

National Disability Policy: A Progress Report

December 2004–December 2005



**National Council on Disability
Date: November 9, 2006**

National Council on Disability
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Publication date: November 9, 2006

202-272-2004 Voice
202-272-2074 TTY
202-272-2022 Fax

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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 9, 2006

The President
The White House
Washington, DC 20500

Dear Mr. President:

On behalf of the National Council on Disability (NCD), I am pleased to submit NCD's *National Disability Policy: A Progress Report*, as required by Section 401(b)(1) of the Rehabilitation Act of 1973, as amended. This report comes at a pivotal time; a time when American citizens and leaders call for dramatic change in a range of areas of public policy and programs for people with disabilities consistent with the vision of the Americans with Disabilities Act of 1990 (ADA). For example, an Equal Employment Opportunity Commission report has recently noted that the proportion of federal employees with disabilities has decreased to less than 1 percent of the federal workforce.

The attached progress report covers the period December 2004 to December 2005. It reviews federal policy activities noting progress where it has occurred and makes further recommendations where necessary. The recommendations apply to the Executive Branch, to the Legislative Branch, and in some instances to both. While NCD believes the country is moving forward, expanding opportunities and inclusion for Americans with disabilities, the rate of progress is slow. Federal policy still contains inconsistent messages and unrealistic requirements for people with disabilities who rely on such federal programs as Social Security disability benefits, Medicaid, Medicare, special education, and Temporary Assistance for Needy Families.

NCD believes that to accomplish the vision of ADA, it is critical that the Administration work with leaders in Congress to implement an effective disability agenda that results in quality lives for over 50 million Americans with disabilities. Thank you for the opportunity to play the independent role that our mission requires and to offer an objective assessment of progress. As the nation celebrates the 16th anniversary of the ADA, NCD stands ready to work with you and stakeholders outside the government to see that the public policy agenda set out in the attached report is implemented.

Sincerely,

John R. Vaughn
Chairperson

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Acknowledgments

The National Council on Disability wishes to express its sincere appreciation to Steve Mendelsohn, Esq., for all his work in the development of this report.

Table of Contents

Executive Summary	9
MAJOR TRENDS.....	29
(a) Applying the ADA to the 21st Century	29
(b) A Time of Scarcity	30
(c) Accountability in Disability Programs	31
(d) Specific Evaluation Issues	31
(e) Innovation	32
(f) Timing	33
(g) Conflicting Trends	34
(h) Partnership and Collaboration	35
(i) Asset Development.....	37
(j) Conclusion.....	39
Chapter One—Statistics	41
Introduction	41
(a) Legally-Mandated Statistics	42
(b) The Census	43
(c) Labor Market Data.....	44
(d) Quality of Life	44
(e) Data and Database Coordination	45
Recommendations	47
Chapter Two—Civil Rights.....	49
Introduction	49
(a) The ADA.....	49
(b) Civil Rights Forum	58
(c) Assisted Suicide	58
(d) Genetic Nondiscrimination.....	60
(e) Voting	62
(f) Rights of Institutionalized Persons.....	64
Recommendations	65
Chapter Three—Education.....	67
Introduction	67
(a) Burden of Proof	67
(b) Implementation of IDEA	68
(c) IDEA and No Child Left Behind	74
(d) Costs of Compliance.....	79
Recommendations	79
Chapter Four—Health.....	81
Introduction	81
(a) Disparities in Health Care or Outcomes	81
(b) Medicaid	83
(c) Mental Health Parity.....	88
(d) Veterans Health	89
Recommendations	92

Chapter Five—Long-Term Services and Supports	95
Introduction	95
(a) Background	95
(b) Critical Distinctions	97
(c) Insurance	98
Recommendations	103
Chapter Six—Children and Youth.....	105
Introduction	105
(a) Juvenile Detention	105
(b) Foster Care and Adoption.....	106
(c) Comprehensive Health Insurance	108
Recommendations	109
Chapter Seven—Employment.....	111
Introduction	111
(a) The Continuing Statistical Problem.....	112
(b) The Vocational Rehabilitation System	113
(c) One-Stop Centers	116
(d) Social Security Initiatives.....	119
(e) Employer Education and Law Enforcement.....	121
(f) Innovation.....	123
Recommendations	124
Chapter Eight—Welfare Reform	127
Introduction	127
(a) Background	127
(b) The Problem of Definitions	127
(c) Work Activity	128
(d) Pathways to Independence Act.....	129
(e) The Hard-Core Unemployed	130
Recommendations	131
Chapter Nine—Housing	133
Introduction	133
(a) Civil Rights	133
(b) Homelessness.....	136
(c) Rental Assistance	141
(d) Home Ownership.....	142
Recommendations	143
Chapter Ten—Transportation.....	147
Introduction	147
(a) Surface Transportation	147
(b) Paratransit	150
(c) Other Surface Transportation Programs	153
(d) Air Travel	154
Recommendations	156
Chapter Eleven— Assistive Technology and Telecommunications.....	159
Introduction	159
(a) Assistive Technology Research	159

(b) Federal Procurement Under Section 508	162
(c) Telecommunications	164
Recommendations	171
Chapter Twelve—International Affairs.....	173
Introduction	173
(a) The U.S. as Model, Teacher, and Student	173
(b) Health Promotion.....	175
(c) The UN Convention.....	176
(d) International Travel and Commerce	176
Recommendations	177
Chapter Thirteen—Homeland Security.....	179
Introduction	179
(a) Context.....	179
(b) The Report	180
(c) Critical Infrastructure.....	180
(d) The Needed Response.....	182
Recommendations	185
Appendix A: Mission of the National Council on Disability	187

Executive Summary

The National Council on Disability (NCD) is required by law to produce an annual progress report to the President and Congress identifying issues of concern to citizens with disabilities and of importance to policymakers, and highlighting developments occurring in the previous year. As such, it can be regarded as America's Disability State of the Union Message.

Subjects covered in the report are of two kinds: those topics (transportation, housing, education, etc.) required by statute to be included, and subjects (e.g., assistive technology, and homeland security) whose growing importance has led NCD to add them to the report. In addition, this year's report continues the practice begun two years ago of including at the front of the report, as an introduction to the specific topical chapters, of a Major Trends section. This section attempts to draw out the common or recurrent themes that run through and serve to unite the different subject areas. It also attempts to place disability-related policy issues as fully as possible within the context of the broader range of decisions that government is being called upon to make.

This year's Major Trends begins with the premise that in all social policy areas, our nation stands at a crossroads, facing major choices and attempting to incorporate new approaches. The section endeavors to relate these broad themes to many of the specific issues facing people with disabilities and disability policymakers. Scarcity of resources, accountability of agencies, methods of program evaluation, application of innovations, role of government-private partnerships, and the development of asset-development as a major antipoverty strategy are among the issues discussed as they specifically relate to disability policy.

Chapter One of the report deals with statistics. Recognizing the growing importance of data, especially statistical data, in the formulation of goals and the evaluation of programs and strategies, the chapter addresses some of the ways in which our choice of what data to collect reflects assumptions about what is important and about the nature of such relationships as the one between disability and work.

The chapter also discusses current statistical requirements, including progress toward collection of data elements mandated by law. Progress is appreciatively noted in connection with several ongoing data-collection requirements, but concern is also expressed regarding the scope and viability of other collection efforts.

Particular attention is focused on the work of the Census Bureau in gathering disability-related demographic data. The need for recognition of the difficulties involved and the importance of involvement of people with disabilities in the formulation and field testing of proposed questions are noted.

Recommendations are offered for a thorough review of a variety of data collection efforts in light of current needs, informational resources and research capabilities. In particular, the need for updated cost-benefit methodologies is stressed, including methodologies that track the indirect, cross-programmatic and long-term impacts of various measures and decisions.

Chapter Two addresses civil rights. Civil rights differs from almost every other subject area, because the enforcement choices we make and the results achieved cannot be evaluated in the same ways as decisions in other policy areas. Determinations can be made of the per settlement costs of enforcement efforts, of case-processing backlogs and timeframes, and of other important indicators. But determinations of what allocation of resources is best between civil rights enforcement and other methods, or within civil rights between enforcement and technical assistance, these are far more complex and involve questions that cannot be answered with statistics or numbers.

As any discussion of civil rights and disability must, the chapter begins with a review of developments in the Americans with Disabilities Act (ADA) during 2005. On this historic 15th anniversary of its enactment, the chapter addresses issues surrounding the assessment of current ADA enforcement strategies, including the role and efficacy of technical assistance, mediation and other key components of the government's approach.

Not strictly related to the ADA but reflective of its spirit, NCD participated in the convening of a major civil rights forum during 2005. As important as the specific issues and recommendations coming out of the forum is the diversity and the broadening of input that this forum represented.

In light of the profound emotions and agonizing debate that surrounding the Teri Schiavo case, the chapter also deals with the issue of assisted suicide. In light of the Schiavo case, NCD reissued its paper on that subject, with a revised introduction raising additional concerns and marshalling new evidence in favor of the Council's opposition to assisted suicide.

Another area that could conceivably fall within the jurisdiction of the ADA, but that has not yet been viewed in that light, is genetic discrimination. Reiterating its support for pending legislation to outlaw genetic discrimination in employment, insurance or other settings, the report notes new concerns that can be foreseen if such legislation is not passed. With the rapid progress of work on sequencing the human genome, the time is close at hand when almost everyone can be found to have some genetic characteristic that has a statistical linkage to some illness or undesirable propensity.

The chapter then discusses developments in voting rights under the Help America Vote Act (HAVA), again noting the inevitable interplay between technological developments and law.

Lastly, on the 25th anniversary of the major federal governing statute, the chapter considers the civil rights of institutionalized persons. The very nature of institutionalization has changed in the intervening years, and this presents major issues for reauthorization of the act. On this important anniversary, NCD's report on this subject, and on the vulnerable and isolated population it affects, is reviewed.

Chapter Three concerns education. Second perhaps only to health, education is the area of public policy undergoing the greatest transformation today as we strive for more effective methods of preparing our population to meet the demands of the 21st century global economy, and as we strive to develop adequate methods for assuring accountability in educational performance and results.

Reflecting the continuing importance of the Supreme Court in clarifying the law and framing the terms of debate, the chapter begins with a discussion of the Court's Schaffer decision. This case clarified that in disputes between parents and schools over students' individualized education plans (IEP's) in special education, the burden of proof rests with the party objecting to the decision, which in most cases will be the parents. The case represents one dimension of the ongoing effort to allocate responsibility and control between families and schools.

Even as the courts were resolving one issue, the regulatory process to implement the IDEA Amendments of 2004 was underway. Accordingly, the second section of the education chapter reviews the current status of four key issues that the new law and its implementing regulations do or will need to address. These issues are: the problem of minority overrepresentation among special education students; the prospects for full-funding (meaning ultimately up to 40%) of special education costs by the federal government; the extent to which the law does or can assure private school accessibility, especially when federal funds are involved; and issues raised in the law's application of disciplinary principles to potentially complex emotional or behavioral problems. In regard to each of these, NCD recognizes the delicate balances that must be struck between powerful but occasional conflicting goals, and with this in mind seeks to offer prudent recommendations, based on the best available experience and data, to assist the Education Department and the states in their implementation and elaboration of the law.

As important as the Individuals with Disabilities Education Act (IDEA) may be, it does not exist in isolation from broader educational practices and policies. For this reason, the chapter then proceeds to a discussion of the several critical areas in which IDEA and the nation's No Child Left Behind Act (NCLB) intersect, overlap, and potentially conflict. Issues considered in this context are: the application of assessment requirements to students with disabilities; the role and utilization of standardized tests and test scores in the education and evaluation of students with disabilities; and the issues surrounding high school graduation rates for students with disabilities. In regard to each of these, NCD notes the extent to which attention must be directed to differences in the way these issues affect the educational outcomes of individuals with disabilities and of schools and school districts. Tensions between standardization and fairness, as mediated by the need for reasonable accommodations and by the assessments being made of

schools themselves, form the basis for this analysis and for the substantial recommendations made for reconciling these complex concerns in pragmatic, consistent and principled ways.

Finally in connection with the interplay between IDEA and NCLB, two statutes which need to be meshed and made to work smoothly together, issues relating to the allocation of costs between the two programs are analyzed. NCD knows from experience that only by addressing these issues forthrightly in the implementation of these still new laws can unnecessary controversy, waste and delay be avoided.

Chapter Four turns attention to health care. Perhaps no area of life nor topic covered in this report touches more directly on every other topic than does health. From its connection to employment through the role of employers as major providers of health insurance coverage in this country, to its confusion with disability in the minds of so many, to its increasingly profound economic impact throughout our society, health and more particularly health insurance and health services play an increasing role in a broadening range of contexts and decisions.

Our nation is currently engaged in the process of rethinking many of our traditional assumptions regarding the nature and delivery of health care. Put globally, we are engaged in the process of trying to figure out how innovation can be encouraged and access be broadened and made more equitable, while at the same time maintaining control on upwardly spiraling costs. Under no circumstances can this be easy, but when it comes to applying these principles and goals in the lives of people with disabilities a number of additional complexities, some reasonably well-known, others not, are introduced.

The purpose of this chapter is to clearly identify some of the unique ways in which our questions and their answers have affect Americans with disabilities, and to offer recommendations concerning how the available data suggests these questions can best be answered.

In light of the tremendous emphasis placed on evidence-based medicine today, data on the availability of health care and the outcomes of various modalities and interventions is more vitally important than ever. In this light, the chapter opens with a discussion of statutorily-mandated health data collection efforts that have thus far failed to include people with disabilities

among the subpopulations studied and compared. Significant differences exist in the access of people with disabilities to health care. These disparities arise partly from economic and insurance considerations, but also from the inaccessibility of some medical facilities and procedures. Outcomes are likely to differ, and are in need of being measured, as a result.

One of the most important sources of health coverage for many low-income Americans with disabilities is the Medicaid program. This program, because of its rapidly escalating costs, has been the subject of intense scrutiny, particularly with a view to limit the financial burdens it poses. Accordingly, the second section of the chapter reviews the key issues, proposal and activities surrounding Medicaid reform, with a view to assessing their impact on recipients with disabilities and identifying measures that could be taken, consistent with the cost-cutting, fairness and state-flexibility goals of the reform effort, to ensure that the health of Americans with disabilities will not be adversely effected by the changes.

One equity issue that has proved particularly troublesome and that results in different treatment for people with different disabilities is that of mental health parity. NCD has long and fervently advocated for changes to our health care system, experimental and voluntary at first so as to alleviate sincere but misguided cost or other fears, that would demonstrate the viability and lead to the implementation of policies and rules assuring equal access to treatment and benefits for those with mental or emotional as for physical conditions.

The third section of this chapter deals with mental health parity, noting urgent developments during 2005 that make progress toward its achievement all the more imperative. These new imperatives arise largely from our painful experience with and our hard-won new knowledge about trauma. We cannot hope to requite one dimension without paying equal heed to all dimensions of the effects of trauma on individuals.

Of all the new challenges facing the health care system, none has emerged with greater urgency than that of providing adequate care and support to our wounded veterans. Not only the numbers of these courageous citizens but also the nature of their injuries, the extent of the disabilities and the definition of the needs require new structures and new thinking. From better methods to ensure the timely sharing of relevant information among involved federal agencies, to new

definitions of disability that recognize the variable and episodic nature of trauma-related conditions and consequences, NCD seeks to draw attention to the issues and needs that must be addressed if we are to honor our commitment to those who have given so much.

Chapter Five of the report focuses on long-term services and supports. Long-term services and supports is one of the least well-defined but yet one of the most important policy areas considered by the report. As our population ages, questions relating to how it is defined, how it is provided and to whom will steadily grow in importance.

In view of our nation's need to systematically address the issues of income maintenance, community-based services and related matters encompassed in long-term services, NCD produced a major report on this subject in 2004. With that report as background, and with the conceptual framework deriving from the ADA and from the movement in favor of home- and community-based services instead of institutional services and care, the chapter addresses many of the issues that must be confronted, as they relate to individuals with disabilities. The first of these is to recognize their presence among the population in need of long-term services and supports. Although this population is commonly thought of as an aging one, that aging cohort includes many people with disabilities. The population at issue in connection with these services also includes younger persons under the age of 65, almost all of whom are people with disabilities. At the same time, the financial resources of people with disabilities in the LTSS system are likely to be less than those of other persons, both because their earnings may have been curtailed during the working years and because of savings and resource limitations in the income-maintenance and other service programs designed to help take up that slack.

NCD believes that insurance must represent the central component of a national strategy for defining the continuum of LTSS needs and for funding those costs. But the issues confronting the creation of effective and comprehensive LTSS insurance, insurance that goes beyond paying for institutional care, requires attention to the specific needs of people with disabilities, to the lack of any inherent connection between people's incomes and their services needs, and the implications for public expenditure of emphasizing home- and community-based settings.

As the section goes on to make clear, LTSS insurance must also address other emerging needs and respond to key themes. It must accommodate the need for a high degree of consumer-control, and it must allow for and encourage asset development and accumulation among those who would be eager to take fuller responsibility for their lives if given access to financial or other tangible assets.

Chapter Six turns our attention specifically to children and youth. The chapter begins with renewal of concerns and recommendations that NCD has made before regarding the urgent need of ending the practice of using criminal or quasi-criminal juvenile detention facilities as a custodial strategy for children in need of other sorts of services or care.

The next section of the chapter addresses the intricate web of requirements, state- and private-assistance and incentive programs and tax provisions comprising the nation's foster care and adoption systems. Serious gaps in the collection of required data are themselves worrisome and make evaluation of the system difficult. But these gaps, together with data that do exist, lead to concerns regarding the ability of the current systems to fully meet the needs of many children, including hard-to-place children with disabilities. A number of specific areas of concern are identified and recommendations are made for measures to determine the effectiveness of current measures and to take further remedial action if required.

The final section of the chapter deals with health care, as this subject uniquely relates to children and youth. Whatever may be one's view regarding the solutions to the nation's overall health care problems, NCD believes that comprehensive health care for children is critical to our future, from both an economic and a moral point of view. The issue is discussed in that light.

Chapter Seven is directed to the question of employment. Perhaps no issue has received more attention among people with disabilities, policymakers and scholars than those surrounding the attempt to determine the comparative labor market and employment status of people with disabilities, the effort to decide what works, and the attempt to design new strategies that will yield improved results and that will prove responsive to the demands of a rapidly and dramatically changing labor market. Few can doubt that if the employment rates and career

patterns for persons with disabilities could be made more comparable to those of other workers, many of the problems facing this sector of our population could be greatly reduced.

Because of the centrality of statistics to any discussion of employment, the chapter begins with a review of the frustrating statistical vagaries that continue to bedevil formulation and evaluation of employment policy. Three continuing problems continue to impede the collection of satisfactory data. While efforts to fill the gaps continue, it is unlikely that we will have clear answers to many key questions in the near future. Nevertheless, available data do point to the feasibility and desirability of certain measures.

One of the unique features of federal employment policy for people with disabilities is the way services are organized. Two parallel systems exist, a specialized state-federal vocational rehabilitation system (VR) designed to serve the needs of job-seekers with disabilities, and the one-stop employment development system designed to provide integrated and comprehensive services to all job-seekers including persons with disabilities. For the system to work, each of these must function effectively and they must operate cohesively together.

In this light, the chapter proceeds to a discussion of recent findings regarding the need for upgrading of performance monitoring in the VR system. Of additional concern to NCD is the related problem of waiting lists and potentially lengthy delays in service to eligible persons arising from possible short-falls in funding for the VR system. Concern is warranted whether such delays may make the difference between people obtaining and not obtaining employment, and whether they may significantly limit the ability of the VR system to act as a partner to the one-stop system in the manner contemplated by the law. As in past reports, inquiry into these questions is recommended as a means of finding out and in order to remedy the situation if these fears are confirmed.

The third section of the chapter concerns itself with the one-stop centers, in terms of their ability to serve job seekers with disabilities. As outlined by NCD, this ability can be measured in terms of three factors: the accessibility to people with disabilities of one-stop facilities and programs; the capacity of the one-stop centers to assist their community partners in offering comparable levels of accessibility to persons with disabilities referred to them by the centers; and the ability

of the one-stops, working through the experimental disability navigator program, to achieve the requisite degree of service and resource sharing and coordination with the VR system, the Ticket to Work program and other disability-specific labor market resources.

The chapter's fourth section brings the role of the Social Security Administration (SSA) into play. Through its role in administering the SSI and SSDI programs, with their complex economic and medical eligibility rules, and through the linkage of these programs to health insurance coverage under the Medicare or Medicaid programs, SSA has been central to reducing the work-disincentives inherent in the benefits system.

SSA has engaged in a number of experimental and demonstration initiatives designed to minimize the work disincentives and simplify the use of the anti-disincentive provisions in the law. While generalizations are not yet warranted concerning what if anything works to penetrate the existing regulatory morass, NCD remains concerned that the anti-disincentives are so complex as to be unavailable as a practical matter to many people with disabilities who would utilize them if they could be confident that the risks are not too great. NCD is concerned that SSA's current efforts, while well-intentioned and desirable, may in the end serve only to further complicate the regulatory framework within which individuals, benefits counselors and others must make decisions which, if wrong, are perceived as all too easily resulting in the loss of cash benefits and health insurance without acquisition of stable employment.

Taking a longer view, the next section of the chapter reviews the ways we have tried to strike a balance between employer education and traditional enforcement of the implementation of employment rights laws. NCD believes that a two-pronged commitment designed to maximize the potential of both strategies is necessary for either to be effective.

The final section of the chapter is concerned with innovation in the provision of government services. Specifically, NCD recommends enactment of legislation to protect the jobs of federal employees with disabilities when their positions are privatized. NCD also recommends legislation to enhance the leverage value of federal contracting in bringing about private sector employment of qualified workers with disabilities.

Chapter Eight of this report follows the progress of welfare reform. NCD applauds the steep declines in welfare rolls since passage of the 1996 reform legislation, but the Council is concerned that too narrow or formulaic an understanding of the reasons why some people remain in need of welfare benefits may hinder efforts to lower caseloads even further.

After reviewing the background of congressional efforts to reauthorize the 1996 law, NCD discusses the definitions of work and the requirements for work activity likely to be incorporated into the continuation statute. By adopting a sanctions-based approach to forcing people back to work, and to penalizing states for failure to enforce work requirements rigidly enough, Congress risks overlooking or even exacerbating the real causes of subsisting dependence.

NCD recommends that the law be revised in a way that, while maintaining the central and unswerving commitment to work, more fully recognizes that remaining welfare recipients, many shown by recent studies to be people with disabilities, need a variety of training resources and supportive services, ranging from assistive technology to accessible transportation, if they too are to be enabled to join and remain in the workforce.

Among other things, NCD recommends that the statutory definition of work, and the work requirements that will meet the federal requirements, reflect that intensive participation in necessary specialized training needs to be viewed as an acceptable work activity, at least for a period of time, if employment is to be achieved. NCD notes that the hard-core temporary assistance to needy families (TANF) recipients may well be composed of a high proportion of people with disabilities, hidden or evident, or of people with primary caregiver responsibilities for family members with disabilities. Until the unique needs of this population are addressed, utilizing a variety of existing resources and services in a coordinated fashion, it is not likely that the goal of productive work will be achieved, even if they are dropped from the welfare rolls.

Chapter Nine is housing. Safe and affordable housing, reasonably convenient from one's place of work, is becoming an issue for more Americans, even as home ownership rates approach record high levels. For people with disabilities, housing presents issues of affordability, accessibility, discrimination and location that make it even more of a problem. Moreover, the interactions between housing, transportation, employment and community participation have become

increasingly evident to advocates and policymakers in recent years. NCD has explored these interconnections in its previous reports.

This year's status report begins its review of developments in housing with a discussion of major fair housing civil rights settlements during the year. Noting that almost all major enforcement occurred through settlements and that all major settlements arose from citizen complaints, NCD expresses concerns arising out of these circumstances. Principally, these concerns relate to the need for government to be more proactive, both in the identification of housing discrimination and in the monitoring of settlements to ensure compliance. Although complainants must be the primary monitors of compliance with the terms of settlements, responsibility for vindicating the public interest in such compliance should not rest on private parties alone. NCD finds that the Department of Justice and the Department of Housing and Urban Development need to do more to make sure that the terms of consent decrees and other settlements are carried out and sustained.

Based on several reports, NCD also expresses concerns over fair housing complaint intake and processing. Owing to a number of factors, grounds exist for concern that the case-handling process may not be able to maintain the full trust and confidence of the citizenry on whom the government is principally relying for information and for follow-up.

The next section of the chapter concerns itself with homelessness. Natural disaster has brought us both a new awareness of the ways homelessness can occur, and new opportunities for building accessible housing stocks and livable communities. In that light, NCD urges Congress and the administration to take a variety of measures aimed at ensuring first that temporary or emergency housing, such as trailers, provided to storm survivors will be accessible wherever possible. Beyond that, measures are urged to ensure that accessibility is a required and fundamental feature of new construction and community renewal in the hurricane-devastated areas, and in any other areas that may in the future fall victim to natural disasters.

The chapter also addresses problems of chronic homelessness, problems of a more familiar but perhaps also of a more intractable nature. In reviewing the variety of statistical data sources required to be collected on the subject, NCD is particularly concerned that existing data-

gathering instruments and reporting requirements may be inadequate to give an early warning of any rise in the number of homeless veterans, particularly homeless veterans with disabilities, among the homeless population. If the country is to avoid repeating its failure to adequately meet the needs of injured and traumatized veterans of the Vietnam era, it is important that sentinel data of the kind that veterans' homelessness would yield be quickly and accurately collected.

The next major issue addressed by the chapter relates to the rental assistance programs currently operated through HUD. In previous reports NCD has discussed the budgetary issues of these programs and other issues in their design and operation which bear upon their effectiveness for and their relevance to person with disabilities.

In this year's report, in light of a commendable campaign to wipe out fraud and abuse in the rental programs, NCD raises additional issues. NCD is concerned that though not intended to do so, innocent rental-assistance recipients with disabilities may fall under suspicion. This is because of the complexity surrounding the calculation of "adjusted income." Housing subsidies in these programs are generally calculated based on a percentage of adjusted income, but how income is to be adjusted (and how serious unintended consequences can be avoided in the interaction of complex housing program rules with equally complex but rarely cross-referenced medical-assistance, income-support, food-assistance and other program rules) remains far from certain. Accordingly, NCD urges interagency efforts aimed at identifying and clarifying all points of possible overlap or contradiction between and among the rules governing all these programs, as they operate in the lives of individual recipients.

Lastly the chapter deals with home ownership. Recognizing the universality and the symbolic power of home ownership in the fulfillment of the American dream, NCD praises the administration for its role in bringing about historic increases in the national home ownership rate. At the same time, the New Freedom initiative has yet to document comparable increases in levels of home ownership among Americans with disabilities. NCD therefore calls for measures aimed at understanding what the barriers are and at finding means for their eradication.

Chapter Ten deals with transportation. In June 2005 NCD issued a major report on the state of transportation for persons with disabilities in this country.

Transportation is unique among the topics covered in this report in that it is both a means and an end. We seek to have effective and accessible transportation options and resources for communities, because transportation is the primary means by which we avail ourselves of education, employment opportunities, health care, even housing. Without transportation, none of these other goals and services can be achieved for the great majority of people, disabled and nondisabled alike.

For persons with disabilities, transportation presents a number of issues not encountered by other citizens. From the need for accessible vehicles and nondiscriminatory services, to the role of paratransit, to the importance of adequate transportation in maintaining community living and avoiding unnecessary institutionalization, these complexities must inform discussion of all transportation-related policy issues.

The chapter begins with a discussion of ADA and related civil rights and access issues in surface transportation. In particular, NCD commends the Department of Transportation (DOT) for going beyond vehicle and station-design compliance issues and beginning to consider to carry out assessments of public transit services under the ADA. For example, it is not enough for vehicles or stations to be accessible if timetables and route information are not.

Nonetheless, NCD continues to commend the DOT for promulgation of new guidelines clarifying and updating accessibility requirements for physical design. However, promulgation this year of guidelines for new station platform design leads NCD to wonder how the pace of retrofitting existing stations for accessibility can be speeded up. Recognizing that public funds are not available to expedite this process to a pace that many advocates, and probably most transit agencies, would consider acceptable, NCD urges the Department of Transportation to convene experts and advocates to identify possible strategies involving private sector partners, the tax system and other resources for use in accelerating the accessibility of the existing facilities of public and private transit operators.

The chapter next turns to recreational sea travel, commending the Supreme Court for its Spector decision holding that the ADA covers cruise ships doing business in U.S. ports. Based on the legal clarity provided by Spector, NCD urges the DOT to take measures to ensure both the

broadest possible accessibility of recreational shipping to persons with disabilities and the competitive equality of American carriers with foreign carriers who may operate under weaker or no accessibility requirements in their countries of registration.

Among specialized transportation services designed for people with disabilities and others prevented by age from using fixed-route public transit or from driving, paratransit is the largest and most well-known. NCD commends the DOT for issuance of guidelines clarifying the responsibility of paratransit to provide door-to-door service where required, not merely curb-to-curb as some have believed. But as important as these clarifications are, NCD also expresses concern that they may inadvertently worsen another underlying problem and put more stress on an already hard-pressed system.

At issue here is the fact that eligibility for paratransit services cannot be predicated on financial considerations. This means that financially strapped transit agencies may attempt to use other permissible eligibility criteria to cloak decisions that are being made simply on the basis of scarcity of resources to meet growing demand. Paratransit agencies are vested with sufficient discretion under criteria for trip-by-trip or overall eligibility decisions as to make such confusion readily possible and all too understandable. Out of this concern, NCD urges measures to determine the extent of such practices and to address them if they are found to be widespread.

A number of other innovative transportation projects, including programs aimed at enhancing the availability of transportation needed by people to get to and from jobs, and including programs operated under the auspices of the NFI, are identified and commended. A number of these are recommended for permanent inclusion in federal authorizing legislation and budgetary appropriations.

The final major section of the chapter deals with air travel. Although supportive of DOT initiatives such as the inclusion of disability-related concerns in customer-service performance reviews of commercial airlines, and although also supportive of the Department's efforts, begun in a late 2004 NPRM, to overhaul and update its regulations implementing the Air Carrier Access Act (ACAA), NCD has grown concerned with the pace and scope of this overhaul.

A major problem identified by NCD in past reports is the accessibility of e-ticket machines, luggage-inspection and other automated, self-service equipment being increasingly deployed at airports. Many of these devices pose transportation barriers to people with one or another disability, and few if any of them appear to be field tested under real-time conditions by passengers with disabilities.

NCD had believed that the NPRM would provide an appropriate basis for developing procedures for testing and rules for defining and assuring the accessibility of such equipment. But no indication of DOT follow-through in this area has been discovered. Accordingly, NCD reiterates its recommendation with renewed urgency, for once such equipment is deployed, the opportunities for its retrofitting will, as a practical matter, be small.

In a similar vein, DOT has yet to take action to apply the ACAA to the range of web sites which increasingly represent the means for buying tickets, requesting seating assignments and services, or otherwise obtaining the opportunities and benefits of air travel. While web sites are constantly being revised and updated, making the introduction of accessibility less problematic than with the case of hardware devices, real people are experiencing exclusion and restricted opportunity with each that inaccessibility is allowed to continue. Therefore, NCD has again urged DOT to adopt the necessary regulations as part of its ACAA update process.

Chapter Eleven is assistive technology and telecommunications. It should come as no surprise that developments in technology and communications now play an increasingly important role in the lives of people with disabilities, defining options and mediating opportunities, just as they do for other Americans in this information age.

The chapter begins with a section on assistive technology (AT) research. Publication in 2005 of an AT compendium is discussed, and the uses of this documents, including its role as a basis for further key research, is discussed.

In reviewing a 21st century AT research agenda, NCD notes the importance of going beyond engineering and technological research itself in favor of a broader research agenda designed to maximize our understanding of the social and economic impact of AT. Without such data and

without attention to the distribution system, technological advances will take far longer to be transmitted to the public and key cost benefit and resource allocation decisions cannot be made with accuracy or confidence. NCD recommends means for beginning to define and gather the necessary data.

The next section of this chapter deals with federal procurement. Section 508 of the Federal Rehabilitation Act provides for the purchase of accessible electronic and information technology E&IT by the Federal government in its purchase of such technology for its own use. As such, powerful positive leverage is brought to bear on behalf of encouraging design advances by private sector competitors for these contracts.

NCD has grown increasingly concerned because of the failure of the Department of Justice to issue periodic monitoring reports on implementation of section 508, as specified in the law. In light of recent research indicating possible deterioration in the accessibility of public-sector web sites, NCD regards resumption of regular monitoring reports as especially critical. NCD also believes that, consistent with the full scope of the law which covers web sites, hardware and software, subsequent monitoring reports should not be limited to the evaluation of Federal web sites, as was the almost exclusive focus of DOJ's earlier reports.

The chapter next turns to a number of telecommunications issues falling under the jurisdiction of the Federal Communications Commission (FCC). The first and most broadly encompassing of these is broadband. Access to broadband is becoming increasingly basic to all web-based activities of commerce, employment, and social life.

Prior to getting to the specific legal and regulatory contexts in which pro-accessibility development of broadband can be encouraged, NCD has felt it necessary to put to rest a common myth. Although economic and geographical factors often determine the availability and cost of broadband service, these variables have nothing to do with the access issues confronting people with disabilities. This is easily seen in the fact that people with sufficient means living in fully "wired" communities are nevertheless unable to access broadband if it is not designed and delivered with accessibility in mind. Thus they are placed in the same position as people living in underserved areas.

Among the specific issues arising in any consideration of broadband, perhaps the most well-known relates to Section 255 of the Telecommunications Act. This provision requires that telecommunications equipment and services be accessible, where readily achievable. Despite this relative non-demanding standard, NCD has frequently expressed its disappointment over the failure of the FCC to make any serious effort to monitor compliance with the law or to achieve its enforcement. A 2005 Supreme Court decision vesting increased discretion in the FCC over the definition of “information services” leads to the conclusion that no remedy currently exists in law to compel the FCC to apply Section 255 more vigorously. With this reality in mind, NCD has called upon the FCC to make clear its views regarding where Section 255 fits on the spectrum of “telecommunications services” (which are covered by Section 255) versus “information services” (which are not). NCD has called upon the commission to indicate how it intends to secure the access rights of people with disabilities to new telecommunications technology, if the commission believes that such technology is not covered by Section 255.

Closed-captioning is an area of FCC responsibility perhaps as well-known as any other that affects people with disabilities. While commending the commission for its vigor in articulating and enforcing content requirements for captioning of TV programs, NCD is concerned about a number of potential threats to captioning. In addition to technical threats associated with reallocation of the spectrum and use of digital communications, NCD has expressed concerns, based on complaints filed by consumers and upon additional anecdotal reports, that the quality of captioning may be in danger of eroding. For this reason the Council supports legislation to train qualified captioners to meet growing real-time demand.

A final area of concern is the e-rate program under which funds are channeled to schools and libraries for the purchase of telecommunications technology and access. A GAO report presented in 2005 highlighted failures in the FCC’s governance of the e-rate program, including a failure ever to specify exactly which federal regulations or policies apply to the use of e-rate funds. If, as NCD believes warranted, FCC reaction includes formulation of clearer policies on the obligations of subsidy-recipients, NCD hopes that the FCC will include accessibility, as required by a number of laws, among the values that the e-rate program is intended to support.

Chapter Twelve brings us into the arena of international affairs. It begins with a discussion of America's unique world leadership position in the area of opportunities and rights for, and inclusion of, its citizens with disabilities. This uniqueness consists in two things. First, it is a function of the vast experience America has amassed, and the constructive attention it has long paid, to these issues. But second, and in this day and age perhaps as important, America's unique leadership role derives from its being a case of leadership by example. There is little economic or other power we can bring to bear on behalf of access and equality in this area, yet our leadership in these realms is widely accepted and respected, even by many who might challenge us on other grounds. Accordingly, the report begins with a discussion of the origins and implications of this remarkable status and role.

The next section of the chapter deals particularly with the nation's foreign aid and international development work in health promotion. While praising the humane and far-sighted recognition of the importance of health promotion, NCD is also concerned to ensure that key distinctions between illness and disability not be overlooked in the conduct of this important work. NCD recommends that persons leading lives with chronic medical conditions or disabilities, especially persons saved from death by medical advances or treatments supported with U.S. funds, be recognized in terms of their need for rehabilitation and access. As part of the health promotion programs, the functional status and the opportunities of people with disabilities must be addressed in an integrated and coordinated fashion.

The third area addressed in this chapter is the UN Convention on the rights of people with disabilities. NCD has provided numerous and in-depth technical assistance papers and consultations, designed to assist the delegates to the AD Hoc Committee drafting the convention for submission to UN member nations. In part through this assistance, NCD believes that a treaty of high quality and enduring value, enshrining American values and validating much of our experience, will emerge.

Mindful of understandable hesitancy about the convention, NCD urges the administration and Congress to sign and ratify the treaty, confident that if signed and submitted to the Senate, any serious defects that might exist would be quickly identified and disclosed.

The fourth and final section of the chapter deals with the role of accessibility and of the rights of people with disabilities in international commerce and travel. The section addresses a number of issues in the context of ensuring that America's leadership in access and opportunity will be a benefit, not only to the citizens it serves, but to the businesses and other institutions that have made the effort to make their goods and services more inclusive. A variety of means are suggested for ensuring that inadvertent competitive disadvantage is avoided, and for strengthening requirements for a level playing field that will increase the likelihood that competitors from other nations will be held to the same high standards as American entities are committed.

Chapter Thirteen is homeland security. The past year has witnessed a profound change in our understanding of the homeland security challenges our nation faces, elevating natural disaster alongside human-made tragedies as a cause of possible devastation.

Amidst the key questions posed by NCD is that of whether people with disabilities suffered disproportionately to their fellow citizens, and if so why, and what can be done to prevent such disparities, as we strive to prevent and minimize all suffering, in our planning for future eventualities. Based in part on its eerily prophetic report *Saving Lives: Including People with Disabilities in Emergency Planning* [1] that preceded the disaster, and on data emerging in the storms' aftermath, NCD believes there is ample basis for believing that suffering was proportionally greater for people with disabilities than it need have been.

Issues of infrastructure played a large role. To the extent that emergency communications, transportation, evacuation facilities and other resources are not accessible, it becomes progressively more difficult for people with disabilities to utilize or benefit from them.

As painful are the lessons of our preparations for and responses to the hurricanes, the real question must relate to how and what we do to prevent similar disasters and loss in the future. With this goal in mind, the chapter proceeds to a discussion of how people with disabilities and issues of concern to them can and must be incorporated in our broader disaster relief and planning efforts. NCD places great emphasis on the planning process itself, recognizing that, as with all groups who have specific concerns or face unique barriers, participation in the planning process represents the best means for ensuring that their concerns will be heard and taken into account.

MAJOR TRENDS

An addition to this annual status report over the past two years has been the inclusion of a major trends section. This section is designed to identify key themes in disability policy and to relate the year's major disability issues to broad themes in public policy and program administration. In each of these previous sections, NCD has sought to emphasize the key choices and decisions that our nation faces with and for its citizens with disabilities, as these decisions relate to ways we are defining or going about solving other problems. But rarely in modern history have we stood at more important or fateful crossroads than we do today.

(a) Applying the ADA to the 21st Century

Presentation of this report on the 16th anniversary of the signing of the ADA offers an occasion for analyzing the role of this historic civil rights law in contemporary policy discussions. As reflected in almost every chapter of this report, there are two ADA's: the ADA as a law to be enforced, and the ADA as a source of technical assistance and guidance. As such, the complexity and scope of this law give ample scope for it to be seen as a tool for requiring appropriate behavior and as a platform for fostering broad awareness and change.

But for the law to be effective in either of these contexts, key issues of its application to the modern world need to be addressed. As commerce shifts more and more from a location- to an internet-based format; as contractual, temporary and multi-career employment patterns replace traditional career paths; as the interagency dimensions of most problems become clear; and as private sector partners are given broader discretion to experiment and innovate in the implementation of traditional public programs, questions about how, whether and by whom the ADA should be applied become both more vexing and more critical.

Because many people still fear or misunderstand the law, or resent its perceived potential for government intrusion, supporters of the law have been understandably reluctant to risk its narrowing by opening it to major updating. A stalemate appears to exist in which supporters and opponents alike agree to leave the status quo alone. Meanwhile, technical updates, including

most notably the recent revision of the ADA Standards (the ADAAG) [2] point the way to the kinds of consensus building efforts that are necessary to keep the law relevant and vital.

Based on NCD's recommendations as embodied in the ADA Restoration Act, [3] the Council believes that effective policymaking can accommodate a broad range of concerns and interests. As such, NCD believes that modernizing the ADA may well represent a case study for broader efforts that are clearly needed in other areas if governmental expenditure and efforts are to be rationalized, coordinated, evaluated and made fully cost effective.

(b) A Time of Scarcity

In the area of domestic programs, austerity will increasingly be the watchword for the foreseeable future. Resources for new initiatives, even resources for maintenance of current efforts, may be difficult to command. People with disabilities understand and fully accept, as all citizens do, this unpleasant fact. But rather than seeing it solely as a cause for disappointment and sadness, NCD believes that budgetary constraint can provide the impetus, all too sadly lacking in the past, for bringing coherence and coordination to the mass of often conflicting, over 200 disability-oriented programs spread over approximately two dozen federal agencies, and involving the expenditure of several hundred billion dollars per year.

As reflected throughout this report, expenditure control coupled with heightened attention to accountability has become central features of government policy. These twin priorities have already affected a number of disability-related programs, as well as the role of mainstream programs in the lives of people with disabilities. But application of these new imperatives is not simple or straightforward.

Until program stakeholders and program operators can achieve clarity in defining the goals of each program and as to the proper criteria for evaluating programs, the results are likely to be haphazard and in the end likely only to add to disruption and uncertainty.

(c) Accountability in Disability Programs

Consistent with all other programs, those designed to specifically impact the lives of people with disabilities need to be rigorously and regularly evaluated. No waiver of accountability is possible or desirable. But this does not mean that mechanical tests such as number of people served per dollar spent can be applied reflexively. Nor does it follow that devising accountability standards to meet the program or situation at issue constitutes the introduction of undue subjectivity or inconsistency into the process.

Based on its knowledge of many disability-related programs, NCD believes that the worthiness of their goals and the soundness of their methods will reward any evaluative scrutiny that is undertaken with knowledge of the issues and history involved. Many other program, even if well-run and effective in achieving the goals, no longer embody objectives that command a priority in the allocation of scarce public resources, and such programs will likewise be revealed through the application of well-designed evaluation procedures.

(d) Specific Evaluation Issues

Within the widespread discussion of what criteria should be used to evaluate domestic spending priorities, there is often a lack of recognition of some of the unique factors that underlie implementation of full and meaningful accountability in disability-oriented programs. One issue is the question of cost-benefit. For the achievement of any given benefit, whether it be education or employment, transportation or housing, the per capita costs of success or accessibility are likely to be somewhat larger in application to people with disabilities than other persons. Partly this is a simple matter of economy of scale. There are more people without disabilities in almost any comparative setting. Partly it is because of the need for accommodations (such as lift-equipped buses), specialized services (such as special education), or assistive technology (such as computer access software). But without some sound baseline for anticipating what the relative costs of such services and technology should be, how is the cost effectiveness of programs that provide them to be assessed? Moreover, how are longer-term or indirect savings to be measured and factored into the equation?

The accountability and cost-cutting effort, as it relates to all programs, has thus far developed along limited lines. Currently, costs are all too often assessed in a static framework or even a vacuum, meaning that appropriated funds are considered in a program by program way, with the result that no reliable methodology yet exists for measuring the long-term impact on other costs of proposed expenditures or expenditure cuts. Similarly, costs are reckoned from the standpoint of institutions and entities that have the means to identify and publicize their costs, but rarely if ever from the standpoint of unaffiliated individuals for whom aggregate costs or benefits might be quite considerable. This problem has been widely publicized in the area of environmental regulation over recent years, where efforts have been made to weigh the costs of proposed measures against the health savings or increased longevity that arguably would result from them. But in the area of disability policy, little progress toward developing credible methodologies has taken place.

Throughout this report examples are cited of attempts to balance the concerns of government and private entities for cost versus the potential economic or other benefits to people with disabilities or to the taxpayers of various measures or programs. But too often these balancing efforts remain speculative only, and they are resolved by power or by public attitudes rather than by data gathered in the service of clear criteria.

As resources become scarcer across the spectrum of domestic programs, we cannot rely on a conflict model for the resolution of the increasingly painful allocation decisions that lie before us. While the political process is designed to help resolve disputes over values and priorities, the issues before us can no longer be resolved by struggle and conflict. In a complex interdependent society there can be no absolute winners or absolute losers. The scientific knowledge and goodwill that we possess must be turned to the task of making the most intelligent and transparent decisions among the host of alternatives and difficult choices that confront us.

(e) Innovation

One of the chief themes in domestic programs today is that of experiment and innovation, involving new methods and new partnerships. In the area of disability this is powerfully illustrated by President Bush's New Freedom Initiative (NFI). In furtherance of deeply felt and

broadly shared goals for full participation and access to opportunity for Americans with disabilities, the NFI has encouraged innovation and experimentation in many areas, from self-directed services under Medicaid, to the United We Ride experiments in transportation, to the fostering of evidence-based practices in many areas.

Many of these initiatives have been implemented through discretionary funding initiatives, and the granting of waivers to facilitate flexibility in the rules ordinarily governing program operations or expenditures.

The accountability and outcome-measurement standards applied to these demonstration projects, experiments and initiatives are of great importance. So too is their transparency, and the dissemination of results. The administration, through a number of web portals, [4] has made tremendous progress in bringing information about a wide range of programs and services to the attention of people with disabilities, their families and other interested persons. But information about the ever-changing range of experiments, about the criteria used to create them, and about the standards used to evaluate them is yet to be fully developed.

With resources scarce, it is important that advocates and policymakers know what the Social Security Administration (SSA) believes to be the results and the cumulative lessons and findings of the various demonstrations it has conducted. The public and policymakers need to know when and how the Center for Medicare and Medicaid Services (CMS) will seek to institutionalize or standardize methods for increasing consumer control of Medicaid or other decision-making.

The value of innovation is potentially unlimited, but unless the nature of current or prospective experiments and demonstrations is widely discussed, and unless their results and implications are widely known, much of this potential may go unrealized and opportunity for smoothly incorporating findings into broader policy may be overlooked.

(f) Timing

One area where innovation remains urgently needed relates to the timeframes over which cost-benefit assessments and accountability determinations are made. As reflected in the 2005 interim report of the President's National Medicaid Commission, opportunities for cost and savings were

permissible for consideration only if they had been “scored” by the Congressional Budget Office (CBO). Scoring, whether by CBO or by the Office of Management and Budget (OMB) within the executive branch, is vital to the kind of integrity and transparency discussed above. But scoring is limited by factors going well beyond the accuracy or the relevance of the information.

Among other things, scoring is limited in how many years into the future projections can ordinarily be made, even when the projections are based on generally-accepted auditing principles.

For many disability programs, no less than for education and workforce development programs generally, the real benefits to society, in terms of heightened incomes, reduced dependency, lessened social problems, even improved health, are undisputed but are measurable only over the course of many years, even over the course of a lifetime. We know that high school graduates earn far more over the course of their working lives than those who drop out, and it is partly on that basis that we fund public education. We do not make each student prove their individual likelihood of repeating that pattern as an eligibility condition for access to education. Yet such exceptions to the technicalities of and to the limitations imposed by scoring are far less common in disability programs.

(g) Conflicting Trends

Two major trends thus find themselves in collision: the long-term trend of assuring the accessibility and availability of basic opportunities and resources for all people, versus the increasing need to target program resources to those who most need them. All too often, people with disabilities find themselves sandwiched between these powerful colliding imperatives.

This is perhaps best exemplified by the one-stop career centers discussed in Chapter Seven. One-stop centers are designed to serve all job seekers, but the costs of facility, communications and program accessibility, along with the lack of knowledge concerning the issues confronting many job-seekers with disabilities, have resulted in some short-fall in the ability of one-stops to be as inclusive as intended. Thus individuals with disabilities are in many cases remitted to specialized programs such as vocational rehabilitation (VR) in which they must meet various eligibility,

need, and potential-benefit requirements in order to receive services. Moreover, if the o-stops are evaluated based on the proportion of service-users who obtain employment or their per capita costs of service, economic and administrative disincentives to serving potentially harder-to-place individuals with disabilities may exist.

(h) Partnership and Collaboration

One thing is demonstrated by the attempt to create seamlessness among the several specialized employment systems for people with disabilities (including VR, Ticket to Work, Social Security waiver, supported employment and a few others) and the mainstream employment development system. It is a very difficult process.

One experimental strategy being tried is the Disability Program navigator, a liaison position created within one-stops to make certain that their staffs are best able to serve people with disabilities. Whether adding a new layer of personnel and a new set of functions will solve the problem remains to be determined. Likewise, whether the growing complexity of rules governing various programs can be made comprehensible or can be offset by our investments in advisory and technical assistance resources (such as the various protection and advocacy (P&A) programs remains to be determined.

The trend in question is to make laws and programs more complex but to invest correspondingly more effort and resources in informational resources designed to make the programs understandable and viable. But whether this strategy is working is itself a question worthy of fundamental evaluative research.

In the end, as we have seen in other areas of our national life, integrated planning and shared responsibility, between and among agencies and levels of government, represents the only way of assuring that programs will not work at cross-purposes or push people in conflicting directions.

Accountability remains largely a program by program affair, but few programs exist in isolation. Whether an employment program is successful may depend as much upon the transportation infrastructure or upon the proximity to workplaces of accessible housing as it does on the job

skills taught to the participants. Whether a health care intervention proves effective may and often does depend upon cultural, family and other variables bearing upon compliance or follow-up. Among few population groups is this more frustratingly evident than people with disabilities. Yet, sophisticated means for identifying the inter-program and inter-agency dimensions of current or proposed measures either do not exist or are not used.

No one should underestimate the enormous difficulty involved in developing and implementing integrated planning tools and sophisticated evaluation methodologies that take account of these realities. Yet once again, even we do not, only further arbitrariness and irrationality are likely to emerge.

OMB procedures designed to foster intergovernmental review [5] do not appear to have had much impact in resolving this problem. To use an example cited in Chapter Nine on housing, it is unlikely that current intergovernmental review processes would identify rules governing the award of housing subsidies that operate to offset savings opportunities conferred by the SSA under the SSI program.

It is likely that procedures aimed at increasing intergovernmental review and joint efforts between and among government agencies, through formal agreements or otherwise, will continue and expand. One way of giving more substance and weight to such reviews might be to require coordinate agencies not merely to give their approval or sign a memorandum of understanding (MOU) but to identify and comment upon all known points of probable interaction or impact between the program being reviewed and those that the reviewing agency operates.

In connection with private sector partners too, much can be done. The involvement of the banking and financial sectors with assistive technology loan funds, [6] of technology companies with accessibility research, and of many industries in a variety of matching funds efforts touching upon almost every policy area—all of these are examples of how a growing trend is being applied in areas of particular concern to people with disabilities.

Consumer financial education and financial literacy are key elements in any effort to empower individuals with disabilities. Involvement of such diverse partners as the Federal Deposit Insurance Corporation [7] to the Money Smart curriculum and the credit union movement [8] reflect extension of partnership concepts in ways that must continue to develop and expand. Accessibility of such information and of the places where it is provided, as well as customization of training materials to reflect the complexities associated with participation in needs-based programs are all necessary if these partnerships are to be effective in the disability community.

Similarly, the partnership with community and grass-roots organizations, through the Volunteer Income Tax Assistance (VITA) program, in bringing tax preparation assistance to people with disabilities is an important step in helping to bring more people with disabilities into the financial mainstream. As we continue to look for new partners and new partnerships to advance national goals, we must be alert to the nuances that will determine whether these efforts are as inclusive as we would wish them to be.

(i) Asset Development

Over the past decade, an increasing focus in attempts to break the cycle of poverty has involved the piloting of strategies for facilitating asset development among low-income Americans. With the emergence of the values of the ownership society, these efforts are likely to continue. But when it comes to the application of asset development strategies on behalf of low-income Americans with disabilities, a number of additional complexities are encountered which have yet to be systematically addressed.

Although precise statistical data are not available, there is likely to be a considerable overlap between low-income persons with disabilities who could benefit from asset development, on the one hand, and people who are currently or periodically receiving benefits under various cash and in-kind service programs, on the other. Central to the design of all these major benefit programs—from Medicaid to food stamps to SSI to Section 811 housing vouchers—is strict means-testing designed to ensure that only those most in need of the assistance and most closely fitting the profile of those intended to be served will in fact receive the aid. Thus far, efforts to reconcile these needs-based restrictions with asset-development goals appear to have proved

relatively ineffective. Accumulation limits generally bear no relationship to the sanctioned goals for which the individual development accounts (IDA's) or other matched fund accounts are authorized. It is in the huge gulf between what one is allowed to save toward purchase of a home and what home down payments actually cost, in the shadows between what one is able to earn without forfeiting Medicaid or Medicare and what one needs to earn before being able to afford private sector insurance, and in the contradictions between programs that encourage asset accumulation and programs that punish it, that the future of asset development for people with disabilities will be decided.

A classic example will show how widely-favored asset development strategies are unavailable to, and even dangerous for, many people with disabilities. The earned income tax credit (EITC) [9] is an important source of funds for low-income working families, primarily those with children. EIC refunds are excluded from consideration as income under SSI. This means that an SSI recipient who receives an EIC payment will not risk any loss of cash benefits or Medicaid health insurance coverage by reason of the income involved. But nine months after the refund is received, it is subject to consideration as resources, meaning that if it pushes the recipient over the limit for countable resources, typically \$2,000 for a single individual, it could result in benefit or coverage curtailment. Of course, there are ways, exceedingly complex for the most part, involving combining the EIC with an IDA or with a plan for achieving self-support (PASS) or with any of several other vehicles for sheltering savings, but anecdotal information reaching NCD suggest that few if any recipients are eager to risk the uncertainties and face the complexities of trying to combine so many laws and systems. For them, it may be far better to spend the money or to conceal it.

If self-sufficiency for people with disabilities is truly our goal, we must therefore implement current trends in two specific ways. First, consistent with our commitment to employment as a principal engine of economic growth and as the key pathway to self-sufficiency, we must ensure that the resources are in place that will maximize the ability and opportunity of people with disabilities to work. Second, as an adjunct to employment, and for those who cannot work, we must find ways to leverage public benefits, savings and other resources and potential asset sources in order to bring about the aggregation of meaningful assets over the course of time.

Given our commitment to these goals for the population at large, we can hardly expect less for citizens with disabilities and their families.

(j) Conclusion

The dramatic policy choices that our nation is now making are a source of great anxiety to many. Depending on what we do, they can be the occasion for widening of the gaps, economic and social, between people with disabilities and others. But grasped for the necessity they reflect and the opportunities they create, these decisions and the trends underlying and amplifying them can lead to bold and energetic measures that will reshape the way Americans with disabilities live in the most positive and inclusive ways. The choices are ours.

Chapter One—Statistics

Introduction

Statistics are more and more recognized as the foundations of policy. From evidence-based medicine (which seeks to subject treatments to a rigorous standard of proof), to the Office of Management and Budget's (OMB) Program Assessment and Rating Tool (PART) system for evaluating the effectiveness of federal programs, to the annual projections by the Social Security trustees as to the solvency of the trust fund, statistics are at the heart of what we do and statistics provide the framework for our debates and choices.

In few areas have statistics been more important or more elusive than that of disability. As demographic changes lead to a growing association of disability with advancing age, and as environmental catastrophes and armed conflict produce new people with disabilities, the importance and complexity of accurate data can only increase.

When it comes to disability statistics, great energy and attention have been lavished on the quality of data our government collects. Issues surrounding the quality of statistical and demographic data have been regularly addressed in NCD's prior reports. Issues relating to the accuracy of data on unemployment, data on health status and outcomes, data on educational participation and attainments, and data on the total incidents of disability are among the areas that have received the greatest attention and that have the greatest significance in the formulation of policy. Readers interested in further background on these issues are urged to review NCD's annual progress reports for the past three years. [10]

As NCD's analyses have made clear, much of the debate over data accuracy and completeness reflects conceptual and organizational problems in the formulation and utilization of the right questions.

The formulation of questions is critical for obvious reasons. One of these is that the questions we ask serve to indicate our notions of what is important.

The questions and answers through which statistics are created are implicated in every chapter that follows in this report. With that in mind, this chapter examines some basic statistics and some key issues relating to their collection, validation and use. The chapter begins by discussing disability statistics that are legally required to be collected. The chapter next considers recent developments with the Census. Following that it examines labor market data. Next, the chapter discusses the statistical dimensions of efforts to track quality of life indicators. Finally, the chapter considers issues inherent to all data collection as they relate specifically to people with disabilities, and recommends fundamental research designed to clarify and rationalize our current and future practices.

(a) Legally-Mandated Statistics

Chapter Four of this status report will address health disparities data that the law requires to be collected and presented to Congress on an annual basis. That chapter reports on the fact that the disability-related portion of this data has not yet been collected. Likewise, last year's report [11] discussed the failure to gather child-abuse data, as also required by law.

NCD is pleased to note significant progress during 2005 in the collection of the child-abuse state data. In connection with health disparities data meanwhile, a working group, spearheaded by the Agency for Healthcare Research and Quality (AHRQ) is also expected to make progress on resolving the health disparities data issue.

But as important as these successes are, they raise the question of what other statutorily-required and critically necessary data are going unreported. For the sake of gathering all key data and enforcing the law, and for the sake of identifying and removing data collection requirements that may be unwieldy, duplicative or irrelevant, NCD recommends that OMB undertake a comprehensive statutory review, aimed at identifying all disability-related data-collection requirements in current federal law, and followed-up with an assessment of the current status, usefulness and viability of each.

(b) The Census

As with other population and demographic data, one of the chief instruments for collecting information about who we are is the Census. The Census is best known through the major counting process that takes place each ten years, as specified by the Constitution. [12] But Census Bureau activities include a number of other ongoing surveys and other data collection efforts. These track population movement, shifts and other changes and patterns over time. They also provide a forum for asking new questions that have become important to us. Over the past twenty years, the role of the Census Bureau in tracking disability data, especially data bearing on employment, has been increasingly recognized. Efforts to improve the relevance and quality of that data, as discussed in NCD's prior reports, have been a focus of advocacy, experimentation and methodological discussion.

According to current plans, the nation's every-ten-year census will be changing dramatically in 2010. Among other changes, it is expected that the long-form census questionnaire, distributed in recent decennial census surveys to selected households, will be replaced by an ongoing inquiry, the American Community Survey (ACS). [13] The ACS is not new, but these plans reflect its expanded role and growing importance.

The ACS has contained and will continue to contain a disability question. [14] The significance of this question and the importance of making it meaningful and informative are heightened by the growing role played by the ACS as a whole.

NCD is pleased to have had the opportunity to participate in the effort to formulate the new ACS. It is currently being field tested. [15] NCD recommends that the results of this field testing be shared with the disability community, and that opportunity for input and further refinement based on the results of this field testing be made available.

One of the key issues in the development of the ACS is the extent to which it captures reliable employment data. Through use of various self-reported questions that ask respondents to say whether they experience disabling conditions that prevent them from working, the Census Bureau has collected data over the years which, though valuable, are regarded as too subjective

or uncertain to be useful in the formulation of public policy. The concerns about this data have been spelled out in earlier NCD reports. Suffice it to say, self-reported data of the kind the Decennial Census and the ACS have collected are questionable for three fundamental reasons. First, such data rely on the assumption that people will use the same standards in deciding whether they have a disability. Second, they assume some objective or predictable connection exists between people's assessment of their physical or mental conditions and their ability to work. And third, such data assume that people possess sufficient information to know the range of jobs available or the kinds of assistive technology or support services available to enable them to work.

But what may be even more important about these data is the light they shed on our deeply-held policy assumptions regarding the connection between disability and work. Questions focusing on assessments, subjective or otherwise, of the connection between impairment and work reflect this assumption. Would it not be just as reasonable to ask people with a self-reported physical or mental limitation whether they have encountered employer attitudes or practices that either enhance or interfere with their ability to work?

(c) Labor Market Data

Another important source of disability-related labor-market data is the Current Population Survey (CPS). In this connection, the Bureau of Labor Statistics (BLS) has an important role to play in developing disability-related questions. A new set of questions has been expected from the BLS. NCD continues to offer its assistance to the bureau in developing, field-testing and finalizing these questions. NCD recommends that the BLS meet with advocates and knowledgeable professionals in the area of disability statistics and labor market analysis to help finalize the development and validation of disability-related questions for the CPS.

(d) Quality of Life

Much of the attention to disability data has focused on the absolute number of people with disabilities in the country; the comparative employment, income, educational and health status of people with disabilities; the family composition, life expectancy, racial, ethnic and gender

distribution of people with disabilities; and related demographic matters. But other, often more subtle issues cry-out for qualitative and statistical analysis.

Among these, one of the most important is quality of life. The nature and proper measurement of quality of life indicators, ranging from subjective measures of well-being to indicators of community participation, have intrigued us for many years. Hardly can one pick up a popular magazine without reading some group's latest rankings of the ten best communities in which to live. The criteria used usually reflect upper-middleclass values, focusing on home prices, schools, recreation, transportation and health services. The criteria that people with disabilities would use are in many respects identical to those that would appeal to other people, but for many people with disabilities additional factors must also be considered.

As a follow-up to NCD's Livable Communities report, [16] and in order to better understand the broad range of quality of life indicators that can be used by and on behalf of people with disabilities to assess progress in this most important of realms, NCD plans to initiate a study of quality of life indicators. Accordingly, NCD will issue early in 2006 an RFP entitled National Disability Performance Indicators and Data. [17] This research will attempt to objectify and operationalize the criteria and measurement techniques that are relevant to assessing quality of life and to measuring improvements in the quality of life over time.

(e) Data and Database Coordination

Whenever data on a given subject is collected from multiple sources or through the use of more than one data collection instrument, different results are likely. For example, in calculating national employment data, payroll employment and self-reported employment typically differ.

In a similar vein, much controversy has been generated by variations in disability statistics achieved by different researchers, using varied data collection instruments, differing data sources and different data mining techniques. Under these circumstances, questions about discrepancies and divergences become ever-more difficult to answer. Are dramatically different conclusions a function of poor research, or are they simply the result of these legitimate differences in methods?

As the importance of statistics grows, so too do the stakes involved in these arguments. Whether rates of unemployment among people with disabilities have or have not declined since enactment of the ADA is a matter of great significance. The law itself has further contributed to the complexity and difficulty of basic statistics-gathering. For instance, in its series of decisions (summarized in NCD’s *Righting the ADA* papers) [18] the U.S. Supreme Court has interpreted the ADA definition of disability in a way that makes statistical analysis more difficult. In dealing with the main part of the ADA’s disability definition—that someone is a person with a disability if they have a mental or physical impairment that “substantially limits one or more major life activities”—the Court has de-emphasized condition and emphasized context. From the standpoint of advocates who have long argued for a social- rather than a diagnosis-based standard for identifying disability, this is a positive development. It means that a person with a given impairment might be a person with a disability in one situation, in relation to one major life activity, but might not be in another. But precisely because of this variability, this approach makes it impossible to count the number of people who meet any legal standard of having a disability.

Earlier in this chapter we recommended a comprehensive review of all legally-required disability data collection efforts. NCD further recommends that OMB conduct a broader study, taking all contemporary data collection practices and experience into account, into the strengths and weaknesses of, and the conceptual and practical issues surrounding, the gathering of data on all aspects of the lives of people with disabilities. This study should include an assessment of what sorts of data are needed, what are the most legally and economically feasible methods of compiling and validating them, and how different data sources can best be synthesized to form the most complete picture. The research should also extend to categories of data that are needed but do not yet exist, including such matters as how to measure the impact upon employment of the provision or withholding of various supports and services such as assistive technology or public support for reasonable accommodations. Finally, the study should address methods for gathering and verifying data on the relationship between various program rules (such as those bearing upon asset and resource limitations in needs-based programs) and comparative family status (such as the number of couples who divorce or refrain from marriage as a result of the financially adverse consequences resulting from the rules).

Recommendations

Recommendations 1.1: NCD recommends that the Office of Management and Budget (OMB) undertake a comprehensive statutory review, aimed at identifying all disability-related data-collection requirements in current federal law, and that OMB follow-up with an assessment of the current status, usefulness and viability of each and with appropriate recommendations.

Recommendation 1.2: NCD recommends that the results of field testing of the new ACS disability question be shared with the disability community, and that opportunity for input and further refinement be made available.

Recommendation 1.3: NCD recommends that the Bureau of Labor Statistics meet with advocates and knowledgeable professionals in the area of disability statistics and labor market analysis to help finalize the development and validation of disability-related questions for the CPS.

Coupled with other ongoing NCD research, the development of these indicators will provide policymakers with new tools for use in the design and evaluation of a variety of programs.

Recommendation 1.4: NCD recommends that OMB conduct a broad study into the strengths and weaknesses of, and the conceptual and practical issues surrounding, the gathering of data on all aspects of the lives of people with disabilities.

Chapter Two—Civil Rights

Introduction

The chapter begins with a discussion of the ADA, including reflections on the fifteenth anniversary of the law, and discussion of issues that have arisen during 2005. The issues discussed relate to the technical assistance provided under the Act and to the approach taken by the Federal government to mediation of ADA complaints. The ADA section concludes with discussion of important pending court cases on the applicability of the ADA to state prisons.

Returning to a major theme of last year's status report and of the Council's work in 2004, the ADA section closes with a renewed call for passage of the ADA Restoration Act.

The chapter then goes on to discuss the civil rights forum which NCD helped organize during the year. Following this, two long-standing issues are revisited in the light of recent developments, assisted suicide and genetic discrimination.

Next the chapter turns to voting, with a discussion of new technical guidelines for voting machine access that will prove relevant in future elections.

Finally, based on a major NCD study completed in 2005, the chapter addresses the Civil Rights for Institutionalized Persons Act, which turned 25 years of age in 2005.

(a) The ADA

1. A Time for Taking Stock

In observance of 2005's fifteenth anniversary of the enactment of the Americans with Disabilities Act (ADA), NCD issued its report, *NCD and the ADA: 15 Years of Progress*. [19] Summarizing the state of affairs for Americans with disabilities, the report finds: "It has been 15 years since the enactment of the ADA, and while it is clear that the legislation has assisted countless people, there are still major obstacles that prevent equal access for people with disabilities."

Reflecting this mixture of accomplishment and persisting needs, the report goes on to cite preliminary findings of NCD's ADA Impact study. These findings include progress in accessible transportation and in the availability of accessible public facilities; greater utilization of telephone relay services; increases in 2004 in the percentage of Americans with disabilities voting; and narrowing of the education gap between people with and people without disabilities. But NCD's ADA Impact Study also indicates that a number of barriers remain, such as the lack of affordable housing for people with disabilities, "which have slowed the realization of the ADA's objectives." [20]

It thus emerges clearly that there is much to be proud of and thankful for, but also that tremendous opportunity still lies ahead. A number of developments occurred in 2005 which highlight our accomplishments to date and point the way to the risks and opportunities of the future.

To more fully understand these, NCD commissioned the ADA Impact Study noted above, and a subsequent ADA Implementation Study. [21] Through focus groups and other forms of research, these projects will combine to produce a wealth of data concerning the impact of the ADA on the lives of people with disabilities and on the practices of employers. They should also produce rich data concerning what various key constituencies regard as major barriers to the effectiveness of the law in achieving the ADA's four key goals of equality of opportunity, full participation, independent living, and economic self-sufficiency.

One of the major issues to be addressed by the ADA Implementation Study relates to the question of information dissemination. It is widely believed that lack of knowledge concerning the ADA, and lack of understanding concerning its provisions, have combined to create unnecessary fear of the law and to delay some of the progress that it could bring about. NCD believes that in an age of abundant information, available from printed and electronic media, important messages must increasingly compete for attention among the public. For this reason, NCD recommends that Congress undertake a comprehensive study into the public-awareness and information-dissemination methods currently used by federal agencies in connection with all major disability rights statutes. This study should be conducted with a view to determining

whether different methods, venues or messages would result in a higher level of awareness concerning the requirements, benefits and opportunities existing under the ADA and other disability civil rights laws.

Another major development of 2005—and one that underscores the need for effective outreach just discussed—is the adoption of revisions to the major federal regulations governing implementation of the ADA, the ADA Accessibility Guidelines (ADAAG). [22] If the ADA is to remain a living vibrant document, periodic updating of these implementing regulations is crucial to the continued viability and relevance of the Act. NCD trusts and expects that the Access Board (which developed the guidelines) and the Department of Justice (which adopts and will ultimately enforce them) will monitor both the impact of the guidelines and the changing conditions surrounding them to ensure that the goals of the law can continue to be achieved and so that barriers can be identified and addressed. To that end, this report will discuss issues in Chapter Four on Health and in Chapter Eleven on Technology that implicate the ADA in issues that were beyond the imagination of anyone when the law was drafted.

2. Technical Assistance and Coordination

The ADA touches on many areas of life, as evidenced by the range of issues covered by court decisions and DOJ settlements during 2005. As discussed in subsequent chapters of this report, 2005 witnessed ADA cases involving the operation of state Medicaid programs, [23] cases involving the operation of state welfare agencies, [24] and cases involving private business's emergency evacuation plans, [25] to name just a few. Many of the interactions and potential overlaps are familiar, such as the role of the ADA in housing, but many others are new and complex.

To add to the challenges facing those charged with interpreting the ADA and those who disseminate information about its meaning, court decisions and legal interpretations by various executive branch agencies often result in inconsistency between agencies or between courts concerning either the meaning of the ADA or its interaction with other laws. While such inconsistencies are to some degree inevitable, NCD believes that the Department of Justice

(DOJ) can take a stronger leadership role in clarifying matters and resolving inconsistencies that lead to uncertainty and confusion for both people with disabilities and covered entities.

Through its Disability Rights Online News, and through the publication of many technical assistance and informational resources, including the major CD-ROM it issued in 2005, [26] the DOJ has taken the leading role in communicating the meaning of the ADA to the public. In addition, DOJ has a lead role under statute in coordinating the government's ADA implementation activities, through its rulemaking, complaint handling, and interagency cooperative agreements and initiatives.

At a time when federal civil rights enforcement efforts have increasingly focused on non-confrontational strategies such as technical assistance and information dissemination, the need to ensure the effectiveness of these strategies is clear. At a time when the cost effectiveness of all expenditures and programs must be subjected to intense scrutiny, NCD believes DOJ could do more than it currently does to make the law clear to those affected and governed by it, and for those who look to it for protection and definition of their important civil rights.

Three specifics may serve to illustrate the use of readily achievable steps NCD believes should be taken. First, DOJ should expand the focus of its publications. This would include broadening the focus of its regular online ADA update reports. Currently, these reports focus largely on cases or initiatives in which the DOJ itself has been directly involved. Inclusion of information about all significant ADA-related developments, including court decisions in cases to which the U.S. government may not have been a party, and including actions of other federal agencies in which DOJ was not directly involved, would go a long way toward providing the public with an authoritative, timely and comprehensive window into the evolving meaning of the law.

In this connection, all informational publications should be regularly reviewed to ensure their timeliness and comprehensiveness. For example, one of the important publications updated and issued by DOJ in 2005 was on requirements and methods for effective communications by hospitals with persons who have hearing impairments. [27] During 2005, several court settlements combined to suggest that the requirements applicable to hospitals under the ADA extend to ensuring that medical equipment is also accessible to and usable by persons with

disabilities. While not an effective communications issue as such, the prospects and requirements of the law in this area are surely of significance to hospital administrators and patients alike. Important as a publication on effective communication is, NCD believes that it would prove even more helpful to the public to have a publication covering all existing and imminent requirements bearing on hospitals.

The second significant step the DOJ should take in fulfilling the responsibilities it has both taken upon itself and been assigned by law is to update applicable regulations whenever definitive change in the law occurs. While we commend DOJ for its role in the periodic ADA Accessibility Guidelines revision process, discussed above, what we have in mind here is the need for interim regulations to implement Supreme Court decisions and indeed to reflect DOJ's own determinations and rulings.

For instance, as long ago as 1996 the DOJ formally expressed the view that covered entities which disseminated information to the public, including by computer, were obliged under the law to make that information available to persons with disabilities. [28] As of yet, a decade later, no clarification on what constitutes such parity, or when and how it is required, has been. By the same token, the Department has never withdrawn or renounced its statement.

Some may argue that in an era of rapidly changing communications technologies, any attempt to specify means or other details would be anachronistic and harmful to commerce and to creativity in the development of the Internet. But others would counter that failure to clarify the types of access required by the law is irresponsible and an abdication of responsibility. Without guidance, individuals with disabilities, designers of web sites, and internet service providers, telephone companies and others are left uncertain, vulnerable to misunderstanding, and subject to avoidable controversy including needless litigation, all of which could be minimized, with consequent benefit to the productivity of our economy, by thoughtful analysis and rulemaking on DOJ's part.

In this connection, NCD fears that hostility to the ADA resulting from vexatious litigation could be greatly reduced if DOJ would take a leadership role in clarifying its views as to the meaning of the law in certain controversial areas, especially where DOJ's own opinion letters, settlement

agreements or other policy pronouncements have legitimately given rise to expectations that may or may not be warranted.

The third area where significant measures could be taken in this regard involves the relationships among federal agencies with coordinate jurisdiction for implementing and enforcing the ADA. The ADA is unusual in that so many agencies have fragmented or overlapping responsibility for its interpretation and enforcement in their areas of jurisdiction. To the degree that the ADA applies to private sector and to state and local governments entities whether in health care, transportation, emergency preparedness or education, all of the federal agencies that administer programs in these areas are involved in implementing the ADA as well. It is impossible in such a setting to avoid differing interpretations or inconsistent applications of the law. When complexities arising from the intersection between the ADA and other laws are taken into account, the likelihood for inconsistent, even conflicting interpretations, becomes all the greater, and with it the risk that unresolved differences between and among executive branch agencies will exacerbate the inherent complexity of the law.

Once again in this area, DOJ has a historical and statutory role to play. By law DOJ has and exercises coordinate jurisdiction with other agencies, including the Access Board and the Department of Transportation, in the development and promulgation of ADA regulations. The department counsels and represents other federal agencies in ADA-related litigation, and maintains cooperative agreements to assure case referral and continuity in processing with other agencies such as the Department of Housing and Urban Development. Finally, the DOJ has jointly published informational and technical assistance materials in conjunction with other agencies over the years.

In light of these long-standing precedents, established relationships and clear responsibilities, DOJ should develop a proactive strategy for working cooperatively with other federal agencies to ensure uniform interpretation and application of the law, and to develop clear and common positions on issues involving the interplay of the ADA and other laws. To do less may be to inadvertently contribute to an increased risk of litigation. We should do everything possible to avoid the risk of individuals being forced to seek recourse in the courts for the resolution of

disputes which are really between, and hence are best settled by, executive branch agencies. The goals of clarity and efficiency are best served by agencies working together to understand and apply the laws under which they all work and under which we all live.

An illustration of the problems faced by citizens may suffice to make this point clear. Several court cases brought under the Medicaid Act in the wake of the *Olmstead* decision have raised profound questions about the relationship of Medicaid and ADA provisions. One important lower court decision in 2005 held that the ADA required states to fill all available home and community-based waiver (HCBW) slots. [29] But where is a citizen seeking to enforce her *Olmstead* rights, or a state official seeking to apply the law in good faith now to look for an authoritative answer to the question of how and when slots are deemed to exist, and when or whether they must be eliminated. How are advocates to best work with their states in maximizing the potential of *Olmstead*? Only the DOJ and the Department of Health and Human Services, working in close collaboration, can provide the necessary clarity and guidance.

No one suggests that the Department of Justice has final authority to decide these questions. Ultimately, they are likely to be decided by the weight of a number of authorities including DOJ, the Centers for Medicare and Medicaid Services, and the courts. But the executive branch, spearheaded by DOJ working in collaboration with CMS, has an urgent responsibility and an unequalled opportunity to offer citizens and officials alike as much clarity and certainty as the executive branch is capable of offering on this and other important issues.

For the fullest possible solution to this problem, NCD recommends that Congress enact legislation authorizing citizens to petition the DOJ to initiate joint rulemaking procedures with other coordinate agencies to resolve any inter-agency discrepancies in the interpretation or application of the ADA. Action on such petitions should be required where the discrepancies hold potential for creating uncertainty on the petitioners' parts as to their legal rights or obligations. Such a step would go farther toward eliminating needs ADA litigation than divisive proposals like the ADA Notification Act [30] (which would impose burdens on ADA complainants that are utilized nowhere else in U.S. law) ever could. Such procedures would also

offer a straightforward means for citizens to obtain clarity without having to resort to the complex, expensive and cumbersome pursuit of a declaratory judgment through the courts.

3. Mediation

Consistent with its emphasis on avoiding litigation wherever possible, and in light of its desire to see cases settled as rapidly and fairly as possible, the DOJ has placed increasing reliance on mediation in recent years. While NCD has supported the principles and goals underlying this effort, NCD has also grown increasingly concerned about the equality of the parties in mediation settings and about the potential of mediation to effect the behavior of covered entities.

For some individual complainants, mediation may impose heavy burdens of time, travel and acquisition of informational resources. These are burdens which obviously are not shared by the many covered entities who have *hr* or legal staffs and who have experience representing their interests in a variety of official forums.

With the growing use of arbitration clauses in employment and commerce, issues surrounding the real fairness and actual impact of all manner of nonjudicial settlement practices are in need of systematic assessment. As it relates to the ADA in particular, one development during 2005 has led to renewed and increased concern.

In April 2005 DOJ summarized the results of nine case mediations involving denial of access by public accommodations to service animals. [31] All of these resulted in the acknowledgment of error by the respondent, and some in the payment of contributions to various advocacy or relevant educational organizations. Some resulted in commitments by the respondent to undertake appropriate staff training. But as summarized by the DOJ, none resulted in the payment of any damages to the complainant and none appears to have included any mechanism for monitoring or verifying respondents' successful commitments to long-term change.

NCD therefore recommends that the DOJ undertake a study to determine the extent to which complainants are able to participate effectively in and gain reasonable satisfaction from the mediation process, and the extent to which commitments made by respondents are in fact maintained overtime.

4. The ADA Restoration Act

Although not widely discussed during 2005, NCD remains strongly committed to the recommendations contained in our December, 2004 Righting the ADA report. [32] Among these, the ADA Restoration Act is one of the most central.

The ADA Restoration Act, which was proposed in 2004, [33] would modify a number of judicial decisions interpreting the ADA. It would not modify any constitutional decisions, but it would, as its name suggests, restore the law in several key areas to what we believe Congress intended in enacting it. Accordingly, NCD believes that careful congressional review of the ADA Restoration Act will serve to allay many fears and misconceptions both about the current law and about its original intent. NCD recommends that Congress adopt the ADA Restoration Act. Following hearings on the proposal, NCD is confident that most of the objections to its adoption, as well as many of the fears surrounding the basic law, will be erased.

5. The Rights of Prisoners

In early 2004 the Supreme Court decided the historic *Lane v. Tennessee* case. [34] Although the Court had previously ruled that the Constitution barred lawsuits for employment discrimination under the ADA, [35] the *Lane* decision held that in the case of the denial of fundamental rights such as access to courthouses, no constitutional bar to such lawsuits existed. [36]

Left unanswered in the wake of *Lane* was the question whether other state activities were so fundamental as to justify granting individuals the right to sue for violation of their rights.

It has been established that state prisons must comply with the ADA, [37] but what remains to be determined is how this obligation can be enforced. Two cases scheduled for decision by the Supreme Court early in 2006 may answer the question whether prisoners can bring suit against states for violation of the ADA. [38]

NCD has issued a position paper on these cases. [39] NCD believes that the law and the Constitution uphold the right of prisoners to protect their rights through litigation where necessary. But beyond the specifics of these cases, NCD hopes the Court will take the

opportunity afforded by these cases to articulate broad principles concerning the range of situations and rights in which citizens with disabilities may have recourse to the courts where states have abridged their fundamental human and civil rights.

(b) Civil Rights Forum

In its research and reports, NCD has been mindful of the overlaps between issues facing people with disabilities and the concerns of other civil rights constituencies. [40] NCD has also endeavored to remain sensitive to the variations of culture and experience that contribute to determining how given measures, resources or information-dissemination strategies will effect different groups of people. Without a deepened understanding of how varying cultural experiences influence the experience of living with disability, the issues facing our nation and the options available to it cannot be fully understood.

Consistent with these ongoing concerns and coinciding with the fifteenth anniversary of the ADA, NCD undertook a major outreach effort to other disability-related civil rights groups and civil rights groups outside the traditional disability sphere. In March the Council co-convened a civil rights forum including other disability groups and representatives of senior citizens' organizations and other groups. Three forum workgroups were facilitated by members of NCD's Cultural Advisory Committee. These workgroups dealt with educational excellence and equity, creating and rewarding diversity-friendly workplaces, and restoring civil rights legislation.

Following lengthy deliberations, participants were able to identify focal points deemed beneficial for policy development. It was the sense of one member who reported in detail on the meeting that common causes were found. However, settling on specific agenda items that anchor future work together was more challenging. On the whole, the discussion was described as quite dynamic.

(c) Assisted Suicide

Few will ever forget the anguish and debate in 2005 over issues relating to the rights to life and death. Focused on the tragic Schiavo case, our nation's exposure to these issues also included major litigation pitting the U.S. Government against the State of Oregon. The case, determining

the legality of Oregon's death with dignity act, will be decided by the Supreme Court early in 2006. [41] The decision may answer the narrow question whether states have the constitutional right to enact such statutes, [42] but the web of ethical, moral, economic and social questions that it raises cannot be resolved, no matter the High Court's pronouncement.

Last year's attention to the Schiavo case led NCD to reissue and update its 1997 position paper, *Assisted Suicide: A Disability Perspective*. The Original 1997 paper, expressed and explained NCD's opposition to the practice. As the updated memorandum makes clear, none of the fears or concerns that NCD expressed in 1997 have in the least degree been dispelled. Nothing in our experience under the Oregon law during the eight years it has been in effect, and nothing in the general culture of the nation (including Academy-award winning films that take it as self-evident that anyone would prefer death to quadriplegia) [43] have given the Council any ground for believing the fears it expressed a decade ago were exaggerated or premature.

NCD urges all those with concerns over these vital issues to read its updated analysis. For purposes of this report, it may be sufficient to say simply this: To talk about death with dignity has little meaning without life with dignity. It is NCD's firm belief our nation must avoid rationalizing utilitarian statutes on the grounds of respect for human dignity, when the individuals in question have been denied access to the basic services, technology and opportunities that would have imbued their lives with dignity and a sense of personal worth.

Early in 2005, a sit-in was held in the office of the governor of Tennessee. It involved protests on behalf of 18 ventilator-using individuals who were slated to lose funding for their equipment unless they left their own homes and entered nursing facilities. [44] One wonders what sense of autonomy or dignity such people would have, faced with a choice between being able to breathe and being able to live. This matters because, according to data on the reasons specified by doctors for giving lethal drugs to patients in Oregon, loss of autonomy (87%) and loss of dignity (80%) were the most frequent grounds cited by patients who were assisted in ending their own lives. [45]

Government cannot have it both ways. It cannot make the conditions of life intolerable, then glorify people's desire to end their lives on the grounds of concern for those people's dignity.

Still less can it withhold the resources necessary to provide a minimal quality of life, then take refuge in the facile assumption that the disability is the grounds for people's terminal despair.

As NCD stated in its 1997 position paper: "At least until such time as our society provides a comprehensive, fully-funded, and operational system of assistive living services for people with disabilities, this is the only position that the National Council on Disability can, in good conscience, support." [46]

In this light, NCD recommends that Congress and the states, in the consideration of any potential assisted suicide or death with dignity legislation, require that no individual be considered eligible for assisted death until and unless such person has been given the fullest opportunity to learn of and to use all appropriate and applicable independent living services including but not limited to personal assistant's services, assistive technology, home modifications, and other community supports.

(d) Genetic Nondiscrimination

NCD has addressed the issue of genetic nondiscrimination in a number of papers over the years. [47] NCD's concern with this issue has grown with the ability of noninvasive and all-too-routine health screenings to identify genetic anomalies that may reflect the existence of disease or may disclose a vulnerability to one or another abnormality. Why this matters is that such information is becoming ever-more readily available to employers, health and life insurers and all manner of other people and institutions who have the power to make critical decisions about our lives.

In the face of this reality, NCD has strongly endorsed legislation that would bar genetic discrimination in employment or health insurance. We commend the Senate for its passage of this legislation, S. 1053, in 2005 [48] and urge the House of Representatives to follow suit early in the 2006 session of Congress.

The reasons why America needs such protections have been stated in prior NCD reports. [49] We recommend that those interested in this subject review our findings.

Developments during the past year have strengthened and made more urgent the case for genetic civil rights. Chief among these developments is the administration's strategy for major federal health programs. Over the past year, consensus has grown around the notion that government health insurance programs, including most notably Medicare and Medicaid, are growing at unsustainable rates. It is clearly part of the administration's consumer-directed health care agenda to increase citizens' access to private health insurance. Health savings accounts (HSA's), along with a number of other initiatives reflect this intention. If successful, these initiatives will increase access to health insurance for the uninsured, will reduce the costs of coverage for current payors, and may reduce the demand for public-funded health coverage on the part of those excluded from private sector coverage.

But if genetic exclusion remains permissible, how can the contemplated measures yield nearly the savings or yield anything approaching the benefits that all hope they will? As documented linkages between the human genome and actual or latent abnormalities grow in number, and as techniques for genetic screening become more sophisticated and pervasive, the number of people likely to face denial or restriction of coverage can only grow.

It does no injustice to the insurance industry to suggest that it should use every means available to it to identify and weed-out potential coverage risks. Risk assessment, underwriting and classification are and have been for many years a fundamental tool in their business. So long as insurers are free to obtain or use genetic information in screening for eligibility, for benefit levels or for pricing, failure to do so would be a disservice to their stockholders.

Piecemeal solutions such as individual state legislation or banning discrimination based on certain genes or particular conditions are unlikely to be effective. Such measures would create confusion and introduce competitive distortion into the insurance marketplace which would work to the advantage of no one. Only clear and comprehensive federal legislation, that puts no insurance provider at a disadvantage to any other, and that sets forth clear rules that can be enforced and applied, will help to achieve the goal of reaching the uninsured without huge increases in public expenditure.

As it relates to the labor market too, genetic nondiscrimination legislation can do nothing but good. Today an employer, fearful of potential health insurance costs, may feel obligated to use genetic information to screen out job applicants, even perhaps if the applicant in question is a superior candidate for the job. Elimination of these distortions in the market economy can only redound to the benefit of employers and workers alike, and can only contribute to the productivity of our economy.

It is argued by some that a ban on genetic discrimination would be difficult to enforce. It is further argued that such a ban, by forcing insurers to extend coverage to persons who would not otherwise meet their underwriting standards, or who pose future risks, would impose premium increases on all purchasers, with resultant unaffordability for some who would be priced out of the market. Such concerns cannot be dismissed out of hand, but they are largely conjectural. They overlook a variety of other methods for lowering health care costs. Moreover, they presuppose that genetic selection already plays some role in keeping premiums down.

Sooner or later the problem will have to be confronted. As our knowledge of the human genome and its links to disease or disease-potential grows, more and more people will become genetically risky. Unless action is taken to stop the trend, the day may come when the majority of Americans are uninsurable, and in many cases unemployable. It would be better to face the issue squarely now, at a time when many of the basic assumptions of our health care system are undergoing scrutiny and in-depth rethinking. We will discuss this matter further in Chapter Four, Health Care.

(e) Voting

As the 2006 effective date for the Help America Vote Act (HAVA) approaches, [50] people with disabilities look forward to the dawning of a great new era of participation in one of the most treasured civic duties in our nation. NCD has noted with pleasure in its ADA fifteenth anniversary report the increases in voter participation among people with disabilities that occurred in 2004. If diligently implemented, HAVA should assure and accelerate the continuation of this gratifying trend.

Few things could be more crucial, in practical and symbolic terms, than the admittance of people with disabilities to full participation in the civic life of our nation, through being enabled to vote with the same autonomy, privacy and dignity that is afforded to other citizens. It is a right for which many people have died, and for which many have lived.

NCD has continued to follow the progress of HAVA implementation with great interest. The first crucial test will come in the primary and general elections of 2006. In the meantime, NCD notes with approval the publication of the Voluntary Voting Systems Guidelines (VVSG) by the U.S. Election Assistance Commission (EAC). [51] It is expected that these guidelines, which place much attention on accessibility-related issues, will receive wide acceptance and be broadly adopted, as their predecessor guidelines were. But because of their voluntary nature, NCD is concerned that some jurisdictions may pursue alternative strategies to voting-machine accessibility which, though well-intentioned, may not fully meet the needs.

Consistent with its stated commitment to effective implementation of the right to vote, under both the HAVA and the ADA, NCD recommends the Department of Justice remain alert to situations in which measures taken within or outside the VVSG fail to fully comply with the requirements of the law. NCD hopes to be able to open channels of communication with other advocacy groups, with the DOJ and with the EAC that will allow problems that may come to NCD's attention to be quickly brought to the attention of the appropriate federal entities, and that will allow these agencies to seek input from the Council in any instances where we may be able to be of help.

In this connection, a detailed summary of the VVSG prepared in November, 2005 by the Congressional Research Service (CRS) [52] notes concerns by some that the guidelines may not adequately address the accessibility needs of people with all types of disabilities. CRS also notes concerns regarding unusual terminology used in the guidelines, and regarding uncertainty as to whether several relevant provisions are intended to be only temporary or permanent in nature.

Such concerns contribute to NCD's emphasis on the need to couple hopefulness with watchfulness. Likewise, should substantive complaints arise in the course of implementation, or should proposed voting systems fail to obtain certification because of not meeting accessibility

requirements, or should jurisdictions appear to be seeking to avoid the need for certification, then NCD would urge consideration of mandatory guidelines or other appropriate regulations.

Finally in this regard, it should be remembered that the VVSG do not purport to address all accessibility issues covered by HAVA. The VVSG deal with the accessibility and usability of voting machines themselves. They do not deal with the accessibility of polling places, or the training and knowledge of election officials. These matters too must continue to be carefully monitored.

(f) Rights of Institutionalized Persons

With the increasing emphasis placed by advocates and officials over recent years on maximizing opportunities for community-based living and services for as many people as possible, it is all too easy to think of persons residing in nursing homes or other institutionalized settings only through the prism of how they can be returned to the community. Underlying such a perspective is the notion that institutions are generally inferior from a public policy point of view and less satisfactory from the standpoint of the individual.

NCD hopes the day will come when no one will need to be in an institution, except those who with full opportunity to choose, genuinely prefer to do so. But until that day comes, the conditions of life for persons with disabilities in nursing homes, mental hospitals, correctional facilities or other institutional settings must remain an area of attention and concern.

A primary source of protection for the civil rights of these persons is the Civil Rights for Institutionalized Persons Act of 1980 (CRIPA). [53] In 2005 NCD published a major report, “The Civil Rights for Institutionalized Persons Act: Has it Fulfilled its Promise?” [54] This report finds uneven results and paints a mixed picture.

Detailed recitation of the findings of the CRIPA study are beyond the scope of this report. Suffice it to say, NCD’s report identifies a number of areas where results have fallen short of expectations, and a series of measures, relationships and approaches that could be improved or developed in order to vindicate the interests served by the law.

A number of the recommendations are within the power of federal oversight agencies, particularly the Department of Justice, to implement, some by regulation, others without need for formal rulemaking. Others would require the involvement of Congress, either for budgetary reasons or because of substantive issues with the law itself.

Accordingly, NCD recommends that Congress hold oversight hearings on CRIPA, with a view to determining whether amendments to the act are warranted. NCD is eager to share its findings with Congress and to be of all possible assistance to the appropriate committees in the effort.

As the implementation of Olmstead proceeds, residents of institutions are likely to represent an increasingly vulnerable population. As such, it is all the more urgent that their needs and concerns not be overlooked, and that their civil rights be protected, all the more because of their relative lack of resources for enforcing those rights on their own.

Recommendations

Recommendation 2.1: NCD recommends that Congress undertake a comprehensive study into the public-awareness and information-dissemination methods currently used by federal agencies in connection with all major disability rights statutes.

Recommendation 2.2: NCD recommends that Congress enact legislation authorizing citizens to petition the DOJ to initiate joint rulemaking procedures with other coordinate agencies to resolve any inter-agency discrepancies in the interpretation or application of the ADA

Recommendation 2.3: NCD recommends that the Department of Justice undertake a study to determine the extent to which ADA complainants are able to participate effectively in and gain reasonable satisfaction from the complaint mediation process, and to determine the extent to which commitments made by respondents as elements of mediated settlements are in fact fulfilled overtime.

Recommendation 2.4: NCD recommends that Congress adopt the ADA Restoration Act.

Recommendation 2.5: NCD recommends that Congress and the states, in the consideration of any potential assisted suicide or death with dignity legislation, require that no individual be considered for eligibility for assisted death until and unless they have been provided with the fullest possible range of potentially relevant independent living services.

Recommendation 2.6: NCD recommends enactment of legislation outlawing discrimination based on genetic factors.

Recommendation 2.7: NCD recommends that in addition to monitoring the effectiveness of the Voluntary Voting Systems Guidelines issued in 2005, the Department of Justice remain alert to situations in which measures taken within or outside the guidelines fail to fully comply with the voting accessibility requirements of the law.

Recommendation 2.8: NCD recommends that Congress hold oversight hearings on the Civil Rights for Institutionalized Persons Act, with a view to determining whether amendments to the act are warranted.

Chapter Three—Education

Introduction

This chapter deals with issues that are not new, though some have emerged in new contexts or with new urgency over the past year. It begins with a discussion of the Supreme Court's major special education decision. There follows a discussion of the implementation of the Individuals with Disabilities Education Act amendments of 2004. The chapter then proceeds to a discussion of the complexities arising from the interaction between this law and our nation's broader public education statutes. Finally, the chapter identifies several legislative proposals currently pending in Congress that NCD regards as worthy of attention and enactment.

(a) Burden of Proof

In November, 2005 the U.S. Supreme Court ruled in *Schaffer versus Weast* [55] that in disputes between parents and school districts over students' individualized education plans (IEP), the burden of proof rests with the party challenging the plan. As a practical matter, this means that parents who oppose the decisions school systems have made regarding the needs of and the services to be provided to their children with disabilities face a higher legal hurdle in winning their appeals. The school district does not have to prove that its assessment and provisions are correct. In practice, the parents must prove that these are wrong.

In anticipation of the oral argument and decision of the *Schaffer* case, NCD issued a position paper on the subject in August. [56] For those who have an interest in the subject, and for those who are inclined to believe that issues such as burden of proof are merely academic, review of this paper is highly recommended. Given that the impact will be real, much depends on the decision is interpreted and applied by school districts, hearing officers and in some cases by courts.

NCD is concerned that those charged with interpreting the decision will recognize that though the burden of proof now rests with parents, that burden is not proof beyond a reasonable doubt. Rather, as in most other legal contexts outside of criminal law, the standard is proof by a

preponderance of the evidence, that is, there is more reason to believe than to not believe the parents are correct. Accordingly, to ensure that the decision is not interpreted with undue harshness, NCD recommends that the Secretary of Education (ED) issue guidance to state directors of special education clarifying what the decision does and does not mean, and making clear what federal regulations and expectations it may change.

(b) Implementation of IDEA

Like any major statute, the Individuals with Disabilities Education Improvement Act [57] of 2004 not only renewed IDEA but modified it in a number of important ways. Many of these modifications were discussed in last year's NCD annual status report. [58]

New federal regulations were required to implement the IDEA amendments. Proposed regulations have been released. [59] A Congressional Research Service (CRS) report offers analysis of these proposed regulations, with emphasis on how they reflect the requirements of the amendments. [60] It was expected that final regulations would be published by the end of 2005, [61] and this appears to have been the intent of ED's Office of Special Education and Rehabilitative Services (OSERS), but administration review processes appear to have taken more time than anticipated. [62]

Although the period for public comment on the regulations has closed, NCD wishes to address a number of issues the council believes to be of particular importance. The following subsections (b) (1) through (b) (4) will address matters that are specific to IDEA. In Section (c) issues that overlap with other federal statutes, most notably with the No Child Left Behind Act, will be addressed.

(b) (1) Overrepresentation

Over recent years, various data sources, including monitoring done pursuant to the IDEA Amendments of 1997, [63] have confirmed overrepresentation of students from diverse backgrounds among children referred for and receiving special education services. By overrepresentation is meant that the proportion of students from diverse backgrounds in special education consistently exceeds their proportion in the overall student population. [64]

While the reasons for this overrepresentation are matters of some uncertainty, fears have grown increasingly widespread that the disparity reflects a “dumping” of students who, for whatever reason, the mainstream school system finds it difficult to serve.

To prevent overrepresentation, the 2004 amendments include provision for the use of up to 15% of districts’ special education funds for various “early intervening” behavioral and academic support services, and for related personnel training, aimed at reaching at-risk students before referral for special education services. [65] NCD has discussed this problem in past status reports, and has commended Congress for its attention to the overrepresentation issue.

NCD is hopeful that the 2004 amendments will lead to reduction of ethnic or racial disparities in special education. To that end, NCD is concerned that monitoring evolve in a way that will ensure the availability of timely and reliable information on the basis of which Congress can determine whether the problem is being solved. Specifically, NCD believes that ED’s IDEA regulations should include further guidance to school districts on such matters as: the range of services that may be offered; on best practices for identifying at-risk students at a time when intervention has the greatest likelihood of being effective; on evaluating the impact of any diversion of funds on schools’ ability to meet the needs of students who are in need of full special education and related services; and of course on the numbers of students from diverse backgrounds referred for or diverted from special education.

Accordingly, NCD recommends that ED’s Office of Special Education Programs (OSEP), through amendment to its proposed IDEA regulations or through instructional letters to state directors of special education, provide guidance on monitoring requirements, outcome goals and best practices in connection with efforts to reduce minority overrepresentation.

(b) (2) Full Funding

Broadly understood, full-funding is understood to mean federal funding of 40% of the costs of the Part B grants-to-states portion of IDEA. According to a CRS report, federal funds accounted for 18.6% of these special education costs in FY 2005, and are expected to account for about the same proportion of total expenditures in FY 2006. [66]

NCD has expressed its appreciation for Congress's recognition of the need to increase federal funding levels over the coming years. NCD recognizes the persistent barriers that federal budget deficits will pose to efforts to significantly increase this percentage, particularly if the overall costs of special education and the numbers of children receiving special education services continue to rise. NCD therefore urges Congress to seek additional funding sources that can be used to add resources to local and state funds for the provision of special education services and for the implementation of accessibility in all phases of the educational environment and process. Tax-based approaches, incentives for business-education partnerships and other methods should be considered. For this purpose, NCD recommends that Congress establish a national special education funding commission to identify creative and alternative strategies for supplementing existing federal and state funds for special education.

In 2005 a new dimension has been added to the full-funding controversy by the litigation that has occurred in relation to the takeover by the state of Maryland of eight special education-related departments of the Baltimore public school system. [67] Without getting into the details of this controversy here, it is enough to note that allocation of costs between the city and the state has emerged as one of the key disputes.

What matters is that because states differ in the ways they allocate educational funding responsibility between local and state funds, the discussion over full-funding may overlook some of the most contentious issues if it focuses solely on percentages of federal funding. The impact of given levels of federal funding may be quite different in states with a robust centralized funding structure than in states where the cost burden falls more heavily on local communities.

Discussions of full-funding have frequently taken place as if there were two participants in the process. But in fact there are often three, because vast differences will exist from place to place as to the role of state and local funds in making up the nonfederal share. This may matter considerably, because in those school districts where, as is commonly the case throughout the country, school expenses are met largely out of local property tax collections, the danger exists that special education will become a hot-button political issue. The existence of federal mandates and the existence of conditions that states and local education authorities (LEA) must meet may

ensure that special education will receive priority in the expenditure of local or state funds, but such mandates will not prevent the development of tragic hostility toward special education in sectors of the general public who feel that mainstream students are being denied services and resources they should have.

Faced with these concerns, NCD believes it is important for the long-term viability of special education that means for diffusing and countering such public misconceptions and suspicions be found. In order to do this, NCD recommends that Congress ask the Government Accountability Office (GAO) to study the ways that special education is represented to the taxpaying public in local communities around the country, and based on its findings make recommendations of how the important benefits and values of this national commitment can be incorporated into community outreach around educational issues.

(b) (3) Private School Accessibility

The 2004 IDEA amendments made changes to the law in the area of parent-initiated private school placements. [68] It is clear that students placed in private schools at the insistence of their parents, and not pursuant to IEP determinations made by the school, are not entitled to public payment for tuition and similar costs. But such students will still be entitled to various special education services. In light of the proposed regulations bearing upon this entitlement, [69] questions have arisen regarding the allocation of responsibility for the cost of such services. NCD however is concerned with another element of this subject that has not featured prominently in this year's debate. As discussed in previous annual status reports, [70] NCD is concerned with the risk that federal special education funds will be provided on behalf of students with disabilities to private schools that are not necessarily accessible or that exercise discretionary admissions policies to exclude children with the most significant disabilities. While private and parochial schools certainly retain the right to pick and choose their students in ways that the public schools cannot, means must be found for assuring that special education funds will not be used to support students in institutions that exclude students on the basis of disability or that by failing to meet minimum program or facility accessibility standards either exclude outright or seriously disadvantage students with disabilities.

(b) (4) Student Discipline

Few special education issues are more controversial than student discipline. This is so for two reasons. First, there are the questions surrounding what is the appropriate response to bad behavior or rule infraction, especially where withdrawal of important educational services may be one result. But second and overarching are the questions arising from the perception that disciplinary rules and procedures for special education students with disabilities differ from those applicable to other students. Fairly or unfairly, the perception appears to have become widespread that somehow students with disabilities are treated more leniently than other students or receive dispensations that other students do not.

Against this background, the 2004 IDEA amendments include an elaborate set of provisions designed to balance the complex and sometimes competing goals of good order with those of fairness. NCD likewise commends ED for the effort, clearly evident in the proposed implementing regulations, to balance a range of competing concerns. NCD wishes to express its concern on several points that have not been fully resolved by the proposed regulations.

(b) (4) (A.) Manifestation Determinations

The first of these unresolved discipline-related points is the so-called manifestation determination. In the wake of the 2004 IDEA amendments, the precise nature of disciplinary procedures, including alternative placements or changes in services, will in many instances depend on whether improper student behavior is deemed to be related to the disability, or to be caused by the LEA's failure to implement relevant IEP provisions. [71] If the behavior can be attributed to either of these causes, then it may be regarded as a "manifestation" of the disability.

Because the regulations favor a case-by-case process in making all disciplinary determinations, questions surrounding how manifestation determinations will be made become all the more important. NCD is concerned that local officials may not yet have sufficient guidance in how to make these determinations. And while the due process protections afforded to students facing disciplinary proceedings are extensive, such protections are only as valuable as the criteria they use are appropriate and fair.

With this in mind, NCD recommends that ED issue further guidance reflecting all the recognized pathways through which disability and behavior can be connected. These guidelines should make clear that behavior which is not intentional and not subject to volitional control should not be regarded as appropriate for a disciplinary or punitive response. The guidelines should also recognize how failures on the part of the school system, including failures to include various services in an IEP, can contribute to the buildup of frustrations that, in the absence of any other suitable method of expression, may manifest themselves in immature or inappropriate behavior or in disruptive ways.

(b) (4) (B.) Due Process

In an effort to minimize legal disputes between parents and schools, the 2004 amendments included provisions designed to increase opportunities for discussion and dispute-resolution prior to the filing of formal complaints or the resort to litigation. Principal among the new procedures is the “resolution session.” [72]

At the same time, requirements for notices to parents of their due process rights, and of time frames for exercising those rights, have been expanded. [73] NCD once again commends ED for its efforts to address and respect both school-system and parental interests and concerns. What concerns the Council is whether the new notice requirements, and the proliferation of procedures they reflect, may run the risk of creating confusion among parents.

NCD recommends that ED incorporate several features in its implementation requirements that will help ensure the effectiveness of notices. Monitoring requirements should also be developed that will help determine the effectiveness of current due process notice provisions, as well as the effectiveness of the due process provisions themselves.

Finally in this regard, provisions should be added to the proposed regulations to ensure that the combination of numerous procedural options and tight timelines will not lead to unanticipated hardship. For example, where non-English proficiency or non-literacy, mailing-address mistakes, or inaccessibility due to print disabilities prevent parents from asserting their rights in a timely fashion, the regulations should provide for flexibility in the granting of waivers or in the taking

of other steps to assure that the spirit of the law is implemented. Where parents fail to exercise their rights or meet tight deadlines through no fault of their own, they and their children should not be punished unduly.

In a related vein, NCD is concerned about a change made to the mediation provisions of the new law by the proposed implementing regulations. ED has proposed to eliminate any role for parents in the selection of mediators, but to ensure that this not result in unfairness, ED has also proposed that school systems choose mediators on a randomized basis from a list of individuals with knowledge of special education. [74]

Random selection may indeed prevent bias in the selection of mediators, and it may ensure that mediators will be persons with knowledge of special education generally, but it does not provide any basis for recruiting a mediator with relevant specialized knowledge, where such knowledge could be instrumental in helping the parties to achieve an appropriate resolution. Special education is a vast subject, and mediators could have considerable experience and general knowledge but not know about a specific disability, about particular categories of assistive technology devices (AT), or about new developments in assessment or treatment.

Accordingly, some means should exist by which parents or educators who believe that specialized mediator expertise is required can have input into the selection process. NCD recommends that ED revise or expand its regulations to bring this about.

(c) IDEA and No Child Left Behind

Many of the issues surrounding special education in this country now involve the interactions between IDEA and the No Child Left Behind Act (NCLBA). [75] In some measure, these issues reflect the ordinary complexities of reconciling two statutes with overlapping provisions that were not necessarily drafted with close attention to one another. But in another sense the issues are unique, arising from inherent tensions between the two laws.

To understand the potential for and the likely persistence of tension between IDEA and NCLBA it is necessary to consider the underlying premises of the two laws. NCLBA approaches the goal of improving educational attainments for America's students primarily through the use of

aggregate test results. Schools and school districts are rewarded to the degree that their students show progress, primarily through standardized test results, and are either assisted or in the view of some punished if their students do not. To the extent that students with disabilities may not have been taught to the identical curriculum, may need accommodations in taking tests, may be unable to take standardized tests in regular ways, or may present other highly individualized issues, questions of how and whether special education students are to participate in standardized testing have emerged at the center of discussion. As the following discussion will show, the past year has witnessed more confusion than clarification of many of the most difficult issues.

(c) (1) Statewide Assessments

NCLBA and IDEA are consistent in their commitment to student assessment. As such, students with disabilities are expected to participate in, and to have their scores counted in, statewide assessments and in performance measures such as the National Assessment of Educational Progress (NAEP). In this light, key questions surround when and how many students with disabilities are tested with alternative measures, and when and how many students with disabilities are excluded or exempted from the tests.

A July, 2005 GAO report to the ranking minority member of the Senate Committee on Health, Education, Labor and Pensions (HELP) found a high degree of student participation, concluding that some 95% of students participated in the test in the most recent academic year for which data were available. Two months after the issuance of this report (GAO 05-618), ED submitted additional data to GAO. Based on the work of the two agencies in analyzing these new data, GAO reported on October 28th that not 5% of students with disabilities as originally determined, but something like 40% of the students, had been excluded from the NAEP reading test in 2002. [76]

While ED is to be commended for its forthrightness in working with GAO to unearth these statistics, these new revelations are shocking by any measure. It is clearly unconscionable that so large a percentage of students with disabilities should be excluded from the computation of what is popularly known as the Nation's Report Card. Nearly as disconcerting is the fact that readily available data did not immediately and clearly disclose this fact.

While all surely hope that the percentage of excluded students has decreased in the subsequent three academic years, and that it will continue to do so, these shocking findings are sufficiently worrisome as to require urgent investigation, full explanation and implementation of corrective measures. Owing to its long-standing interest in this subject, the Senate HELP Committee should convene hearings into the participation rates of students with disabilities in NAEP and in related assessments under NCLBA.

(c) (2) Test Scoring

A related issue concerns how the scores of students with disabilities are computed and aggregated, when those students' scores are counted at all. For states eager to achieve the required levels of annual yearly progress (AYP) required by NCLBA, this question has emerged as one of potentially great significance.

States, school districts and in the end individual schools are required by NCLBA to demonstrate AYP. What AYP means is complex, but essentially it involves aggregate statistical progress in terms of the number of students achieving proficiency for their grade-level. Many districts and individual schools, particularly those with large enough special education cohorts to form definable subgroups, complained that these requirements would prove harmful to them. The assumption underlying these complaints was that special education students wouldn't or couldn't perform as well as other students, and that therefore aggregate results and progress toward achievement of AYP would be adversely affected by counting their scores.

Whether these concerns were well-taken and whether they reflect weaknesses in the NCLBA approach are beyond the scope of this report. However, federal sensitivity to them has resulted in a confused and shifting situation that has probably served none of the goals or interests involved.

As early as 2003, ED allowed for the scores of a certain number of special education students with the most significant cognitive disabilities, including those tested by alternative means, to be counted as proficient, whether or not they actually were. [77] Evidently, this was not enough to allay the concerns of some school officials, because in May, 2005 the Secretary of Education announced a formula, called the two percent rule, for use for one year only, that would allow scores to be adjusted for some students with moderate disabilities as well. [78] Under this one-

time formula, schools that failed to achieve AYP because of the scores of students with disabilities are allowed to adjust those scores, so that an additional number of students with “persistent academic disabilities,” equal to two percent of the students assessed in the grade in question, will be deemed proficient. This sounds and is complicated, but the point is that, according to data collected from a number of states including California, Virginia, Florida and Georgia, it significantly reduced the number of schools that failed, by reason of the scores of their students with disabilities, to achieve AYP.

By the time this annual status report is published, the 2005-06 school year will be complete, and the ED will likely have published regulations dealing with this issue on a long-term basis. NCD is not aware of what if any adjustments ED will make for 2006, but it is clear to all that ad hoc, temporary solutions cannot bring fairness, rationality or efficiency to the assessment process.

What remains unclear is how the seemingly intractable tension can be resolved between NCLBA emphasis on aggregate data and IDEA emphasis on the fashioning of individualized solutions and measures that achieve and document the maximum progress that each individual can attain. Fortunately, a balanced solution does appear to be in view. NCD recommends that in the formulation of rules governing inclusion of all students with disabilities in standardized AYP testing programs, emphasis be placed on identifying and recognizing the achievements of all students through the use of measures reflecting progress toward grade-level proficiency, though not necessarily at the same pace as would be expected of the general student population. If schools can demonstrate material progress by a sufficiently large proportion of their students with academic disabilities, this should represent AYP in ways that vindicate the objectives both of NCLBA and IDEA. NCD also reiterates its recommendation that efforts be undertaken to identify a range of accommodations applicable to students with various nonacademic disabilities, such as physical or sensory disabilities, and that efforts be undertaken to norm the use of these accommodations so that their routine provision will not distort the results of testing and so that no obstacles will be posed to the full and fair participation of all students with disabilities in the assessment process.

(c) (3) High School Graduation Rates

A 2005 GAO report casts grave doubt on the reliability of current data regarding high school graduation rates across our nation. [79] Because methods used by states to calculate graduation rates among the general student population vary widely, and because data are suspect, there is no reason to believe that our knowledge regarding graduation rates for students with disabilities is any more reliable. But so far as graduation is concerned, other issues are faced by these students.

Outside the scope of federal law but highly relevant to its objectives, a number of states have instituted exit exams which students are required to pass in order to receive high school diplomas. In at least one state, the requirement that all students pass this exit exam has resulted in litigation.

The Chapman case, brought under California law, challenges the exit exam as discriminatory and unfair to students with disabilities, because they had not necessarily been taught to the test curriculum in their special education placements and for a number of other reasons. A proposed settlement would temporarily exempt these students from the requirement, until better long-term arrangements could be made. [80]

Issues such as those raised in the Chapman case are important for a number of reasons. First, they dramatically illustrate the issue raised by all standardized testing. Second, they highlight the complicated interactions between federal and state law in the fashioning of education policy and the setting and meeting of outcome requirements.

This interaction between federal and state law is likely to cause confusion in a number of ways. The nature of due process protections available to students and their families is a prime example. The nature of requirements to graduate, as illustrated by the California case, is another.

Pending any reassessment by Congress and by the education community of the proper allocation of authority and responsibility between the federal government and the states, some clarification of the existing arrangements might be helpful to all stakeholders. For this reason, NCD recommends that ED Office of Civil Rights (OCR) undertake and disseminate a study of all intersections between state and federal law in the implementation of IDEA.

(d) Costs of Compliance

In Section (b) (2), above, we discussed the issue of full-funding as it relates to federal participation in the costs of special education. Now, the involvement of NCLBA adds a new dimension to the full funding debate.

States have widely protested the financial burdens they believe NCLBA imposes upon them. Whether or not such costs constitute impermissible unfunded mandates, at least one state (Utah) has threatened to adopt legislation restricting uncompensated compliance, [81] while another (Connecticut) is reported to have filed suit against the Federal government. [82]

Less discussed are the questions of special education costs attributable to NCLBA, and the accounting mechanisms used to track such costs as an element of overall compliance costs. NCD takes no position on whether states should receive additional funding to compensate for the costs they incur in implementing NCLBA. But the Council is concerned that if provision is made to help states meet their added NCLBA costs, those costs incurred in connection with special education compliance will not be omitted from the calculation.

Recommendations

Recommendation 3.1: NCD recommends that the Secretary of Education (ED) issue guidance to state directors of special education clarifying what the Schaffer decision does and does not mean, and making clear what federal regulations and expectations it may change.

Recommendation 3.2: NCD recommends that ED's Office of Special Education Programs (OSEP), through amendment to its proposed IDEA regulations or through instructional letters to state directors of special education, provide guidance on monitoring requirements, outcome goals and best practices in connection with efforts to reduce minority overrepresentation.

Recommendation 3.3: NCD recommends that Congress establish a national special education funding commission to identify creative and alternative strategies for supplementing existing federal funds for special education.

Recommendation 3.4: NCD recommends that Congress ask the Government Accountability Office (GAO) to study the ways that special education is represented to the taxpaying public in local communities around the country, and based on its findings make recommendations of how the important benefits and values of this national commitment can be incorporated into community outreach around educational issues.

Recommendation 3.5: NCD recommends that ED issue further guidance reflecting all the recognized pathways through which disability and behavior can be connected. These guidelines should make clear that behavior which is not intentional and not subject to volitional control should not be regarded as appropriate for a disciplinary or punitive response. The guidelines should also recognize how failures on the part of the school system, including failures to include various services in an IEP, can contribute to the buildup of frustrations that, in the absence of any other suitable method of expression, may manifest themselves in immature or inappropriate behavior or in disruptive ways.

Recommendation 3.6: NCD recommends that IDEA implementation regulations include provisions for the selection of mediators with specialized knowledge or expertise, where any party believes that the involvement of such persons would contribute to the success of the mediation process.

Recommendation 3.7: NCD recommends that in the formulation of rules governing inclusion of students with disabilities in standardized AYP testing programs, emphasis be placed on identifying and recognizing the achievements of all students through the use of measures reflecting progress toward grade-level proficiency, though not necessarily at the same pace as would be expected of the general student population. NCD also reiterates its recommendation that efforts be undertaken to identify a range of accommodations applicable to students with various nonacademic disabilities, such as physical or sensory disabilities, and that efforts be undertaken to norm the use of these accommodations so that their routine provision will not distort the results of testing and so that no obstacles will be posed to the full and fair participation of all students with disabilities in the assessment process.

Recommendation 3.8: NCD recommends that ED undertake and disseminate a study of all intersections between state and federal law in the implementation of IDEA.

Chapter Four—Health

Introduction

Building upon NCD's long-standing commitments and concerns in this vital area, this chapter addresses key issues in health care for people with disabilities that have emerged or come to the fore during 2005. The chapter begins with a discussion of health care disparities and their reporting, as these relate to people with disabilities. Next, in light of the major administration and congressional focus on curtailment in the growth of the Medicaid program, the chapter addresses the implications for people with disabilities of the work and findings of the national Medicaid Commission. Following this, the chapter addresses the continuing effort to obtain insurance parity for mental health treatment and to obtain equal treatment for people with mental health conditions. Finally, the chapter deals with a number of emerging issues connected to the problems faced by veterans returning from the service of their country with physical or psychological disabilities.

(a) Disparities in Health Care or Outcomes

In recent years numerous studies have documented the existence of differences in treatment patterns and patient outcomes. Some of these differences are regional, some based on predominant genetic makeup of people from various backgrounds. But others appear to correlate with economic status, with race or ethnicity, or with gender.

The existence of distinctions based on economics, age, gender or race have in turn given rise to debate over whether such distinctions constitute disparities, and if so what accounts for them and what can be done to reduce them. Until apparent disparities can be satisfactorily explained by other factors, statistical and demographic evidence of their existence must remain matters of great concern.

Any effort to deal with disparities must therefore begin with careful monitoring and solid empirical data. Recognizing this need, Congress in 1999 directed the Agency for Healthcare Research and Quality (AHRQ) to develop and prepare two annual health care monitoring reports,

the National Healthcare Quality Report and the National Healthcare Disparities Report. [83] The disparities report has been an important source of information regarding disparities associated with various factors including race and ethnicity. But the AHRQ disparities reports have not yet addressed disparities associated with disability.

This gap is particularly troubling in light of the fact that Congress has mandated the collection and inclusion of disability-related disparities data. This mandate was clearly set forth in the Health Care Research and Quality Act of 1999. [84] This gap is also of significance since it is well established that a major gap exists between people from culturally and linguistically diverse backgrounds. If, as it is suspected, there is a considerable overlap between the population subgroups (people with disabilities and people from diverse backgrounds), health policy makers should be able to address persistent gaps in health care access, coverage, and quality of care for a most vulnerable group of citizens.

NCD is gratified that efforts to include disability within the range of covered variables are currently underway. NCD recommends that Congress conduct hearings into AHRQ's processes to determine what if any statutory changes, budgetary appropriations or oversight reforms might expedite the achievement of health care quality and disparities monitoring practices that take our nation's more than 50 million citizens with disabilities fully into account.

Pending the development of the necessary data collection methods, several factors give rise to concern that serious disparities, materially affecting the quality of care and the character of outcomes, may be widespread. Settlements in two major civil rights cases, including the 2005 Washington Hospital Center case [85] and the earlier California Kaiser-Permanente case [86] have documented the inability of hospitals and other facilities to utilize the same diagnostic and treatment modalities for some patients with disabilities as would be used for the general public. Many factors appear to account for this, ranging from communications barriers to facility inaccessibility.

As documented by the work of the Rehabilitation Engineering and Research Center on Accessible Medical Instrumentation, equipment and apparatuses used in the diagnosis and

treatment of many conditions may often be inaccessible to (and therefore not usable by or for) people with various disabilities. [87]

Further recognition of disparities comes from the Department of Health and Human Services (DHHS). NCD wishes to commend the DHHS Office on Disability. As part of its preparation for DHHS' National Leadership Summit on Eliminating Racial and Ethnic Disparities in Health, scheduled for early January, 2006, the Office on Disability prepared a concept paper on addressing the health care and wellness needs of women of color with disabilities. [88]

(b) Medicaid

(b) (1) National Medicaid Commission

A large number of persons with disabilities rely on Medicaid for their health insurance and care. For this reason, changes in Medicaid are a subject that NCD has always followed closely. Moreover, Medicaid recipients with disabilities are widely perceived to have higher per capita health care costs than recipients without disabilities. In light of this perception, proposals for Medicaid reform that focus on program budgets or on limiting low-incidence discretionary Medicaid services are naturally also of concern.

(b) (1) (A.) The Commission Report

In May, 2005 the Secretary of Health and Human Services appointed a national Medicaid Commission [89] whose charter focused on the preparation of two reports. The first report, submitted on September 1st 2005, dealt with shorter-term budgetary issues, specifically with how to trim \$10 billion from the projected costs of the program over the next five years. The commission's second report, due at the end of 2006, will deal with long-term measures to assure the sustainability and effectiveness of the program.

As the commission's appointment makes clear, the escalating costs of Medicaid have become a serious budgetary problem for many states, and have dangerous long-term implications for our federal budget deficit. As such, the need for carefully-crafted cost-saving strategies is indisputable. NCD is eager to be of all possible assistance to the commission and to Congress in

identifying methods and approaches that will be responsive to the nation's fiscal concerns and that will minimize any hardship to Medicaid recipients with disabilities and their families.

With these goals in mind, NCD wishes to offer several observations concerning the six short-term cost-cutting recommendations made by the commission in its September, 2005 report. First, NCD is dismayed by the lack of any apparent effort to identify or to quantify potential effects upon health and quality of life that might arise from the particular strategies recommended by the commission, as opposed to the effects that might result from any number of alternative possible cost-cutting measures.

In the exercise of its statutory responsibility to provide feedback and advice to the President, Congress, and federal agencies, NCD's point here is that the impact of proposed cost-savings measures upon health care-delivery and health-outcomes should always be an integral part of discussions about Medicaid. In this light, the Council is concerned that the commission's initial report lacks any consistent recognition of the linkage between how we spend our money and the quality of care or nature of outcomes we achieve. A cut of \$10 billion, whether its details are specified by Congress or left largely to the states, will not be achievable through administrative savings alone. Whether implemented through caps on reimbursement rates, through restriction in eligibility or through narrowing in the definition of covered services, such cutbacks will result in the reduction or elimination of some or all care to real people. Imperative as these budget measures may be, it is surely not too much to ask that someone take responsibility for attempting to determine what their impact upon life and health will be.

No one believes that the availability of health insurance is unrelated to health outcomes. But where expenditure control is necessary, only an honest appraisal of these relationships can provide us with the knowledge necessary to implement the cuts in ways that will minimize the costs in life and suffering.

NCD does not presume to know the answer, but with such of the strategies recommended by the commission as increasing co-payments, the questions of how people will be affected and how they will be affected need to be asked in a manner that integrates substantive and budgetary decision-making.

(b) (1) (B.) Other Proposed Savings

NCD appreciates that the National Medicaid Commission was restricted in the range of cost-cutting measures it could consider. As the commission's report explains, it could only consider those reforms for which reliable cost-saving estimates were available, and such estimates were available only for proposed measures that had previously been "scored" by the Congressional Budget Office (CBO). [90] In the hope that 2006 will offer an opportunity for the commission, working with CMS and CBO, to score other proposals, NCD wishes to offer several ideas for potentially significant cost-savings that would have no adverse impact upon meeting the legitimate health care needs of those Americans who rely on Medicaid for their care.

NCD's principal recommendation in this regard derives from a 2005 Government Accountability Office (GAO) report which pointed out underinvestment of resources by the Centers for Medicare and Medicaid Services (CMS) in helping states to combat fraud, waste and abuse in the Medicaid program. [91] Senate testimony in June of 2005 by the CMS inspector-general indicates the agency's belief that it is performing effectively in this area. [92] It is not NCD's place to suggest whether a discrepancy exists in the views of the two agencies, let alone which is correct. What NCD does wish to suggest however is that strategies like fraud and abuse-control should, if possible, be included among the savings methods the national commission is authorized to consider.

Accordingly, NCD recommends that the national Medicaid Commission, working in conjunction with CMS and the CBO, broaden the range of cost-saving measures that can be considered in formulating Medicaid fiscal policy into the future.

(b) (1) (C.) Indirect Savings

Once again, depending on the difficulties of "scoring," NCD urges the commission to be given tools that will allow it to estimate costs and benefits to other programs and other budget categories that can reasonably be foreseen to result from proposed reforms. There are, for instance, a number of potential programmatic initiatives, particularly in the area of demonstration projects as discussed below, that would require short-term expenditure, but that would be undertaken because of the high likelihood of their yielding much larger long-term savings. The

commission should have the means and the mandate to recommend these as well, or at least to analyze the potential government-wide cost savings that could result.

Along similar lines, the costs of some potential savings also need to be accountable, if truly accurate projections are to be made. A great deal of attention has been focused in recent years on the growing financial pressures on many hospitals resulting from their provision of uncompensated care, or resulting from increasing demand for the services of their emergency departments. Even if these cannot be scored in the technical sense that public accounting standards require, plausible estimates can certainly be made regarding the impact of various Medicaid cuts on demand for emergency services or for the provision of other uncompensated care. One way or another, government will end up footing the bill for much of this care. Will these costs exceed the savings? No viable cost-cutting strategy can be developed without taking these potential offsetting costs into account.

(b) (2) Demonstration Projects and Waivers

Operating largely through waiver programs, states have been given increasing flexibility to experiment with creative strategies for addressing the issues confronting their Medicaid programs and their citizens who are involved in those programs. The Deficit Reduction Act of 2005 dramatically increases the authority of CMS to grant state requests for exceptions to normally applicable Medicaid rules. [93] At the same time as the authority of states to experiment and innovate is being broadened, national pilot and demonstration projects have continued to proliferate. Such initiatives as the life accounts demonstration, currently underway in two states, typify the exciting and diverse possibilities for innovative program development. [94]

Amid the possibilities though, the risk of confusion, of wasted efforts or of premature conclusions must also be frankly faced. These risks derive from a number of sources. These sources include: the interactions among programs that must mesh and cooperate in order to mount a successful demonstration; the number of agencies, jurisdictions and laws involved, and the lack of any central authority able or willing to resolve conflicts or inconsistencies among them; the difficulty of designing outcomes research and outcomes measures that allow for reliable comparisons of differing approaches and strategies; and the difficulty of providing the

necessary technical assistance and information to all interested parties and stakeholders on a timely basis.

In August, 2005 the Administration submitted the New Freedom Initiative Medicaid Demonstration Act to Congress. [95] This legislation, which will be further discussed Chapter Five of this report, proposes a number of national demonstrations aimed at reducing the use of nursing homes and enhancing the availability of community-based services, and aimed at reducing work disincentives affecting married couples. But ironically, if this legislation is passed (as NCD hopes it will be), it might actually have the ironic effect of creating further confusion in navigating the benefits system, and of running afoul of short-term cost-cutting imperatives.

The demonstration programs proposed by the Administration in this bill address some of the problems discussed in Subsections (b) (1) B and (b)(1) C, above. That is to say, they propose short-term expenditures for the sake of long-term, but not technically scorable, long-term savings. NCD commends the Administration for its willingness to go beyond the technical constraints of public accounting rules to take a leap of faith that common sense and common decency alike require. But without something else, these and other demonstrations are less likely to achieve or document their goals than should be the case.

A mechanism needs to be created whereby data are centrally collected and available regarding the existence and details of every demonstration and waiver program in operation. This mechanism should include procedures for identifying and resolving any inconsistencies between waiver or demonstration programs and the rules governing any other programs.

Accordingly, in this light NCD recommends that Congress establish a demonstration projects and waiver clearinghouse, covering programs under the jurisdiction of CMS, the Social Security Administration, and the VA. This clearinghouse should maintain and disseminate detailed descriptive, legal, comparative and other information on all demonstration and waiver programs operated under the Social Security Act by any of these agencies; should work to facilitate improved collaboration among these agencies; and should provide technical assistance and information as to the means for obtaining authoritative resolution of inter-agency or inter-program conflicts.

(b) (3) Emergency Medicaid

Along with almost every other major federal program, Medicaid was strained, tested and spotlighted by the tragedy of Hurricanes Katrina and Rita. Based on a CRS report [96] it is likely that future disasters will share one key characteristic of the hurricanes of 2005. Many of the uprooted and dislocated victims are likely to face mental health and substance abuse issues that are caused or worsened by their trauma. It will be critical therefore that the emergency Medicaid services available to these populations be expansive, including a broad range of mental health services that may be needed.

Since evacuees are unlikely to be in possession of personal documents, it is also important that presumptive eligibility be used. Where evacuees can present any plausible basis for believing they were Medicaid recipients, or where there is plausible reason to believe they may be eligible, such temporary recipient status should be granted.

Finally in this connection, the legislation should deal realistically with financial and other non-medical eligibility criteria and requirements. In such cases, especially where the emergency coverage is for a limited time, it is better to err on the side of inclusiveness than to attempt to apply tests that cannot have any practical meaning.

(c) *Mental Health Parity*

Addressed in NCD's recent annual status reports [97] and in other major NCD reports, [98] events during 2005 added renewed urgency to the effort to obtain equality in health care for those with mental illnesses to those with physical ones. These events include the introduction of a number of related bills in Congress [99] the impact of Hurricanes Katrina and Rita, and the growing recognition (discussed further in Subsection d, below) of the stress-related problems faced by many returning American service personnel.

The case for mental health parity, meaning for the extension of equal benefits and coverage for mental as for physical illness and treatments, has been made in detail in NCD's earlier reports. It is enough to reiterate here that none of the arguments against parity are predicated upon ethical or fairness grounds. That is, all of the opposition appears to be predicated upon economic

predictions such as that parity would drive up insurance costs and make all health coverage less available. Other arguments address not the rightness or fairness of parity but the undesirability of governmental intrusion in the private sector insurance marketplace.

From the public policy standpoint, the problem with these arguments is that they are wholly conjectural. None appears to have been confirmed by research or experience.

It is increasingly difficult to avoid the conclusion that the real basis for our failure to implement insurance parity is prejudice, either toward individuals who face mental health issues or toward the diagnoses themselves. In the face of the demonstrable harm caused by continued restriction of coverage, such prejudice can no longer be allowed to dictate public policy in our nation.

(d) Veterans Health

Until a few years ago, our major concerns with veterans' health care revolved around the provision of adequate resources and services for aging veterans, on coping with the lingering dysfunction still faced by many Vietnam vets, and with issues such as Gulf War syndrome affecting veterans of the 1991 Gulf War. Today a new generation of veterans and new health care issues have forced themselves to the forefront of our consciousness and concern. With fatalities fortunately reduced, we find ourselves facing the future with a new type and a new generation of Americans with disabilities.

(d) (1) A Parallel System

Health care for veterans with disabilities, beginning with health care for active-duty service personnel, is provided by a set of agencies and institutions that do not deal with the general public. The Department of Defense (DOD) and the Department of Veterans Affairs (VA) are the two principal entities involved. The people receiving medical care or rehabilitation services may be either regular military personnel, reservists or National Guard members, all of whom are entitled to slightly differing benefits and receive treatment and services in different ways. And disability may arise either during or after, potentially long after, a tour of duty with which its onset is connected.

(d) (2) Findings and Issues

Reports and studies issued by a number of sources during 2005 point up serious gaps in our nation's response to the needs of our veterans with disabilities.

(d) (2) (A.) Risk Monitoring

A July 2005 GAO report indicates serious weaknesses in the Department of Defense's (DOD) collection, reporting and utilization of occupational and environmental health and safety (OEHS) data. [100] Such data are critical in identifying exposures that could put service members at risk of suffering adverse health effects or of becoming disabled. Such data may also be crucial to the adjudication of individuals' claims for benefits or requests for services, insofar as they serve to document possible exposures. Needless to say, knowledge of such exposures can also be important for diagnosis and treatment.

Recommendations already made by GAO, and largely accepted by DOD and VA, are endorsed by NCD but need not be reiterated here. In addition, we suggest that in view of the acknowledged deficiencies in documenting environmental exposures, VA adopt procedures and requirements that place the burden of proof on government to demonstrate that no exposure occurred, in cases where alleged toxic exposures are asserted by service personnel to be a major contributing cause of disability, including of disability among spouses or children who may have experienced secondary exposure or who may have been genetically effected.

(d) (2) (B.) Transition Services

Traditionally, the term transition services has been used most often in connection with the movement of people from school to adult settings. More recently, it has also begun to be used to describe the movement from adult to senior services. Now the term has acquired yet another meaning. When we speak of transition here, we refer to the movement of an individual from DOD to VA health and rehabilitation services.

A May 2005 GAO report finds lack of data sharing between DOD and VA, resulting in VA's lacking key information on seriously injured veterans that is needed for them to obtain vocational rehabilitation or other services. The GAO report indicates that owing to this lack of key

information, the VA has been forced to rely on informal data sharing arrangements made between its regional offices and local military treatment facilities. Clearly, such arrangements are too haphazard, both in the information they provide and in when they provide it, to be regarded as a satisfactory solution to the problem.

While the lack of data sharing is an issue for all veterans, it is particularly harmful to veterans with disabilities who need vocational or other services from the VA. NCD recommends that Congress act swiftly to identify the measures or resources that would be required to assure a smooth and timely flow of relevant information from the DOD to the VA regarding seriously injured veterans, and that Congress then enact legislation ensuring that the necessary coordination will take place.

(d) (2) (C.) Post-Traumatic Stress Disorder

One of the greatest challenges to our nation in meeting the health care needs and in rehabilitating military service personnel is that of post-traumatic stress disorder (PTSD). In a February 14, 2005 release, GAO called upon DOD and VA to expedite implementation of recommendations for better addressing this problem. [101]

PTSD presents unique challenges to any health care or human-service system, and may require a substantial rethinking of our definition of disability. PTSD can be chronic and invisible, or it can be episodic. In the chronic state, coping strategies may keep it at bay, to the point where it would not necessarily meet predominant definitions of disability, such as that contained in the ADA. [102] In its episodic manifestations, while clearly limiting one or more major life functions, it may nevertheless be misconstrued as temporary, again resulting in limited application of prevailing statutory definitions of disability.

From the standpoint of VA services, the problems are of a practical and immediate nature. VA has accepted the existence and recognized the severity of PTSD, but according to GAO, implementation of these awareness may be complicated by difficulties in maintaining adequate contact with veterans who have PTSD, by issues in diagnosing the problem, by the need to anticipate resource needs, and by other factors.

The Institute of Medicine (IOM) has been studying PTSD on an ongoing basis for more than two years. [103] While recognizing that the diagnosis, treatment and prognosis of PTSD may in some cases be uncertain, and in all cases will be highly individualized, NCD recommends that Congress conduct further oversight hearings into the VA's understanding of the PTSD problem and into the agency's ability to deal with it effectively, and that all necessary resources be made available to enhance VA's work in this area.

Recommendations

Recommendation 4.1: NCD recommends that Congress conduct hearings into the practices of the of the Agency for Healthcare Research and Quality to determine what if any statutory changes, budget appropriations or oversight reforms might expedite the achievement of health care quality and disparities monitoring practices that take our nation's more than 50 million citizens with disabilities fully into account.

Recommendation 4.2: NCD recommends that the national Medicaid commission, working in conjunction with CMS and the CBO, broaden the range of cost-saving measures that can be considered in formulating Medicaid fiscal policy into the future.

Recommendation 4.3: NCD recommends that Congress establish a demonstration projects and waiver clearinghouse, covering the programs under the jurisdiction of CMS, the Social Security Administration, and the VA. This clearinghouse should maintain and disseminate detailed descriptive, legal, comparative and other information on all demonstration and waiver programs operated under the Social Security Act by any of these agencies; should work to facilitate improved collaboration among these agencies; and should provide technical assistance and information as to the means for obtaining authoritative resolution of inter-agency or inter-program conflicts.

Recommendation 4.4: NCD recommends that Congress act swiftly to identify the measures or resources that would be required to assure a smooth and timely flow of relevant information from the DOD to the VA regarding seriously injured veterans, and that Congress then enact legislation ensuring that the necessary coordination will take place.

Recommendation 4.5: NCD recommends that Congress conduct further oversight hearings into the VA's understanding of the PTSD problem and into the agency's ability to deal with it effectively, and that all necessary resources be made available to enhance VA's work in this area.

Chapter Five—Long-Term Services and Supports

Introduction

This chapter begins by reviewing the significant contributions made during the past year to our understanding and awareness of long-term services and supports. These include a major NCD study, *The State of 21st Century Long-Term Services and Supports: Financing and Systems Reform for Americans with Disabilities*. This report analyzes the demands that will be placed on the nation's long-term services and supports (LTSS) system in the coming decades; explains that persons needing and utilizing LTSS include not only persons over 65 but many younger persons as well; articulates goals that LTSS must meet; and suggests innovative funding partnerships and strategies to help bring an effective system into being.

The chapter then proceeds to detailed consideration, in light of the NCD study, some of the key distinctions, such as between medical, income maintenance and LTSS services and expenses that must be taken into account in designing LTSS policy for our nation. The chapter next proceeds to discuss the potential role for insurance in fashioning LTSS policy. On the assumption that an insurance-based system will represent the single most important funding source for an LTSS commitment, the chapter therefore discusses some of the goals and outcomes that such a system might seek to achieve.

After this, the chapter addresses the role of interagency coordination and demonstration programs in the gathering of key data. Finally, the chapter examines structural barriers to the full participation of people with disabilities in any future LTSS system, and recommends ways these can be overcome.

(a) Background

The solution to every major problem begins with recognition of its existence, and with the creation of a framework for its discussion. In that light, the year 2005 marks a watershed in America's recognition of the growing problem of long-term services and supports for its aging citizens and for many of its younger citizens with disabilities.

The year was marked by five major focal points of attention and thought. These are: (1) a National Academy of Social Insurance (NASI) blue-ribbon panel report calling for reform in the provision of long-term care and identifying the need for new commitments of federal funds; [104] (2) a Government Accountability Office (GAO) report on the financial demands on the federal government associated with the aging of the population; [105] (3) the President's Commission on Bioethics Report "Taking Care: Ethical Caregiving in an Aging Society;" [106] (4) The White House Conference on Aging; [107] and (5) NCD's report, "The State of 21st Century Long-Term Services and Supports: Financing and Systems Reform for Americans with Disabilities," released on December 15th [108].

The NASI and GAO reports provide new insight into the fiscal dimensions of LTSS in the 21st century, while the President's Commission report seeks concentrates on ethical dimensions of the policy. The White House Conference attempted to develop consensus around an updated understanding of the subject. NCD's report attempts to rectify what many regard as the omission of people with disabilities under the age of 65 from much of the discussion concerning LTSS.

The report states:

"Despite multiple studies by the Congressional Budget Office (CBO) and other federally sponsored research centers on the costs of long-term care for seniors, the population under age 65 with disabilities has not been a priority. The traditional definition of long-term care identified acute care needs as well as non-medical services and supports for seniors. Today's definition of long-term care has changed to reflect the ongoing growth and integration of disability into mainstream culture. LTSS for people 65 years and younger is about many non-medical services and supports, such as personal assistance, assistive technology, financial management, housing, transportation, and nutrition." [109]

The White House Conference on Aging (WHCOA) report is scheduled for release in 2006. Among the many findings, WHCOA learned that while there are many groups of aging baby boomers who are in need of services and/or supports, Native Americans face unique issues, for example:

“...priority for Tribes across Indian Country is how best to assist Elders to age well while remaining in their communities. The resolutions that address how to develop a coordinated approach to long term care, especially those implementation strategies that bring local, regional and national resources together to keep seniors in their homes are the most important to Tribal communities. With only 15 nursing homes throughout the 562 Tribes, the reality that an Elder must be cared for by the family and the community at large is often daunting given the lack of infrastructure present in most of Indian Country, such as adequate health care facilities, skilled health professionals, safe housing, trained caregivers, and varied transportation options.” [See the following url for more, http://www.whcoa.gov/press/gov_input/letters/NCAI_Garcia%20WHCoA%20LTR.pdf]

NCD’s report, which incorporates several of the White House Conference’s major recommendations, provides one of the most in-depth overviews and some of the most penetrating analysis of LTSS that have yet been produced. The report is indispensable background for anyone with interest in this area.

(b) Critical Distinctions

Public and policymaker attention in recent years has focused on the provision of health care to elderly or disabled persons, as evidenced by the attention accorded to the Medicare and Medicaid programs. Public and policymaker attention has also focused on income maintenance, as dramatically demonstrated by last year’s intense debate over restructuring of Social Security. But while access to medical care and to a sufficient cash flow is essential to effective long-term planning, these well-understood concepts do not define the scope of LTSS. LTSS, as NCD’s report makes clear, encompass a host of other non-medical and non-cash elements.

Perhaps Medicaid better than any other program reflects the difficulty but also the importance of distinguishing between medical and non-medical components of a services and supports continuum. Much of the controversy over Medicaid revolves around its non-medical components. As Medicaid’s role grows in the implementation of policy initiatives favoring home- and community-based services over institutional confinement, the tension between

traditional medical and innovative community-based services is likely to increase. As consumer-control and consumer-satisfaction also come into more widespread use, even in regard to the choice of medical services, the difficulties in defining and implementing a national LTSS agenda can only become more acute.

Faced with the need for a continuum of services and supports that extends from traditional medical to innovative non-medical services and interventions, our nation must either greatly expand the definition of medical services, so as to encompass a variety of community- and home-based supports, or we must find sources and strategies outside Medicaid, Medicare and the private health insurance system for meeting emerging LTSS needs and costs.

Our policymakers have at their disposal many sets of goals for America's health care. They range from plans and targets emanating from the Centers for Medicare and Medicaid Services (CMS) to the guidelines and blueprints offered in the Center for Disease Control and Prevention's (CDC) Healthy People reports. We have targets for the reduction of various diseases, for lowering rates of smoking, for curbing alcoholism and drug use, and for measuring our progress toward success in dealing with a number of pathologies or achieving a number of health-related goals. Yet by contrast, consensus goals, timetables, overarching plans, and locus of authority within government have yet to be established for meeting, let alone for defining, our nation's LTSS needs and objectives.

Beyond defining the nature of LTSS, significant time and attention will need to be devoted to the amounts of such services that will be needed, to what people can expect by way of services and supports, and of course to how the costs of this potentially vast array of new commitments and expectations can be met. Against this backdrop, the NCD report offers a new paradigm, a new vision and indeed a new vocabulary for thinking and talking about LTSS.

(c) Insurance

While widespread consensus has yet to emerge about many things having to do with LTSS, there is one point on which most of those who have studied the subject appear to agree. That point is that some sort of insurance-based approach, combining public and private resources;

incentivizing personal savings but not punishing those who lack the breathing-room to save; effectively leveraging government, private sector and individual resources; and preserving individual dignity, flexibility and choice will be required. In this connection, GAO released in 2005 an overview of one model that has been tried, long-term care partnership insurance. [110] This combination of private insurance and Medicaid may well represent one component of a model that can serve as a starting point for the daunting effort to design a system that will be fair, affordable and effective.

But existing insurance structures and assumptions cannot meet the emerging need. While it may be useful to retain a connection between Medicaid and nursing home care, the range of services implicated in LTSS go far beyond the medical care system. For this reason, NCD has set forth in its LTSS report cited above a new model for LTSS, the AmeriWell model. [111]

Explaining the background to this innovative proposal, NCD's report notes, "people who are elderly and people with disabilities both desire and deserve choices when seeking assistance with daily living that maintains their self-determination and maximum dignity and independence. [t]he current financing mechanisms (public and private) will become unsustainable in the near future without significant reform. The system must be affordable to all Americans regardless of income levels and must consider opportunities to leverage public and private support in new ways without impoverishing beneficiaries. [T]here is an opportunity with the changing demographic picture of the United States to explore the possibilities of a universal approach to the design and financing of supports that is responsive to individuals under the age of 65, as well as Americans over 65 who may or may not have disabilities, without sacrificing individual choice and flexibility. [F]ormal and informal caregiving must be sustained, including examination of family needs and workforce recruitment and retention challenges. [T]he approach to quality must examine consumer direction and control of resources in addition to traditional external quality assurance mechanisms. "AmeriWell" is designed "to" provide LTSS for all Americans regardless of income or category of disability through innovative funding from individuals and families, the private sector; and the Federal Government. AmeriWell will delink aging and disability populations from both Medicaid and Medicare that require LTSS to form a

new LTSS program that provides services and supports to middle- and low-income Americans with disabilities.”

NCD recommends that Congress create a high-level national commission, composed of representatives of all relevant stakeholder groups, including the insurance industry, the consumer movement, geriatric and rehabilitation professionals, state government, the employer community, and persons with disabilities, to generate the broadest possible discussion of the issues and options for an effective approach to defining and funding a national LTSS response, and with particular attention to the analysis and feasibility of the AmeriWell approach. This commission should take testimony and hold hearings throughout the country, in a variety of venues, focusing on all aspects of the problem. Its charter should include ample time for the summarization of opinions, the production of discussion documents and working papers, the receipt of feedback, and the building of broad-based consensus that can command a high degree of support from across the political spectrum from all those who recognize the looming crisis foreshadowed by our unmet needs for LTSS.

In addressing questions of what the components of LTSS should be, NCD urges that the commission take as its point of departure the goals and values set forth in our report, and that we believe most Americans share in common as aspirations for themselves and their families. Some of the key values are set forth below.

(c) (1) Quality of Life

Ultimately, the question of what constitutes appropriate LTSS may come down to a question of what constitutes a minimally acceptable quality of life. NCD has addressed this question in its Livable Communities report, [112] wherein the features that make communities viable for people with disabilities are addressed. As this touchstone makes clear, preservation of options for community-based living must be the primary objective of any LTSS system. What goods and services LTSS should cover should largely be predicated upon the achievement of this goal.

As it relates to existing service programs or funding streams such as Medicaid, this definition of quality of life means that we should pursue policies aimed at rebalancing our investments in institutional versus community-based services. The precise methods for doing this are complex

and beyond the scope of this report. Suffice it to say, federal programs, such as several of the ten-year experiments recommended by the Administration in its NFI demonstrations proposal of August 2005, [113] could help do this in several ways. They could help do this by reimbursing states at higher rates for expenditures incurred in establishing community-based alternatives and programs. They could do this by allowing the waiver of provisions that limit eligibility or that disproportionately limit payment rates for community-based services, in comparison to institutional ones. And they could help do this in a number of other ways as well.

In this connection, as an interim but no less vital step, NCD recommends the expansion of money follows the person (MFP) type programs, both through legislation and through the exercise by federal agencies of their demonstration program authority. [114] Beyond this, NCD recommends that Congress instruct the DHHS and CMS to conduct research into all barriers in the Medicaid and Medicare programs in order to heighten use of community-based alternatives, including research designed to identify the complete range of fiscal consequences that would accrue to all agencies and levels of government if these barriers were removed.

(c) (2) Consumer Control

Many reasons exist for believing that increased control by individuals over the choices of goods and services they receive will lead to higher levels of satisfaction and improved levels of dignity and choice. In addition, good reasons exist for believing that greater consumer control will lead to enhanced coping skills and to objectively better outcomes in terms of health, function, community integration and overall well-being.

In developing such programs, the natural wariness of many Medicaid recipients (as well as by recipients under other needs-based programs) must be taken fully and candidly into account. Unless participants are assured of running no risks of loss or curtailment of benefits under Medicaid or related programs, their ability to benefit and their willingness to take part in consumer-control or individual-budget demonstrations may be severely compromised.

Such concerns on the part of Medicaid beneficiaries or persons receiving benefits under other needs-based programs are an extension of the work disincentives problem that is well-known in the vocational setting. As much as people may value greater autonomy and control in their

selection of services and use of funds, the perception, and in many cases the reality, of potentially offsetting benefit losses in other areas poses major barriers to participation.

From the public's standpoint, one reason for supporting consumer-directed services may well be the potential of such services to yield high quality results at lower cost. One method for achieving such results involves creation of financial incentives for participants who manage to save some of their self-directed funds. The opportunity to retain some unexpended funds could be a significant incentive for careful stewardship and wise decision-making, but again, unless it is accompanied by assurances that offsetting cuts to other means-tested benefits will not result, the opportunity can hold little attraction.

In order to design programs that incentivize LTSS partnership-creation and interagency cooperation, NCD believes that the interconnection of various services and benefit programs must be more fully and comprehensively addressed than has generally been the case. Today, all too many statutes and programs are relatively self-contained, including no real coordination with or awareness of the implications for other laws and their rules. This need for real program coordination, including integrated rulemaking and the adoption of multi-program waivers, will become increasingly necessary as LTSS initiatives and related asset-development initiatives are extended to persons with disabilities.

(c) (3) Asset Development

If individuals can be encouraged and assisted to build their own financial assets, it should prove possible to correspondingly reduce the need for governmental or third-party funding as part of the LTSS program. As traditional expectations of employment erode, including fringe benefits, health care, job-tenure and career-track, the importance of asset-building strategies also becomes greater.

Over the past ten years, our efforts to curtail welfare and encourage all people who can work to do so have been paralleled by efforts to assist persons to obtain or retain funds that can be used as the basis for retirement savings, home ownership, business development, higher education or the achievement of other personal or family goals. Such concepts as individual development accounts (IDA's) [115] perhaps best represent this line of reasoning, as do the numerous avenues

for tax-deferred, goal-oriented savings that have been added to the tax law over the past decade. [116]

In 2004, the National Institute on Disability and Rehabilitation Research (NIDRR) entered into a contract with a consortium led by the University of Iowa Law, Health Policy and Disability Center (LHPDC) to study and demonstrate methods for bringing the benefits of asset accumulation to persons with disabilities. Although this multi-centered effort is still actively engaged in its work, some findings have already begun to emerge with clarity. Chief among these is that asset accumulation cannot be a realistic tool for upward mobility of persons with disabilities, unless the impact of means-testing under a variety of interrelated programs is addressed. So long as the price of asset accumulation is offsetting loss of needed benefits (or even simply the fear of such loss), and so long as this loss of benefits typically occurs long before assets can be accumulated at anywhere near the levels needed for self-sufficiency goals, the role of asset accumulation in the lives of many people with disabilities is likely to be illusory. Yet, without a meaningful and effective commitment to asset accumulation, the goals of LTSS are also likely to be more difficult to achieve.

Recommendations

Recommendation 5.1: NCD recommends that Congress create a high-level national commission, composed of representatives of all relevant stakeholder groups, including the insurance industry, the consumer movement, geriatric and rehabilitation professionals, state government, the employer community, and persons with disabilities, to generate the broadest possible discussion of the issues and options for an effective approach to defining and funding a national LTSS response, and with particular attention to the analysis and feasibility of the AmeriWell approach.

Recommendation 5.2: NCD recommends the expansion of money follows the person (MFP) type programs, both through legislation and through the exercise by federal agencies of their demonstration program authority.

Recommendation 5.3: NCD recommends that Congress instruct the DHHS and CMS to conduct research into all barriers in the Medicaid and Medicare programs to the heightened use of

community-based alternatives, including research designed to identify the complete range of fiscal consequences that would accrue to all agencies and levels of government if these barriers were removed.

Chapter Six—Children and Youth

Introduction

The line between chapters dealing with education or health or long-term services and supports, on the one hand, and a chapter dealing with youth, on the other, is never easy to draw. After all, developments in health, housing, transportation and of course education inevitably effect children and youth, as they effect all members of society.

Nevertheless, particular issues can be identified that are of specific relevance or particular importance to children. It is the issues falling within these categories that this chapter tries to address. In that light, this chapter begins by revisiting the urgent questions surrounding the overuse of juvenile detention facilities as placements for children who need treatment. It then goes on to consider a number of issues in the child welfare system. Next it considers developments in the foster care and adoption areas.

(a) Juvenile Detention

No one disputes, however tragic that it should be so, that some delinquents must be incarcerated. Though young, some offenders undoubtedly pose a risk of harm or show a lack of maturity that requires their confinement for their own and society's protection. But as last year's status report documented, there are many children and youth being held in juvenile detention facilities in this country, as if they were convicted or suspected criminals, who in fact are neither guilty nor accused of any crime, and who are in need of mental health services or other community supports.

For those wishing further background information on this urgent problem, NCD recommends review of last year's report and the sources cited therein. For the moment it is enough to note that in 2005, no major steps to address and alleviate this problem are known to have taken place at the federal level.

Faced with the continuation of what NCD believes to be the unconscionable practice of holding children and youth in quasi-criminal confinement, a disproportionate percentage of whom are from culturally diverse backgrounds, the Council urgently calls upon Congress to initiate hearings on the subject, with a view to the expeditious identification and provision of strategies and resources for assuring the availability of appropriate placement alternatives.

In the meantime, NCD urges the Department of Justice (DOJ) to pursue vigorous monitoring of state and local juvenile detention facilities to ensure their compliance with all applicable child-protective laws. Reports during 2005 concerning DOJ investigation of possible abuses of children in Baltimore detention facilities, [117] and other reports highlighting problems in Maryland's system of juvenile detention [118] serve to remind us of the urgency of these issues and of the indispensability of a strong federal leadership role.

(b) Foster Care and Adoption

A web of federal programs undergirds our nation's foster care and adoption systems. Major legislation establishes clear federal policy in favor of maximizing stability and permanency in the lives of children. [119] Laws provide resources for use by states in providing financial assistance to foster and in some cases adoptive families on a needs-based rationale, [120] and states themselves are eligible for financial rewards for maximizing the number of foster children who are adopted. [121] At the same time, the income tax law seeks to subsidize adoptions.[122]

Despite this intricate web of measures, policies, reporting requirements and funding streams, there is strong ground for concern that the foster care and adoption system are failing to meet the needs of many children in fundamental and unacceptable ways. Concerns about this system—including concerns about its ability to achieve adoptions for the greatest possible number of children, its capacity to achieve outcomes in a timely manner, and its capabilities to generate adequate data for monitoring and oversight—have been increasingly widespread and vociferous. Most recently, a June 2005 Government Accountability Office (GAO) report raises and reinforces concerns about many aspects of the system. [123] These findings are of particular concern to children with disabilities, because among the “special-needs” child population, a

substantial portion are surely children with disabilities or with health problems or vulnerabilities likely to eventuate in disabilities if preemptive measures are not taken.

(b) (1) Data Collection and Monitoring

Echoing concerns voiced by NCD in last year's status report, [124] GAO this year found that data available from the states and evaluations conducted or sponsored by the Department of Health and Human Services (HHS) are in many instances inadequate or not reliable.

(b) (2) Adoption Assistance Program

Questions were raised by GAO regarding the effectiveness of the Adoption Assistance Program in facilitating the adoption of special-needs children, including children with disabilities. Here the main question related to the adequacy of subsidies paid to adoptive parents, and in a related vein to the existence and efficacy of post-adoption services available to families.

GAO did not consider the tax benefits available to adoptive parents. NCD has previously commented on the adoption tax incentive, suggesting that its fixed amount deprives it of the flexibility to be maximally useful. As a fixed \$10,000 amount, it may well be too large for some families to absorb, and too small to accurately reflect the legitimate expenses incurred by other families, particularly by families who adopt children with significant disabilities or complex medical involvements.

(b) (3) Adoption Incentive Program

GAO found problems with the Adoption Incentive Program, including apparent barriers to interstate adoption. The Adoption Incentive Program seeks to reward states with funding bonuses for increasing the numbers of foster care children moved to permanent, adoptive homes. [125] Unfortunately, no mechanism appears to exist for allocating incentive credits between states in cases of interstate adoption. If the incentive program is deemed effective in stimulating in-state adoptions, then NCD recommends its governing rules be modified so that interstate cooperation will be fully recognized and equally encouraged.

(c) Comprehensive Health Insurance

At first glance one might think of health insurance as a matter for consideration under the health care rubric. But for children, access to health care is more than just a medical matter. Virtually every facet of children's lives is influenced, if not determined, by access to preventive, diagnostic and treatment services.

Our nation has thus far made no commitment to the coverage of all children. Programs such as Medicaid and SCHIP provide coverage to many lower income children who meet economic and other eligibility criteria, but many children remain outside the scope of these or other insurance programs. A simple approach, requiring less outreach by states and imposing fewer demands and complexities upon hard-pressed families, may represent the only means of assuring coverage for all children.

The model for such a program should be Medicare. Coverage under Medicare is virtually automatic and is easily obtained for persons over the age of 65. It is time that a similar model is implemented at the other end of the age spectrum.

From the standpoint of disability, NCD believes that comprehensive coverage of children, including the range of modalities and services currently available to those who qualify under the early periodic screening, diagnosis and treatment (EPSDT) component of Medicaid, [126] could make a substantial contribution to the prevention of disability in later life. If a significant commitment to health education were incorporated in the program, the savings overtime would be even greater.

NCD recognizes that political and economic considerations, including the nation's looming budget deficit, may combine to render immediate enactment of such a program difficult. Nonetheless, we believe that legislation along these lines introduced during 2005 in the first session of the 109th Congress [127] is worthy of serious consideration. NCD recommends that joint congressional hearings be held to identify what the projected costs and benefits to society would be of a comprehensive program of health insurance for all children, aimed especially at

identifying and forestalling conditions and risk factors that portend the prospect of disability in later life.

Recommendations

Recommendation 6.1: NCD recommends that Congress initiate hearings on the subject of inappropriate confinement of children and youth, with a view to the expeditious identification and provision of strategies and resources for assuring the availability of appropriate placement alternatives.

Recommendation 6.2: NCD recommends that Congress modify the rules governing the Adoption Incentive Program so that states will have as much financial incentive to cooperate in interstate adoptions as they do in facilitating in-state adoptions.

Recommendation 6.3: NCD recommends that joint congressional hearings be held to identify what the projected costs and benefits to society would be of a comprehensive program of health insurance for all children, aimed especially at identifying and forestalling conditions and risk factors that may affect the prospect of disability in later life.

Chapter Seven—Employment

Introduction

Of all the topics covered by NCD's reports, and of all the subjects of importance in the lives of Americans with disabilities, perhaps none is more complex than employment.

Employment's complexity arises from three principal factors that make it unique. First, unlike education where we have embraced mainstreaming as a goal wherever possible, we maintain two parallel employment systems for people with disabilities. One of these, the state-federal vocational rehabilitation system (VR) is specifically designed to facilitate employment for people with disabilities, while the other, the one-stop career development system, is designed to serve all job seekers including those with disabilities. The comparative operations of these two systems give rise to many questions, options and interactions.

The difficulties of combining the resources and capabilities of these two service systems are further complicated by the second unique factor that we face in addressing the subject of employment. That is the interplay between these two employment programs and at least three other major service systems. These are: the Social Security system (which administers the Social Security Disability Insurance (SSDI) and Supplemental Security Income (SSI) programs); The Centers for Medicare and Medicaid Services (CMS) and state Medicaid agencies (which administer the public Medicare and Medicaid health insurance systems on which many job seekers with disabilities depend for medical coverage); and The Ticket to Work and Self-sufficiency program (which provides training and job search alternatives to recipients of SSDI and SSI benefits with disabilities) including provisions for minimizing the disincentives to working that characterize the needs-based income maintenance and health insurance programs.

The third element that makes employment so perplexing and unique is the relationship between the service system and employers. In education, decisions about needs are made by the same people who provide the services. The same educational system and officials who are responsible for outcomes are charged with responsibility for determining what services are needed to achieve

those outcomes. But in employment, the service systems that train and equip people for jobs and the employers who provide those jobs are by no means the same. Although various mechanisms have been tried for involving employers in the design of vocational development programs and incorporating employer experience, evaluations and needs into these programs, consistently reliable means for anticipating and providing what employers and the labor market need and want remain elusive. In a rapidly shifting technology and economy, this task grows more difficult with the passage of time.

Within this framework, this chapter considers a number of developments that occurred during 2005, and updates key concerns addressed in prior NCD reports. It begins with a discussion of employment statistics, as they relate to the development of policy in the employment area. The chapter next considers developments in the VR system. Then attention is directed to efforts aimed at ensuring the accessibility of the mainstream workforce development system to job seekers with disabilities. Following this, the chapter addresses experimental programs designed to ease work-disincentives to employment faced by people with disabilities. After this, outreach to employers and antidiscrimination in employment are discussed. Finally, innovative strategies for using the federal procurement and contracting processes to enhance employment and tenure of people with disabilities are suggested.

It should be noted that action on a long-term reauthorization of the Workforce Investment Act (WIA) is still awaited in Congress. Since NCD cannot know whether a new law will be enacted by the release date of this report, our recommendations attempt wherever possible to address actions which Congress or executive branch agencies could take, either as part of the reauthorization, by separate statute, or without the need for legislation by administrative action.

(a) The Continuing Statistical Problem

One problem that continues to bedevil policymakers is the lack of consistent, reliable and timely data concerning how well we are doing. In theory, the question should be simple. How many people of working-age with disabilities are working, and what proportion are they of the number who want to work? But lurking behind these seemingly straightforward questions are a host of exceedingly difficult issues, ranging from how disability should be defined, to how many

working-age people with disabilities there are, to how many of these in turn are available for work.

Issues pertaining to these and other statistics are addressed in Chapter One of this report. In the meantime, it is important to reiterate three troubling points. First, reliable data available from the Social Security Administration (SSA) show that only a tiny fraction of SSDI recipients (people who left the workforce on account of disability) return to work. [128] Second, although there is controversy, a number of leading experts believe that employment rates have not improved, but may actually have declined, over the past two decades, and that rates did not show major improvement during even periods of historically low unemployment in the late 1990's. Third, despite reports and studies, including several cited below, that attempt to improve the coordination among and the accountability of federal vocational development and job placement programs, the government does not have and OMB has not developed an effective mechanism for holding all the involved programs collectively responsible for the ultimate outcome of their efforts, namely, for whether more people with disabilities are working.

(b) The Vocational Rehabilitation System

(b) (1) Performance Monitoring

In September, 2005 the Government Accountability Office (GAO) issued a report "Vocational Rehabilitation: Better Measures and Monitoring Could Improve the Performance of the VR Program." [129] In this report, GAO made recommendations, most agreed to by the Education Department (ED) according to the report, regarding the need for improving performance measures and monitoring practices used in managing the VR program. NCD applauds ED's responsiveness, and the Council stands ready to be of all possible assistance to the department in applying national standards and uniform criteria to a necessarily diverse service system that accommodates and encourages state diversity and responsiveness to local conditions.

Although GAO did not draw any direct connection between the performance data or monitoring procedures ED uses and the outcomes achieved by recipients of VR services, its report did attempt to determine the extent to which recipients of VR services obtain or maintain employment. For the latest fiscal year (2003) for which data were available, GAO found that

approximately one-third of persons exiting the program did so as employed persons. Of those who did not obtain employment, by far the largest group were found to be comprised of persons who had declined offered services or who had lost contact with the VR agency.

These findings are important, but they also raise many questions going to the heart of the VR system and bearing heavily on its design and operation in the 21st century. While there is apparently some correlation between successful outcomes and the amount of service provided, questions about the mix of services in relation to outcomes remain to be explored. So too do such questions as whether the 90-day post-program follow-up period currently used to measure outcome success is adequate to assess the effectiveness or outcome of services, given the longer duration of many probationary periods for new employees.

As suggested in last year's NCD progress report, NCD believes that further in-depth research into who succeeds and why would shed much light on the types and mix of service the VR system should offer and on the best allocation of the system's resources. For example, it seems probable that heightened investments in assistive technology (AT) devices or services might yield increased rates of employment.

In this connection, GAO was able to determine expenditure levels by type of service. Among other findings, GAO determined that assessment, counseling, guidance and placement were the primary VR services on which state VR agencies expended their case-services funds. Little money, not more than one percent, was spent on postemployment services (meaning services designed to assist already-employed persons in maintaining or advancing in employment). As significant, GAO reported that one factor in the levels of investment in postemployment services may be the belief on the part of some state VR officials that the reporting system does not fully recognize these interventions as successful outcomes. Yet it could well be the case that the number of jobs preserved or the increase in earnings resulting from each dollar invested in postemployment services or in AT are comparatively high.

Accordingly, NCD recommends that the House Committee on Education and the Workforce and the Senate HELP Committee request that GAO continue and deepen this study by carrying out detailed research into how particular VR services correlate with successful outcomes and into

how existing definitions of successful case outcomes may influence the range and content of services provided in the field.

(b) (2) Waiting Lists

In March 2005 NCD offered thoughtful and extensive recommendations to Congress in its reauthorization of the WIA, in its paper, “Workforce Reauthorization Act Recommendations.” [130] Anyone concerned with the issues surrounding employment of Americans with disabilities is urged to review this paper. One of the issues discussed, relating specifically to the VR system, has persisted and potentially grown more serious over a number of years. This is the problem of delays in the provision of VR service due to orders-of-selection.

Although VR is an approximately \$2.5 billion program, adjusted for inflation through a COLA, it has become apparent in recent years that the combination of federal funds and state matching funds available to the program have proved insufficient to meet the needs of all eligible individuals.

Far from either ignoring or remedying this situation, Congress has dealt with it by providing a mechanism, known as order of selection, whereby states can establish modified selection criteria that allow them to concentrate their available resources on persons with most significant disabilities. [131] But whether even all persons with most-significant disabilities are being served in every state cannot be known with certainty. Depending on the severity of the funding shortfall, the length of waiting periods involved and other factors, it is possible that even some people with most-significant disabilities will not receive services within timeframes that meet their needs or allow them to take advantage of real-time opportunities. While literal and permanent denial of service does not occur, the practical consequences of order-of-selection may amount to just that in some cases.

As NCD’s WIA reauthorization recommendations paper notes: “Data has consistently reflected that each year the state VR systems are unable to serve a majority of individuals eligible for services. As a result, Order of Selection within VR means that many individuals with disabilities are unable to receive much needed services to become competitively employed.”

While no one knows what proportion of such eligible persons would have sought services or achieved stable competitive employment through them, the existence of conditions in which so many people are denied the resources and opportunities of VR is unacceptable. It is assumed that some of those who cannot obtain VR services in a timely manner will nevertheless receive meaningful assistance through the one-stop system. However, VR's role as a mandatory partner to the one-stop system means that where order-of-selection prevails, VR's ability to provide supportive services to the one-stops may well also be compromised, thereby negatively impacting the capacity of the one-stops to serve job-seekers with disabilities as well.

The time for determining the full impact of these service delays is definitely at hand, and the time for addressing the problem straightforwardly and effectively is now. NCD believes that order-of-selection policies may represent an inadequate response to underfunding problems that limit the ability of the VR system to serve growing numbers of applicants for service.

Accordingly, NCD recommends that ED's Office of Special Education and Rehabilitative Services (OSERS) convene a high-level task force, including the Office of Management and Budget (OMB), the Council of State Administrators of Vocational Rehabilitation (CSAVR), the National Council of State Agencies for the Blind (NCSAB), the Department of Labor's (DOL) Office of Disability Employment Policy (ODEP), and representatives of the rehabilitation service consumer community. This task force should make recommendations to Congress on behalf of the administration regarding statutory or funding formula changes, or budgetary appropriations required to bring about the progressive reduction and ultimate elimination of undue service delays for persons with significant disabilities.

(c) One-Stop Centers

The WIA was intended to rationalize the federal employment development and job assistance systems. One key element of this effort was the creation of local workforce investment boards (WIB) to guide partnership efforts of the public and private sectors in communities across the country. Another key element was the consolidation of resources and programs within one-stop centers where, as their name suggests, job seekers and employers alike could find an array of resources and services in one place, working together.

(c) (1) Accessibility

Consistent with comprehensive services was inclusiveness. As set forth in Section 188 of the Act, [132] the law was clear and unambiguous in requiring the services of the one-stop centers to be available to job seekers with disabilities on terms of equality with all other persons. From the beginning, many problems have been identified in achieving full physical-, communications- and program-accessibility of the one-stops. Lack of sufficient dedicated resources for the implementation of accessible design or the procurement of access technology, lack of knowledge on the part of one-stop personnel as to the particular needs of job seekers with disabilities or of the specialized services available to them, and concerns relating to the comparative cost and difficulty of finding employment for people with disabilities are among the most pervasive.

NCD commends the significant amount of technical assistance that has been made available to state workforce development system, local workforce investment boards, and one-stop centers. Illustrative of this assistance is the accessibility checklist published by the DOL in 2004. But based on several research studies cited in NCD's March WIA recommendations, [133] NCD remains concerned.

In light of the problems of funding, awareness and problems arising from the use of quantitative accountability-standards that reward number of people served over quality of outcomes, NCD believes that additional measures aimed at enforcement of the law must accompany continued training and technical assistance efforts. Accordingly, NCD reiterates the following recommendations, contained in its March paper. NCD recommends that DOL establish and publicize a complaint procedure for use by individuals who have been denied access, intentionally or by reason of inaccessibility, to one-stop facilities, resources or services; that DOL incorporate accessibility guarantees in requirements for state workforce development plans and funding; and that DOL insist on inclusion of representatives of people with disabilities (or at least of state VR agencies as mandatory partners under the law) on state and local Workforce Investment Boards.

(c) (2) Community Partners

As central as the one-stop centers are to the vision of a coherent national employment development system, these centers are still only one link in a long chain. To achieve their goals and to effectively serve the interests of workers, employers and taxpayers, they must work cooperatively with a variety of partners. A number of these partners, so-called mandatory partners such as the state VR system, are specified in the law, while many other partners, including employers and various nonprofit groups, are voluntary or community partners. Just as the one-stops cannot serve people without disabilities in isolation from the level and quality of service that their partners offer, so too these centers cannot address accessibility in a vacuum. Just as they are the recipients of technical assistance, so must they be its source.

Means need to be found for encouraging and assisting one-stops to expect and obtain the highest possible levels of accessibility from their partners and from the entities to whom they refer people for training, services or jobs. NCD cannot here recommend the precise measures that would best facilitate these efforts. As recommended in previous reports, NCD believes the effort must begin with detailed surveys of the experience of one-stops themselves and of their customers with disabilities in seeking or finding accessibility among one-stop partners in their communities.

Accordingly, NCD recommends that the ODEP undertake research at a cross-section of one-stop centers throughout the country, and with a group of volunteer service recipients recruited through publicizing of the study to determine the extent of accessibility, reasonable accommodations and nondiscrimination among one-stop partners, and to determine the impact of inaccessibility upon the ability of one-stop customers with disabilities to obtain employment.

(c) (3) Disability Navigator Program

As noted above, lack of information on the part of one-stop center staff is a major barrier to the provision of effective service to people with disabilities. While it would be desirable for one-stop staff to be fully familiar with the accommodation needs and AT options associated with successful employment of people with various disabilities, and while it would be desirable for one-stop staff to be knowledgeable about the range of specialized services available on behalf of

these individuals and their prospective employers, it is unrealistic to expect this to occur. The many demands on one-stop center resources underscore the difficulty.

To help fill this gap and to facilitate the coordination and availability of key information and resources, an interesting and potentially important experimental program has been launched with the support of the Social Security Administration (SSA). This is the disability navigator program. [134]

As its name suggests, the program places navigators in one-stops to assist their staffs and service-recipients in maximizing the potential benefits and services available from both mainstream and specialized sources. As an experiment, the disability navigator program is under close evaluation. Results are expected in 2006. If as NCD hopes the findings indicate that the navigator program is effective in securing better and more timely utilization of resources, and that it contributes to better outcomes, then NCD recommends it be made a permanent part of the nation's workforce development system.

(d) Social Security Initiatives

Social Security Disability Insurance (SSDI) and Supplemental Security Income (SSI) protect many unemployed persons with disabilities against the worst ravages of destitution. But it has become increasingly clear that these programs, because of their complex and strict eligibility requirements, and because of the connection through Medicare and Medicaid to health insurance, also operate to prevent many people from finding or returning to work.

As described most recently in NCD's November, 2005 report "The Social Security Administration's Efforts to Promote Employment for People with Disabilities: New Solutions for Old Problems," [135] these work disincentives can be summarized as follows: These programs are designed on the premise that disability and inability to work are synonymous. This means that if a person can work or does earn income, that person's eligibility for cash benefits or for linked medical insurance is potentially jeopardized. Because cash benefits decline and cease at earnings levels far below those that would constitute a living wage, and because linked health insurance benefits are not readily available from other sources (including through employer-

sponsored health insurance, which is widely being cut back), the reality faced by people with disabilities who want to work is that attempting to do so, without any guarantee of successful long-term income and without any access to private health insurance, is simply too great a risk.

To attempt to counter this problem, a succession of work incentive provisions (better called anti-disincentive provisions, in the view of some) have been adopted in recent years. While work disincentives are certainly not the only cause for the small numbers of recipients leaving the benefits rolls for competitive employment, there is also little question that they are one major cause that could be addressed and eliminated by governmental action.

(d) (1) Complexity

Because of the SSA's central role in administration and regulation of the SSDI and SSI programs, including the work incentive provisions, NCD's November, 2005 report studied SSA's efforts in this area. Recognizing that although SSA plays a central role, it does not act in isolation from other government agencies or from a variety of forces in society, NCD's report takes pains to discuss the potential role of various governmental and employer partners in improving the incentives climate. Nevertheless, there are a number of steps SSA has taken and could take to improve the situation.

So far as SSA's own rules are concerned, the NCD report documents a number of measures SSA has taken to address the problem. These include: measures to implement relevant provisions of statutes, particularly of the Ticket to Work and Work Incentives Improvement Act of 1999 (TWWIIA); [136] measures to create community-based advisory and informational resources for beneficiaries; and measures to create better processing and advisory capabilities within the SSA itself.

While commending all of these measures, NCD is obliged to note an overarching problem which, ironically, these efforts may only worsen. That is the problem of complexity, of overwhelming, numbing, sheer complexity that makes clear explanation, full understanding, or confident planning difficult or impossible for many people. Even with SSA's support for community-based benefits counseling and recipient outreach through the Protection and Advocacy for Beneficiaries of Social Security (PABSS) and the Benefits Planning Assistance

and Outreach (BPAO) programs, the limited availability of people with the requisite expertise, the enormous complexity of information that must be imparted to recipients, the continuously changing nature of related rules, and the uncertainty that decision-making personnel in affiliated service agencies will understand and apply the incentives rules properly—all these combine to make it highly unlikely that our current approach to eliminating work disincentives will have a major effect.

For this reason, NCD recommends that the SSA undertake a study of the viability and effectiveness of current work incentives, and that the agency further undertake a small-scale pilot experiment whereby complexity is eliminated and recipients are allowed to work without any loss of cash benefits or insurance for a period of five years, following which the impact of such an approach on their long-term employment and self-sufficiency will be assessed. This freedom from disincentives should be accompanied by appropriate job search and technological support aimed at facilitating their acquisition of and success in employment, and should also be accompanied by guarantees that if the project is not deemed successful, or if the participants drop out, they will face no benefit reduction or other adverse consequences as a result of their participation.

(e) Employer Education and Law Enforcement

NCD wishes to congratulate the ODEP [137] and the U.S. Equal Employment Opportunity Commission (EEOC) [138] for issuance in 2005 of a number of valuable publications aimed at providing critical information and guidance to employers. These deal with subjects ranging from the requirements of the ADA, to the issues faced in working with people with particular disabilities such as those who are blind or have visual impairments, to the role played by workers with disabilities in creating the diverse workforce of the 21st century.

NCD looks forward to additional efforts of this kind aimed at making important and timely information more available and understandable to employers, and NCD is confident that such efforts will result in improvement in the employment picture for Americans with disabilities. But NCD also knows that education and technical assistance cannot by themselves assure employer

compliance with the law. The need for vigorous law enforcement remains great, and in some respects may even be growing.

A disturbing court opinion issued in February, 2005 dramatizes some of the problems. That decision, by a U.S. Magistrate in the case of Brady versus Wal-Mart, [139] involved technical questions surrounding the assessment of damages against the defendant following a jury verdict in favor of the plaintiff, finding that the retailer had committed certain violations of the ADA. While the issues surrounding the assessment of compensatory and punitive damages under applicable federal and New York State law are beyond the scope of this discussion, what is important here is the discussion in the case about two points: first, the inadequacy of current federal punitive damages caps to represent any sort of deterrent for our nation's largest corporations, in the event they violate the law. Second, and closely related, the case indicates evidence of the company's failure to follow-through on prior commitments regarding the education of its workforce on disability-related issues and legal requirements.

While recognizing that follow-up cannot be perfect in any large, multi-facility company, the issue raised is how and whether the Department of Justice (DOJ) or the EEOC is capable of undertaking proactive surveillance to ensure the enforcement of consent decrees and other binding commitments. More broadly, questions are raised regarding the resources available in the DOJ and the EEOC to proactively investigate employer practices in industries where high employee turnover, diminishing fringe benefits, changing job duties, or prior findings of discrimination suggest a need for vigilance in regard to employment practices bearing upon workers with disabilities.

In this light, NCD recommends that the Department of Justice reaffirm, not merely its commitment to the ADA, but its commitment to vigorously enforce the law where violations occur, and to proactively investigate employer practices to prevent violations or intercede before formal enforcement becomes necessary.

(f) Innovation

The enormous purchasing power of the Federal government has long been used to encourage desirable practices on the part of the private sector. From laws requiring nondiscrimination to requirements that employees be screened for use of illegal drugs, the federal contracting power has long been deployed to reward companies who cooperate in the implementation of national policy and, by withholding business, to punish those that do not. One very effective strategy, perhaps best known in the area of veterans employment, involves the extending of contracting preferences to firms who follow desirable practices. Recent developments in federal procurement practice have dramatically changed the context in which the contracting power can or should be used to further national employment goals.

Current federal policy favors privatization of all possible government functions, that is, the use of private sector contractors to perform functions on behalf of the government that might once have been carried-out directly by government agencies and employees, but that are now deemed more efficiently done by skilled contractors. Sometimes called outsourcing, this practice has been of concern to some because it has not always been carried-out with full awareness of its implications for either federal-sector or private-sector workers with disabilities.

Legislation was proposed in Congress in 2005, the Federal Employees with Disabilities Protection Act, [140] which would provide that federal employees engaged in the carrying-out of an activity or the provision of a service would be protected from job loss if that activity or service is converted to private or contractual auspices. While NCD would not suggest that private contractors should be required to incur undue burdens in attempting to accommodate workers with disabilities, or that they should ever be required to retain workers who are unqualified, NCD knows from experience that reasonable accommodations are almost always available, and that opportunities for job restructuring and reassignment usually exist. To expect federal contractors to adhere to high standards in assuring job retention for employees with disabilities is not a great deal to ask.

Accordingly, NCD recommends that this legislation be given full hearings and be enacted. NCD further recommends that legislation to extend contract preferences in federal procurement to firms that competitively employ persons with disabilities also be adopted.

Recommendations

Recommendation 7.1: NCD recommends that the House Committee on Education and the Workforce and the Senate HELP Committee request that GAO continue and deepen its recent VR study by carrying out detailed research into how particular VR services correlate with successful employment outcomes and into how existing definitions of successful case outcomes may influence the range and content of services provided in the field.

Recommendation 7.2: NCD recommends that the Assistant Secretary of Education for Special Education and Rehabilitative Services convene a high-level task force, including the Office of Management and Budget, the Council of State Administrators of Vocational Rehabilitation, the National Council of State Agencies for the Blind, the Department of Labor's Office of Disability Employment Policy, and representatives of the rehabilitation service consumer community. This task force should make recommendations to Congress on behalf of the administration regarding statutory or funding formula changes, or budgetary appropriations required to bring about the progressive reduction and ultimate elimination of undue service delays for persons with significant disabilities.

Recommendation 7.3: NCD recommends that the Department of Labor establish and publicize a complaint procedure for use by individuals who have been denied access, intentionally or by reason of inaccessibility, to one-stop facilities, resources or services; that DOL incorporate accessibility guarantees in requirements for state workforce development plans and funding; and that DOL insist on inclusion of representatives of people with disabilities (or at least of state VR agencies as mandatory partners under the law) on state and local workforce investment boards.

Recommendation 7.4: NCD recommends that the ODEP undertake research at a cross-section of one-stop centers throughout the country, and with a group of volunteer service recipients recruited through publicizing of the study to determine the extent of accessibility, reasonable

accommodations and nondiscrimination among one-stop partners, and to determine the impact of inaccessibility upon the ability of one-stop customers with disabilities to obtain employment.

Recommendation 7.5: NCD recommends that the SSA undertake a study of the viability and effectiveness of current work incentives, and that the agency further undertake a small-scale pilot experiment whereby complexity is eliminated and recipients are allowed to work without any loss of cash benefits or insurance for a period of five years, following which the impact of such an approach on their long-term employment will be assessed.

Recommendation 7.6: NCD recommends that the Department of Justice reaffirm, not merely its commitment to the ADA, but its commitment to vigorously enforce the law where violations occur, and to proactively investigate employer practices to prevent violations or to intercede before formal enforcement becomes necessary.

Recommendation 7.7: NCD recommends that proposed legislation to strengthen the role of the federal contracting process in facilitating competitive employment for persons with disabilities be given a full hearing and be enacted. NCD further recommends that legislation to extend contract preferences in federal procurement to firms that competitively employ persons with disabilities also be adopted.

Chapter Eight—Welfare Reform

Introduction

This chapter deals with three related issues. First, it discusses a major Government Accountability Office (GAO) oversight report on the temporary assistance to needy families (TANF) program. Next it addresses legislation that NCD believes should be part of Congress's welfare reform agenda. Finally, it discusses the existence and methods for addressing the problem of the chronically unemployed welfare recipient.

(a) Background

Each of NCD's last three annual status reports has been written with the expectation that the nation's welfare law (the Personal Responsibility and Work Opportunity Reconciliation Act of 1996) [141] (PRWORA) would be reauthorized in the next session of Congress. Reauthorization has yet to take place. Instead, the existing legislation has been maintained largely without change by a series of short-term extensions.

NCD expects that full-scale reauthorization, with the revisions that are always a part of the reauthorization process, will take place during 2006. NCD wishes to remind readers of the concerns addressed, the issues raised and the solutions proposed in our previous reports, including a 2003 paper on TANF. [142] We also wish to relate those discussions to developments in the debate over welfare reform that have occurred in the past year.

(b) The Problem of Definitions

Central to PRWORA is the notion that work is the only viable solution to the economic disadvantage or social isolation that many recipients face. While public assistance, known as welfare, is required by some families, the sensation had grown widespread by the mid 1990's that for some people, welfare had become a long-term source of support, if not a way of life. Although explanations differed over why such long-term dependence had arisen, virtual unanimity existed and continues to exist for the proposition that such dependence is not a

positive thing. As inclusion of the word “temporary” in the new program’s name made clear, assistance was not intended to become indefinite.

One of the chief mechanisms used for ensuring that states, in carrying out the goals of federal policy, would adhere to these principles was a structure in which specific work requirements were established. These related to both the number of people entering work activities, the definition of work activity, and the amount of work people did. States which fail to meet their work requirements were subject to fiscal penalties.

As it relates to people with disabilities, NCD has been strongly supportive of the goal of work. Where we have continued to express concern is over the ability of the current system to generate meaningful work opportunities for TANF recipients with disabilities. A related concern has been what would happen to these people if, despite their own best efforts, a lack of necessary linkages and support services resulted in their failure to gain employment.

With its emphasis on sanctions and work requirements, the system appeared to be designed on the assumption that lack of desire to work or lack of knowledge of the requirements of the work world were the principal causes for long-term dependency. However this may be so in the cases of some individuals, with and without disabilities, NCD’s long experience and commitment to employment for persons with disabilities led us to recognize that far more is involved.

(c) Work Activity

A 2005 GAO report found that administration of PRWORA’s work requirements was hindered by a lack of federal leadership in certain key areas from the Department of Health and Human Services (DHHS). [143] DHHS, which according to the GAO report has acknowledged and undertaken to correct some of the problems, was found to have failed to set forth clear and uniform guidelines for defining what constitutes work activity. Inasmuch as states could face penalties for failing to meet their work targets, such clarity and uniformity are a basic element of fairness in the administration of the program. Without them, states might become overzealous in order to make sure they did not risk falling short.

What particularly concerns NCD in this connection is that neither the GAO report nor the cited DHHS response reflect any recognition that a viable and inclusive definition of work activity needs to take the circumstances faced by many TANF recipients with disabilities into account. Specifically, no recognition appears to exist here or elsewhere in the discussion of work targets that many recipients with disabilities may have specialized training, rehabilitation, transportation or other support services needs. When these needs are recognized and addressed, employment in many instances will result. But where they are not addressed, failure is likely.

Accordingly, NCD recommends that in defining the concept of work requirements under current law, or in implementing any new statutory definition of this concept, HHS consider the circumstances of recipients with disabilities, the resources available for training and supporting them, and the attitudes of prospective employers regarding these welfare-to-work participants.

(d) Pathways to Independence Act

A 2002 study concluded that 44% of TANF recipients were either individuals with disabilities or individuals with primary caretaker responsibility for someone with severe disabilities. [144] As one avenue for addressing the issues posed for welfare reform by individuals with severe disabilities, NCD recommends adoption by Congress as part of its TANF reauthorization of the Pathways to Independence Act of 2005. [145] Through a carefully calibrated approach, this bill would allow states to avoid potential penalties by enabling them, subject to appropriate safeguards, accountability measures and coordination, to count time spent in approved rehabilitative activities and in other work-related activities toward the work requirements they and their citizens must meet. Under Pathways all the activities that could be counted toward work would be directly work-related, and quarterly extensions with justification would be required for any continuance of these alternative work requirements for more than 3 months in any 24-month period.

If Congress is uncomfortable in adopting Pathways, NCD recommends that it initially be implemented on a two-year trial basis in six to ten states. NCD believes that it will result in net employment increases among welfare recipients with disabilities in those states after two years that will exceed those achieved by TANF recipients with significant disabilities in other states

during the same timeframe. NCD is confident that after the trial period, the benefits of this approach, in expenditure and revenue as well as in human and administrative terms, will be clear and that Congress will then extend the program across the nation.

(e) The Hard-Core Unemployed

Current proposed TANF reauthorization legislation [146] and the current debate around the program continues to emphasize the work requirement. Little analysis seems to be forthcoming regarding why there exists a small but seemingly intractable hard-core of persons who have not been able to move to employment or to leave the rolls, and as to what proportion of this population may be composed of people with significant disabilities. Unless Congress believes that lax work requirements explain this phenomenon, then it may be that emphasis on increasing work requirements misses the point.

An individual who cannot get to a workplace because of the unavailability of a lift-equipped van, or who cannot do home-based computer work because of the unavailability of broadband or of needed access technology, or whose recurrent bouts of illness and hospitalization render them undesirable to employers—these people are not likely to be motivated or empowered to find jobs by tightening in the work requirements of the law, or indeed by any financial penalty arising from their failure to meet such requirements.

We do not mean to suggest that work requirements should not be stiffened and clarified. We mean only to suggest that for many of the very people who vex and frustrate Congress the most, and who leave public assistance administrators scratching their heads in frustration, work requirements are immaterial. For this reason, NCD recommends that Congress instruct the DHHS to undertake a study into the nexus between hard-core TANF receipt and disability. This study should be carried out with a view to identifying what services, resources and training would be most effective in facilitating the transition into work of such persons, and to determining the availability of such resources under current law and practice. Until then, increased work requirements are likely to have the same counterproductive impact on actual work as punitive tax increases would have on federal revenues.

Based on its previous work in this area, NCD stands ready to work with DHHS and Congress to help craft provisions that will honor the goals of work while recognizing the need for flexible methods and procedures for bringing it about.

Recommendations

Recommendation 8.1: NCD recommends that in defining the concept of work requirements under current law, or in implementing any new statutory definition of this concept, HHS consider the circumstances of recipients with disabilities, the resources available for training and supporting them, and the attitudes of prospective employers regarding these welfare-to-work participants.

Recommendation 8.2: NCD recommends adoption by Congress as part of its TANF reauthorization of the Pathways to Independence Act of 2005. NCD further recommends that if Congress is uncomfortable with implementing this concept nationally, it initially be implemented on a two-year trial basis in 6-10 states, with a view to its extension to the entire nation if evaluation proves that it increases net employment while reducing projected long-term dependency costs.

Recommendation 8.3: NCD recommends that Congress instruct the DHHS to undertake a study into the nexus between hard-core TANF receipt and disability. This study should be carried out with a view to identifying what services, resources and training would be most effective in facilitating the transition into work of such persons, and to determining the availability of such resources under current law and practice.

Chapter Nine—Housing

Introduction

In America today, many of our assumptions about housing are being rethought. From what is and is not desirable density, to whether housing values will continue to climb, to what the role of public housing for the poor should be traditional notions that have been dominant since at least the end of World War II are being scrutinized and questioned. It could hardly be expected that closely-related issues of affordability and accessibility would not also require considerable attention.

This chapter discusses some of the major themes and issues relating to housing for people with disabilities that marked progress, debate and activity during 2005. A number of these issues have been addressed by NCD before, either in earlier editions of this progress report or in major research studies such as the Council's monumental *Reconstructing Fair Housing* report of 2002. [147] But though some of the issues are familiar, the context in which they emerge is an ever-shifting one.

The chapter begins with a discussion of fair housing enforcement, with particular emphasis on emerging areas of concern and on the integrity and credibility of complaint processing procedures. The chapter then goes on to discuss new data sources for the collection of information on homelessness, and it analyzes the extent to which these need to ensure the capture of key data about homeless people with disabilities and particularly about homeless veterans with disabilities. After this the chapter discusses issues that have arisen in the context of federally-supported rental assistance programs. Finally, the chapter addresses barriers to home ownership for many people with disabilities.

(a) Civil Rights

(a) (1) Fair Housing Enforcement

For our nation to have any hope of meeting its accessible housing goals and needs, it is vital that fair housing laws be widely understood and vigorously enforced. In that connection, NCD

wishes to commend the Department of Justice (DOJ) and the Department of Housing and Urban Development (HUD) for pursuing a number of important and potentially precedent-setting cases through to resolution in 2005. These cases, brought and resolved under the Fair Housing Act Amendments (FHAA), [148] helped extend the scope of civil rights protection to areas where some might have assumed such laws played no part or were not applicable.

Among the most important settlements were a case involving discrimination by the operators of a group home; [149] a case in which a municipality agreed to adopt ordinances that would ensure flexibility and fairness in the zoning process as it related to group homes; [150] and a case making it clear that the FHAA extends to retirement communities. [151] NCD heartily commends the cooperating federal agencies for the vigor, focus and commitment that led to the successful resolution of these and other cases. But NCD remains deeply concerned that without two other measures, the hard work by enforcement officials will yield less returns to society than should be the case.

As discussed in prior reports, the problems are, first that all of these settlements appear to have arisen from citizen complaints rather than from any sort of proactive monitoring or patterns-and-practices oversight. Second, few if any of these settlements appear to include follow-up mechanisms for assuring long-term compliance, including by subsequent employees or officials of the firms involved, who may have no institutional memory to fall back on.

Once a complaint has been found sufficiently meritorious to be taken on by the federal government as a party to the case, and once an entity has reached an agreement with the government to take certain actions, it should not become the responsibility of the complainants to monitor implementation and call attention to shortcomings. Some method for enabling the government to regularly review at least a random sample of previous settlement agreements to ensure compliance is required, especially where compliance appears to be ongoing over a period of time, as for example where it involves not merely one-time design changes but also ongoing improvements in practices and procedures.

(a) (2) Intake and Complaint Processing

So long as complaints are the chief pathway for fair housing problems to reach the attention of government, it is especially important that HUD and state fair housing agency (FHAP) processes for receiving, investigating and resolving fair housing complaints be effective, timely and transparent. This report has therefore dealt with the issue of complaint backlogs and outcome data over the past two years. A new Government Accountability Office (GAO) report requires us to address this issue again.

In October, 2005 GAO issued a follow-up report to its 2004 study of fair housing case outcomes. This new report is entitled: “Fair Housing: HUD Needs Better Assurance That Intake and Investigation Processes Are Consistently Thorough.” In essence, what the report finds is that, notwithstanding the existing standards and procedures promulgated by HUD, methods, quality and documentation of intake, investigation and resolution appear to vary widely among HUD field offices and FHAPs. As discrepancies in required documentation show, this makes evaluation of the process’s effectiveness difficult.

More seriously, as reflected in disturbingly high levels of consumer dissatisfaction reported in the study, it places the entire complaint-based enforcement effort in jeopardy. How could the nation take pride in a declining number of complaints, if the real possibility existed that that decline was due to public ignorance of or skepticism about the efficacy or value of the process?

In this light, NCD recommends that the HUD Office of Fair Housing and Equality Opportunity (FHEO) make upgrading of the complaint intake and investigation processes its top reform item. NCD further recommends that HUD assure the establishment of accountability and management goals and timetables that will assure completion of the review and implementation of reforms by a specified date. And NCD also recommends FHEO identify and the administration request from Congress such funds as may be necessary to assure fulfillment of the goal by the appointed date, including funds to provide the necessary technical assistance to state-agency partners and the private sector housing community.

(b) Homelessness

Our awareness of homelessness was dramatically heightened in 2005 with the terrible scourge caused by hurricanes Katrina, Rita and Wilma. But while it is hoped that the massive outpouring of effort and concern will lead to the building and repair of homes along the Gulf Coast soon, there are also other kinds of homelessness that are more difficult to identify and understood and more complicated to address.

(b) (1) Rebuilding a Housing Stock

(b) (1) A. Emergency Housing

In the wake of the disaster, many people continue to live in temporary accommodations, often trailers. It is vitally important that all temporary accommodations provided by the federal government, whether FEMA, the Department of Defense (DOD) or other agencies, or any temporary accommodations provided by others with support from public funds be accessible, to the maximum extent that current knowledge, design expertise and materials will permit. In order that people with disabilities be spared disproportionate suffering in any future disasters or their aftermath, NCD recommends immediate adoption of legislation, as developed in consultation by the DOJ Civil Rights Division and by the HUD FHEO along with appropriate congressional housing committees, to ensure that such accessibility will be included as a uniform feature of all funding and procurement contracts and of all grants. To the degree that existing design standards may be deemed insufficient, this legislation should also authorize the Access Board to undertake a standards-setting effort, required for completion within no more than one year, to rectify any such gaps or ambiguities in current ADA design guidelines. The legislation should nevertheless be effective immediately.

(b) (1) B. Permanent Structures

The need to rebuild the housing stock of an entire region of the country arises from tragic causes. But faced with this need the opportunity it presents for creating inclusiveness and building community should not be missed. That opportunity has already been widely recognized, and can be seen in many of the currently unfolding debates over how communities should be rebuilt. But

as an element of that debate, the role of accessibility is at least as important and far-reaching as many of the other issues most frequently discussed.

For example, debate currently rages over how high off the ground foundations should be required to be built, but if numbers of people with disabilities cannot enter or use the refurbished housing, much of the purpose and value of such safety measures is lost. Likewise, debates continue over the scale and attention to be accorded to pedestrians and neighborhoods in rebuilt towns and cities. But if attention is not paid to the ability of all pedestrians to get around, to livability for all, the number of people who can benefit from implementation of modern urban design concepts will be greatly restricted. Put simply, the capital expenditure involved in rebuilding the Gulf Coast's housing stock and communities is so large that inclusion of the fullest possible accessibility at all levels represents, if incorporated from the outset, only minimal additional cost.

Taken together, guidelines and technical assistance materials already developed or disseminated by the Access Board, by HUD, by the DOJ and by the Department of Transportation (DOT) provide a template of what is needed and what will work. What remains is to weave these guidances and requirements into a clear, coherent and accountable structure that federal, state, local and private sector groups can reliably use and easily access for the guidance and resources they need to comply with the principles of accessibility in their work of renewal. To achieve this goal, NCD recommends that the President by executive order set up an interagency task force charged with gathering the necessary informational and technical resources, creating appropriate technical assistance materials, and working with Congress to swiftly enact any statutory changes that may be necessary to ensure the existence and enforcement of clear standards.

(b) (2) Chronic Homelessness

(b) (2) A. Statistics

According to a Congressional Research Service (CRS) report issued in November 2005, the Homelessness Management Information System (HMIS) mandated by Congress in 1998 is coming close to fruition. The first annual homelessness assessment report (AHAR) required under this system will be released by HUD early in 2006. Based on previous data-collection

efforts over the past five years in which the AHAR has been under development, it is estimated that America's homeless population includes somewhere between 600,000 to 2.5 million people.

It is expected that the HMIS will allow for refinement of this estimate. In addition, data collection requirements pertaining to the report should lead to the provision of useful information by local housing agencies and organizations around the country. One of the data elements required to be collected and provided is "disabling condition" of clients served by the various housing programs. Coupled with other data on a wide range of variables such as age, ethnicity, gender, prior residence and other factors, these data should provide a valuable snapshot of the homeless population, including its members with disabilities. But depending on how the information is used, additional opportunities for analysis and planning may exist.

Several issues emerge in this regard relating to matters that the proposed data collection likely will not address but that are critical to its value. Whether and how these topics can be addressed should be a matter of concern while it is still early enough in the AHAR reporting process to allow for needed modifications, and while early monitoring of the new system is still focused and intense. First, assuming aggregate numbers of persons with self-reported disabling conditions can be generated, it will be crucial to cross-tabulate these data with other collected information in order to assess who the homeless people with disabilities are. What would be vital to learn is whether increases in their numbers, if any, are coming from persons with developmental disabilities who have not been well-served by adult resources, or from among the growing number of returning veterans with disabilities as to whose needs and services great concern already exists. An increase of these veterans, of the kind that harks back to the Vietnam era, among homeless people today would be a key sentinel statistic that we are failing in our responsibility to these brave heroes.

Accordingly, NCD recommends that the secretary of HUD make clear, in a Federal Register Notice, whether the department expects the HMIS to gather such information, or whether the system has the capacity to generate such information. If not, the secretary should undertake, pursuant to formal authorization from the President, a planning effort, involving interagency cooperation from the Department of Veterans Affairs and the Social Security Administration, to

develop, field test and implement suitable techniques for parsing existing data or collecting new data that are needed to monitor the status of veterans in the context of the HMIS program.

A related issue concerns identifying the causes of homelessness. To the degree that people with disabilities are included among the homeless population, meaningful policymaking requires more information than the HMIS appears likely to provide. While HMIS is not our only source of data, it is important that it recognize that the causes of homelessness are not confined to personal or social adjustment issues faced by homeless individuals and families. If the scarcity of accessible housing or the unaffordability of this restricted supply are causes, this information needs to be known. If the inability to maintain employment due to the lack of accessible housing or accessible transportation is a factor, this too must be documented. If lack of coordination among HUD-assisted programs and those operated by the VA, by Transportation or under Medicaid are factors, this too must be factored into our understanding and our response.

Accordingly, NCD recommends that the Interagency Committee on Disability Research be charged by the president with the responsibility for assessing the degree to which all ongoing information-gathering efforts permit assessment of the role of inaccessible housing, inaccessible transportation and lack of interagency coordination in homelessness among people with disabilities. Based on its findings, the committee should recommend measures for identifying and gathering the data that would be requisite to assess and address these issues.

(b) (2) B. Many Programs

As listed in a 2005 CRS report, the number of federal programs designed to assist people who are homeless, and the number of programs through which local housing agencies, nonprofit and faith-based groups can obtain funds for work with people who are homeless, is truly astounding. This report, “Homelessness: Recent Statistics, Targeted Federal Programs, and Recent Legislation” lists the following as major federal homelessness programs:

1. The Education for Homeless Children and Youth (EHCY) program;
2. The Emergency Food and Shelter Program (EFSP);
3. The Health Care for the Homeless Program (HCH);

4. The Projects for Assistance in Transition from Homelessness program (Path);
5. The Consolidated Runaway and Homeless Youth Programs (the Basic Center Program and the Transitional Living Program);
6. The Street Outreach Program (SOP);
7. The Supportive Housing Program (SHP);
8. The Shelter Plus Care (S plus C) program;
9. The Section 8—Moderate Rehabilitation of Single-Room Occupancy Dwellings (SRO) program;
10. The Emergency Shelter Grants (ESG) program;
11. The Homeless Veterans Reintegration Program (HVRP);
12. The Health Care for Homeless Veterans (HCHV) program; and
13. a number of other federal programs for homeless veterans.

A number of initiatives aimed at introducing greater flexibility into this system are currently underway, but these are outside the scope of this report. What is of concern here is the different ways these programs define, serve, accommodate and account for participants with disabilities. Two programs, both aimed at transitioning or restoring people to permanent, long-term housing, are of particular interest in this regard, for the notice they take of people with disabilities.

The Supportive Housing Program (SHP) and the Shelter Plus Care (S plus C) programs both include requirements that a certain portion of funds, in most cases about 25%, be used for individuals and families with disabilities, sometimes any disability, sometimes mental or developmental disabilities. Among other differences between these programs, while SHP requires provision of a variety of supportive services in an integrated fashion with housing itself, S plus C contemplates the inclusion of referral capabilities for needed services but does not require or include the provision of such services itself.

Whether support services are provided directly or offered by community partners under a referral relationship, the key question to be asked is whether the mix of services available is maximally responsive to the needs of program participants with disabilities. The mix of services is valuable,

including social services of several kinds and job assistance, but concern exists that a more specialized range of services, including job-coaching and assistive technology, should be provided.

In this connection, NCD recommends that Congress task the GAO to undertake a study of the precise nature of supportive services offered within all HUD-assisted competitive and formula grants, voucher or project-based programs, with a view to determining whether the services currently offered are as responsive as possible to the needs of program clientele with disabilities. Public housing tenants, emergency housing tenants, low-income Section 811 subsidy and services recipients, and persons with disabilities receiving housing, housing subsidy and related services under other housing programs should play an important role in designing and evaluating this research.

(c) Rental Assistance

Rental assistance, including in the form of subsidies to renters and capital advances to property owners or project developers, has been a part of the mix of national housing programs for many years. People with disabilities participate in all these programs of course, but so far as rent-based efforts specifically targeted at people with disabilities are concerned, the Section 811 program is probably the best known.

In 2005 the GAO issued a report on improper rent payments made under a variety of HUD programs, and regarding measures taken by HUD to deal with the improper payment problem since its identification by GAO and by the President's Management Initiative as a serious one. [152] Although people and projects for people with disabilities were not highlighted or specifically mentioned as sources of the problem, the study nevertheless gives grounds for concern. This is because some of the reasons for improper payments cited generally are of a nature that could readily come up under Section 811 or other disability-related programs.

Perhaps the most important of these reasons is complexity. In listing the items to be studied, GAO includes: "the status and potential impact of HUD's efforts to reduce the risk of improper payments by simplifying the subsidy determination process." [153]

One major source of complexity, which is likely greater in disability-related programs and for rental tenants with disabilities than for other tenants in all the housing subsidy programs, is that of computing the level of the subsidy. Generally, subsidized renters are expected to pay 30% of their “adjusted monthly income” toward rent. Based on anecdotal reports reaching NCD, computation of this 30% is extremely difficult for people who receive benefits and assistance under other non-housing, needs-based programs, and for people who have expenses of an unusual disability-related nature, including work expenses and personal assistance services costs, that program administrators may not fully appreciate how to deal with in “adjusting” of monthly income.

NCD recommends that the administration undertake an interagency study, including HUD, the Social Security Administration (which administers the needs-based income-support programs), and the Centers for Medicare and Medicaid Services (CMS) (which oversees the Medicaid program) to identify interactions, consistencies and conflicts among the rules defining adjusted income under the housing programs and the rules applicable to the other needs-based income-support, food-assistance and medical-assistance programs. This study should also examine the adequacy of the current adjustment rules as they relate to other public policy goals of fostering savings, employment and home ownership.

(d) Home Ownership

For most Americans with disabilities, no less than for Americans without disabilities, home ownership is the most tangible symbol of the American dream. But while low-income is a barrier to home ownership for many people, its role in the lives of people with disabilities is exacerbated by income and resource restrictions under the variety of key needs-based, means-tested programs. The paradox is this: If people with disabilities could be enabled to acquire homes and other tangible assets, appreciation in value and upward mobility would likely occur, to the point where for many people the combination of assets and employment would make benefits unnecessary. But so long as people need benefits, the flexibility to begin acquiring assets or to earn as much as possible from employment is severely limited.

In no area is this more apparent than that of home ownership. A number of experimental programs currently allow savings, up to designated amounts (including \$10,000 under the individual development account (IDA) program) [154] toward purchase of a home. But existing provisions of this kind are unlikely to allow people to meet minimum down payment requirements, except through the use of predatory lenders (offering ruinous interest only mortgages) who it is clearly not the goal of public policy to subsidize or encourage.

Home ownership represents the most important step on the ladder of upward mobility for most people. It is past time for the government to comprehensively address how this goal can be brought to fruition for more people with disabilities. Accordingly, NCD recommends that Congress authorize the creation of a national commission to study this issue from the broadest possible standpoint and to make recommendations within one year as to how a target of 60% home ownership for people with disabilities can be met within five years.

Recommendations

Recommendation 9.1: NCD recommends that the HUD Office of Fair Housing and Equality Opportunity (FHEO) make upgrading of the complaint intake and investigation processes its top reform item. NCD further recommends that the HUD secretary assure the establishment of accountability and management goals and timetables that will assure completion of the review and implementation of reforms by a specified date. NCD also recommends that FHEO identify and the administration request from Congress such funds as may be necessary to assure fulfillment of the goal by the appointed date, including funds to provide the necessary technical assistance to state-agency partners and the private sector housing community.

Recommendation 9.2: NCD recommends immediate adoption of legislation, to be developed and submitted in consultation by the DOJ Civil Rights Division and by the HUD FHEO along with appropriate congressional housing committees, to ensure that accessibility will be included as a uniform feature of all funding and procurement contracts and of all grants related to rebuilding after natural disasters.

Recommendation 9.3: NCD recommends that the President by executive order set up an interagency task force charged with gathering the necessary informational and technical resources, creating appropriate technical assistance resources and materials, and working with Congress to swiftly enact any statutory changes that may be necessary to ensure the existence and enforcement of clear standards as to the meaning of and need for accessibility in post-disaster relief and housing stock rebuilding efforts.

Recommendation 9.4: NCD recommends that the secretary of HUD make clear, in a Federal Register Notice, whether the department expects the new homelessness management information system (HMIS) to gather key information regarding the status and prevalence of homeless veterans with disabilities, or whether the system has the capacity to generate such information. If not, the secretary should undertake, pursuant to formal authorization from the President, an interagency planning effort, in cooperation with the Department of Veterans Affairs and the Social Security Administration, to develop, field test and implement suitable techniques for analyzing existing data or collecting new data that are needed to monitor the status of veterans in the context of the HMIS program.

Recommendation 9.5: NCD recommends that the Interagency Committee on Disability Research be charged by the president with the responsibility for assessing the degree to which all ongoing information-gathering efforts permit assessment of the role of inaccessible housing, inaccessible transportation and lack of interagency coordination in homelessness among people with disabilities.

Recommendation 9.6: NCD recommends that Congress task the GAO to undertake a study of the precise nature of supportive services offered within all HUD-assisted competitive and formula grants, voucher or project-based programs, with a view to determining whether the services currently offered are as responsive as possible to the needs of program clientele with disabilities.

Recommendation 9.7: NCD recommends that the administration undertake an interagency study, including HUD, the Social Security Administration (which administers the needs-based income-support programs), and the Centers for Medicare and Medicaid Services (CMS) (which oversees

the Medicaid program) to identify interactions, consistencies and conflicts among the rules defining adjusted income under the housing programs and the rules applicable to the other needs-based income-support, food-assistance and medical-assistance programs.

Chapter Ten—Transportation

Introduction

This chapter addresses issues of concern and notes developments of importance in 2005 in relation to surface, cruise ship and commercial air transportation. Noting the comprehensive review of the subject of surface transportation contained in NCD's report, *The Current State of Transportation for People with Disabilities in the United States*, [155] published in June 2005, the chapter begins with a discussion of civil rights enforcement of ground transportation access rights.

The chapter then discusses new guidelines and related suggestions for improving access to rail transportation. Following this, one of the civil rights highlights of the year, the Supreme Court's decision upholding accessibility in cruise ship travel, is discussed.

The chapter next proceeds to a discussion of paratransit, noting tensions between conflicting requirements of the law and offering suggestions for making the nature of paratransit's problems clearer to riders and policymakers alike.

Returning to ground transportation, the chapter then reviews provisions that NCD believes should be retained in or added to the forthcoming revision of the national highway act.

Finally, the chapter reviews issues in air transportation, noting progress in some areas of access but calling for urgent action in others, lest the gains of many years be eroded or lost.

(a) Surface Transportation

In June, 2005 NCD released its major report, *The Current State of Transportation for Persons with Disabilities in the United States*.

This report comprehensively assesses progress, identifies barriers, recognizes best practices, and highlights issues in all forms of surface transport, including in the areas of public mass transit, private bus and rail transit, alternative transportation initiatives, and pedestrian transit. Review of

this report is strongly recommended for all those with an interest in this subject, and especially for those whose lives are affected, for better or for worse, by the availability or unavailability of transportation options.

(a) (1) Enforcement of ADA Access Rights

No right to transportation exists in America, but rights to equal access to transportation do. Under the ADA and other laws, local and state governments, public authorities and private firms providers are required to take a variety of measures to ensure equal access to their transportation services for persons with disabilities. In summing up the situation, NCD's report states:

“As a consistent theme in most transit systems across the United States, the Americans with Disabilities Act of 1990 (ADA) has spawned great improvements, but many compliance gaps remain that pose significant problems to transportation for people with disabilities. Additionally, because the ADA merely requires that, where public transportation is provided, it must be made accessible for people with disabilities, where there is no public transportation, it is likely that no transportation exists at all for people with disabilities. In some sectors, such as in rural areas, grossly insufficient funding imposes harsh gaps in the transportation grid. In other sectors, such as accessible taxis, a lack of requirements has meant very uneven progress. As a result, people with disabilities are still at a significant disadvantage compared with the general public.” [156]

By way of specifics, some of the issues that go into an assessment of progress to date and into the identification of remaining barriers include: administration of paratransit services, requirements for the procurement and use of lift-equipped, wheelchair-accessible buses, and requirements for accessible signage and announcements. Each of these is a result of the intersection between transportation and civil rights. As these requirements relate to mass transit, they operate largely through accessibility requirements that must be met as a condition for the receipt of federal funds. But perhaps because federal funds are primarily available to help transit systems defray capital costs of equipment and facilities, attention has tended to focus on design issues surrounding the design and initial procurement of rolling-stock or facilities.

In this light, NCD is particularly gratified by a major civil rights settlement reached by the Department of Justice (DOJ) and the city of Detroit in November 2005. [157] This settlement

dealt largely with bus maintenance and deployment, concentrating not on assuring that accessible equipment would be purchased, but instead seeking to ensure that shortcomings in the maintenance and deployment of accessible buses would be monitored and corrected.

With technical and design requirements (though always evolving and subject to research and periodic review) now widely understood, it is vital that enforcement efforts place increased emphasis on the actual provision of accessible services by transit operators of fixed-route services. Such emphasis includes vehicle and facility maintenance, operator attitudes, and accessibility of travel information, including station announcements, agency web sites and other trip planning resources.

NCD commends the Department of Transportation's (DOT) Federal Transit Administration (FTA) for conducting a growing number of public transit agency ADA assessments. [158] The DOT, in cooperation with the Department of Justice (DOJ), should continue this effort, and should place enforcement emphasis on the procedures and practices of transit systems, with a view to ensuring that the accessibility rights established in law and made possible through technology and design are in fact vindicated in the daily transportation experience of riders.

To do this, NCD recommends that DOT continue to conduct regular, proactive audits or assessments of transit systems to assure that maintenance, deployment, information accessibility (including stop announcements and web- or phone-based route or scheduling information) and other components of truly accessible service remain priorities, once accessible capital equipment has been purchased and deployed.

(a) (2) New Guidelines

DOT issued several important new ADA guidelines during 2005. One of these establishes requirements and standards for full-length, level-boarding platforms at new commuter or intercity rail stations. [159] NCD commends the DOT for these guidelines and looks forward to their effective implementation.

The problem of older station inaccessibility remains a perplexing one. Under the "key station" concept embodied in current law, the timeframes likely to be needed for all stations to become

accessible is widely recognized to be far too long. Yet, no clear solution has been found, and no source of funding for faster or more comprehensive renovation has been identified.

Recognizing that funds for such renovation or retrofitting cannot be derived from public spending increases, from tax increases or out of the fare box, NCD recommends that the DOT convene an advisory panel, including public and private rail transit operators and representatives of the disability community, as well as business and other community leaders, with a view to exploring innovative strategies for identifying new sources of funds that could be used to expedite the accessibility renovation of older rail stations.

(a) (3) The ADA and Cruise Ship Travel

In 2005 the U.S. Supreme Court decided the *Spector versus Norwegian Cruise Lines* case. [160] The Court ruled that foreign-registry commercial passenger ships operating into and out of U.S. ports were not exempt from the requirements of the ADA. Explaining those requirements in a judicious manner that showed keen awareness of the balance between conflicting interests and rights, the Court nevertheless provided clear guidance for industry and consumers.

NCD prepared a position paper in advance of the decision, [161] and the Council is particularly gratified that the sound policy and legal arguments set forth in its paper were largely reflected in the Court's ruling. NCD commends the High Court for its sensitivity to all of the parties and issues implicated in the case.

(b) Paratransit

(b) (1) Systemic Problems

NCD's 2005 study [162] identifies a number of ongoing, and some fairly new, problems in the provision of paratransit service to persons with disabilities around the country. Issues of timeliness, trip-by-trip eligibility and others continue to plague the system.

One finding was that some transit systems, faced with growing demand for their services and shrinking funding resources, may have resorted to tightened eligibility standards or to the use of trip-eligibility determinations as a means for reducing the increasingly unsustainable demands upon their services. If this is so, it underscores the need for increased funding for paratransit and

all forms of public transit. It also suggests a growing confusion between eligibility and economics.

Under current law, all eligible persons are required to be served and all appropriate trip requests are required to be met, including next-day service. If operators acting in good faith and in accordance the best practices cannot meet these requirements due to resource inadequacies, the cause of access would be better served by a frank assessment of their resource needs than by resort to pretenses of ineligibility.

NCD therefore recommends that Congress explore possibilities for decoupling user-eligibility from operator-capacity in ways that focus attention and resources on operator compliance and needs and that, while not excusing noncompliance, relieve all parties of the pretense of engaging in pointless disputes over eligibility.

(b) (2) Door to Door Access

Another of the guidelines issued by DOT in 2005 has potentially great significance for paratransit access. This guideline requires paratransit systems to provide more than curb-to-curb service, if that is required in order for people to effectively utilize the service.

While the significance of this guideline remains to be determined, NCD believes it could have two unforeseen consequences, one beneficial, the other not. On the positive side, it could contribute to greater availability of paratransit for persons with visual impairments who are reportedly often denied service on the theory that they can utilize available fixed-route services. Such denials have been controversial, because they often fail to take account of pedestrian barriers that make access to and from fixed-route stops problematical or even dangerous.

The potential consequence of the guideline, the more negative one, is that the increased responsibilities it will place upon service providers will only exacerbate the resource problems noted above. If this guideline causes operators to restrict eligibility further, much of its positive effect could be offset, and many of the people who need paratransit services the most could find it less available.

(b) (3) Human-service Transportation Coordination

(b) (3) (A.) United We Ride

NCD wishes to commend the administration for its recognition of the existence in this country of a broad group of people who are transportation-disadvantaged, meaning they cannot drive their own cars. People with disabilities are one major component of this population, but so are older persons and those of low income who cannot afford a car.

The United We Ride initiative, operated by the FTA, attempts to address the problems faced by transportation-disadvantaged persons through providing assistance to states and regional or local governments in maximizing the efficiency and flexibility of existing transportation resources, in developing transportation alternatives, and in fostering enhanced coordination between transportation and human services agencies and providers. [163]

(b) (3) (B.) MEDICAID, LTSS and Transportation

As indicated above, NCD commends the administration for its recognition of the issues and for its continued support for United We Ride initiatives. But as NCD's June, 2005 report shows, the implications of transportation policy for health care, institutionalization and other federal budget items may be far greater than most people realize.

Accounts included in the NCD report document numerous cases and various ways in which the lack of accessible transportation, particularly to and from medical care, can force people into nursing homes who would otherwise not need or choose to enter institutional care settings. Beyond medical transportation however, anecdotal evidence leads to the conclusion that inability to drive, whether associated with advancing age or the onset of disability, results in social isolation, depression, and a great deal of premature or unnecessary institutionalization of people who, as a practical matter, find themselves with no alternative and no means of maintaining viable lives within their own communities. These consequences are believed to be particularly harsh for people in rural areas, but they are by no means limited to such areas.

As recommended in Chapter One on statistics, better data are needed on the costs to taxpayers and to the economy generally of transportation-disadvantage. Such data should include not only

the cost categories already mentioned or those already identified for data collection, but the costs should also be estimated for health care for persons injured in accidents involving persons who should not be driving but who feel compelled to do so because of the practical and emotionally devastating consequences of being careless in America.

(c) Other Surface Transportation Programs

The ADA is not the only law that has a bearing upon the transportation access of people with disabilities. The Transportation Equity for the 21st Century Act (TEA) [164] awaiting reauthorization at the end of 2005, provides authority and funding for a number of grant programs that have a major impact on the mobility of persons with disabilities.

A lengthy negotiating process aimed at reconciling House and Senate versions of the legislation has been underway. A June, 2005 CRS report [165] describes the differences between the two bills, including a number of differences that are important to people with disabilities. NCD wishes to draw attention to some of these and to offer its recommendations as to the choices Congress should make.

(c) (1) Employment

A number of alternative transit programs, most notably the Job Access and Reverse Commute (JARC) program, [166] have assisted persons of low income with mobility disabilities, who do not own or drive their own cars, to get to and from work. It is important for many people that these programs be continued. It is especially important for people with disabilities that these programs take their circumstances and needs into account, through availability of accessible vehicles, through appropriate pickup and drop-off policies, through provision of adequate and accessible information, and in other ways.

(c) (2) Mixed Projects

While alternative transportation projects that target specific transportation-disadvantaged groups should be encouraged, the law should also provide sufficient flexibility for projects to work together or to share funding where benefits to all target populations, or significant cost savings, or avoidance of redundancy can be achieved. Targeted funding, while it should be available, should not require segregated programs as a condition for its allocation and use.

(c) (3) New Freedom Initiative

Through the Real Choice Systems Change grants (RCSC) program, and through other strategies, [167] the President's New Freedom Initiative (NFI) has recognized the centrality of transportation in the lives of Americans with disabilities. NFI funds have contributed to innovation and experimentation in the transportation area.

It is important that NFI programs and other programs for transportation-disadvantaged persons remain a part of, and be fully integrated into, all U.S. transportation policy. NCD therefore recommends that Congress include permanent authority for NFI projects and initiatives in all transportation-related legislation and budgeting.

(d) Air Travel

(d) (1) Customer Service Compliance Review

In September, 2005 the Department of Transportation's (DOT) Inspector-General's office announced a periodic review of air carriers' compliance with customer service commitments in areas ranging from overbooking to disclosure of frequent flyer program restrictions. NCD is particularly gratified by inclusion in the review of airlines' performance in accommodation of passengers with disabilities and special needs. Incorporation of accessibility and accommodations into the mainstream of airline customer service is an important development, and one which NCD hopes will be continued and extended into other realms of DOT oversight of the transportation industry. But customer service commitments, whatever their public relations value, do not have the force of law. For the rights of passengers with disabilities to be secure, efforts to apply key civil rights laws must continue.

(d) (2) Air Carrier Access Act

(d) (2) (A.) Self-service Machines

NCD is concerned about the speed and progress of DOT's efforts to update its Air Carrier Access Act (ACAA) regulations governing the provision of equal access to air travelers with disabilities. In particular, as noted in last year's status report, the rapid introduction of self-service, electronic machines for performing many activities, from boarding pass-issuance to luggage-screening, has created serious new barriers to equal access for passengers with various

disabilities. Moreover, as personnel are reduced to take maximum advantage of the new technology, the waiting times endured by people who cannot independently operate the ticket kiosks or equipment appear to be growing dramatically longer. Today for example, based on anecdotal information, passengers who are blind often feel compelled to arrive at the airport an hour or more in advance of the recommended time, because they expect to have to stand in long lines to get to the ticket counter for human assistance in obtaining their boarding passes and selecting their seat assignments.

NCD has repeatedly urged DOT to comprehensively address the access issues associated with the deployment of e-ticket machines and other self-service technology. When in late 2004 the Department issued an NPRM aimed at gaining input for use in revising its ACAA regulations, [168] NCD praised the action in its annual status report, believing that this modernization would furnish the occasion for addressing new issues.

NCD is unaware that new rules have been finalized or published, or of any attempt on DOT's part, working with the airline industry and with the Department of Homeland Security where indicated, to address the accessibility issues surrounding the deployment of new technology. Neither testing procedures incorporating accessibility nor requirements for accessibility appear to have been promulgated. As significantly, no systematic arrangements appear to be in place for assuring that persons with various disabilities will be regularly involved in the testing of new self-service airport technology before it is rolled out.

NCD strongly reiterates its recommendation that the DOT address these issues in a comprehensive fashion, working with the airline industry, with airport security agencies and with the traveling population of people with disabilities to develop evaluation methods, functional and workable performance requirements for the array of devices being deployed.

(d) (2) (B.) Accessibility of Air Travel Web Sites

In order to clarify the legal complexities surrounding application of civil rights laws to airline and other travel industry web sites, and in order to help identify what requirements should apply, NCD has commissioned a paper on accessibility of air travel-related internet sites. [169] That

paper should be completed early in 2006. In the meantime, NCD once again urges the DOT to proceed along the lines indicated in its November, 2004 NPRM. [170]

In this case, the department should, at the very least, make clear whether it regards air-carriers' ticketing sites to be governed by the ADA, by the ACAA, by state law, or by no civil rights statutes at all. The implication drawn from the NPRM was that DOT regarded ACAA as conferring jurisdiction over air line web sites, [171] but for the sake of all industry, governmental and consumer stakeholder groups, this matter needs to be clarified. Only when DOT's views are clearly known concerning what laws apply, as NCD indicated in its last status report, and as should be made clear once more in the kiosks paper noted above, clear, workable and widely understood guidelines exist for defining what constitutes accessibility and how to achieve it. Such standards existed well before the current generation of airline web sites came online.

Recommendations

Recommendation 10.1: NCD recommends that DOT continue to conduct regular, proactive assessments of transit system compliance with ADA requirements to assure that maintenance, deployment, information accessibility and other components of truly accessible service remain priorities, once accessible capital equipment has been purchased and deployed.

Recommendation 10.2: NCD recommends that the DOT convene an advisory panel, including public and private rail transit operators and representatives of the disability community, as well as business and other community leaders, with a view to exploring innovative strategies for identifying new sources of funds that could be used to expedite the accessibility renovation of older rail stations.

Recommendation 10.3: NCD recommends that Congress explore possibilities for decoupling user-eligibility from operator-capacity in ways that focus attention and resources on operator compliance and needs and that, while no in any way excusing noncompliance, relieve all parties of the pretense of engaging in pointless disputes over eligibility.

Recommendation 10.4: NCD recommends that Congress include permanent authority for NFI projects and initiatives in all transportation-related legislation and budgeting.

Recommendation 10.5: NCD recommends the DOT comprehensively address the access issues posed by the introduction of a growing array of self-service devices at airports, and that relevant stakeholders be engaged to work with the department in fashioning solutions that assure accessibility of such equipment to these passengers.

Chapter Eleven— Assistive Technology and Telecommunications

Introduction

This chapter addresses key current issues in the areas of assistive technology and telecommunications. It begins with a discussion of a major assistive technology projects compendium released in 2005. The chapter discusses ways to build on the compendium to address broader assistive technology and universal design research needs.

Following this, the discussion addresses indications of concern regarding federal performance under Section 508 of the Rehabilitation Act, calling for beefed-up reporting as the starting point for resolution of potential problems.

Following this, the discussion addresses the issue of telecommunications and reviews the growing centrality of broadband access in all our lives and discusses legal threats to that access for people with disabilities, as well as measures that could be taken to reduce those threats. The chapter then specifically relates these issues to the civil rights protections afforded people with disabilities under Section 255 of the Telecommunications Act of 1996.

Following this, the chapter reports on major developments in closed-captioning, and finally discusses reforms needed in the e-rate program to assure that major goals of accessibility and accountability are best served.

(a) Assistive Technology Research

1. Assistive Technology Compendium

In April, 2005 the Interagency Committee on Disability Research (ICDR) published *Compendium of Assistive Technology Research: A Guide to Currently Funded Research Projects*. [172] This compendium is an invaluable source of information for those seeking both broad perspective and in-depth knowledge of the assistive technology (AT) research activities of Federal government entities. While greatly valuing and appreciating this report, NCD is

concerned that it raises more questions than it answers, and that it exposes gaps in the federal government's approach to the subject of AT.

Setting forth the background for the report, the compendium states: "the New Freedom Initiative directs the Interagency Committee on Disability Research (ICDR) to improve the coordination of federal assistive technology research and development programs. The administration provided funding to the committee so that it could prioritize assistive technology needs in the disability community and foster collaborative projects between federal laboratories and the private sector. This compendium is designed to serve as a basis for the ICDR to identify federal assistive technology research priorities and coordinate funding activities." The report goes on to delineate "not included" subjects, among which are universal design projects and medical technology such as respirators, inhalers and oxygen tanks, as well as functional electrical stimulation devices used by medical personnel or therapists in providing treatment.

ICDR is of course free to determine the scope of its own research. But if the goal of the compendium was to achieve the objective of component one of the NFI's AT agenda, (namely, "increasing access to assistive and universally designed technologies"), then explicit omission of universal design (UD) projects from the compendium is inexplicable. It may well be that ICDR plans to add universal design projects to the compendium at a later date, but NCD has discovered no indication that this is the case.

With accessibility of the mainstream physical and communications environment a hallmark of current policy and an increasingly important premise for design work throughout industry, any long-term omission of UD from a compendium such as this would be extremely detrimental to a meaningful understanding of the current role and emerging priorities for technology research. All that can be said now is that no evidence has been noted in ICDR priorities that UD research is given the same prominence as AT research.

Apart from the question of capturing information on UD-related federal research, NCD remains eager to learn how the ICDR will use the information contained in the compendium to prioritize federal AT research activities and to coordinate funding activities. Neither this compendium, nor

anything else NCD is aware of as emanating from the Committee, provides any insight into how federal funding categories are defined or how priorities are established among them.

At this time of unprecedented and likely long-term pressure on all discretionary domestic spending, including AT or UD research, the need to establish research priorities and the related question of how and by whom such priorities are to be established emerge with new forcefulness. In particular in this regard, the role of individuals with disabilities in establishing the government's research agenda is a matter of concern. Until and unless people with disabilities are enabled to have input into formulation of the federal AT research agenda, there is little likelihood of that agenda yielding the best or most relevant results.

2. A 21st Century Research Agenda

Research into AT is urgently needed. From identifying areas where the private sector cannot or will not meet identified needs, to enlisting individuals with disabilities in identifying needs, to evaluating and improving the delivery and distribution systems for existing AT and UD, to developing methods for assessing the cost benefit of AT research and deployments—in each of these areas and others, research is vitally needed to ensure the most effective use of scarce and shrinking governmental resources.

This report is not the place to detail this agenda. Suffice it to say, NCD stands ready to work with the ICDR, with the Office of Management and Budget, the National Institute on Disability and Rehabilitation Research, the National Science Foundation, or such other entities as may be appropriate in helping to define, operationalize and implement the research agenda that will answer key open questions, that will ensure meaningful prioritization of federal research funding, and that will create the greatest likelihood of products and systems that meet real needs among the greatest number of people.

Pending such an opportunity, two issues should be highlighted. The first is that in the absence of attention to what we may call the infrastructure of AT (that is, the support and distribution systems, the availability of training, or the availability of consumer choice), emphasis on new product development may create more imbalance and potentially increased frustration. Without

an understanding of the marketplace and the infrastructure, products and systems, however innovative and well-designed, are not self-executing.

The second key issue we wish to note here relates to what is surely the most underdeveloped area of AT research. Here we refer to the need for sophisticated econometric models to track the real costs and benefits of AT and UD research and deployment. For example, if the provision of AT devices or services to an individual by the federal-state vocational rehabilitation (VR) system results in that person's obtaining or maintain employment, real savings may accrue, both short- and long-term, for a number of programs and a number of agencies. Everything from future rehabilitation costs to income maintenance potentially even to health care costs may be positively affected. Yet, under current government accounting and accountability principles, no reliable method exists for identifying and tracking such savings, for taking them into account, or for crediting the agency or program whose actions or expenditures made the savings possible.

The problem is even worse for intergovernmental federal-state than for interagency federal-to-federal agency relationships. For example, as the Centers for Medicare and Medicaid Services (CMS) endeavors to reduce federal expenditures for powered mobility devices under the Medicare program, no systematic assessment is forthcoming about the effects of such federal savings on state and local expenditures in a number of related program categories.

Some would say cynically that we simply do not care, or that we lack long-term perspectives. NCD believes the problem to be much simpler and yet more complex. We lack mechanisms for tracking the connections and aggregating the impacts. AT and UD represent a prime area where that gap can and should be addressed. AT and UD can also provide research methodologies that can be applied to other complex funding programs and service systems.

(b) Federal Procurement Under Section 508

Perhaps the greatest laboratory for AT and UD research is the current system of federal procurement for technology. Section 508 of the Workforce Investment Act (also known as the Rehabilitation Act) provides that in its development, deployment and procurement of electronic and information technology (E & IT) for its own use, the federal government is required to

obtain technology that is accessible to and usable by persons with disabilities, to the extent “readily achievable.” [173] Through the harnessing of the enormous buying power of the U.S. government, Section 508 has the potential to dramatically redefine the design practices of the telecommunications, computer and related industries.

As important as its provisions bearing upon E & IT hardware and software are Section 508’s requirements for web sites maintained by government agencies for use by members of the public or by their own employees, and other web sites maintained or designated for use by federal employees. Regulations developed to implement Section 508 set forth detailed functional and in some cases feature specifications not only for hardware, but also set forth the meaning of and the requirements for accessibility of covered web sites. [174]

NCD’s ability or that of other interested observers to monitor the implementation and measure the effectiveness of Section 508 has been hindered by the lack of critical data from federal oversight agencies. In particular, Section 508 vests in the Department of Justice (DOJ) responsibility to prepare a biannual report to the President and Congress on Section 508. This report has not been forthcoming in four years.

In the reports that DOJ has produced, it has focused on compliance with the web site provisions of the law by covered federal agencies. Based on data from other sources, NCD is concerned that federal agency performance in this area may have deteriorated since the last DOJ survey. Whether the lack of reports has contributed to this circumstance it is not possible to say with certainty.

In the Brown University annual e-government survey, one of the items reviewed is the accessibility of federal and state governmental web sites. Based on a random sample of web sites studied during mid 2005, the study reports that only 50% of federal web sites surveyed met minimal accessibility requirements. [175] The performance of state government sites, at 44%, was even more disappointing.

While the screening software (Bobby) used to make these determinations does not use the identical standards to those applicable under 508, the criteria for web sites are similar enough to

leave no doubt that literal application of the 508 guidelines would have yielded comparable results.

This finding alone should vividly convey the need for intensive inquiry into the extent of 508 compliance, and if these findings of noncompliance are confirmed, into the reasons why greater progress has not been achieved in making public information as accessible to people with disabilities, including federal employees and federal contractor employees with disabilities, as it is to other citizens.

Accordingly, NCD recommends an immediate high level collaboration, involving the DOJ, the E-government Office, the General Services Administration, and the Council of Chief Information Officers to develop and implement a strategy that will facilitate preparation for Congress and the President by the DOJ of its long overdue Section 508 report, and that will develop information that gives meaningful insight into the operation of Section 508 and into what if any changes need to be made in the law or its implementation in order for it to be effective in achieving its access goals.

(c) Telecommunications

Without a doubt, telecommunications have become as central to life as housing, transportation, shopping or any of the other daily activities we take for granted. Indeed, telecommunications have become integral parts of all of these other activities. From mapping one's route online, to ordering one's clothing via e-commerce, to getting one's college credits remotely through online courses, to researching one's doctor's diagnosis through the National Library of Medicine or self-help groups, to paying one's taxes—in short, in every aspect of our lives, access to the online world has become central to our ability to participate and to benefit.

When we speak of telecommunications, it is precisely these opportunities to participate in society that we have in mind. In the legal context, discussions may focus on more abstract questions, such as the proper role of the federal government, the creativity of the private sector, and the like, but at bottom, nothing less than the ability of people to lead full lives is implicated in having or not having full access to the communications technology and systems of our age.

1. Broadband

Broadband communications have become the fastest, most utilized technology for increasing speed and access to information via the Internet and wireless communications. A recent Congressional Research Service (CRS) report to the members of Congress provides a working basis for the discussion that follows. [176] Broadband is high-speed connectivity that features digital communications over video and/or voice of delivery platforms. People with disabilities can benefit from broadband in a number of ways. For example, broadband makes allows for remote interpreting, which greatly enhances the quality of life for people who are deaf or hard of hearing. As another example, broadband supports the use of real time webcasting which allows for the inclusion of text captioning (for people who are deaf or hard-of-hearing) and streaming audio (for people who are blind). Suffice it to say for the moment, broadband gives computer users the ability to do more things and to do them more quickly online than can be done with a traditional modem connected to a standard telephone line.

Some may think this reflects the interests and aspirations of high-end or “power users,” and that as such it is a lifestyle issue that has no place in this report. But increasingly, nothing could be further from the truth. Today it is ever-more the case that access to the web sites people must use to transact all manner of business and obtain all sorts of information and services; that access to the software required in many settings; that access to multimedia—that each of these, including increasingly even the ability to perform our jobs, require access to broadband.

That broadband access is no mere conceit of a technological elite, but is a necessity for full participation in contemporary society, can be gleaned from a number of sources. A recent detailed research report sets forth the enormous economic implications surrounding the question of whether America’s 70 million citizens over the age of 65 and under the age of 65 with disabilities are or are not able to access broadband. [177] Similarly recognizing broadband’s importance, President Bush has called for universal broadband access by 2007. [178]

No one contends that the marketplace has thus far performed effectively in bringing broadband access to the majority of Americans. A number of bills introduced into the Congress during 2005 highlight these problems, including unavailability of broadband in rural areas, [179] in inner-city

areas, and including the possible need for tax credits to stimulate its provision. If broadband access is a priority for our economy and society, as President Bush clearly recognizes it to be, there can be little doubt that, whatever one's overall attitude toward government intervention, the federal government must play a major role in bringing this about, whether by tax or other incentives, by regulation, or by other means.

The barriers to broadband access for people with disabilities are different and more complex than for other people. Generally, when we speak of the availability of broadband, it is economics and geography that determine people's access. You cannot have broadband if telephone companies, cable companies or other providers have not installed the requisite cables or towers in your area, and brought them to your home. In rural and inner-city areas, where populations are sparse or incomes low, the rate of return is often deemed insufficient to justify the expense of "wiring" a neighborhood or town.

Many people with disabilities live in underserved areas where broadband, DSL or other variations are not available. But even for those who live in areas that have such service, serious obstacles to access still exist. Without going very far into the details here, it is enough to note that various design features of the hardware, interfaces and networks that people use will determine the availability and accessibility of broadband service to individuals with disabilities. These are design features that are totally beyond the control of the user. They are not by and large costly or difficult issues to anticipate and address, but broadband access for people with disabilities has become a hostage of other, unrelated concerns. Broadly speaking, broadband and other internet and telecommunications access issues for people with disabilities have been caught up in, but also obscured by, the broader debate over the proper role of government regulation of the internet and of the worldwide web.

As early as the Federal Communications Act of 1934, our nation's policy favoring universal telecommunications access (meaning telephone access at that time) was established in law. Supported by a host of related measures, this goal was realized, to the point where today few if any Americans live in places where basic telephone service is unavailable. But beginning in 1980, the Federal Communications Commission (FCC) began to draw legal distinctions between

basic voice telephone access and service, on the one hand, and newer types of service, including computer-based data and video services, on the other. By degrees, the chasm between traditional “communications services” and new “information services” began to emerge.

Until 2005, there were reasons for believing that this distinction would not prevent the FCC from taking reasonable measures to protect the civil rights of people with disabilities to broadband and other forms of access. But a June 2005 Supreme Court decision in the case of *National Cable and Telecommunications Association versus Brand X Internet Services* [180] shrouds that hope in considerable doubt.

In its most elemental form, the Supreme Court held that deference should be paid to the FCC’s determination of what are “information services.” Why this is important is that information services are not subject to regulation, including to regulation under those statutes originally written to protect the telecommunications access rights of people with disabilities. It is as if the deregulation of the air line industry that occurred in the late 1970s had included authorization for airlines to refuse to allow people with disabilities to travel on their planes. Let us elaborate in the context where issue is most vividly joined.

2. Section 255

Adopted as part of the general revision of the Federal Communications Act in 1996, [181] Section 255 of the Act provides that “telecommunications equipment,” “customer premises equipment” (meaning phones, etc.), and “telecommunications services” (meaning the networks and capabilities that phone companies, internet service providers, cable companies, even utility companies) provide, must be “accessible to” and independently “usable by” persons with disabilities, to the extent “readily achievable.” [182]

The readily-achievable standard is a low one, meaning achievable without much difficulty or expense. Yet the FCC has given little guidance over the years as to what accessibility needs it finds to be most pressing, or as to the measures it would regard as readily-achievable in meeting those needs. Nor has the Commission, which began its enforcement of Section 255 by producing a Market Monitoring Report, [183] conducted any research in over five years, so far as is known, into the accessibility needs of telecommunications users with disabilities or into the extent to

which manufacturers and service providers are identifying or responding to such needs. Nor, so far as can be determined, has the FCC conducted any audits or inquiries to whether and how manufacturers or service providers are taking accessibility into consideration in their design, selection or implementation of equipment and services, as the statute requires them to do.

NCD has expressed its concern over the FCC's passivity in its annual status reports going back over the past three years. Speculation is possible as to the reasons for the Commission's attitude, especially when its role here is contrasted with the positive and energetic stance it has taken in regard to the protection of rights and the enhancement of access under other statutes, discussed below.

While the possible reasons for the FCC's apparent indifference to Section 255 are beyond the scope of this report, one speculation is worthy of note, however. Most new services and the equipment that supports them come under the rubric of "information services." As such, the FCC takes the view that they are not covered by Section 255, which applies only to that rapidly shrinking backwater of analog, dial-up voice telephony cover by the Act, coming under the umbrella very "communications services."

Day by day, as even traditional voice telephone calls migrate to unregulated VoIP computer-based transmission modes, Section 255 is withering away.

Despite the Supreme Court's National Cable decision, the FCC is not without authority or resources to stem the erosion and forestall the oblivion of Section 255. But if the commission does believe itself bound to adhere to its previous course of action (as there are reasons why it might), the way is still open to the commission to work with NCD and other interested groups to seek from Congress the limited authority that would be necessary to extend civil rights protections to modern telecommunications, without in any way interfering with the potential for innovation or the economic robustness of the burgeoning internet economy.

Accordingly, NCD recommends that the FCC announce its intentions with respect to Section 255, and that it indicate its views, in an appropriate declaratory or rulemaking setting, concerning the viability of the law. NCD further recommends the FCC to indicate whether it would

favorably entertain a petition for rulemaking to institute a full review of the operation of Section 255, similar to the petition discussed in the next subsection that it has accepted in connection with closed-captioning.

3. Closed-captioning

Since enactment of the Television Decoder Circuitry Act [184] in 1990, captioning has become a staple of American life. As the FCC has noted, its benefits have extended far beyond people with hearing loss to including people learning English and people in noisy environments where the sound cannot be heard. [185]

New impetus was given to captioning by the Telecommunications Act of 1996. Pursuant to that law the FCC has established requirements and timetables for the captioning of increasing amounts of television programming. Beginning in 2006, a new plateau of access will be reached, as all new programming (with certain limited exceptions) is required to be captioned.

NCD urges the Commission to closely monitor the implementation of these requirements, and to continue to review exemption requests with full awareness that programmers and distributors had eight years notice of these requirements.

Guaranteeing the amount of programming is one thing, but ensuring its quality is another. In this regard, the Commission's commitment to periodically review its captioning rules is especially important. NCD is pleased that the FCC has seen fit, in response to a petition from a number of consumer and advocacy groups, to issue a notice of proposed rulemaking (NPRM) opening an inquiry into the operation and effectiveness of its closed-captioning rules. [186] Of particular concern to the petitioners appears to be the accuracy of captions. NCD applauds the FCC for its energetic response to the concerns of caption users, and hopes that this review will lead to improvements in the quality of information available through captions.

A related matter has to do with the supply of qualified captioners. As use of captioning increases, the need for skilled persons is also destined to grow. For this reason, NCD recommends passage of the Training of Realtime Writers Act of 2005. [187] We urge

Congress to adopt this legislation or make other specific provision for ensuring that adequate personnel will be available to meet growing demand.

4. The E-Rate

Established under the 1996 act and funded by interstate telephone companies, largely through small fees charged to subscribers, the e-rate program reflects our nation's continuing commitment to universal access in a different way. It was designed to subsidize the costs of internet and other telecommunications access for schools and libraries. With its expenditures currently capped at \$2.5 billion per year, it received in 2004 applications totaling over \$4 billion. [188]

Sharing and appreciating the goals of the e-rate program, NCD has expressed concerns in its recent status reports about certain aspects of the program. Principally we have been concerned with the lack of requirements that services or equipment acquired or subsidized with e-rate funds be accessible to individuals with disabilities. NCD has therefore urged the FCC to add requirements for accessibility to the e-rate guidelines, and to include the necessary assurances among the commitments and undertakings that funds recipients must provide.

In 2005 the Government Accountability Office (GAO) completed a major report on the e-rate program. [189] As embodied in the report and in subsequent GAO testimony summarizing its findings, [190] GAO identified a number of problems in the FCC's governance of the e-rate program. Most striking among these is the finding that the FCC has never clearly indicated which federal regulations or policies apply to e-rate funds recipients. [191]

GAO indicates that the FCC believes its case-by-case approach is adequate for resolving such questions. But however this may be in general, NCD sees no indication that the FCC's approach has resulted in clarification to grantees that accessibility is expected of them, let alone in the denial of funds owing to lack of information or commitments on this point. With funding requests outstripping available funds, use of accessibility as one evaluation criterion would make eminently good sense.

While GAO does not specify any particular regulations or policies that it believes should be applied to e-rate recipients, NCD cannot imagine any reason why civil rights regulations should not be in the first rank. After all, the e-rate program was created to ensure that institutions and individuals with limited means would not be denied access to and participation in the information society. This logic applies forcefully to people with disabilities.

Consistent with GAO's findings, NCD therefore recommends that the FCC, as part of the larger management review and goal-setting processes recommended by GAO, act swiftly to institute the proceedings necessary to require accessibility and related certifications from e-rate grantees. NCD further recommends that the federal government's own 508 regulations be used to define the specific obligations of grantees in this regard.

Recommendations

Recommendation 11.1: NCD recommends an immediate high level collaboration, involving the Department of Justice, the E-government Office, the General Services Administration, and the Council of Chief Information Officers to develop and implement a strategy that will facilitate preparation for Congress and the President by the DOJ of its long overdue Section 508 report, and that will develop information that gives meaningful insight into the operation of Section 508 and into what if any changes need to be made in the law or its implementation in order for it to be effective in reaching its access goals.

Recommendation 11.2: NCD recommends that the FCC announce its intentions with respect to Section 255, and that it indicate its views, in an appropriate declaratory or rulemaking setting, concerning the viability of the law. NCD further recommends the FCC to indicate whether it would favorably entertain a petition for rulemaking to institute a full review of the operation of Section 255.

Recommendation 11.3: NCD recommends passage of the Realtime Writers Act. It is imperative that the nation develop a cadre of trained personnel who able to meet the growing demand for qualified captioners.

Recommendation 11.4: NCD recommends that the FCC, as part of the larger e-rate management review and goal-setting processes recommended by GAO, act swiftly to institute the proceedings necessary to require accessibility and related certifications from e-rate grantees. NCD further recommends that the federal government's own 508 regulations be used to define the specific obligations of grantees in this regard.

Chapter Twelve—International Affairs

Introduction

Almost every area of public policy, even matters once thought to be entirely domestic, now has implications for or interactions with other nations. In the area of disability, this is also true, though in relation to people with disabilities the nature of these ramifications and interactions are unique.

In addition, the United States, through a variety of governmental and nonprofit agencies, has attempted to engage with other nations and international organizations in addressing disability-related issues of worldwide concern and in helping these nations and international bodies to utilize our experience in their work.

This chapter reviews several key areas where these relationships and aspirations were most significantly demonstrated during 2005. It begins with a discussion of the role of NCD in providing technical information and advice to a major UN project, and includes a discussion of efforts to share experience and expertise with our nearest neighbors Mexico and Canada. The chapter then discusses the role of disability in U.S. support for the Global Fund and for other worldwide efforts to eradicate disease. Following this, and returning to the UN theme, the chapter discusses U.S. concerns regarding the forthcoming convention on the rights of persons with disabilities. Lastly, the chapter briefly raises some issues posed by growing levels of trade and travel, as we strive to balance openness with appreciation to those entities that have made accessibility a hallmark of their goods and services.

(a) The U.S. as Model, Teacher, and Student

NCD has pointed out in its previous reports many of the areas in which the United States leads the world in the creation and implementation of opportunity and equality for its citizens with disabilities. Of all the areas where America's influence, prestige and impact derive from leadership and example, few are as dramatic or as important as its role in disability policy and rights.

2005 provided a number of striking examples of this exemplary role. In connection with the work of the UN Ad Hoc Committee on a Comprehensive and Integral International Convention on Protection and Promotion of the Rights and Dignity of Persons with Disabilities, (also discussed in Section c, below) NCD (which has been in the forefront of disseminating America's achievements and experience) issued a number of summary papers, including papers on education, [192] employment and right to work, [193] and transportation. [194] These papers summarized U.S. law and experience, with a view to providing the delegates to the UN Committee with data and insight to assist them in clarifying the issues before them and reaching conclusions regarding the eventual contents of the Convention.

Leaving aside for the moment one's views concerning the Convention, there can be little doubt that these informational resources will prove of value in contributing to the final product. In addition, they will likely be of value to developing nations in formulating and refining their policies in these and related policy areas. Even for U.S. readers interested in these topics, the papers provide excellent overviews of the legal and historical context, and are recommended for those wishing more information on them.

At the same time, the U.S. remains eager to share and learn from the experiences of other nations, particularly those of neighboring countries. In that regard, the U.S. Access Board hosted in July, 2005 a meeting of U.S., Canadian and Mexican representatives to discuss and share information about each country's approach to accessibility of the built environment. [195] In view of the increasing interdependence of these nations' economies, increases in the movement of goods and people between and among them, and growing reliance on standardization of rules and design standards for information technology systems and other technology, such efforts represent an important, mutually respectful effort to glean and share the best practices arising in a variety of settings and cultures. NCD commends the Access Board for this effort, and hopes that such efforts, in physical- and communications-environment accessibility, will continue and expand in the years to come.

(b) Health Promotion

In this era of rapid international transportation and extensive international trade, it is more than ever the case that disease knows no international boundaries. To the degree that significant numbers of people throughout the world are effected by HIV, tuberculosis, malaria, infant mortality, blindness, and a host of other conditions, these conditions cause large numbers of people to become disabled, and have a tremendous impact on society, economy and the slowing of progress toward development throughout the world.

Recognizing the value of disability prevention, the United States has increasingly sought to incorporate disease prevention and treatment into its international and multilateral foreign assistance programs. One important example, highlighted by an August, 2005 Congressional Research Service (CRS) report is U.S. participation in and contributions to the Global Fund. Focusing on the three major worldwide conditions of HIV, tuberculosis and malaria, the Global Fund represents a major international initiative for combating these conditions. As such, though often spoken of in terms of its potential role in reducing mortality, it represents a major thrust in the effort to prevent and curtail the incidents of disability arising from these conditions.

NCD applauds U.S. support for the Global Funds and similar initiatives aimed at improving world health and preventing disability. NCD, as discussed at length in its 2004 Progress Report, [196] also commends steps taken under the Foreign Assistance Program to incorporate disability rights into our nation's broader human rights commitment, as we attempt to use aid to encourage positive developments in recipient and candidate nations.

NCD also expresses the hope that U.S. efforts to address health concerns will reflect the fullest possible awareness of the disability-policy implications of these disease-fighting measures. Specifically, NCD believes that efforts to prevent and treat disease through vaccination and other medical interventions need to be accompanied by parallel efforts aimed at ensuring that people with chronic diseases whose lives are preserved or prolonged will not suffer discrimination or exclusion on account of their diagnoses or health status. In this connection, NCD recommends that the Agency for International Development (AID) undertake a study of the extent to which the Global Fund and other multinational efforts currently do, or prospectively could, expand their

scope of concern, without diverting resources from ongoing efforts, to ensure nondiscrimination and full opportunity for those who benefit from the medical interventions and resources that these programs make available.

(c) The UN Convention

During 2005 efforts and deliberations continued in the UN Ad Hoc Committee to draft and submit to the member nations an International Convention on Protection and Promotion of the Rights and Dignity of Persons with Disabilities. Considerable controversy has surrounded this proposed convention in the U.S.

While NCD continues to strongly support the Convention, the Council recognizes the depth of feeling and the good faith of those who question its necessity and who may oppose its adoption by the U.S. An event that occurred in October, 2005, may be particularly valuable for helping to dispel many of the fears that have led some to oppose U.S. adoption of the Convention.

In October NCD cosponsored a symposium on the monitoring and implement of the convention. [197] While this symposium was held mainly for the purpose of responding to the desire of Ad Hoc Committee members for information that would help them to formulate these provisions of the convention, the presentations at the symposium are also of great value in clarifying that the U.S. has nothing to fear from this advance in international law. Review of the symposium is recommended for all those with an interest in this matter, especially for those with concerns about any potential of such a convention to limit the sovereignty or interfere with the legitimate policy prerogatives of signatory nations.

Accordingly, in view of the already significant and positive input the U.S. has had into the development of the International Convention, NCD recommends that the United States sign and thereafter ratify the proposed convention promptly upon its submission.

(d) International Travel and Commerce

In light of the Supreme Court's Specter decision [198] holding that the ADA applies to foreign-flag cruise ships embarking and disembarking in U.S. ports, major new opportunities for

international cooperation on behalf of accessibility have begun to emerge. NCD urges the U.S. to build upon the principles of the Specter decision to continue the process of ensuring that, so far as possible, U.S. entities and firms engaged in international travel or commerce will not face competitive disadvantages as a result of their adherence, required and voluntary alike, to the principles of design and reasonable accommodation embodied in the ADA.

Specifically, in all contexts where bilateral treaties or international covenants or conventions govern trade, communication and travel among nations, the U.S. should work to ensure that the highest principles of accessibility be observed by foreign entities competing with U.S. entities, and that full and equal access to U.S. markets, resources and facilities by foreign entities be predicated upon the willingness of such entities to adhere to the same high standards as their American counterparts must meet.

Accordingly, NCD recommends the Department of Commerce undertake a review of all major trade agreements, including the WTO, NAFTA and other regional trade pacts, and a review of international conventions in areas ranging from air travel to postal and telecommunications, with a view to identifying areas where heightened accessibility is possible and to instituting negotiations for the enhancement of such agreements to ensure that such high standards will be met by all participants.

Likewise, in connection with non-U.S. firms contracted to provide various goods and services to or on behalf of the U.S. government, NCD recommends that the OMB direct each contracting agency to review its regulations and policies in order to ensure that such entities will be held to the same high standards, as relates to physical accessibility, to communications accessibility and to nondiscrimination, as U.S. firms performing functions for the Federal government in the domestic arena are obliged to maintain.

Recommendations

Recommendation 12.1: NCD recommends that the Agency for International Development (AID) undertake a study of the extent to which the Global Fund and other multinational efforts currently do, or prospectively could, expand their scope of concern to ensure nondiscrimination

and full opportunity for those who benefit from the medical interventions and resources that U.S. foreign assistance programs make available.

Recommendation 12.2: NCD recommends that the United States sign and thereafter ratify the proposed international convention on the rights of persons with disabilities promptly upon its submission.

Recommendation 12.3: NCD recommends the Department of commerce undertake a review of all major trade agreements, including the WTO, NAFTA and other regional trade pacts, and a review of international conventions in areas ranging from air travel to postal and telecommunications, with a view to identifying areas where heightened accessibility is possible and to instituting negotiations for the enhancement of such agreements to ensure that such high standards will be met by all participants.

Recommendation 12.4: NCD recommends that the OMB direct each Federal agency contracting with non-U.S. firms for goods or services to be provided in other countries to review its regulations and policies in order to ensure that such entities will be held to the same high standards, as relates to physical accessibility, to communications accessibility and to nondiscrimination, as U.S. firms performing functions for the Federal government in the domestic arena are obliged to maintain.

Chapter Thirteen—Homeland Security

Introduction

This chapter attempts to place the issues faced by people with disabilities in the broader context of emergency preparedness, evacuation planning, and disaster relief and recovery efforts. It begins with a discussion of NCD's April, 2005 Saving Lives report, analyzing some of the major issues addressed in that report. From there, utilizing findings made in the aftermath of the Gulf Coast disaster, the chapter goes on to consider procedural steps that should be taken to ensure that the goals of inclusiveness are incorporated into all future planning efforts. As a backdrop to all this, some attention must be directed to the contextual framework within which emergency planning takes place.

(a) Context

For many Americans, the devastation, horror and loss wrought by Hurricanes Katrina and Rita will remain vividly etched in memory for a lifetime. The very fact that discussion of homeland security this year unashamedly takes natural disaster, rather than terrorism, as its point of departure testifies to how our consciousness has been permanently altered.

The massive failure of government to respond to the crisis has been amply and painfully documented in numerous forums, images, testimonies and reports. Along with their fellow citizens, people with disabilities endured the consequences of the inadequate planning and execution that preceded and followed the hurricanes. But in addition to the generalized effects, many people with disabilities experienced further adverse consequences that might have been avoided had planners taken issues of their safety, evacuation, relief and related matters into account. When a person with a disability is made to abandon a wheelchair at an airport, or when a person with a hearing or vision disability cannot access vital but inaccessible emergency information or instructions, the consequences of disaster are exacerbated by the very measures society has taken to respond to them.

Little purpose would be served by pointing the finger of recrimination now. All are united in the objective of learning and applying the lessons of the disaster, for the purpose of ensuring that such tragedies will never occur again. Fortunately, as reflected in NCD's April 15th 2005 report "Saving Lives: Including People with Disabilities in Emergency Planning," blueprints and models do exist for how to go about inclusive and effective emergency planning.

(b) The Report

As the letter of transmittal accompanying the NCD Saving Lives report to the President states: "All too often in emergency situations the legitimate concerns of people with disabilities are overlooked or swept aside. In areas ranging from the accessibility of emergency information to the evacuation plans for high-rise buildings, great urgency surrounds the need for responding to these people's concerns in all planning, preparedness, response, recovery, and mitigation activities."

Two very different timeframes are being addressed by this quote. However it may be that evacuation and disaster relief efforts inevitably involve ad hoc strategies and hurried decision-making, the planning processes for these activities did not take place under the same pressure of circumstance and time. It was in the conceptual framework surrounding these planning efforts, and in the nature of community input into those planning processes, that the fundamental problems became institutionalized.

(c) Critical Infrastructure

One of the key components of homeland security policy as it evolved over the four year period from 9/11 through the advent of the hurricanes is the need to identify and protect critical infrastructure. As described in a February 2005 Congressional Research Service (CRS) report, critical infrastructure refers to the transportation, energy-producing, communications and other key facilities and resources necessary for maintenance of the economy and for enabling emergency personnel to do their work in the event of disaster. [199] For people with disabilities, one shortcoming of this preoccupation is its assumption that the existing infrastructure, if preserved and protected, would meet relevant evacuation, sustenance and other needs. But for many people with disabilities, it could not.

To illustrate this point, let us examine two elements of the critical infrastructure: emergency communications and evacuation. In the case of emergency communications, it is not that they suddenly became inaccessible to people with disabilities when the emergency occurred. To varying degrees these resources have always been inaccessible, as they continue to be where they are provided only in one format, such as visually or verbally, without redundancy (meaning without simultaneous visual, audio and digital transmission, so that neither people with hearing or people with visual impairments will be denied access). The implications of inaccessible emergency information and instructions was not unknown, but until access to the information became crucial to the protection of life it was easier either to overlook the problem or to adopt a utilitarian position that refused to delay communications for the many while addressing the economic and technical complexities of access for the supposed remaining few.

This is also true in circumstances involving emergency evacuation. For many people with disabilities, leaving their homes on short notice or leaving their homes for any extended period at all would have been difficult or impossible under any circumstances. Lack of accessible transportation, lack of funds or connections for lodgings at the other end, lack of accessibility of shelters or other possible destinations, and many other factors are at play, but again, so long as the need to evacuate was only a hypothetical matter, left to the self-contained world of planning, these problems were not considered.

All this is not to say that the existence of people with disabilities was omitted from the calculations of planners. It is to say that the real issues facing this population, like the issues confronting people who did not own cars or who feared to leave their homes, were not understood or factored into the mix.

The consequences for many people with disabilities, particularly those who are poor and those who are from culturally and linguistically diverse backgrounds, are evident in many harrowing accounts. A panel and briefing sponsored by NCD and other organizations including the Congressional Bipartisan Disabilities Caucus on November 10th 2005 graphically recount many of these consequences. [200] As moving as are these reports and images, their ultimate

significance must lie in the incentive they provide to address the needs of survivors, and in the guidance they offer on how to ensure that such tragedies will never be repeated.

(d) The Needed Response

Serious consideration of how to achieve these objectives involves three distinct phases. First, there are the questions of what must still be done by way of ongoing disaster relief and reconstruction, of buildings and of society, to minimize the long-term harm and loss that will accrue to persons with disabilities. Second, in the rebuilding of critical infrastructure measures must be taken to assure its accessibility and availability to all who it is intended to serve. Third, planning processes must be put in place that assure the timely input of people with disabilities into all future homeland security planning processes, as knowledge and techniques evolve in the years to come.

(d) (1) Disaster Relief

However it may be that New Orleans and its environs have faded from the headlines and disappeared from our nightly television screens, the consequences of the disaster have not. Indeed, in economic and health terms, in dislocation and in trauma, those effects are likely to linger and spread out throughout the lifespan of those who were involved.

Several major legislative enactments have of course addressed hurricane relief in a number of ways. While such measures as tax relief for hurricane victims, [201] relaxation of eligibility-determination procedures for receipt of emergency Medicaid by evacuees, [202] or federal expenditures for temporary housing [203] are not specific to people with disabilities or targeted to people with disabilities, but of course they affect people with disabilities as much as they affect everyone else.

In Chapter Four of this report on health care, NCD suggested structural changes that should be made in the Medicaid program as a result of the lessons of the hurricanes. In this and other areas, some long-term issues emerge that may prove of particular relevance to people with disabilities and that may require reassessment of some traditional program models. For example, for all state-based service and assistance programs, we have seen that massive upheaval and rapid

movement of people creates enormous issues of documentation and of the applicability of differing eligibility criteria.

To the degree that many such programs have a role in the lives of people with disabilities, NCD recommends that Congress adopt overarching procedures to address interstate issues for all federal-state programs in evacuation situations.

More broadly, the definitions of disability used in a number of programs may need to be reconsidered, much along the lines that posttraumatic stress and toxic exposures have required our reassessment of veterans benefits, and much along the lines that our treatment of the health problems of 9/11 emergency-responders is now under review. NCD recommends that Congress respond to the implications of post-traumatic stress disorder (PTSD) by ensuring that the definition of disability used to determine eligibility for benefits and services under a range of federal and federal-state programs be defined in such a way as to take account of the medically recognized, long-term and cumulative consequences of experiences such as the hurricanes. These definitions should also include provisions for identifying and tracking the long-term consequences of toxic exposures that may undermine health overtime.

(d) (2) Specific Planning

In our immediate effort to rebuild critical infrastructure and communities, opportunity exists for creating a more inclusive and accessible environment, or conversely for creating or hardening an exclusionary and inaccessible one. Whatever the decisions made in this regard, they will be as a practical matter irreversible, and will affect the course of our lives for decades to come.

Some of the imperatives are clear. In designing the emergency communications systems of the future, both those designed to provide key information to the public and those aimed at facilitating coordination among official responders, accessibility must be a watchword. Many issues currently surround the building of a robust emergency communications infrastructure, not least the allocation of scarce telecommunications spectrum (that is, frequencies and wavelengths) among competitive users including emergency communications and commercial high-definition TV. [204] Far from making accessibility more difficult, the need to confront these and other basic questions anyway makes it all the more appropriate and timely to consider accessibility as well.

Similarly with respect to rebuilding of the physical infrastructure, federal guidance and federal resources are centrally involved in the reconstruction process. From rules governing the availability of flood insurance to capital funds for road and housing reconstruction, national policy is implicated at every level of the rebuilding.

As such, it seems timely and essential to insist that full accessibility be required for all projects planned or carried out with federal funding. Currently, debate is taking place regarding what flooded areas will be supported to rebuild, and regarding such issues as how high off the ground new housing will have to be raised. Given that the capital investment, public and private alike, will be enormous, and given the transformative nature of whatever rises to replace the devastated neighborhoods and structures, a commitment to accessibility as a hallmark of this new future makes indisputable sense from every point of view.

NCD therefore recommends that accessibility standards utilized under the ADA be strictly applied to all buildings, facilities, thoroughfares or other amenities or structures planned or built with the aid of federal, state or local funds. This commitment to accessibility should extend to the rebuilding of communications infrastructures, utilizing the well-understood and successful standards developed under Section 508 of the Rehabilitation Act to guide the implementation of this requirement.

(d) (3) The Planning Process

Assuming we are successful in factoring people with disabilities and their concerns into the current hurricane recovery and critical-infrastructure modernization processes, the effort to build an inclusive society is an ongoing one. No one knows what new issues or new technological possibilities will exist as procedures and infrastructures evolve and are periodically renewed over time.

What emerges therefore is a need not merely to incorporate the insights and the concerns of people with disabilities now, but to develop planning procedures that insure this continued input in the future.

Most reviews of the recent catastrophe have concluded that a lack of input from effected groups contributed to our unpreparedness. The challenge of that recognition is to fashion for the future a planning process that is as inclusive in its inputs as it is in its outcome scenarios.

Accordingly, NCD recommends that Congress should review all emergency planning mechanisms with a view to incorporating procedural and outreach provisions aimed at guaranteeing timely participation in preparedness planning by individuals with disabilities and groups representing them, and so as to maximize the responsiveness of plans, emergency services and emergency response practices to the issues facing these citizens. Congress should also provide for monitoring of the effectiveness of these procedures, so that any lack of timely and effective input can be quickly identified and remedied. Persons with disabilities should play a leading role in this monitoring.

Recommendations

Recommendation 13.1: NCD recommends that Congress adopt overarching procedures to address interstate issues for all federal-state programs in evacuation situations.

Recommendation 13.2: NCD recommends that Congress respond to the implications of Post-Traumatic Stress Disorder by ensuring that the definition of disability used to determine eligibility for benefits and services under a range of federal and federal-state programs be defined in such a way as to take account of the medically recognized, long-term and cumulative consequences of experiences such as the hurricanes. These definitions should also include provisions for identifying and tracking the long-term consequences of toxic exposures that may undermine health overtime.

Recommendation 13.3: NCD therefore recommends that accessibility standards utilized under the ADA be strictly applied to all buildings, facilities, thoroughfares or other amenities or structures planned or built with the aid of federal, state or local funds.

Recommendation 13.4: NCD recommends that Congress should review all emergency planning mechanisms with a view to incorporating procedural and outreach provisions aimed at

guaranteeing timely participation in preparedness planning by individuals with disabilities and groups representing them, and so as to maximize the responsiveness of plans, emergency services and emergency response practices to the issues facing these citizens. Congress should also provide for monitoring of the effectiveness of these procedures, so that any lack of timely and effective input can be quickly identified and remedied. Persons with disabilities should play a leading role in this monitoring.

Appendix A: Mission of the National Council on Disability

Overview and purpose

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

Specific duties

The current statutory mandate of NCD includes the following:

- Reviewing and evaluating, on a continuing basis, policies, programs, practices, and procedures concerning individuals with disabilities conducted or assisted by federal departments and agencies, including programs established or assisted under the Rehabilitation Act of 1973, as amended, or under the Developmental Disabilities Assistance and Bill of Rights Act, as well as all statutes and regulations pertaining to federal programs that assist such individuals with disabilities, to assess the effectiveness of such policies, programs, practices, procedures, statutes, and regulations in meeting the needs of individuals with disabilities.
- Reviewing and evaluating, on a continuing basis, new and emerging disability policy issues affecting individuals with disabilities in the Federal Government, at the state and local government levels, and in the private sector, including the need for and coordination of adult services, access to personal assistance services, school reform efforts and the impact of such efforts on individuals with disabilities, access to health care, and policies that act as disincentives for individuals to seek and retain employment.
- Making recommendations to the President, Congress, the Secretary of Education, the director of the National Institute on Disability and Rehabilitation Research, and other officials of federal agencies about ways to better promote equal opportunity, economic self-sufficiency,

independent living, and inclusion and integration into all aspects of society for Americans with disabilities.

- Providing Congress, on a continuing basis, with advice, recommendations, legislative proposals, and any additional information that NCD or Congress deems appropriate.
- Gathering information about the implementation, effectiveness, and impact of the Americans with Disabilities Act of 1990 (ADA) (42 U.S.C. § 12101 et seq.).
- Advising the President, Congress, the commissioner of the Rehabilitation Services Administration, the assistant secretary for Special Education and Rehabilitative Services within the Department of Education, and the director of the National Institute on Disability and Rehabilitation Research on the development of the programs to be carried out under the Rehabilitation Act of 1973, as amended.
- Providing advice to the commissioner of the Rehabilitation Services Administration with respect to the policies and conduct of the administration.
- Making recommendations to the director of the National Institute on Disability and Rehabilitation Research on ways to improve research, service, administration, and the collection, dissemination, and implementation of research findings affecting people with disabilities.
- Providing advice regarding priorities for the activities of the Interagency Disability Coordinating Council and reviewing the recommendations of this council for legislative and administrative changes to ensure that such recommendations are consistent with NCD's purpose of promoting the full integration, independence, and productivity of individuals with disabilities.
- Preparing and submitting to the President and Congress an annual report titled *National Disability Policy: A Progress Report*.

International

In 1995, NCD was designated by the Department of State to be the U.S. government's official contact point for disability issues. Specifically, NCD interacts with the special rapporteur of the United Nations Commission for Social Development on disability matters.

Consumers served and current activities

Although many government agencies deal with issues and programs affecting people with disabilities, NCD is the only federal agency charged with addressing, analyzing, and making recommendations on issues of public policy that affect people with disabilities regardless of age, disability type, perceived employment potential, economic need, specific functional ability, veteran status, or other individual circumstance. NCD recognizes its unique opportunity to facilitate independent living, community integration, and employment opportunities for people with disabilities by ensuring an informed and coordinated approach to addressing the concerns of people with disabilities and eliminating barriers to their active participation in community and family life.

NCD plays a major role in developing disability policy in America. In fact, NCD originally proposed what eventually became ADA. NCD's present list of key issues includes 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.

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