion is well beyond the scope of this report. But what is definitely appropriate to be noted here is the relative lack of attention to these issues in the Rehabilitation Act and in other potentially relevant sources of guidance and public policy. For instance, VR has not traditionally served people over 65, usually not even over 60, and the current version of the WIA gives states authority to request waivers of certain federal requirements, including one bearing upon older worker programs. The statute gives states the right to seek such “Flex Plan” waivers to more effectively serve adults, dislocated workers, and youth. It says nothing about using such waiver authority on behalf of workers with disabilities or older workers, however [141].

Whatever else comes out of the current debate over Social Security reform, it is likely that the trend toward raising the retirement age for full benefits will continue. Does it follow that for workers in age brackets 65 to 70 who may lose eligibility for full retirement benefits, the upper age limit for SSDI will be raised in a parallel way above its current 65? Does it follow, without regard to the availability of SSDI for older workers with disabilities, that the workforce development system and the VR system will concentrate on developing resources to help these workers and their employers maintain productive working relationships?

3. The Role of Insurance

The Medicare Modernization Act of 2003 [142] provides for federal subsidies to businesses that agree not to eliminate pharmaceutical benefits under their retiree health plans. The theory apparently is that subsidizing the continued provision of private sector coverage will allow many businesses to maintain it and will cost the taxpayer less than Medicare coverage for these retirees would cost. Would similar approaches for insuring pre-Medicare-eligible older workers, including older people working with disabilities, also be worth considering as means for providing insurance to more people at lesser cost to the taxpayer? And would such broadened availability of health insurance for people who are working or trying to work after the onset of disability possibly contribute to the ability of such individuals to remain in the workforce and to the ability of employers to continue to benefit in productivity from their services and experience? Finally, does the VR system have any role or expertise to bring to bear in asking and answering these questions?

4. The Tax System

This moment, when major revision of the tax code is under serious consideration, affords a unique opportunity for assessing the potential of tax policy to enhance the employment of people with disabilities. A number of tax law provisions currently exist to encourage businesses to hire or accommodate workers with disabilities. As discussed in previous reports, and as indicated in a 2002 GAO report [143], these provisions cannot be shown to have had much discernible effect. As indicated in last year's report, NCD believes that the potential of these provisions to enhance employment for people with disabilities has not been achieved. This is due to inconsistency, narrow definitions, and administrative peculiarities in their design and implementation [144]. As they relate to business, the key provisions—including the disabled access credit [145], the work opportunity tax credit (WOTC) [146], the welfare-to-work (WTW) credit [147], and the architectural and transportation barriers removal deduction [148]—all operate under certain assumptions that may or may not be viable. First, with the exception of the WTW hiring credit, which grants a larger tax benefit to the employer in the second year of an eligible worker's employment than in the first, none of these provisions confers any greater benefit on workers or employers for long tenure. In fact, provisions like the WOTC may actually encourage turnover and short-term employment in some cases.

It is beyond the scope of this chapter to offer a detailed critique of the tax law provisions or to make detailed recommendations as to how the law could be used to more effectively encourage hiring of workers with disabilities, their job retention, or their access to fringe benefits such as health insurance that would make maintenance of employment more viable. NCD does believe that creative models exist, holding out high promise of contributing to these goals.

As a starting point for the discussion that must be part of the broader tax reform conversation in the nation, NCD recommends that the President's commission studying tax reform should seek testimony on the issues pertaining to workers with disabilities and on the potential of tax incentives to contribute to the hiring, retention, full integration, and upward mobility of these workers. More broadly, at a time when tax policy is moving steadily to the forefront as a national economic planning tool, its potential for and impact upon workers and job seekers with disabilities should never be omitted from the discussion of methods and goals. To be effective, tax reform must take all who pay taxes or whose lives are influenced by our tax system into account.

Recommendations

Recommendation 7.1: NCD recommends that SSA review its current programs and plans to ensure that available resources and authority for innovative work-incentive projects are being utilized and documented to the fullest possible extent.

Recommendation 7.2: NCD recommends that before applying any mechanical cost-effectiveness formula to one-stops, Congress authorize the DOL to undertake and report detailed research concerning the predictable and appropriate levels of these costs. This report should also analyze the implications of varying degrees of one-stop center inaccessibility on the numbers of people with disabilities seeking their services, on the per capita costs of serving such people, and on the relationship between costs and outcomes.

Recommendation 7.3: NCD recommends that the President's commission studying tax reform should seek testimony on the issues pertaining to workers with disabilities and on the potential of tax incentives to contribute to the hiring, retention, full integration, and upward mobility of these workers.

Chapter Eight—Welfare Reform

Introduction

The legal framework for welfare reform has not changed in the past year. Thus, NCD believes that the detailed recommendations set forth in both our 2002 and 2003 status reports continue to apply to the reauthorization of the nation's welfare law.

Rather than repeat those recommendations yet again, this brief chapter seeks to point up their close relationship to achieving the employment outcome goals of welfare reform. Given the available data, the chapter also suggests that failure to incorporate appropriate support services for welfare-leavers with disabilities only results in the exchange of welfare for SSI dependency.

(a) Background

In 1996, America witnessed a sea change in its approach to welfare with the passage of the Personal Responsibility and Work Opportunity Reconciliation Act (PRWORA) [149]. PRWORA formalized and strengthened the goal of work as the end-product of welfare assistance and created a variety of incentives, sanctions, and procedures to bring that result about in the largest number of cases.

PRWORA has yet to be reauthorized or modified. It has been maintained in operation by a series of short-term extensions and continuing resolutions, most recently by legislation continuing it largely in its present form through March 31, 2005 [150].

NCD's interest in this area is long-standing. Most recently, it is evidenced by our 2003 report *TANF and Disabilities—Importance of Supports for Families with Disabilities* [151]. That report reflected the findings of a 2002 GAO report that some 44 percent of TANF recipients were people with disabilities or people who have children with disabilities. This finding warrants particular attention, because the public discussion and debate over welfare does not, we believe, generally include recognition of the issues faced by this population or the techniques and resources needed to ensure that they too can enjoy the fruits and achieve the objective of work.

(b) The Goals

The goals of work and self-sufficiency are shared by everyone. To say that people with disabilities represent a substantial and potentially distinctive segment of the TANF population is to say that if the goals of welfare reform are to be achieved by all, a strong infrastructure of resources, supports, and techniques that take their unique situations into account must be used.

For this reason, NCD has expressed support for the provisions of the proposed Pathways to Independence Act of 2003 [152] and advocated for supports ranging from childcare to accessible transportation to rehabilitation training and assistive technology, as well as for more individualized assessment of compliance and high levels of state flexibility in relevant areas of program administration [153].

One key finding of the GAO report puts the problem in clear focus. Rates of employment among welfare-leavers with disabilities were significantly lower than for other former recipients.

For people with disabilities, successful welfare reform, NCD believes, is possible, but must be judged by the degree to which the rates, quality, and tenure of employment for postrecipients with disabilities can approach comparability with those achieved by other former beneficiaries. All too often though, the terms in which welfare reform is discussed make this goal harder to explain. Frequently the debate turns on such questions as how many hours of employment activity per week should be mandated, how much funding and discretion should be allocated to states in the area of childcare, what support and training services should be available, and what provisions should govern the ability of the states to waive time limits for the receipt of benefits or for the completion of transition from benefits to employment.

NCD recognizes that these issues are all critical elements of the legal framework within which welfare reform takes place. We also believe that if the overriding question for recipients with disabilities were posed differently, a clearer and more useful answer could be derived. The issue is less one of mandates than of what services, supports, and infrastructure are required to equalize the rates of postwelfare employment and, so far as possible, to ensure that the quality and tenure of such employment is also comparable.

Accordingly, NCD believes that the question should be posed as follows: What needs to be done to maximize the rate of successful transition to employment for TANF recipients with disabilities or TANF recipients who have dependents with disabilities, and what features of the law would have the most instrumental role in bringing this outcome parity about?

(c) Specific Proposals

In its 2003 welfare reform report and its 2002 and 2003 annual status reports, NCD has offered a number of specific suggestions aimed at better ensuring that welfare reform works successfully for all recipients. Rather than reiterating these suggestions here, we propose that, as part of the reauthorization Congress is likely to adopt in 2005, provision be included for a systematic study, conducted by individuals and organizations with detailed knowledge of employment issues for people with disabilities, of what services, supports, and safeguards are required to bring about comparable employment outcomes for this segment of the target population. Accordingly, NCD recommends that the Secretary of HHS should be instructed to conduct a study of the means by which employment outcome parity for postrecipients with disabilities can be best ensured and to implement the findings and recommendations of this study. Among the issues to be considered are (1) job skills and vocational training, including training in the use of job-related assistive technology (AT); (2) specialized childcare for children or other dependents with disability-related needs; (3) accessible and affordable transportation to and from job training or work; (4) availability of AT devices and services needed for full participation and productivity in work; (5) broadening of the permissible uses of TANF individual development accounts (IDAs) to include accessible transportation and technology needed on account of disability among approved savings goals; (6) extent and nature of postemployment and follow-along services required to maximize long-term job success; and (7) such other issues as the expert panel may deem pertinent.

(d) Cost-Shifting

No one would contend that it is the responsibility of the welfare reform program to ensure that all recipients find employment. Equally though, merely reducing welfare rolls represents only half the goals of the program. It is easy enough to cut people from the rolls after their eligibility period has run out or as a sanction for failing to comply with program requirements. But what happens to them then cannot be a matter of indifference, particularly if it has financial consequences for the public sector.

The GAO report found that a large number of postrecipients with disabilities end up on SSI. We may well take pride in the shrinkage of the welfare rolls, but cost-shifting and welfare reform should never be confused. With the full range of support services demonstrated to be effective in other settings, the rates of employment and reemployment among TANF recipients with disabilities can and should be raised to higher levels. Without efforts targeted at bringing about such an increase and at approaching parity, the question will remain out of which pocket the unnecessary costs of dependency are met. So far, the debate over welfare reform has been largely devoid of any apparent awareness of this issue and of any attempt to answer the important questions it raises.

Recommendations

Recommendation 8.1: the Secretary of HHS should be instructed to conduct a study of the means by which employment outcome parity for postrecipients with disabilities can be best ensured and to implement the findings and recommendations of this study.

Chapter Nine—Transportation

Introduction

We have touched on transportation in a number of other chapters of this report. Its emergence in so many contexts reflects its integral role in virtually every area of life.

In this chapter, we address transportation not only as a key link in other chains but as an area of concern in its own right. Section (a) addresses accessibility-related issues in transportation security. Section (b) deals with developments under the Air Carrier Access Act. Section (c) reviews developments in local and regional transportation policy during 2004, and section (d) looks forward to possible enactment of a new national transportation bill.

(a) Airport Security

NCD continues to support and applaud the efforts made by the Transportation Security Administration (TSA) to ensure that the concerns of people with disabilities are taken into account in the formulation of security and screening procedures. NCD also applauds the continuing efforts by the TSA to reach out to the disability community and to take its views into consideration.

New developments, however, could challenge the effectiveness of these efforts. In last year's report, NCD expressed concern that developments in the technology of airport security and passenger and luggage screening could result in the creation of new, unintended barriers to travel for some people with disabilities. We continue to be concerned about two trends: first, the trend to self-service, interactive machines for everything from obtaining boarding passes to screening luggage and even to verifying identity. Second, we are concerned about the use of documentary, biometric, and other measures or identifiers that can present problems for travelers with disabilities.

To put the matter graphically, a machine on or into which one's bag must be lifted for tagging or screening can be an all but insurmountable barrier to a person who cannot lift it. A machine that scans irises for identification purposes can be a source of great delay and frustration to an individual with an artificial eye.

The move toward greater use of interactive technology by passengers at airports has complex causes. NCD believes that considerations of security and cost have combined to accelerate the trend and that air carriers are understandably eager to minimize costs by greater utilization of e-ticketing kiosks and other such technology. It only stands to reason that as the use of this equipment increases, the number of personnel available to assist passengers, with and without disabilities, together with the clarity of procedures for dealing with unusual situations and needs, will dwindle.

The two dramatic examples given previously illustrate possible problems. But NCD does not presume to have foreknowledge of all the potential issues and problems that may result from the interaction between a broad range of people and new technology.

Therefore, we believe it necessary for the TSA, in cooperation with the airline industry, to develop procedures for ensuring that accessibility will be incorporated into the design, testing, and certification of all interactive technology used at airports. Without a procedural standard to ensure that these assessments are routinely and timely done, avoidance of accessibility problems or of costly accommodations may be a matter of chance. Accordingly, NCD recommends that the TSA develop regular procedures for testing the accessibility of all security-related airport technology and for incorporating passengers with disabilities into such focus groups or testing protocols as are used to assess the viability of new designs.

(b) Air Carrier Access Act

1. Foreign Carriers

NCD commends the Department of Transportation (DOT) for its announced intention to extend the coverage of the Air Carrier Access Act (ACAA) to foreign carriers flying into or out of U.S. airports. DOT has taken this step in the context of a larger effort, its notice of proposed rulemaking (NPRM) issued in November 2004, to reorganize and update the regulations governing the ACAA [154]. We believe this measure to be long overdue.

Effectively bringing foreign carriers into the orbit of the ACAA will involve more than changing regulations. It may require education and training, and these efforts may be complicated by cultural differences. For this reason, NCD recommends that DOT develop a detailed plan for identifying and meeting the resources needs that newly covered international air carriers may face in implementing their responsibilities under the ACAA.

2. Accessibility

The NPRM mentioned in the last section also takes important steps forward by recognizing ACAA jurisdiction over airline Web sites used to sell tickets. It requires that these be accessible, as defined by the standards applicable under Section 508 of the Rehabilitation Act. DOT does not take the position that Section 508 applies to commercial air carriers' Web sites, but it uses the technical and substantive standards developed and now widely accepted under Section 508 as the basis for specifying what design goals the Web sites covered by the ACAA must meet.

This action on DOT's part is important for two reasons. First, the decision to cover Web sites that sell tickets reflects the fact that discrimination can occur and barriers to equality in travel can be constructed at places physically far distant from any airport. Second, the determination by DOT that the ACAA covers airline ticketing Web sites helps to clarify a recent federal appeals court decision that has received a great deal of publicity.

In September 2004, the U.S. Court of Appeals for the Eleventh Circuit dismissed the appeal in the case of *Access Now v. Southwest Air Lines* [155]. In *Southwest*, the lower court had rejected a claim that ADA required the airline's Web site to be accessible to people with disabilities who use screen-reader software. In throwing out the ADA claim, the lower court had concluded that Title III of ADA does not apply to Web sites.

By dismissing the appeal, the Eleventh Circuit Court of Appeals has been thought by some to have endorsed this lower court decision. Nothing could be further from the truth. The appeals court did not affirm the lower court decision. Instead it dismissed the appeal, meaning that although the lower court decision stands, the appeals court expressed no opinion about the correctness of that outcome or the soundness of the lower court's reasoning. In fact, as the Court of Appeals made clear, the arguments made by the plaintiffs for why it should reverse the lower court decision could not be considered, because for certain technical reasons those arguments were not properly set before it. The Court of Appeals reached no conclusion on the merits and expressly acknowledged the importance and difficulty of the questions raised but not answered by the case.

One of the questions not answered is whether ADA applies to the air transportation sector at all. At least where airlines and other ticketing Web sites are involved, a good argument can be made that ACAA, not ADA, governs. By including airline Web sites in its recent NPRM, DOT appears to be adopting the view that ACAA controls.

NCD is therefore hopeful that ticketing options will soon become far more equal. But other technologies also need to be addressed if new barriers are not continually to replace the old ones. DOT must go further and must address the accessibility of ticketing kiosks, luggage cart dispensing machines, vending machines, parking ticket machines, and a host of other interactive point-of-sale (POS) machines that increasingly dominate and characterize the transportation environment.

The law has been clear for some years (albeit, in this case, ADA) that mass transit fare machines must be accessible. Established guidelines, proven technology, and successful examples exist of the accessibility of a host of different kinds of machines. So far as NCD can determine, no serious conceptual, technological, or economic barriers exist to the incorporation of accessibility into the design of e-ticket and other interactive, airport-based machines.

Nevertheless, with every day that goes by, the problem grows worse. As the installed base of inaccessible machines rapidly grows, the economic arguments against retrofitting or retooling what have become mass-market designs will become more and more strident.

The continued failure by DOT to require accessibility of at least e-ticket machines is unacceptable. Accordingly, NCD recommends that DOT amend, extend, or reissue the current NPRM to include such requirements and the opportunity to comment thereon in its plans for modernizing its ACAA regulations [156].

3. Service Animals

Two years ago, DOT broadened the range of service, companion, and support animals that would be allowed to accompany people with disabilities (and potentially even people who did not meet the ADA definition of having a disability) on commercial airline flights. Based on anecdotal information reaching us, many of the problems that some feared would result from this broadening of access have not materialized. But some other, unforeseen problems may have materialized, and their resolution may require coordinated efforts by DOT and DOJ.

Because the ACAA standard is now broader than the ADA definition of covered service animals, we believe there is significant danger of confusion. For many people, the fact that access to different settings is governed by different laws may not be obvious. Many people may assume that if federal law allows them to bring their service or companion animal with them in the cabin of a plane, they also have the right to bring the animal with them into a hotel or other public accommodation at the end of their trip. But this is not necessarily true.

The Departments of Transportation and Justice need to collaborate on technical assistance and public educational materials explaining the two laws together, so that people can better understand where they do and do not mesh smoothly. Accordingly, NCD recommends that DOT, in conjunction with DOJ, develop informational resources to enable travelers to understand which law and which standards apply to their companion and service animals in various settings and make clear how to know which venues are governed by which law.

(c) Human Service Transportation

In recent years, the links between transportation and such major life activities as employment, education, health care, and community participation have become increasingly clear. So has the recognition that there exists a sizable and growing group of people—older Americans, children, low-income people, and many people with disabilities—who can be classified as transportation-disadvantaged. In a nation where much of everyday life is organized around movement by private passenger automobile, transportation-disadvantaged people face many barriers to full participation and independent living. Indeed, judged from the standpoint of the range of activities it limits, prevents, or distorts, transportation-disadvantage, meaning the inability to drive one's own car, could be counted as one of the most serious disabilities facing people in our nation. Moreover, as the population ages, it is likely to be one of our fastest growing disabilities, as well.

1. Executive Order

The year 2004 witnessed important milestones in the recognition of these issues and significant developments in the effort to create and coordinate policy aimed at meeting the problem. Developments included the issuance in August of a major GAO report on transportation-disadvantage and senior citizens [157], and actions emanating directly from the White House.

In February, the President issued an Executive Order (EO) on human service transportation coordination [158]. The order makes reference to enhancing mobility to increase opportunities for transportation-disadvantaged people to participate in employment and to access community services. To help accomplish its coordination goals, the EO established the Interagency Transportation Coordinating Council on Access and Mobility within the Department of Transportation.

Consistent with the values of the New Freedom Initiative (NFI), the EO laid out the case for transportation access. Noting that available resources are often fragmented, underused, or altogether unused, the EO calls for a “seamless, comprehensive, and accessible” system.

2. Coordination Activities

As designated by the EO, the new interagency council is to include the Departments of Agriculture, Education, Health and Human Services, Housing and Urban Development, Interior, Justice, Labor, Transportation, and Veterans Affairs, as well as the Social Security Administration. NCD is hopeful that this interagency council will succeed in addressing issues at a high enough level to ensure the sustained attention and effective program coordination that are needed. We are concerned though, in light of the previous existence of other multiagency coordinating efforts, that confusion may result.

Going back at least to the creation in 1998 of the Coordinating Council on Access and Mobility, DOT and HHS have been involved in coordination efforts [159]. In January 2004, just one month before issuance of the EO, the Departments of Labor and Education were added to this council [160]. Because the goals of coordination would not be served by the existence of two parallel interagency councils, NCD assumes that the interagency council established under the EO replaces the one expanded just the month before. NCD is unable to find documentation making this element of the new arrangements clear, and requests that the Secretary of Transportation clarify the situation as quickly as possible.

3. Program Initiatives

Under NFI and through other sources, DOT supports a number of discretionary and competitive grant programs aimed at fostering coordination among transportation providers and resources, and aimed at providing resources for experimental and innovative local and regional programs. A recent GAO report noted the existence of 62 federal programs in this area, and each of the federal agencies mentioned in the presidential EO have some involvement in transportation. For example, the Medicaid program spent over $976 million on transportation services during FY 2001 [161]. Nonetheless, our discussion in this section will be limited to programs funded through or administered by DOT, which have transportation as their principal aim, rather than addressing it only as a means to some other end.

Programs funded by DOT, primarily to meet the needs of transportation-disadvantaged people, include Job Access and Reverse Commute Grants, the Capital Assistance Program, United We Ride State Coordination Grants, and the projects coming under the Real Choice Systems Change Grants (RCSC) program.

NCD recommends that these and other demonstrations receive continued support in the FY 2006 federal appropriations process. But beyond this, NCD is concerned with how and whether the lessons learned and the experience derived through these demonstrations is being parlayed and used.

The question must be raised whether the projects carried out under these auspices to date, while each small in its own right, have combined to create a critical mass of data concerning what works and how. In an era of evidence-based policy and programming, it is vital to know whether these transportation programs have shown the potential to delay or prevent unnecessary institutionalization, whether they have reduced the costs to Medicaid of transportation to and from health care facilities, or whether they have enabled older people or those with disabilities to enter or remain in employment. Each of these potential benefits results in significant savings in other programs and for other agencies' budgets, but savings to taxpayers nonetheless.

In evaluating the costs and benefits of these small transportation demonstration programs, the documentable and reasonably foreseeable savings across program and agency lines must be taken into account. If these savings are not studied and included, no reliable assessment of programs' impact can be made.

DOT should develop aggregate and global findings regarding the current and potential impact of each of the programs and experimental modalities and demonstrations it has supported or encouraged. These should be submitted by the Administration to Congress and should form an important part of budgetary allocations in the transportation area.

The Executive Order discussed in subsection 1 calls for the submission of a report by the new council within one year. NCD is confident that this report will greatly increase our knowledge about how coordination can be achieved and what has been done to achieve it thus far. But we also hope that it will go beyond this to discuss the real benefits and savings that we believe effective coordination can help bring about, and that it will suggest ongoing research initiatives to document such savings and other benefits.

(d) The National Transportation Act

The nation's transportation law, often called the highway bill, expired in 2003. It was not reauthorized in 2003, but it was expected that a six-year reauthorization of the law would be enacted during 2004. This did not occur. Instead, legislation extended funding and authorization for current transportation programs through May 31, 2005 [162].

Whether Congress will adopt a multiyear reauthorization or continue to administer the program through short-term extensions, NCD believes it is essential that certain provisions of the current law be maintained and enhanced. First, NCD believes that explicit statutory support for the NFI be made part of the overarching statement of national transportation priorities. Accordingly, NCD recommends that in its findings of fact accompanying enactment of a national transportation bill, Congress should include the need for and the value of NFI and other initiatives designed to increase and ensure adequate transportation options for older people and people with disabilities.

As discussed in last year’s status report, NCD also remains concerned about coordination between the transportation bill and ADA in relation to issues of paratransit and pedestrian-safety research. Innovative projects supported with transportation funds should in all cases support the goals of ADA with regard to the availability of paratransit and the guarantee of pedestrian access. In addition, the law should encourage partnerships wherever possible so that providers of transit services for a variety of transportation-disadvantaged groups can work together to maximize the efficiency and ensure the fullest utilization of resources and systems.

In this connection, Section 5310 of the current law authorizes transportation projects for older people and people with disabilities. NCD urges Congress to extend this authority, but to do so in a way that avoids use of the funds for mainstream transit operations or expenses, but at the same time does not result in segregated services or projects. In some cases, augmentation of existing resources may represent the best way to meet the needs of transportation-disadvantaged citizens. These should not be prevented by requirements for totally new or separate projects that by themselves would be too small to achieve or demonstrate their potential impact.

Recommendations

Recommendation 9.1: NCD recommends that the TSA develop regular procedures for testing the accessibility of all security-related airport technology and for incorporating passengers with disabilities into such focus groups or testing protocols that are used to assess the viability of new designs.

Recommendation 9.2: NCD recommends that DOT develop a detailed plan for identifying and meeting the resources needs that newly covered international air carriers may face in implementing their responsibilities under the ACAA.

Recommendation 9.3: NCD recommends that DOT reissue its current Air Carriers Access Act NPRM to include accessibility requirements for airport ticket kiosks and to include the opportunity to comment thereon.

Recommendation 9.4: NCD recommends that DOT, in conjunction with DOJ, develop informational resources to enable travelers to understand which law and which standards will apply to their companion and service animals in various settings and making clear how to know which air-travel-related venues are governed by which law, the ACAA or ADA.

Recommendation 9.5: NCD recommends that these and other demonstrations receive continued and appropriate support in the FY 2006 federal appropriations process.

Recommendation 9.6: NCD recommends that in its findings of fact accompanying reenactment of the national transportation bill, Congress include the need for and the value of NFI and other initiatives designed to increase and ensure adequate transportation options for older people and people with disabilities.

Chapter Ten—Housing

Introduction

As housing prices throughout the nation have soared to record levels, issues of housing affordability and availability have gained increasing attention among government officials and the public. As part of this awareness, the implications of housing for employment, transportation, education, and other spheres of life have become steadily more apparent. For many Americans with disabilities, the anxieties and limitations posed by the unavailability or unaffordability of accessible housing are nothing new, however.

Because housing issues are so central to the lives of many people with disabilities, NCD has paid close and sustained attention to the subject. Most recently, through our "Reconstructing Fair Housing" report of 2002 [163] and through discussions and updates in each of our annual status reports, NCD has continued to address concerns relating to the coherence and organization of federal civil rights enforcement, the adequacy and sufficiency of funding and staffing in key program areas, and the extent to which long-term planning and goal-setting in the housing area have taken the needs and concerns of citizens with disabilities into account.

Appreciative as the Council has been of the Department of Housing and Urban Development's (HUD's) openness and readiness to enter into dialog regarding our concerns, we have also become increasingly concerned about the level of follow-up to key findings. This year's status report notes a number of key accomplishments and updates of several of our key concerns in the light of developments occurring during 2004.

Section (a) deals with civil rights enforcement and policy. Section (b) deals with the role of people with disabilities in housing goals and planning. Section (c) addresses key linkages that underlie the role and importance of adequate housing. Finally, section (d) reviews a number of innovative strategies that should be considered for improving the housing situation for people with disabilities.

(a) Civil Rights

1. Enforcement

NCD congratulates the Department of Justice (DOJ) for its vigorous enforcement of the Fair Housing Act during 2004. Settlements in three major housing discrimination cases reflect this commitment [164]. The announcements of each of these settlements was accompanied by strong and reassuring expressions from departmental officials of the government's commitment to fair housing enforcement. But as gratifying as these settlements and statements of commitment are, concern seems warranted whether the Department of Housing and Urban Development (HUD) will be able to provide the day-to-day administration, oversight, and enforcement that is required for these commitments to be fully meaningful.

2. The GAO Fair Housing Report

In September 2004, GAO issued a report on civil rights complaint processing by HUD's Office of Fair Housing and Equal Opportunity (FHEO) and by the cooperating Fair Housing Assistance Program (FHAP) agencies around the country [165]. While undertaken primarily to determine the extent to which complaints are processed within prescribed time frames and to identify factors involved in whether those time frames are met, the study also probed many issues that are key to understanding the scope and effectiveness of civil rights enforcement in the fair housing area.

Interested readers are urged to review the detailed procedural and historical data gathered in this report. While it is not NCD's purpose to reiterate that data here, several findings do warrant attention and emphasis, particularly insofar as they mirror long-standing concerns that the Council has addressed in its earlier studies.

Among the chief findings of concern in the GAO report are these three:

1. HUD's automated case-tracking system fails to collect certain key data, including data on complaint adjudication and other information that would be valuable in evaluating existing procedures.

2. Complaint investigation personnel are perceived by their regional managers as often lacking the necessary training or other resources to perform their jobs with full effectiveness, and technical assistance and training resources available through HUD may not be sufficient to meet current needs.

3. Information about effective methods and procedures adopted by particular FHEO Regional Offices or by particular FHAP agencies is not collected or disseminated, with the result that replication may not occur.

Other findings could also be mentioned, but NCD wishes to focus here on something that is not among the findings of the report but that does appear to be a necessary implication of them. Over the years, as shown by the report, the size of complaint backlogs has ebbed and flowed. Similarly, the proportion of complaints resulting in the filing of discrimination charges has varied. HUD has been understandably sensitive to backlogs and delays, and has placed great emphasis on reducing backlogs and bringing median complaint-processing times as near to statutory and regulatory expectations as possible. But beyond the desire to comply with the law and avoid embarrassment, NCD is able to find scant evidence of systematic efforts by HUD to make overall qualitative judgments or to conduct outcomes research into its complaint processes. In light of the GAO findings, NCD recommends that HUD review the entire scope of its complaint processing, from intake to adjudication, with a view to determining how intake procedures can be made maximally accessible to the public, how the scope of the law can be most widely and clearly communicated to the public, how investigative staff can be provided with adequate resources to timely and effectively evaluate complaints, and how complaints deemed worthy of adjudication can be most effectively carried through to successful resolution. At a time when resources available for civil rights enforcement are likely to decrease, such quality control and accountability are more important than ever.

3. Accountability

The extensive numerical data contained in the GAO report, as well as parallel data collected by the U.S. Commission on Civil Rights in its most recent “Funding of Civil Rights Enforcement” report [166], provide a valuable window on fair housing enforcement, but these data raise as many questions as they answer. Changes in the size of backlogs, in complaint processing time, in the proportion of complaints that are found upon initial investigation to be without merit, and in other data create a significant but as yet largely untapped opportunity to assess the relationship between managerial inputs and program outputs. For example, does the reported upsurge in disability-based housing discrimination complaints in 2003 reflect heightened publicity given to disability rights in housing in the wake of NCD's 2002 "Reconstructing Fair Housing" report? Or does that increase in complaint volume reflect the devotion of additional staffing, funding, or other resources to the process by HUD? Likewise, do the recent data suggest that an increasing proportion of complaints are being found to be without merit? Does this mean that the public misunderstands the scope of fair housing jurisdiction? Does it mean that screeners and intake workers have changed their criteria for passing complaints on to the next level? Does it mean that inadequate resources have resulted in complaints becoming stale before they can be fully investigated? The sad truth is that we do not know, and HUD appears to lack means for finding out.

In its past reports, NCD has repeatedly expressed concerns that the level of resources dedicated to enforcement of the three major disability-related fair housing laws—the Fair Housing Act Amendments (FHAA) [167], ADA [168], and Section 504 [169] of the Rehabilitation Act—may not be adequate. NCD continues to have these concerns, but the Council recognizes that in the current environment of scarce resources and increasingly limited funding, adequate resources are unlikely to be available no matter how much we might recognize the need for them. In that light, the need for accountability in the deployment of scarce existing resources becomes greater than ever.

It is no longer enough for HUD or Congress to react to criticism or to perceived problems by announcing the dedication of some level of resources to a particular problem. Proactivity supported by evidence-based research is necessary in the articulation of enforcement goals and in the allocation of personnel, budgetary, and other resources.

Accountability also requires scrutiny of the information that is collected and disseminated. In view of the GAO finding that information on success of local strategies is not being disseminated, the importance of this dimension of evidence-based administration becomes all the more clear. Resources are simply not sufficient to allow for reinventing the wheel.

Any effort to embrace accountability will involve facing up to difficult questions and choices. For example, should some kinds of complaints be prioritized over others in terms of case-finding and processing? If so, does it make more sense to emphasize issues of design and construction, on the theory that violations are more easily proved in these areas and that cases of this kind have impact on more people due to their influence on the practices of other builders and architects? Or, by contrast, does it make more sense to focus on discriminatory practices by owners, rental agents, real estate brokers, or others in the housing industry, on the theory that such practices artificially restrict the supply and increase the price of housing for people with disabilities?

Perhaps it is not necessary to make such choices at all. Perhaps HUD can rely on the public, through the kinds of complaints people bring forward, to answer these questions in a way that allows the Department to establish clear priorities and effective processes. We simply do not know, and until HUD and Congress are able to find a vehicle for asking and answering such questions, only continued drift and ad hoc policymaking or continual shifting of resources can be expected.

4. Technical Assistance

There may be no area of fair housing enforcement that cries out for evidence-based assessment as much as that of technical assistance. The issue here is not simply one of resources but one touching the basic assumptions underlying HUD’s and DOJ’s efforts in this area.

To put the issue in context, consider the major settlement announced by DOJ in the *Wilmark* case [170]. Among other things, the discriminatory conduct in that case consisted in the imposition by a Chicago condominium association, though its front entrance was accessible, of a rule that wheelchair users must enter and exit by the back door. Consider also the *Fugitt* settlement [171], in which systematic violations by major developers, occurring in several thousand units, contained in several dozen complexes, built in six states, were at issue. How is it that a big-city condominium association could have been unaware of the illegality, not to say the outrageousness, of requiring wheelchair users to enter and leave in secret? And how is it possible, after more than 15 years of education, outreach, and technical assistance to the homebuilding and state building code communities, that among the consortia of developers, engineers, architects, bankers, and building inspectors involved in the design and construction of the complexes in the *Fugitt* case, no one blew the whistle?

NCD has repeatedly asked HUD and DOJ to evaluate the effectiveness of existing educational and technical assistance efforts, in light of indications that large sectors of the housing community either remain ignorant or feel themselves unencumbered by the law. As pleased as NCD is about the cases DOJ has pursued and the outcomes it has achieved, our appreciation is tempered by unease that the reasons such cases could have occurred do not appear to be a subject of urgent and high-level concern once the press releases have faded into the next day's headlines. Accordingly, NCD recommends that HUD and DOJ jointly conduct a study of the efficacy and impact of current and projected technical assistance, public outreach, and housing-profession educational activities to determine what kinds of outreach and what mix of education and enforcement will prove most effective in ensuring knowledge of and compliance with fair housing laws.

(b) Long-Term Planning and Housing Goals

In past reports, NCD has had occasion to commend HUD for its efforts to set and evaluate goals in matters such as home ownership. Where NCD has been concerned, however, is in the relative failure of HUD to reflect the needs and circumstances of people with disabilities in its numbers. Thus, although the Department and the Administration as a whole are rightly concerned with minority home ownership and with narrowing the gap in that vital area, comparable awareness and attention have not been forthcoming regarding low levels of home ownership among people with disabilities.

Broadly speaking, NCD believes that in all areas of housing policy and related planning, HUD needs to be alert to issues and disparities affecting people with disabilities, and the Department needs to incorporate this population into all aspects of its planning and projections. Whether in forecasting the need for new housing units, establishing goals for home ownership, setting and enforcing design guidelines for federally assisted properties, or any other of its far-flung responsibilities and partnerships, HUD must be certain that, just as other groups facing distinctive housing issues, people with disabilities are not overlooked.

It is no longer possible to forecast the need for new housing units without also estimating the demand for accessible units. Nor is it reasonable to discuss issues of affordability without analyzing the impact on supply and demand and, through them, on pricing of accessibility. And it cannot be wise to consider measures to stimulate the creation of new housing units without considering their proximity to mass transit, centers of employment, commerce, and community resources, all of which have particular significance for various subgroups among people with disabilities.

Implementation of an inclusive housing-policy planning process involves both procedural and substantive elements. As a first step, NCD recommends that the Secretary of HUD undertake a high-level review of all long-term strategic and operational planning processes and of all required data collection activities to determine the extent to which people with disabilities are explicitly recognized among population groups under consideration. This review should also develop procedures for obtaining appropriate feedback as a routine part of all housing policy development and planning to ensure that issues of concern to people with disabilities will be identified and addressed in a timely, integrated fashion.

(c) Linkages

In recent years, an increasingly important dimension of HUD’s work has involved its participation in multiagency initiatives designed to fulfill the goals of the President’s New Freedom Initiative (NFI). From the first NFI progress report [172] to the interagency committee discussed in the previous chapter on transportation, HUD’s participation has been recognized as a crucial component of a broad range of interagency efforts. NCD believes that the challenge now is to move beyond this recognition to the development of methods and procedures by which the findings and conclusions of interagency efforts can be incorporated into the daily work and basic mission of the department.

NCD commends the department for the variety of demonstration projects and specialized planning and funding efforts undertaken in fulfillment of the NFI and in recognition of the multijurisdictional nature of most problems. Nevertheless, NCD is concerned about when these small-scale efforts will generate a critical mass of data and results sufficient to warrant their incorporation into mainstream programs on a large scale.

For example, as discussed earlier, asset accumulation programs utilizing individual development accounts (IDAs) are being increasingly used in welfare reform and by the Social Security Administration in its work with recipients of SSDI and SSI payments. These programs generally identify home ownership as one of the goals for which savings are authorized. To promote savings for approved goals, IDA funds are largely exempted from the application of needs-based resource limitations in these programs (up to $10,000, for instance, in Social Security Act resource countability provisions). To what extent has HUD incorporated its awareness and support for asset accumulation through the use of IDAs into its practices and policies? Have the numerous income- and resource-eligibility standards applicable to participation in HUD-sponsored home-ownership or rental-subsidy programs been systematically reviewed to ensure that the exclusion of IDA funds is clearly stated in the governing regulations? Have they been examined to make certain that program administrators and program partners are fully familiar with the nature of these provisions, or to guarantee that current or prospective assistance recipients are apprised of the options that IDAs may afford them? Have measures been considered to protect IDA users against other forms of discrimination that may arise from unwarranted stereotyping of asset-development program participants?

NCD is unable to determine whether any of these steps have been taken. But more important than whether particular actions have been taken is another question, the question of what procedures exist for facilitating the necessary changes, for initiating them, and for monitoring their impact on an ongoing basis.

Another key concern in regard to implementation of NFI goals can be found in the area of *Olmstead* follow-up. HUD has indicated in many ways its awareness of the importance of housing to the achievement of the *Olmstead* decision's and ADA's goals of community integration of people with disabilities. Other policy initiatives, also participated in by HUD, have created and sought to operationalize similar commitments with respect to older Americans.

The question that must be asked, therefore, is how and whether these initiatives have been incorporated into the full range of HUD programs. Do the criteria used to review applicable state and local plans, proposals from private developers, or responses to discretionary funding opportunities differ in any systematic way from what they would have required or emphasized before the *Olmstead* decision? Should they? In this age of diminishing resources, the increased need for proactivity and accountability requires that HUD address questions such as these in its planning processes. To do less is to abdicate its responsibility and squander its resources at a time when coherence and cost-effectiveness are as crucial as they have ever been.

NCD stands ready to assist the Department in any way possible in addressing and answering these key questions. In light of HUD's responsiveness in the past, we are confident that much can be accomplished.

(d) Innovative Strategies

Even as the lessons and opportunities resulting from recent experiments are being incorporated into policy and day-to-day practice, the need is great for additional innovations to maximize the availability of accessible, affordable housing in our nation. NCD believes that new and innovative partnerships with the private sector, underscored by the enlightened use of federal resources, represents the best means for leveraging the resources and energies of the housing sector and the marketplace.

1. Visitability

NCD has been impressed by the development of visitability as a cost-effective and nonobtrusive alternative to full accessibility of housing. Short of full accessibility as defined under ADA, visitability is a concept that ensures that at least access to a home and the ability to use a bathroom and other basic amenities will be available. The Council believes that the time has come when visitability should become a baseline for the construction or major renovation of all housing. In this connection, we express our support for the principles of the Inclusive Housing

Design Act of 2004 [173] and urge its reintroduction and careful consideration in the 109th Congress. This does not mean that efforts in support of full accessibility should be diminished in any way, only that so far as new construction or major renovations are concerned, the baseline or starting point should be upgraded.

2. Valuation

One of the chief barriers to adoption of either accessible or the less stringent visitable design practices by the housing community is thought to be the widespread belief that accessibility does not pay for itself in terms of its impact on home prices. In other words, as reflected by many anecdotes reaching the Council, developers, architects, condo associations, real estate brokers, and others in the housing industry appear to believe that customers do not want accessibility; indeed, that in some cases the notion that property is designed with “the disabled” in mind makes it less attractive to potential buyers. From this, the opinion also follows that expenditures made by builders for accessibility will only serve to increase production costs, because they will not be reflected in the prices at which properties can be sold.

NCD appreciates that the research on the economics of accessibility is limited and inconclusive. But the Council is also convinced that as the population ages, more and more homebuyers and renters will come to recognize the value of accessibility, prospectively for themselves or for aging family members or other visitors. Accordingly, NCD recommends that HUD undertake a study to authoritatively determine the current and foreseeable market impact of both accessibility and visitability design features or improvements on housing prices and sales. The methodology adopted for conducting this study is likely to be key to its results. While this is not the place to go into the statistical and matching issues that will need to be confronted, NCD trusts that the Department will convene an advisory committee, including people with disabilities and other knowledgeable housing-accessibility advocates, to ensure that the study takes all relevant and complicating factors fully into account.

3. Disclosure

NCD believes that one barrier to increased customer demand for accessibility is lack of knowledge concerning the options and lack of a commonly held vocabulary among the general public for discussing the issue. If the accessibility status of homes were more routinely made known to buyers, consciousness would be raised and, in its wake, interest and demand would follow.

For this reason, NCD recommends that the Department undertake a study into the feasibility and impact of including accessibility status as a mandatory disclosure item under the Real Estate Settlement Procedures Act (RESPA). This would in no sense make accessibility a requirement of federal law. It would not require any property owner to drive a single nail or remove a single brick. All it would do is elevate the issue of accessibility, as defined by objective guidelines that DOJ has already been using for 15 years to certify state building codes under ADA [174]. No ambiguity or excessive inspector discretion would be involved. No burden would be placed on the private sector.

Numerous other initiatives could be proposed that could help to engage the energies and resources of the private sector in a partnership on behalf of greater housing accessibility and affordability. Rather than making specific proposals here, NCD wishes to reiterate its belief that it is within the province of HUD to develop long-term plans and goals for steadily increasing the accessibility of the U.S. housing stock. Consistent with this growing imperative, the Department must work energetically to identify and test a variety of strategies for helping to bring this about, and those that cooperatively engage the private sector are surely preeminent among them.

Recommendations

Recommendation 10.1: NCD recommends that HUD review the entire scope of its complaint processing, from intake to adjudication, with a view to determining how intake procedures can be made maximally accessible to the public, how the scope of the law can be most widely and clearly communicated to the public, how investigative staff can be provided with adequate resources to timely and effectively evaluate complaints, and how complaints deemed worthy of adjudication can be most effectively carried through to successful resolution.

Recommendation 10.2: NCD recommends that the Departments of Housing and Urban Development and of Justice jointly conduct a study of the efficacy and impact of current and projected technical assistance, public outreach, and housing-profession educational activities, to determine what kinds of outreach and what mix of education and enforcement will prove most effective in ensuring knowledge of and compliance with fair housing laws.

Recommendation 10.3: NCD recommends that the Secretary of HUD undertake a high-level review of all long-term strategic and operational planning processes and of all required data collection activities to determine the extent to which people with disabilities are explicitly recognized among population groups under consideration. This review should also develop procedures for obtaining appropriate feedback as a routine part of all housing policy development and planning to ensure that issues of concern to people with disabilities will be identified and addressed in a timely, integrated fashion.

Recommendation 10.4: NCD recommends that HUD undertake a study to authoritatively determine the current and foreseeable market impact of accessibility and visitability design features or improvements on housing prices and sales.

Recommendation 10.5: NCD recommends that the Department undertake a study into the feasibility and impact of including accessibility status as a mandatory disclosure item under RESPA.

Chapter Eleven—Technology and Telecommunications

Introduction

This chapter deals with a variety of issues involving uses of and decisions about technology that directly and significantly affect the lives of people with disabilities. The chapter begins with a discussion of the reenactment of the Assistive Technology Act and discusses some of the benefits of that program, including the AT loan programs developed under its auspices. The chapter goes on to consider the broad range of technology initiatives undertaken by the government, arguing for their importance and urging that they be maintained intact until the results of major ongoing research are published.

Taking NCD's universal design report as its point of departure, the chapter next considers the role of federal policy and programs in supporting universal design practices. A study into how this could be done more effectively is recommended.

We next consider Section 508 of the Rehabilitation Act in terms of developments during 2004, the need for enhanced monitoring, the ways Section 508 has had an influence on policies and practices even where it does not directly apply, and the ways cost-effectiveness research can be done in a technology environment.

The remainder of the chapter addresses a constellation of increasingly important access and civil rights issues falling within the domain of the FCC. These include the commission's seemingly lackluster approach to the enforcement of Section 255 of the Communications Act; the need for action in the face of threats and challenges facing both closed-captioning and telecommunications relay services; the importance of formally incorporating existing accessibility requirements into the administration of the e-rate schools and libraries Internet access subsidy program; and the need for the FCC to address the profound implications for accessibility of the move to VoIP.

(a) Assistive Technology Act Renewal

1. The New Law

On October 25, 2004, President Bush signed the Assistive Technology Improvement Act of 2004 into law [175], This statute reauthorized and amended the Assistive Technology Act of 1998 [176], and represents an important demonstration of the nation's commitment to AT.

NCD applauds Congress and the Administration for their reenactment of this law. We believe that the stability and continuity that reauthorization offers will provide the basis for continued innovation and expansion of AT informational, advocacy, and technical assistance resources at state and national levels.

NCD notes that the state-based AT programs established and funded under the Assistive Technology Act have been the springboard for and the organizers of the AT loan programs operated under Title III of that Act and highlighted in the President's NFI progress report of February 2004 [177].

2. Loan Programs

As noted in the NFI report, one of the major achievements of the NFI in removing barriers to AT acquisition and use by people with disabilities has been the establishment, beginning in FY 2002, of two alternative equipment financing loan programs. These are the original alternative financing program, which offers loans to purchase technology for a variety of purposes, and the newer telework program, which offers loans targeted specifically to people with disabilities who work at home.

Programs such as these hold great promise for increasing the availability of needed AT for use in a variety of settings. But, like other programs, their efficacy must be subjected to the rigors of evidence-based policymaking, and sound data on their overall impact must be collected. In that connection, NCD was pleased to learn that an evaluation study had been undertaken [178]. As of this writing, we are not aware that any results have been published. NCD urges the National Institute on Disability and Rehabilitation Research (NIDRR) to report on the impact and operation of these programs and to indicate its findings, if any, concerning what may need to be done to make them more effective and relevant.

A related initiative is the pilot research grants announced by the Department of Labor's Office of Disability Employment Programs (ODEP) in July 2004 [179]. Aimed specifically at increasing the opportunities for telework, these grants are further discussed in Chapter 7 of this report.

(b) The Broad Range of AT Initiatives

As important as the AT Act is, it represents only a small part of the federal commitment in this area. As programs and initiatives operating across the spectrum of federal agencies attest, the national commitment to AT is strong and varied. These initiatives include other NIDRR programs, such as the Rehabilitation Engineering and Research Center (RERC) program; the export-promotion and business-outreach programs developed by the Department of Commerce; the work of the Department of Defense's Computers Electronic Accommodations Program (CAP); the technology distribution included in the Federal-State Vocational Rehabilitation (VR) program and the Individuals with Disabilities Education Act (IDEA); and the technology-related research and dissemination efforts sponsored by the Department of Veterans Affairs, the Centers for Medicare and Medicaid Services (CMS), the National Aeronautics and Space Administration (NASA), and the National Science Foundation.

Two major multiyear studies are currently under way aimed at developing criteria and procedures for assessing the outcomes achievable with the use of AT [180]. Pending the findings of these studies, it is important that the federal commitment to AT remain strong and vigorous. Accordingly, NCD recommends that no existing AT program be eliminated or defunded until the results of these and related research projects are forthcoming.

1. Universal Design

An important, if complicating, factor in the AT equation is universal or accessible design. First conceptualized and still perhaps best understood in the context of the physical design of buildings and facilities, the principles of universal design are also increasingly understood to be applicable to communications, information technology, appliances, medical tests, and other spheres of society and life.

References to AT in various federal documents are increasingly accompanied by references to universal design (as in such phrases as “assistive and universally designed technology”). Nevertheless, with a few notable exceptions (such as Section 508 of the Rehabilitation Act, discussed in the next section of this chapter), few federal initiatives to promote the development and dissemination of universally designed technology appear to have gained much traction.

The 2004 NFI report refers to the importance of defining universal design. In the variety of settings where the concept has potential applicability, this definitional effort, involving a variety of partners from the public sector and from the standards-setting parts of the private sector, is a necessary first step.

In 2004, as part of its contribution to this effort, NCD released a major report on universal design [181]. This report provides unique insights into many of the key issues and processes surrounding present and future efforts to implement universal design in our various technological environments. We urge all those with interest in the accessibility of society to read this report.

In this ground-breaking study, NCD believes that the potential and benefits of universal design, together with some of the obstacles to its achievement, have been made clearer than they were in the past. Also emerging with growing clarity is the enormous opportunity for coordinated and focused federal efforts to increase awareness, design, and deployment of universally designed technologies, under circumstances that yield benefit to all involved.

In light of the universal design report, NCD recommends that universal design research and implementation be included as an integral part of overall federal technology policy. To begin this process, NCD recommends that the administration undertake a study of how current resources and partnerships aimed at bringing about technological innovation and progress can be as effective as possible in encouraging and fostering a universal design philosophy throughout industry and design.

The levers available for encouraging and rewarding universal design, and for stimulating private-sector-based voluntary standard-setting and definitional efforts, are numerous. Judged by the success of federal efforts in enhancing other technology policy goals, from broadband and high-definition television (HDTV) to electronic check-processing and tax-filing, they are both effective and beneficial to the overall economy. From the tax system to the patent and copyright laws, from federal research and development (R&D) to procurement, from definitions of rehabilitation to educational or medical equipment, existing strategies with demonstrated efficacy in promoting other worthwhile goals can be harnessed and brought to bear on behalf of universal design, in a manner wholly consistent with and conducive to the values and goals of the competitive market economy.

(c) Section 508

Section 508 of the Rehabilitation Act of 1998 [182] is the leading example of the commitment to universal design in our law. Section 508 obliges and commits the government, in its purchase of electronic and information technology (E&IT) for its own use, to procure technology that is "accessible to" and "usable by" all people, including people with disabilities. Section 508 also applies to Web sites maintained or utilized by the government, requiring that they, too, meet standards that ensure their accessibility to federal employees or members of the public with disabilities [183].

1. Developments in 2004

NCD is particularly heartened by the renewed expression of support for Section 508 by the President, as embodied in the 2004 NFI report [184]. The report makes clear that Web site accessibility is regarded as one key element of achieving the overall goals of the E-Government Act of 2003 [185]. With this connection, the Office of Management and Budget (OMB), in its effort to achieve greater consistency in the design and management of federal agency Web sites, has issued a set of 10 requirements that all government Web sites under its jurisdiction must meet by the end of 2006 [186]. One of these requirements is the accessibility of these sites to people with disabilities.

A final key Section 508 development in 2004 was the elimination of a major exception to the application of Section 508. In the past, E&IT procurements costing under $2,500, typically made on a decentralized basis by individual federal employees, have been exempt from the requirements of Section 508. As of April 1, 2005, that is no longer the case [187].

NCD is gratified by this decision, especially because it means that a variety of hardware and software products will now be included under the coverage of the law and that the market power of federal purchasing will be brought to bear on behalf of the accessibility of these items. But NCD is concerned that some of the necessary groundwork may not yet have been fully completed for applying Section 508 to E&IT hardware and software purchased and used by federal agencies. It is with this concern in mind that we turn to issues involved in the monitoring and oversight of implementation of the law to date.

2. Monitoring

Because of its historic and innovative nature, Section 508 included provisions for close monitoring and oversight by the Department of Justice (DOJ) [188]. Specifically, DOJ was required to submit a biannual report to the President and Congress addressing the implementation of the law. No report has been published since 2001 [189]. DOJ has made note of its 2002–2003 survey of federal agency implementation, and the 2004 NFI report held out hope that the long-awaited Section 508 report would be published during 2004. But the DOJ report has not yet been published. If it is not published before the release of this report, it will be two years overdue.

NCD hopes the report can be published as soon as possible and that it will provide some of the vitally important information needed to evaluate the effectiveness of Section 508 and to identify areas where resources need to be targeted or upgraded.

In this connection, as discussed in previous annual status reports, NCD is concerned that while considerable attention has been directed to application of the law to Web sites, less focus has been directed to the varieties of other hardware, software, and media falling within the scope of Section 508's coverage. For this reason, NCD recommends that the next DOJ survey and all subsequent Section 508 implementation surveys address compliance and related issues across the spectrum of covered products and services. Tracking Web site accessibility remains vitally important, but the variety of other covered equipment and media that help to form the information infrastructure and influence the use of Web sites present accessibility issues that must not be overlooked.

In this connection, we note the reference in the NFI report to plans for the development of Section 508 guidelines for public accommodations covered by federal law. It appears, however, that Web site accessibility is the prime, perhaps the only, subject intended to be covered [190]. In any event, this guidance has not yet been published by DOJ, and, as indicated in our discussion in Chapter 2 on civil rights, any guidance, even if only on Web accessibility, would be of great value and benefit.

3. The Two Lives of Section 508

Over the years since its 1998 enactment in its current form, Section 508 has cast a long shadow. But its effect has been felt in two very different ways. First, it has been felt in the programs to which it is literally applied, including the Web sites and procurement practices of almost all Executive Branch agencies and those of certain entities providing products or information to the Federal Government.

There have also been significant efforts to extend the scope of the law. Among these are the efforts to amend the Congressional Accountability Act of 1995 [191] to make Congress and the related agencies known as “congressional instrumentalities” subject to its requirements. Most recently, the proposed Congressional Accountability Enhancement Act of 2004 [192] would have accomplished this goal, but it was not adopted. Despite the failure of this and prior efforts to incorporate Section 508 into Congress’s self-governance, NCD recommends that the 109th Congress consider such legislation favorably.

Our additional point at the moment, though, is to offer this as an example of the first of Section 508’s two lives, its direct application in, and potential extension to, a variety of situations. It is likely, as the scope of the law grows, that different interpretations and applications will arise. Assuming that Congress does soon agree to be bound by its requirements, the likelihood is great that differences of interpretation and application between the executive and legislative branches will emerge over time. These differences will make the impact, costs, and benefits of Section 508 more difficult to measure, because different interpretations in different settings may result in differing impacts.

As important but even more difficult to track is what we may call the second life of Section 508. This second life exists in the application of the law's principles in settings where Section 508 itself has no legal role. For example, a number of states have either literally quoted or have incorporated by reference the terms of Section 508 standards into their own IT accessibility laws [193].

Another example is the efforts by various entities to import the spirit, sometimes even the letter, of Section 508 into their design of noncovered E&IT or even into their design of systems and interfaces that do not meet the definition of E&IT at all. Typical of these is the November 2004 NPRM discussed in Chapter 10, in which DOT purports to use Section 508 standards as the basis for requiring that airline Web sites meet basic accessibility requirements [194]. DOT takes this action under the authority of the Air Carrier Access Act, and there is no claim of jurisdiction for Section 508, yet it is centrally implicated because it is relied on to provide the substance of requirements implemented under a different law.

Another potentially important example of the indirect application of Section 508 is in one of the Administration's major current initiatives. Chapter 4 on health discussed the national health information infrastructure program, which will attempt to bring modern electronic technology systematically to bear on behalf of effective medical treatment and improved record keeping. That and other initiatives, whether or not they fall within the jurisdiction of Section 508 or make explicit reference to it, must and will deal with many of the issues Section 508 pioneered and will inevitably be guided by Section 508 in many important ways.

Increasingly, in the public and private sector, one can think of Section 508 as part of the genetic endowment of many programs and policies. This matters because of the need for clarity and consistency in the understanding and application of the principles underlying Section 508. It matters, as indicated previously, because when it comes to placing Section 508 under the microscope of evidence-based policy, we need to be sure, as far as possible, that it is one and not many Section 508s that we are evaluating. These and other factors immensely complicate the cost-effectiveness and related determinations that will increasingly be used as the basis for budgetary and programmatic decision making.

(d) Cost-Effectiveness

Because of this complex dispersion of Section 508 and its values, the design and evaluation of all federally initiated and federally supported technology programs should be undertaken with a view to identifying the specific accessibility requirements adopted; assessing the extent of their achievement; and determining their impact on the program, its operators, and its intended recipients and beneficiaries. As with all programs, this should be done consistently with the highest principles of evidence-based research, but with the recognition that the kinds of evidence deemed relevant will vary. It may not be in terms of dollars and cents, or quantitative measures of people served or units of information rendered, that the real value of Section 508 or of other sources of accessibility will be found.

In assessing the cost-effectiveness or cost benefit of various technology-related programs and policies, today's environment presents challenges that are new and varied. For instance, when OMB conducts statutorily mandated reviews under the Regulatory Flexibility Act or the Paperwork Reduction Act, when CMS or the SSA publishes long-term plans under the Government Performance and Results Act (GPRA), when GAO conducts impact studies for Congress, and when CBO scores the fiscal implications of proposed legislation or expenditures, is there any precedent or even authority for capturing data on many of the indisputable but indirect costs of proposed actions? In particular, in the case of regulations bearing on accessibility, is there any guidance available for whether or how to evaluate the inadvertent impact of inaccessibility on the enforceability or the costs of enforcement of other laws?

As suggested in Chapter 2, one new element of evidence-based measurement in this regard relates to the relationship between accessible information technology and privacy rights under the law. In an era when personal communications between individuals and government are increasingly mediated by technology, including being conducted on the Web or through information terminal machines, inaccessibility, by requiring the involvement of third parties, increasingly represents mandatory waiver and loss of privacy rights. What are the costs of such inadvertent denial of rights, and what are the benefits of taking corrective action?

Obviously, we cannot measure these variables as easily as we can estimate the number of hours required to fill out a form. But that doesn't mean these dimensions of technology's impact are not in need of great attention, for they are as palpable and as significant as the dollar costs of other forms of compliance.

Even in traditional terms, cost-effectiveness, which remains a key element of evidence-based research, is often difficult to measure. This is so because it often involves correlations among agencies and programs that have little apparent connection, or costs and savings that occur over different time frames. In relation to technology, the NFI appears to recognize this, as demonstrated by the report's indication that investment in job-retention AT through the Defense Department's CAP results in significant savings in federal employee compensation costs. These workers, but for the technology interventions, would be unable to return to work.

It is just such a disciplined and comprehensive approach to cost-benefit that must inform all federal technology initiatives and their evaluations, including initiatives aimed at incorporating accessibility into the information, transportation, housing, and other key infrastructures of our nation. If, even beyond preserving privacy rights, accessibility of information saves people who are blind the costs of hiring readers or people who are deaf the expense of retaining interpreters, these benefits, no less than the incremental procurement costs of making the information accessible, must be taken into account when programs seek to be evaluated in cost-benefit or related terms. NCD believes that accessibility, whether literally required by or simply modeled on Section 508, like all AT and universal-design programs, will always more than pass the cost-benefit test, provided the full range of relevant variables, including decentralized costs and benefits to individuals as well as those incurred by institutions and businesses, is taken fully into account.

(e) Telecommunications and the FCC

In our 2003 annual status report, we had occasion to comment on the surprising emergence of the Federal Communications Commission (FCC) as one of the key federal agencies involved in AT and accessibility. Indeed, the FCC is at the center of many of the most compelling and complex issues of our time, and on its decisions, bearing as they do on the accessibility of telecommunications in our country, there hangs an increasingly large share of the hopes of Americans with disabilities for opportunity and full participation.

1. Telecommunications Access Under Section 255

Section 255 of the Communications Act of 1996 [195] placed the FCC in the forefront of civil rights in a way that it had never been before. As enforceable by the commission, the provision requires that telecommunications equipment and services be accessible to and usable by people with disabilities, to the extent "readily achievable." In furtherance of its responsibility under Section 255, the FCC, in conjunction with the Access Board, adopted regulations to implement the law [196].

Since the adoption of these rules, NCD has repeatedly called for vigor in their enforcement and for monitoring to determine the effectiveness of the law and of the commission's oversight. By and large, however, the FCC appears to have adopted and maintained a more passive attitude.

On January 5, 2005, the FCC dismissed the complaint in the matter of *O'Day v. Audiovox* [197]. This dismissal took place pursuant to a settlement between the parties of a complaint alleging that cell phones are inaccessible to people who are blind or have visual impairments, in violation of Section 255. While NCD applauds the parties for their ability to reach a settlement, the case revealed certain critical enforcement problems that the FCC has thus far failed to address.

Given the highly complex technical and legal data and issues involved in any FCC docket or proceeding, the *O'Day* case brought into sharp relief the inherently unequal positions of consumers and manufacturers or service-providers in the Section 255 enforcement process. In the *O'Day* case, the complainant had access to the services of skilled counsel, but for the majority of telecommunications consumers who do not, the Commission has no answer.

In leaving it largely to the parties to negotiate settlements in Section 255 complaints, the FCC is failing to acknowledge the realities of the administrative processes it oversees. NCD therefore calls on the FCC to develop guidelines for how and when it will independently investigate the merits of Section 255 disputes and to clarify what measures it will take to ensure that isolated individuals with serious concerns and complaints will not be overmatched by powerful corporate phalanxes.

2. Closed-Captioning

Of all the areas in which technology and disability have converged, closed-captioning of television programs is perhaps the best known and most pervasive. The role of the FCC, through its enforcement of the Television Decoder Circuitry Act of 1990 [198] (which required that most TVs be equipped with captioning decoder chips) and through its enforcement of the closed-captioning requirements of Section 713 of the Communications Act, is profoundly important in the development of captioning.

NCD commends the Commission for its ongoing work to ensure that the law's mandate for the amount of TV programming available with captioning is enforced. In that regard, we particularly commend the Commission for adhering to the timetable under which 100 percent of new programming in selected categories will be required to be captioned by 2006 [199] and for its resistance to a succession of petitions from broadcasters seeking exemption from the captioning requirements [200]. But in light of developments during 2004, NCD is concerned that captioning may be undermined by concerns about its accuracy and quality.

A rulemaking petition filed with the FCC by a coalition of advocacy groups in September 2004 raises serious questions about the quality of much captioning and requests the Commission to undertake measures to investigate and ensure the quality of this service [201]. NCD urges the FCC to act on this petition and, more broadly, to act, on its own motion if necessary, to address a gathering array of threats to the viability of captioning.

The development of HDTV, new forms of satellite transmission, and other new technologies changes the broadcast spectrum, creates increasing demands for its allocation, and changes the transmission methods utilized. All of these have implications for captioning as well as for video description (a comparable process used to deliver narration of the visual content of television broadcasts or films to people who cannot see the screen). The FCC should undertake an information-gathering process aimed at ferreting out all these implications and deciding, while there is still time, how the interests of access can best be preserved.

3. Relay Services

In the area of telecommunications relay services (TRS) guaranteed under Title IV of ADA, rapid changes in technology and expectations create a need for farsighted assessment that responds to imminent and longer-term contingencies. These are too numerous to address here, involving as they do phone- and Web-based telecommunications, services for people with vocal communication and other disabilities in addition to services for people with disabilities of hearing, and a dramatically changing business and regulatory environment. Once again, the FCC needs to address these systematically, with opportunity for a deliberative process based on input from all relevant constituencies, while there is time to promulgate the comprehensive solutions that alone will provide predictability and freedom from crisis or surprise.

4. E-Rate

More than a year has elapsed without the FCC moving forward on the e-rate docket it opened [202]. The need for accessibility requirements to be made clear to e-rate subsidy recipients (previously discussed in NCD's 2002 and 2003 status reports) remains pressing and unmet. As important, for each day that passes without clear guidance from the Commission, the danger grows that e-rate recipients who have unknowingly violated the law by failing to ensure adequate accessibility of the equipment and services funded under the e-rate program will face potential liability exposure in consequence of that failure.

NCD believes that the FCC owes it to e-rate subsidy recipients to require them to acknowledge and meet the obligations of accessibility that generally apply to recipients of federal funds, whether state and local government entities or public accommodations. The schools and libraries eligible for e-rate funds are potentially covered by Sections 504 and 508 of the Rehabilitation Act, by Titles II or III of ADA, and by their own states' civil rights and IT accessibility laws. Because the FCC has no authority to exempt them from the application of such laws and because lack of adequate notice is not typically a defense, the Commission may be doing recipients a great injustice by not making the obligations of these laws under the e-rate more clear and effective.

5. VoIP

It is a measure of the speed with which contemporary technology moves from the research laboratory into our lives that many people who would not have recognized the term just a year ago are now familiar with the acronym VoIP (Voice over Internet Protocol). Stated in its simplest terms, VoIP involves the set of technologies and processes by which voice telephone communications, traditionally carried over dedicated wire lines provided by phone companies and more recently by wireless or cell phone towers and systems, are instead communicated via computer over the Internet. This migration of voice-telephone communication to the Internet is not transparent from the standpoint of the equipment used, the providers involved, or the law governing it. And it is in connection with the interplay between technology and law that the implications of VoIP for accessibility, and hence for people with disabilities, are of greatest importance and concern.

In a number of contexts, the FCC has taken the position that VoIP is legally defined as an “information service” rather than as a “communications service.” We have discussed the background and implications of this distinction in detail in our two previous annual status reports. Suffice it to say, “communications services” are subject to regulation, including civil rights protection under Section 255; “information services” are not.

Recognizing the potentially significant implications of the loss of legal protections for accessibility that could result from the rise of VoIP, the FCC in 2003 instituted a proceeding to collect information and perhaps establish new rules based on these developments [203]. As of this writing, we are unaware that the Commission has published any findings from its inquiries or proposed any actions to ensure that its commitment to deregulation of information services will not inadvertently undermine the protections for accessibility afforded by law.

Concern over the issue and over the Commission’s failure to act was heightened in 2004 by the introduction of S. 2281, the VoIP Regulatory Freedom Act of 2004. This bill would codify in law the status of VoIP as a nonregulated information service and, moreover, would eliminate any requirements that VoIP providers contribute to the Universal Services Fund. The Universal Services Fund helps to provide the resources for ensuring that underserved areas and populations will be able to obtain basic dial-tone service at affordable rates. It has been part of federal telecommunications policy since the original enactment of the Federal Communications Act in 1934.

NCD urges the FCC to act without delay to publish the results of its inquiries and either to propose rules to ensure the continued applicability of Section 255 in the new telecommunications environment or, if the Commission believes itself without legal authority to extend these protections to what it has denominated as information services, to join with NCD and others to recommend that Congress enact the necessary legislation to protect accessibility and related interests and rights.

It should be noted in this regard that the characterization of VoIP as "information" rather than as "communications" service is not unanimous. In its administration of the long-standing federal excise tax on telecommunications services, the Internal Revenue Service has thus far declined to recognize this distinction [204]. In view of more than a century of experience administering this excise tax, the responsible federal agency's interpretation of its scope and meaning, and its determination that for purposes of tax regulation no basis exists for distinguishing one kind of telecommunications from another, is surely entitled to some weight.

Recommendations

Recommendation 11.1: NCD recommends that no existing AT program be eliminated or defunded until the results of ongoing AT outcomes measurement projects are forthcoming.

Recommendation 11.2: NCD recommends that the Administration undertake a study of how current resources and partnerships aimed at bringing about technological innovation and progress can be as effective as possible in encouraging and fostering a universal design philosophy throughout industry and design.

Recommendation 11.3: NCD recommends that the next DOJ survey and all subsequent Section 508 implementation surveys address compliance and related issues across the spectrum of covered products and services, and not be limited to Web site accessibility.

Recommendation 11.4: NCD recommends that the 109th Congress adopt legislation to extend the coverage of Section 508 to Congress.

Recommendation 11.5: NCD recommends that the FCC develop guidelines for how and when it will independently investigate the merits of Section 255 disputes and clarify what measures it will take to ensure that isolated individuals with serious concerns and complaints will not be overmatched by powerful corporate phalanxes.

Recommendation 11.6: NCD recommends that the FCC act on the petition concerning alleged inaccuracy of certain TV closed-captioning and, more broadly, act, on its own motion if necessary, to address a gathering array of threats to the viability of captioning.

Recommendation 11.7: NCD recommends that the FCC address a variety of threats to and opportunities for the system of telecommunications relay services.

Recommendation 11.8: NCD recommends that the FCC act without delay to publish the results of its inquiries into the impact of deregulation on Section 255 and other civil rights protections, and either propose regulations to ensure the continued applicability of Section 255 in the new telecommunications environment or, if the Commission believes itself without legal authority to extend these protections to what it has denominated as information services, to join with NCD and others to recommend that Congress enact the necessary legislation to protect accessibility and related rights.

Chapter Twelve—International

Introduction

Part of NCD's responsibility extends to international matters affecting people with disabilities. Consistent with our efforts to address relevant international issues, this chapter begins with a discussion in section (a) of the growing convergence between domestic and international issues. Section (b) deals with U.S. foreign aid practices, and section (c) addresses developments concerning the pending U.N. Convention on the Rights of People with Disabilities.

(a) Cruise Ships

Early in 2005 the U.S. Supreme Court heard an appeal in the case of *Spector v. Norwegian Cruise Lines*, raising the question of whether cruise ships operating into and out of U.S. ports, but registered in and flying the flags of other countries, are subject to the public accommodations requirements of Title III of ADA [205]. NCD has prepared a position paper providing background information and explaining why ADA should apply [206].

Until recently, a major issue in the applicability of various federal laws was whether the activities they sought to regulate were part of interstate commerce. Indeed, it is the Commerce Clause of the Constitution that partly provides the jurisdictional basis for Title III of ADA. Increasingly, though, the question may not be about interstate commerce but rather about whether goods or services are involved in international commerce. In such cases, alongside familiar U.S. laws there are treaties, international law, and other nations' laws to be considered. The cruise line case is likely to be the forerunner of new and complex issues for the courts and Congress to wrestle with in the years to come.

Because of America's preeminence in disability rights, Americans with disabilities are naturally concerned about the potential for international complexities to undermine, as they could in the cruise line case, their hard-won protections and rights. It is easily foreseeable that if the Supreme Court finds that foreign-flag cruise ships are not covered by ADA, U.S. companies, citing competitive pressures, will demand exemption from the law as well. For this reason, if for no other, NCD reiterates its strong belief that all cruise ships serving U.S. ports should be governed by the same high standards of law and accessibility.

(b) Foreign Aid

From the enormous potential of world trade to the horrors of terrorism, recent years have left Americans with unforgettable lessons about the close interconnection of our lives with those of other people throughout the world. No longer does any group or political movement advocate for U.S. disengagement from the wider world.

Given the many ways in which our interests interact with those of other nations, difficult questions have arisen over how to advance our values without antagonizing those who fear or do not share them. We know that people throughout the world yearn for the freedom and opportunities we enjoy, but we also know that cultural traditions differ and that antipathies and suspicions are all too easily aroused. How to best encourage and assist others without seeming to overuse our power is one of the chief challenges facing foreign aid today.

1. The Millennium Challenge Account

The Millennium Challenge Account (MCA), established following a 2002 presidential initiative, represents a unique and creative approach to the distribution of U.S. foreign aid [207]. The law governing MCA funding awards and the procedures utilized by the Millennium Challenge Corporation (MCC) in managing the MCA are complex and well beyond the scope of this report. Anyone wishing to know about them in detail should examine the most recent report on this subject by the Congressional Research Service (CRS) covering activities through the end of 2004. [208]

Through the use of formal evaluation criteria, the MCC operates under a more objective and accountable set of standards, and utilizes more verifiable indicators, than have applied to the distribution of foreign aid funds in the past. A key element here is that among these funding criteria, nations' recognition of the rights of people with disabilities is one of the values designated by law for explicit consideration [209].

This criterion was one of four added to the governing law by Congress in late 2003 [210]. NCD applauds the addition of this important criterion to the law. While no one criterion can or should be decisive among the at least 16 human rights, economic development, gender equality and other indicators specified for consideration in the awarding of these competitive MCA grants, NCD is hopeful that disability rights considerations will come to play the important role that they deserve, given the number of people with disabilities and their importance in economic development, poverty reduction, and investment-in-people issues.

But in order for this disability criterion to be effectively implemented, NCD believes that MCA and Congress need to consider a number of issues. In this connection, NCD is gratified by the willingness of MCC officials to meet and talk with the Council's International Watch Advisory Committee. The responsiveness shown by the Corporation leaves us very hopeful that the needed measures will be taken.

Further ground for encouragement arises from report language accompanying the Foreign Operations Appropriations Bill for FY 2005. This language, while not binding, recommends that the CEO of the MCC use appropriated funds "to address the lack of critical data related to the eligibility criteria of 'respect for the human rights and civil rights of people with disabilities'" [211].

The primary source of information on nations' status in regard to the rights of people with disabilities is the State Department's annual human rights report [212]. NCD appreciates the broad-based informational resources and high standards of research underlying this report, but NCD is also concerned with potential limitations on the scope of relevant information that the report may collect and convey. Although the reports will certainly identify abridgments of human and civil rights by government, they may not be ideally suited to capturing information about opportunities or missed opportunities for the broadening of rights in areas not directly related to civil freedoms.

In considering a country's overall level of respect for the rights of its citizens with disabilities, more than traditional human rights considerations need to be taken into account. Disability-related issues are directly implicated in a number of the other program criteria and indicators, including the criteria for investing in people, encouraging entrepreneurship, and reducing poverty. Indeed, one element of the investing-in-people criterion relates to the availability of affordable housing. Whether the State Department report can reasonably be expected to shed light on affordable housing is uncertain, but the Council believes that neither the goals of disability-related information nor those of the State Department reporting process would necessarily be served by the effort to make it do so.

The MCC is reported to be establishing a working group to review indicators used for such other program criteria as environmental and gender concerns [213]. NCD recommends that the MCC also review its application of the disability rights category with a view to identifying data sources and status and trend indicators that will supplement the State Department's annual human rights report in key areas not addressed by that report. As it stands now, the MCC relies almost exclusively on State's Country Reports to determine how disability is treated in the countries that the MCC considers for compact development.

A related concern exists in the area of technical assistance to countries in their efforts to qualify for and obtain MCA funds. The process by which countries are screened for MCA funding is a complex and multistep one. Countries that qualify for consideration next advance to the proposal submission stage. Candidate countries that do not qualify for funding may, on the other hand, be accorded threshold status, meaning they are close to measuring up but not quite there.

Measures to improve a country's score are at the core of efforts to advance from threshold to qualified status. NCD believes that countries seeking guidance with commonly discussed problems—such as trade barrier removal, elimination of corruption, or increasing political freedom—will have many models and sources of guidance to which to turn. But we are concerned that nations seeking to improve their disability rights performance may have fewer options and may have access to less expertise.

It is important to assist countries wishing to improve their performance on disability rights issues, whether in their postqualification funding proposals or in their efforts to cross the qualification-for-funding line in the first place. For this reason, NCD recommends that the MCC evaluate the technical assistance resources available to such nations and take steps to define and to enhance the availability of a broad range of relevant resources.

2. Other Foreign Assistance Developments

NCD has long maintained a high level of concern for the role of disability rights in all our foreign assistance and other foreign relations. Recognizing the inevitable tension between our goals and the frequently limited options for achieving them, we have nevertheless continued to believe that few areas offer a more powerful opportunity for demonstrating our highest principles than does our commitment to the equality of people with disabilities. In this light, NCD published a major report on foreign policy and disability in 2003 [214]. NCD is proud of the follow-up to that report and grateful for the cooperation of the U.S. Agency for International Development (USAID) and the State Department.

Among other major developments occurring in 2004 was the issuance of a notice by USAID in September. The notice set forth guidelines for implementation of USAID's disability policy, including establishment of disability training modules for agency personnel, development of policy guidance on accessibility in USAID-financed construction, and creation (in conjunction with the State Department) of measures to ensure that the interests of people with disabilities are addressed in the formulation of foreign policy and in the provision of foreign assistance [215].

NCD is also particularly heartened by plans, implemented through the U.S. International Council on Disabilities (USICD), to participate in an international conference scheduled for the spring of 2005 designed to address issues of concern to people with disabilities in the reconstruction of Iraq [216]. At meetings in early October 2004 where plans for this conference were discussed, presentations were also made, including by representatives of the Department of Defense (DOD) and the Department of Health and Human Services (HHS), regarding issues of concern to people with disabilities in the Iraqi health care system.

NCD commends all the entities involved in these efforts. The Council also expresses its appreciation for a number of related provisions included in the Foreign Operations Assistance Act of 2005 [217].

(c) U.N. Convention

Developmental efforts aimed at the adoption of a U.N. Convention on the Rights of Persons with Disabilities continued and progressed during 2004. The next meeting of the Ad Hoc Committee on the Protection and Promotion of the Human Rights of People with Disabilities was held in mid-2005. NCD continues to urge the United States to offer all possible support to the work of this Ad Hoc Committee in drafting the Convention for submission for ratification.

NCD continues to hope for an Administration commitment to become a signatory to the Convention and to submitting it to Congress, provided that its provisions do not contravene U.S. law. Pending such a commitment, NCD continues to offer its support to the process of Convention development in a number of ways.

Two of these should be discussed here. To provide the Ad Hoc Committee with technical assistance based on U.S. experience, the Council has commissioned papers in three areas: accessible transportation, independent and community living, and political participation [218]. The Council has also briefed interested congressional members and staff on House Concurrent Resolution (HCR) 169 [219]. As initially adopted by the 108th Congress, this resolution declared the sense of Congress that the United States should support the U.N. Convention. NCD recommends that HCR 169 be reintroduced and readopted by the 109th Congress at the earliest possible date, as a means of underscoring our nation's continuing commitment to fostering equality through international law.

Recommendations

Recommendation 12.1: NCD recommends that the Millennium Challenge Corporation (MCC) review its application of the disability rights criterion with a view to identifying data sources that will supplement the State Department's annual human rights report in key areas of concern not addressed by that report.

Recommendation 12.2: NCD recommends that the MCC evaluate the technical assistance resources available to nations seeking Millennium Challenge Account funds and take steps to enhance the availability of a broad range of relevant resources for use by these nations in improving their human rights performance in the disability area and for perfecting their applications for support.

Recommendation 12.3: NCD recommends that House Concurrent Resolution 169, which was adopted by the 108th Congress, be reintroduced and readopted by the 109th Congress at the earliest possible date, as a means of underscoring our nation's continuing commitment to fostering equality through international law.

Chapter Thirteen—Homeland Security

Introduction

This chapter begins in section (a) with a review of developments during the past year, commending the Executive Order issued in connection with emergency preparedness and people with disabilities. Section (b) goes on to express concerns about the possible inadequacy of existing legal provisions to ensure that critical electronic information resources will be available to all people with disabilities on a real-time basis.

Section (c) reviews the importance of including people with disabilities in emergency planning, especially in emergency planning that is specifically undertaken with them in mind. Section (d) deals with the host of issues confronted in harmonizing and standardizing the accessibility and related practices of the variety of agencies making up the homeland security system. Finally, section (e) reflects on other dimensions of civil rights enforcement in a system comprised of so many diverse organizations and traditions.

Before turning to the specifics, it should be noted that NCD issued a major report on this subject on April 15, 2005. Its findings and recommendations will be comprehensive. We recommend careful review of this report to all those interested in this critical subject. Here we will highlight a few points that we believe are of overarching concern.

(a) Recent Developments

In July 2004, President Bush issued an Executive Order creating the Interagency Coordinating Council on Emergency Preparedness and Individuals with Disabilities (Executive Order 13347: Individuals with Disabilities in Emergency Preparedness). At the Council's first meeting in September 2004, a number of federal agencies reported on initiatives in connection with people with disabilities and emergency preparedness.

NCD commends the Administration for these efforts and for the growing level of awareness that they reflect. But these efforts also disclose a number of gaps in planning that we believe urgently need to be addressed if people with disabilities are to have the same level of protection as other people.

(b) Emerging Legal Issues

1. ADA and Section 504

In our last status report, NCD expressed concern about the lack of sufficient knowledge or oversight of accessibility measures undertaken by state and local emergency preparedness and first responder organizations. For that reason, we are particularly gratified by actions occurring during 2004. One of the important initiatives arising as a follow-up to the President's Executive Order was the publication by the Department of Justice (DOJ) of a technical assistance document designed to acquaint and remind state and local emergency planners of the need to ensure accessibility of emergency preparedness programs [220]. In particular, the document focuses on the obligations of states and localities under Title II of ADA.

Much uncertainty surrounds the application of Title II to emergency planning and preparedness, however. Two key examples can be noted here. First, emergency information communicated by radio or television is not clearly subject to ADA. That is to say, there is no requirement under ADA that public service announcements (PSAs) or emergency information furnished by government be provided in redundant formats so that people with impairments of hearing or vision will be ensured of prompt and full access to it.

This problem of timely information is made still more complex when the information, though created by government, is disseminated by private sector TV and radio stations. While closed-captioning requirements may apply under other laws [221], the relative roles of Titles II and III of ADA remain to be determined. Moreover, even if we knew exactly how ADA applied, there is nothing in the law that prevents a covered entity from raising an "undue burden" defense [222].

The legal complexity surrounding information dissemination in time of emergency can be clearly shown in the overlapping jurisdictions of the Department of Justice (DOJ) and the Federal Communications Commission (FCC). Clarification of broadcasters' responsibilities in the dissemination of instructions or information at times of crisis appears to rest with the FCC. It is not clear to what extent DOJ and the FCC, acting jointly but bringing to bear the combined resources of ADA and the Federal Communications Act, have taken steps to address this problem.

It should be noted in this regard that emergency information relates to more than terrorist threats. For example, if a tornado warning is given by a nonvoiced legend that scrawls soundlessly across the bottom of a TV screen, its availability to people who are blind may be nonexistent.

The second area in which ADA and Section 504 may not be adequate to the task is in the physical accessibility of evacuation centers, shelters, and other places where escapees from or victims of terrorist attacks or natural disasters would congregate. Anecdotal information suggests that many of these facilities are not accessible to people with disabilities. Responding to this problem must begin with attention to surveying and providing data on the accessibility of these facilities for people with disabilities.

Retrofitting of existing facilities would be expensive. But until or unless the scope of the inaccessibility problem can be fully known, the exact level of need cannot be determined. In this connection, NCD has been unable to determine that the Department of Homeland Security (DHS) has sought funds or offered grants for surveying the accessibility of the existing emergency preparedness infrastructure. NCD recommends that such a survey be undertaken at the earliest possible time, with a view to identifying the scope of the problems, the types of access that are most critically lacking, and the availability of alternative facilities or strategies for dealing with the problem in as many communities as possible.

2. Monitoring and Oversight

NCD has not yet been able to determine whether DOJ and DHS have mechanisms for monitoring the activities of state, local, and other grantees in place. NCD believes that all prospective investments in planning, infrastructure, and procedures must be made with full attention to accessibility. This requirement—embodied in Section 504 for all recipients of federal financial assistance and embodied in Titles II and III of ADA—should be made a part of the requirements for all homeland security grants and contracts. Once established as a clear and formal requirement, a grantee’s proposals for meeting these requirements should be one of the criteria going into the evaluation of competitive grant proposals. Once programs are funded, compliance with and success in this dimension of the work should be one of the elements monitored and reviewed by DHS on a regular basis.

(c) Inclusion of People with Disabilities in Planning

A number of training, educational, and technical assistance efforts place great emphasis on advising emergency response program planners and administrators about steps they can take to ensure that their programs are effective for people with disabilities. Less apparent, however, is a clear awareness of the need to involve people with disabilities themselves directly in the design of these programs from the earliest possible moment. People with disabilities may benefit from these programs and, like all other citizens, may be the programs' object of concern. But people with disabilities and community-based organizations (CBOs) need to be involved in the development of programs, resources, and strategies if accessibility and equality are to be ensured. For this reason, NCD urges that inclusiveness of planning processes be a requirement for all homeland security emergency preparedness grants.

(d) Administrative Problems

Homeland security is unique in being a subject that involves virtually every agency and level of government in one way or another. Of course, we have consolidated many homeland security-related activities in the Department of Homeland Security since its creation in 2002, but many homeland security activities remain within the jurisdiction of other agencies. These range from the FBI in its investigative and law enforcement role to the Department of Health and Human Services (HHS) in its responsibilities in protection against bioterrorism.

Faced with so many agencies and jurisdictions, the question is one of how to design overarching accessibility principles that provide clarity and predictability in all relevant emergency preparedness and emergency response systems. NCD recommends that DOJ and the Office of Management and Budget (OMB) work together to develop accessibility requirements, oversight procedures, complaint processes, and other approaches to creating more uniformity and predictability within the system and for generating comparative outcome and tracking data.

NCD understands in this regard that DOJ and DHS are developing a case monitoring and tracking system for receiving complaints and following up and reporting on their disposition. But unless this system takes into account the large number of programs and agencies under which complaints could theoretically arise and unless some standards are created to ensure that complaints lodged against one program or under the jurisdiction of one agency are handled in a manner comparable to how they would be for a different program or different agency, the ability of the system to generate meaningful data may be seriously compromised.

(e) Other Contexts

As the range of DHS's jurisdiction, directorates, and sub-cabinet agencies makes clear, homeland security involves more than emergency preparedness and response. From border security to electronic transfer of funds, homeland security touches upon many areas of our lives.

To say that DHS has responded to the issues confronting people with disabilities, systematic efforts must be undertaken to ensure that each of its units and functions takes accessibility fully into account. For the individual with a physical or visual disability who cannot independently fill out customs or immigration forms required for entry into the United States, real issues of accessibility and privacy are created. For the person who cannot answer the questions of a border patrol officer because he or she is unable to hear them, real hardships and misunderstandings can be foreseen. In each of the component agencies of DHS, we must identify and attempt to correct any issues that may arise.

Like protecting our security, this will be a long and evolving process. NCD stands ready to assist DHS and other federal agencies in all possible ways to help this process to move forward and to achieve meaningful results.

Recommendations

Recommendation 13.1: NCD recommends careful review of its forthcoming in-depth report on this subject.

Recommendation 13.2: NCD recommends that a survey of the accessibility of emergency shelters and similar facilities be undertaken at the earliest possible time, with a view to identifying the scope of the problems, the types of access that are most critically lacking, and the availability of alternative facilities or strategies for dealing with the problem in as many communities as possible.

Recommendation 13.3: NCD recommends that inclusiveness of planning processes be a requirement for all homeland security emergency preparedness grants.

Recommendation 13.4: NCD recommends that DOJ and OMB work together to develop accessibility requirements, oversight procedures, complaint processes, and other approaches to creating more uniformity and predictability within the homeland security system and for generating comparative outcome and tracking data regarding accessibility and civil rights complaints and outcomes.

Appendix

Mission of the National Council on Disability

Overview and Purpose

The National Council on Disability (NCD) is an independent federal agency with 15 members appointed by the President of the United States and confirmed by the U.S. Senate. The 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 improving personal assistance services, promoting health care reform, including students with disabilities in high-quality programs in typical neighborhood schools, promoting equal employment and community housing opportunities, monitoring the implementation of ADA, improving assistive technology, and ensuring that people with disabilities who are members of diverse cultures fully participate in society.

Statutory History

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

Endnotes

[1] 29 USC Section 781.

[2] Livable Communities for Adults with Disabilities (NCD, December 2, 2004) (available at www.ncd.gov/newsroom/publications/2004/LivableCommunities.htm.

[3] Improving Federal Disability Data (NCD, January 8, 2004) (available at www.ncd.gov/newsroom/publications/2004/improvedata.htm).

[4] ICIDH-2: International Classification of Functioning and Disability; (available at www.deakin.edu.au/tedca/ncet/information/resources/ididh.html. A discussion of this alternative approach for defining and understanding disability is contained in NCD's ADA Policy Brief No. 6, infra (in particular, text accompanying Note 50).

[5] Our concerns with CBO scoring, not specifically reiterated in this report but implicit in all of our discussion of program evaluation criteria, relate to the absence of mechanisms for incorporating opportunity, intergovernmental, and cross-program costs into the scoring. Additionally, they relate to the extremely limited time frames within which reliable scoring is currently deemed possible.

[6] www.ncd.gov/newsroom/publications/2003/policybrief.htm

[7] Righting the ADA (NCD 2004) (available at www.ncd.gov/newsroom/publications/2004/rightingada.htm*)*.

[8] Righting the ADA, n.7, supra, particularly Section II; also e.g., ADA Policy Brief No. 13: The Supreme Court's ADA Decisions Regarding Substantial Limitations of Major Life Activities, (NCD 2003) (available at www.ncd.gov/newsroom/publications/2003/limitations.htm), and Policy Brief No. 6: Defining Disability in a Civil Rights Context: The Court's Focus on Extent of Limitations as Opposed to Fair Treatment and Equal Opportunity (NCD 2003) (available at www.ncd.gov/newsroom/publications/2003/limitations.htm).

[9] Righting the ADA, ndd7, supra; see also ADA Policy Brief No. 11: The Role of Mitigating Measures in the Narrowing of the ADA's Coverage (NCD 2003) (available at www.ncd.gov/newsroom/publications/2003/mitigatingmeasures.htm).

[10] Righting the ADA, n.7, supra; see also ADA Policy Brief No. 8: Implications of the Supreme Court's Decision in *Board of Trustees University of Alabama v. Garrett* (NCD 2003) (available at www.ncd.gov/newsroom/publications/2003/garrett.htm).

[11] www.bazelon.org/issues/disabilityrights/lane

[12] For an overview of the many briefs, including friend of the court briefs, filed in the Supreme Court, see the documents collected at the site referenced in n.11.

[13] *Tennessee v. Lane*, 541 U.S. 509 (2004).

[14] Righting the ADA, n.7, supra. See also, S.2088 H.R.3809 (108th Cong.).

[15] A number of foreseeable issues have not yet been addressed by the Supreme Court. Some of these are discussed in NCD's report as well.

[16] HR 728 (108th Cong.).

[17] Righting the ADA, n.7, supra.

[18] Righting the ADA, n.7, supra.

[19] See ADA Policy Brief No. 6, n.8, supra.

[20] *Murphy v. United Parcel Service*, 527 US 516 (1999).

[21] ADA Policy Brief No. 6, n.6, supra (especially cases cited therein at n.36-46).

[22] See National Disability Policy: A Status Report (Chapter TWO (a) (NCD 2004) (available at www.ncd.gov/newsroom/publications/2003/progressreport.htm).

[23] 28 C.F.R. Parts 35-36.

[24] ADA and ABA Accessibility Guidelines for Buildings and Facilities, - Fed. Reg. - (July 23, 2004) (available at www.access-board.gov/ada-aba/final.pdf).

[25] www.adaanprm.org/AANPRM.HTM

[26] Access Board and Department of Justice, n. 24-25, supra.

[27] *Access Now v. Southwest Airlines Co.*, 385 F. 3d 1324, 2004 U.S. App. Lexis 20060 (9th Cir. 2004).

[28] E.g., the DOJ Southwest amicus brief, n.27, supra.

[29] 49 USC Section 41705.

[30] See cases collected in NCD's paper "When the Americans with Disabilities Act Goes Online: Application of the ADA to the Internet and the Worldwide Web" (NCD Position Paper, July 10, 2003; available at www.ncd.gov/newsroom/publications/2003/internet.htm).

[31] Business Brief, www.usdoj.gov/crt/stada/svcanimb.htm.

[32] www.petsonthego.com/pressrm.html

[33] Internal Revenue Code (IRC) Sec. 213, codified at 26 U.S.C. Sec. 213.

[34] *United States v. Gregg Tirone* (Settlement Agreement, January 5, 2004; available at www.usdoj.gov/crt/ada/tirone.htm).

[35] For information on this law, see the Federal Trade Commission's Web site, www.ftc.gov.

[36] Federal Funding for Civil Rights Enforcement: 2005 (US Commission on Civil Rights 2004) (available through www.usccr.gov/pubs/crfund05/crfund05.pdf).

[37] USDOJ Online Newsletter (June 2004) (available at www.usdoj.gov/crt/ada/newsltr0604.htm).

[38] ADA Checklist for Polling Places (Department of Justice, February 20, 2004) (available at www.ada.gov/votingck.htm).

[39] www.eac.gov/finalhfvotereport-4-29-041wcover.asp

[40] NCD ADA Policy Brief No. 15, n.6, supra.

[41] PL 108-446 (December 3, 2004) (available at http://friendwebgate.access.gpo.gov/ cgi-bin/getdocddcgic"dbname equals 108..7).

[42] Improving Educational Outcomes for Students with Disabilities (NCD May 17, 2004) (available at www.ncd.gov/newsroom/publications/2004/educationoutcomes.htm).

[43] PL 105-17. A detailed summary of changes made in IDEA by the new law is contained in the Congressional Research Service (CRS) report "Individuals with Disabilities Education Act (IDEA): Analysis of Changes Made by P.L. 108-446," by Richard N. Apling and Nancy Lee Jones (CRS Order Code RL32716, January 5, 2005).

[44] PL 108-446, Sec. 607. Also n.45, infra.

[45] 69 Fed. Reg. 77968 (December 29, 2004).

[46] PL 108-446 Sec. 607, codified at 20 USC Sec. 1406.

[47] NCD has received few expressions of opinion concerning whether these modifications in the way testing takes place hold out the prospect of significantly reducing the fears of many mainstream educators.

[48] CRS Summary, n.43, supra.

[49] NCD paper, n.42, supra.

[50] "Improved Timeliness and Better Use of Enforcement Actions Could Strengthen Education's Monitoring System" (GAO 04-879, October, 2004) (available at www.gao.gov/new.items/d04879.pdf right-brace. For GAO findings concerning monitoring under NCLB, see "Improvements Needed in Education's Process for Tracking States'

Implementation of Key Provisions" (GAO 04-734 September 30, 2004) (available at www.gao.gov/new.items/d04734.pdf).

[51] PL 108-446 Sections 601 (5(E,) (10(D) and 602 (10). Compare "Additional Assistance and Better Coordination Needed Among Education Offices to Help States Meet the No Child Left Behind Act Teacher Requirements" (GAO 04-659, July 2004).

[52] PL 108-446 Secs. 601 (14) and 602 (34).

[53] PL 108-446 Sec. 664 (1), codified at 20 USC Sec. 664 (1).

[54] PL 108-446 Sec. 615 (1(E). See also CRS report, n.43, supra.

[55] Id. Also PL 108-446 Sec. 612 (1).

[56] PL 108-446 Sec. 615.

[57] PL 108-446 Sec. 615.

[58] Interestingly, Congress not only recognized this possibility but chose to treat deliberate delay by the state or local education agency's counsel very differently, and far less harshly, than comparable behavior on the part of the parent's attorney. Compare Subparagraph F with Subparagraph G in Paragraph 3 of Subsection i of Section 615.

[59] PL 108-446 Sections 602 (7) and 674.

[60] PL 108-446 Section 611. Increasing appropriations levels are authorized through 2011.

[61] *Gaskin v. Pennsylvania Department of Education* (Proviñal Settlement Agreement, Submitted to the Court December 21, 2004) F. Supp. 2d (E.D. Pa.).

[62] PL 108-446 Section 616. See also CRS report, n.43, supra.

[63] PL 108-446 Section 609.

[64] "Additional Assistance and Research on Effective Strategies Would Help Small Rural Districts" (GAO 04-909, September 2004).

[65] See H.R. 4283 (108th Cong.). See also "The Higher Education Act: Reauthorization Status and Issues," by James B. Stedman (CRS Issue Brief, Order Code IB 10097, October 20, 2004).

[66] IRC Sec. 223.

[67] IRC Sec. 25A.

[68] IRC Sec. 530.

[69] P.L. 108-173.

[70] Health Care Spending and the Uninsured (statement presented by the Congressional Budget Office before the U.S. Senate Committee on Health, Education, Labor and Pensions, January 28, 2004).

[71] Hearing before the Subcommittee on Health, U.S. House of Representatives, Committee on Ways and Means (108th Cong. Second Session, Serial 108-50, March 9, 2004).

[72] IRC Section 223, as added by P.L. 108-173.

[73] Testimony of Douglas Holtz-Eakin, n.70, supra.

[74] Adverse selection is the process of using criteria that are intended to screen out various categories of people from coverage, often through the use of indirect means.

[75] "Information for Health: A Strategy for Building the National Health Information Infrastructure" (Report and Recommendations from the National Committee on Vital and Health Statistics, November 15, 2001) (available at http://ncvhs.hhs.gov/nhiilayo.pdf).

[76] FAQ sheet for the National Health Information Infrastructure (available on the NHII Web site, n.75, supra.

[77] These include the Federal Government's own Sec. 508 guidelines, but they also include such computer industry efforts as the Worldwide Web Consortium's (W3C) Web content and other accessibility guidelines.

[78] House Hearing, n.71, supra.

[79] Id.

[80] "Medicaid Program Integrity: State and Federal Efforts to Prevent and Detect Improper Payments" (GAO 04-707, Aug. 16, 2004; available at http://www.gao.gov/cgi-bin/ getreport"GAO04-707).

[81] "Medicaid and SCHIP: States' Premium and Cost Sharing Requirements for Beneficiaries" (GAO 04-491, March 2004) (available through http://www.gao.gov).

[82] E.g., "Medicaid Cuts Continue as Improving State Economic Conditions Insufficient to Pull States out of Budget Slump" (Kaiser Commission on Medicaid and the Uninsured, January 2004) (available at www.kff.org/medicaid/kcmu012704tionr.cfm).

[83] Optional services are those Medicaid services that states are free but not required to provide. When they do provide them, federal matching funds are forthcoming, however. Optional services should not be confused with optional populations.

[84] *Olmstead v. L C.*, 527 U.S. 581 (1999).

[85] National Survey of State Direct-Care Workforce Initiatives (Paraprofessional Health Care Institute, and the North Carolina Department of Health and Human Services, September 2004) (available at www.directcareclearinghouse.org).

[86] P.L.106-170.

[87] HHS Awards $15.7 Million to HELP People with Disabilities Return to Work (CMS Press Release, March 2, 2004) (available through www.cms.hhs.gov/twwiia.asp).

[88] 42 USC Sec. 1395.

[89] n.69, supra.

[90] Presidential Executive Memorandum of February 2003, as cited in "Report on Assistive Technology Mobility Devices" (Interagency Working Group on Assistive Technology Mobility Devices, August 2003) (available at www.icdr.us/atmdreports/index.htm*)*.

[91] Taking the Taxpayer for a Ride: Fraud and Abuse in the Power Wheelchair Program, (Senate Finance Committee Hearing) (available at http://finance.senate.gov/sitepages.hearing042804.htm).

[92] www.itemcoalition.org

[93] www.cms.hhs.gov/medlearn/PowerWheelchair.pdf

[94] This openness has taken a number of forms, including briefings and what are called Open Door Forums, at which interested parties are given an opportunity to react. What remains to be seen is how the views of the disability and supplier communities will ultimately inform the final decision-making process.

[95] "SSA's Disability Demonstration Projects Likely To Provide Important Information About Disability Work Incentives," by Eileen P. Sweeney (Center on Budget and Policy Priorities, August 2004) (report describing the various demonstration programs and providing resources for further information) (available through www.cbpp.org).

[96] 5 U.S.C. Sec. 601.

[97] 44 U.S.C. Sec. 3506.

[98] "Financing Long-Term Care for the Elderly" (CBO Paper, April 2004).

[99] "Assisted Living: Examples of State Efforts to Improve Consumer Protections" (GAO 04-684, April 2004 (available through www.gao.gov).

[100] "Transportation-Disadvantaged Seniors: Efforts to Enhance Senior Mobility Could Benefit from Additional Guidance and Information" (GAO Report to the Chairman, Special Committee on Aging, U.S. Senate, August 2004) (available through www.gao.gov).

[101] www1.eps.gov/spg/NCD/NCDCS/NCDCS1/99L%2DT/listing.html

[102] n.98, supra.

[103] Id.

[104] The notion here is to link long-term care insurance with Medicaid, but many inconsistencies in policy would have to be reconciled before this model could come into widespread use.

[105] Only if the insurance practice in question violates state law can this limitation be overcome. See 42 U.S.C. Sec. 12201.

[106] Incarceration of Youth Who Are Waiting for Community Mental Health Services in the United States (House of Representatives Committee on Government Reform, Minority Staff Special Investigations Division, July 2004) (available through http://govt-aff.senate.gov/files/040707juvenilereport.pdf).

[107] “Child Welfare Issues in the 108th Congress,” by Emilie Stoltzfus (Congressional Research Service Report for Congress, Order Code RL 31746, updated September 17, 2004).

[108] Id.

[109] Id.

[110] 69 Fed. Register 22386 (Apr. 28, 2003).

[111] “Fostering the Future: Safety, Permanence and Well-Being for Children in Foster Care” (Pew Commission on Children in Foster Care, May 2004) (available at http://pewfostercare.org/research/docs/FinalReport.pdf).

[112] IRC Section 23. (Pursuant to inflation-adjustment, the credit will be $10,500 in 2005).

[113] P.L. 108-36.

[114] P.L. 108-446, Sec. 635 (2)(G).

[115] Indian Child Protection and Family Violence Prevention Act Reauthorization of 2004, S. 1601 (108th Cong.). As of December 31, 2004, this legislation had not been enacted into law.

[116] www.ncd.gov/newsroom/testimony/2004/gould_12-15-04.htm

[117] www.ncd.gov/newsroom/advisory/youth/youth.htm.

[118] See CRS report, n.43, supra.

[119] IRC n.33, supra at Sections 25A and 529-530.

[120] Although the aging of the baby boom generation, resulting in the aging of the active workforce, may in part account for the increase, other factors beyond the scope of this paper are also thought to be involved, including perhaps the decline in availability and affordability of private sector health insurance.

[121] www.ncd.gov/newsroom/publications/2000/transition_11-01-00.htm

[122] Social Security Act Section 234.

[123] Plainly written explanations of these provisions are found in a number of SSA publications intended for the general public and in Parts 404 and 416 of Title 20 of the Code of Federal Regulations.

[124] SSA Sec. 234.

[125] "Improved Processes for Planning and Conducting Demonstrations May Help SSA More Effectively Use Its Demonstration Authority" (GAO 05-19, November 2004) (available at www.gao.gov/cgi-bin/getrpt"GAO05-19).

[126] n.87, supra.

[127] Social Security Act Sec. 1619 (b).

[128] Statutory authority for SSA's having moved from HHS to independent status in 1995.

[129] TWWIIA, n.122, supra.

[130] www.gao.gov/htext/d031027t.html

[131] E.g., Interagency Wheelchair Working Group Draft Recommendations (available through www.cms.hhs.gov/mcd/viewtrackingsheet.asp).

[132] States have broad discretion over how to define such services as DME. Although the Medicare definition is not legally applicable to Medicaid in any way, its adoption by states in the Medicaid context affords them convenience and a superficially plausible rationale for a restrictive definition.

[133] P.L. 105-220.

[134] National Council on Disability to Conduct Fort Lauderdale Meeting with Emerging Workforce Conference Participants (News ADVISORY NCD #04-443, January 5, 2004).

[135] P.L. 105-220, Sec. 188.

[136] H.R. 1261 and S. 1627 (108th Cong.) (both houses of Congress had adopted versions of the bill but a conference bill had not yet emerged and it was believed that considerable potential for negotiation still existed).

[137] P.L. 105-220, Sec. 400 et seq.

[138] The complex status of the VR system as a self-contained system and at the same time as a partner in the mainstream system may be seen as one outcome of this debate.

[139] Over the last three reauthorizations of the VR Act—in 1986, 1992, and 1998—new services such as AT, new due process requirements, and new categories of acceptable outcomes and goals (including part-time employment and self-employment) have been added to or upgraded within the program.

[140] 34 C.F.R. Sec. 361.36.

[141] Workforce Investment Act of 1998 Sec. 192; see also 69 Fed. Register 78479 (December 30, 2004).

[142] N.69, supra.

[143] "Incentives to Employ Workers with Disabilities Receive Limited Use and Have an Uncertain Impact" (GAO 03-39, December 11, 2002) (available at www.gao.gov/new.items/d0339.pdf).

[144] For a discussion of flaws in the design of these provisions that may go a long way to explaining their lack of impact, see NCD's 2003 status report, (available at www.ncd.gov/newsroom/publications/2004/ProgressReport2004.htm).

[145] IRC, n.33, supra, Sec. 44.

[146] Id. at Sec. 51.

[147] Id. at Sec. 51A.

[148] Id. at Sec. 190.

[149] P.L. 104-193.

[150] As of November 2005, a long-term reauthorization bill had not been adopted.

[151] www.ncd.gov/newsroom/publications/2003/familysupports.htm

[152] S. 1523 (108th Cong.).

[153] Lex Frieden's op-ed piece, "Temporary Assistance for Needy Families and People with Disabilities" (March 11, 2004).

[154] Nondiscrimination on the Basis of Disability in Air Travel, (Department of Transportation NPRM) 69 Fed. Register 64363 (November 4, 2004).

[155] N.27, supra.

[156] 14 C.F.R. Part 382.

[157] N.100, supra.

[158] Executive Order 13330: Human Service Transportation Coordination (February, 2004).

[159] "Transmittal Letter accompanying Transportation-Disadvantaged Populations: Federal Agencies Are Taking Steps to Assist States and Local Agencies in Coordinating Transportation Services" (GAO Report to the Subcommittee on Highways, Transit, and Pipelines of the House Committee on Transportation and Infrastructure, June 2003) (available at www.gao.gov/new.items/d03697.pdf).

[160] Id.

[161] "Transportation-Disadvantaged Populations: Some Coordination Efforts Among Programs Providing Transportation Services, But Obstacles Persist" (GAO 03-697, June 30, 2003) (available through www.gao.gov/new.items/d03697.pdf).

[162] H.R. 5183 and H.J. Res. 107 (108th Cong. Second Sess.).

[163] Reconstructing Fair Housing report (available at www.ncd.gov/newsroom/publications/2001/fairhousing.htm).

[164] *U.S. v. Wilmark Development Co. et al.* (settlement announced by the Department of Justice; described at length in Universal Design Newsletter: Vol. 7, No. 2 at 3 (July 2004); *U.S. v. Triumvera Tower Condominium Ass'n.* (DOJ settlement announced September 2004); and *U.S. v. Fugitt et al.* (DOJ settlement announced September 2004).

[165] "Fair Housing: Opportunities to Improve HUD's Oversight and Management of the Enforcement Process" (GAO Report to Congressional Requesters, April 21, 2004). Available at www.gao.gov/new.items/d04463.pdf.

[166] US Commission on Civil Rights, n.36, supra.

[167] Civil Rights Act of 1968 as amended, Title VIII.

[168] 42 USC Secs. 12132 et seq. and 12181 et seq. (Titles II and III, depending on the context).

[169] 29 USC Sec. 794.

[170] n.164, supra.

[171] Id.

[172] NFI Progress Report (HHS, May 2002). (available at www.hhs.gov/newfreedom/final).

[173] H.R. 2353 (108th Cong. Second Sess.).

[174] E.g., DOJ announcement of February 18, 2004 (certifying compliance of Maryland's state building code with ADA and making Maryland the fifth state to receive such certification).

[175] P.L. 108-364.

[176] P.L. 105-394.

[177] "New Freedom Initiative: A Progress Report" (March 2004).

[178] Links to the alternative financing loan program and the telework program can be found through the RESNA Alternative Financing Technical Assistance Project (available at www.resna.org/AFTAP/index.html?phpsessid=0fd4c7c14021).

[179] Announcement of pilot demonstration grants by Secretary of Labor Chao's office (July 2004).

[180] Both funded by NIDRR, they are the Assistive Technology Outcomes Measurement Systems project (ATOMS) (available at www.uwm.edu/chs/r2d2/atoms/about/) and the Consortium for Assistive Technology Outcomes Research project (CATOR) (available at www.atoutcomes.org).

[181] www.ncd.gov/newsroom/publications/2004/online_newmarketplace.htm

[182] 29 U.S.C. Sec. 794d.

[183] 36 C.F.R. Part 1194.

[184] N.177, supra.

[185] H.R. 2458 - E-Government Act of 2002.

[186] "OMB Creates Single Policy Document for Web Requirements," by Jason Miller (Government Computer News, December 21, 2004). (available at www.gcn.com/vol1.no1/daily-updates/31407-1.html). Notes issuance by OMB of a set of 10 requirements that all government Web sites must follow by specified date, including maintaining accessibility for people with disabilities.

[187] "Section 508 to Apply Even to Small Purchases Starting April 1," by Jason Miller (Government Computer News November 3, 2004) (available at www.gcn.com/vol1.no1/daily-updates/27814-1.html).

[188] Rehabilitation Act Sec. 508.

[189] www.usdoj.gov/crt/508/report2/index.htm

[190] N.177, supra.

[191] P.L. 104-1, 2 USC 1301 (Congressional Accountability Act).

[192] H.R. 3963 (108th Cong. Second Sess. 2004).

[193] “Accessible Information Technology: An Overview of the Current State of Federal and State Laws and Policies,” by Edward Myers (ATAP and RESNA Technical Assistance Project 2004) (available at www.resna.org/taproject/hottopics.html).

[194] N.154, supra.

[195] 47 U.S.C. Sec. 255.

[196] 36 C.F.R. Part 1193; FCC Rules Part 68.

[197] In the Matter of Dr. Bonnie O’Day, Complainant v. Audiovox Communications Corporation, Defendant (FCC Docket No. DA 03-4116, order released January 5, 2004).

[198] P.L. 104-131.

[199] Notice to Video Programming Distributors and the Public of the January 1, 2004, Requirements for the Closed-Captioning of New Nonexempt English and Spanish Language Video Programming and Reminder Regarding Other Captioning Requirements (FCC Docket DA-04-2, released January 6, 2004).

[200] Most or all of the reported petitions came from religious broadcasters, alleging financial hardship. In addition to the petitions denied, a number were withdrawn; for example the petition of the John Ankyberg Show (motion to withdraw granted February 6, 2004).

[201] Telecommunications for the Deaf, Inc. (TDI) et al. FCC Rulemaking Petition (filed July 23, 2004). For discussion, see press release, September 8, 2004 (available through www.aapd-dc.org).

[202] Since the detailed discussion of this issue in Chapter 11 of last year’s status report, no action on the FCC’s part in this connection has come to our attention. Unrelated activity has occurred with respect to the e-rate.

[203] NCD is unaware of any action on this subject by the FCC in the period that has elapsed since issuance of the Council’s 2003 status report.

[204] Doc 2004-19348. The IRS appears poised to interpret the communications tax under IRC Sec. 4252 as applying to VoIP on the same basis as it does to other forms of telephonic communication. In so doing, the IRS is implicitly rejecting the FCC’s position that “information” services such as VoIP do not meet the law’s definition of “communications” services. See IRS Announcement 2004-61, 29 IRB 67 (2004).

[205]The Court of Appeals for the Fifth Circuit had created a split in the circuits by deciding that, in the absence of a clear statement from Congress that ADA should apply to foreign flag cruise ships, the court would not presume to say that it did. From the standpoint of accessibility advocates, the basic logic was that there was no reason for Congress to have made an explicit statement about foreign registry ships, because no one ever imagined there would be a question.

Prior to the publication of this report, on June 6, 2005, the Supreme Court ruled by a 6-3 vote that Title III of ADA does apply to all cruise ships operating into or out of American ports.

[206] www.ncd.gov/newsroom/publications/2005/spector_norwegian.htm

[207] P.L.108-199, Division D.

[208] "Millennium Challenge Account: Implementation of a New U.S. Foreign Aid Initiative," by Larry Nowels (Congressional Research Service, Order Code RL 32427, Updated January 21, 2005).

[209] Id.

[210] Id.

[211] Id.

[212] This annual report has become the subject of growing attention and contention. It ranks nations with respect to their status and progress on a number of human rights criteria, and various aspects of their relationship with the United States, including foreign assistance and favored trading relations, are affected by the State Department's findings.

[213] USAID Policy Paper (September 12, 2004) (discussed in NCD International Watch Committee FACA q. Report (March 2005).

[214] www.ncd.gov/newsroom/publications/2003/foreign03.htm

[215] USAID, n.213, supra.

[216] NCD International Watch Committee, n.213, supra.

[217] Omnibus Budget Resolution Act of 2004 (OBRA 2004) Sec. 579.

[218] NCD International Watch, n.213, supra.

[219] Id.

[220] Individuals with Disabilities in Emergency Preparedness (Executive Order, July 22, 2004).

[221] www.usdoj.gov/jmd/ps/dojepm.htm

[222] E.g., Federal Communications Act Sec. 713.

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