NATIONAL DISABILITY POLICY: A PROGRESS REPORT

July 26, 1996–October 31, 1997

NATIONAL COUNCIL ON DISABILITY

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National Disability Policy: A Progress Report, July 26, 1996–October 31, 1997

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LETTER OF TRANSMITTAL

October 31, 1997

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 follows up on *Achieving Independence*, NCD's report and recommendations capturing the input of disability community leaders throughout the country at a summit held in 1996. The report included more than 120 recommendations for change in a wide range of areas of public policy designed to facilitate inclusion, empowerment, and independence of people with disabilities consistent with the vision of the Americans with Disabilities Act of 1990 (ADA).

The attached progress report, which covers the period July 26, 1996 through October 31, 1997, reviews federal policy activities since the issuance of *Achieving Independence*, noting progress where it has occurred and making further recommendations where necessary. The recommendations apply to the Executive Branch, to the Legislative Branch, and in some instances to both. Overall, NCD believes the country is moving forward and expanding opportunities and inclusion for Americans with disabilities. Nonetheless, the rate of progress is slower and less steady than many in the disability community had hoped when ADA was enacted into law. Federal policy remains rife with inconsistent messages and unrealistic requirements for people with disabilities who rely on such federal programs as Social Security disability benefits, vocational rehabilitation, Medicaid, Medicare, special education, and Temporary Assistance for Needy Families.

For people with disabilities truly to accomplish the vision of ADA, it is critical that the Administration work with leaders in Congress to forge a disability agenda that brings children and adults with disabilities into the mainstream of American life. Thank you for the opportunity to play the independent role that our mission requires and to offer an objective assessment of progress in the past 18 months. 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 and in *Achieving Independence* is implemented.

Sincerely,

Marca Bristo
Chairperson

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

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INTRODUCTION

On July 26, 1996, the National Council on Disability (NCD) released a forward-looking report that set an agenda for public policy affecting people with disabilities as we approach the millennium. The report, entitled *Achieving Independence: The Challenge for the 21st Century*, was the product of a historic summit of diverse disability community leaders and policy makers charged with reviewing recent progress and developing policy recommendations to facilitate inclusion, empowerment, and independence of people with disabilities. *Achieving Independence* included more than 120 recommendations for change in the areas of policy coordination, civil rights, education, employment, social security and other income maintenance, health insurance and health care, long-term services in the community, technology, housing, transportation, and international issues. The purpose of the report that follows is to provide an update on progress made in advancing disability policy consistent with the vision of *Achieving Independence* and to offer recommendations where necessary. For ease of reference, recommendations appear in italics. This report is required by Title IV of the Rehabilitation Act, which calls for NCD to issue a progress report every October 31. The current progress report covers the period from July 26, 1996 to October 31, 1997. *Achieving Independence* served as NCD's progress report for 1996.

The fundamental challenge for policy makers is the same today as it was in 1996: to bring public policy into line with the values of inclusion, independence, and empowerment and the heightened expectations for economic self-sufficiency, expanded life choices, and options for people with disabilities that are embodied in the Americans with Disabilities Act of 1990 (ADA). A recent article in the *San Diego Union-Tribune* told the story of a young lawyer with quadriplegia who is experiencing firsthand the disconnect between ADA's vision and the reality of our inadequate health and long-term service systems. Assistant U.S. Attorney Holly Caudill, who spends roughly $3,500 a month on personal assistance, was able to put herself through college and law school and obtain a highly competitive legal job with varying levels of federal support for her attendant care. When she was recently transferred from the U.S. Attorney's office in her hometown of Spokane, Washington, to the U.S. Attorney's San Diego office, she lost all federal monetary assistance with the costs of her 24-hour personal assistance. As a result, her entire salary is going to her attendants. Caudill, whose legal work has won her acclaim from Attorney General Janet Reno, has joined the growing number of people with disabilities advocating for a national consumer-directed, community-based long term support and service system that truly rewards and supports people with significant disabilities who seek to work and pay taxes.[1] Her experience illustrates one of the challenges facing policy makers in the post-ADA environment--many people with disabilities require subsidized supports and services at home and in the community to take full advantage of expanded opportunities in the workplace or in the schools.

In some ways, the past year can be seen as a watershed year for people with disabilities in this country. A major political party nominated a man with a disability and long-time supporter of disability rights to be President of the United States, a war veteran in a wheelchair was elected to the Senate from Georgia, and a visually impaired Senate staffer with a service dog successfully fought to accompany her boss on the Senate floor with her dog. The national memorial to Franklin Delano Roosevelt will depict this national hero with his disability, despite strong opposition from many who thought it inappropriate to expose for posterity a condition President Roosevelt found it necessary to hide during his lifetime. In recognition of the unique challenges managed care companies face in meeting the needs of children with disabilities and their families, Congress exempted children with special health care needs or disabilities covered by Medicaid from mandatory managed care that is being implemented by many states for other Medicaid enrollees. Finally, on September 24, 1997, the Music Box Theater in New York City became the first on Broadway to offer real-time captioning during its stage productions; and the Joffrey Ballet of Chicago has cast a boy in a wheelchair for this year's performance of "The Nutcracker."

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[1] "Can't walk, can't grip, can work," *San Diego Union-Tribune*, September 18, 1997.

Although there have been some encouraging developments over the past year, children and adults with disabilities and their families too often continue to fall outside the mainstream of public policy debates. Disability issues and concerns were not a large part of the 1996 elections and have not received significant legislative attention in this Congress. Moreover, the President's State of the Union Address earlier this year did not call attention to the disability policy issues facing our nation. Although the number of people with disabilities in the United States continues to grow, the numerous public policy issues facing this expanding segment of our population are not receiving adequate attention from those setting the federal public policy agenda. Core issues such as expanding consumer-driven, community-based personal assistance services and accessible, affordable, and integrated housing and transportation options; ensuring universal design in emerging technologies; improving education and employment outcomes for people with disabilities; fighting discrimination and disability backlash; making the changing health care system work for people with special health care needs; and revamping our income support programs to encourage work have not received the priority treatment they deserve. And yet, driven largely by the increased expectations that people in the disability community have for themselves, there are signs of progress all around us.

This report will highlight progress, call attention to concerns, and offer recommendations in broad areas of public policy, tracking roughly the categories used in *Achieving Independence* and including some emerging issues not addressed specifically in *Achieving Independence*. This report begins with a discussion of disability demographics, moving on to data collection and analysis. Next, the report discusses a range of return-to-work topics, including Social Security reform, welfare reform, and family supports. It then discusses cuts in federal income support for children with disabilities and their families, and policy issues facing immigrants, minorities and rural residents with disabilities. Next, the report moves into a broad discussion of policy progress in the areas of education, technology, ADA enforcement and implementation, transportation, housing, long-term supports and services, health care, and international issues. Finally, the report discusses a handful of emerging issues, including physician-assisted suicide, genetic discrimination, wilderness accessibility, and currency accessibility. In next year's progress report, NCD will discuss significant policy issues not included herein because action on them was still pending as of October 31, 1997. Such issues include but are not limited to the reauthorization of the Rehabilitation Act, the results of work incentive legislative and administrative activity, and the promulgation and implementation of regulations under the 1997 amendments to the Individuals with Disabilities Education Act (IDEA).

PROGRESS, CONCERNS, AND RECOMMENDATIONS

Disability Demographics

Two important sources of demographic information about people with disabilities became available for the first time in the last year. In August 1997, the U.S. Census Bureau released a report analyzing survey responses at the end of 1994.[2] The Census data does not include individuals with disabilities living in institutions, who have been estimated to number 2.1 million people.[3] In addition, researchers this Fall began to gain access to data from the disability supplement to the National Health Interview Survey.

> One in five Americans, or approximately 54 million people, reported having some level of disability. Approximately one in ten Americans, or 26 million people, reported having a severe disability. Data collected three years earlier showed nearly 49 million people with a disability, 24 million of whom said their disability was severe.
>
> The Census Bureau found some differences by race and Hispanic origin in the prevalence of disability within age groups. Within the 22-to-44-year-old age group, the proportion with a severe disability was 5.6 percent among Whites, 11.8 percent among Blacks, and 6.7 percent among people of Hispanic origin. In the 45-to-54-year-old age group, the severe disability rate was 10.5 percent among Whites, 18.4 percent among Blacks, and 15.7 percent among people of Hispanic origin.

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[2] U.S. Census Bureau, Current Population Reports, "Americans with Disabilities: 1994–95." The Census data are based on the Survey of Income and Program Participation.

[3] See, e.g., Disability Rights Advocates, Inc., *Disability Watch: The Status of People with Disabilities in the United States*, at p. 8 (noting that the vast majority of institutionalized disabled Americans are elderly).

> The employment rate for people 21 to 64 years of age was 82.1 percent among those with no disability, 76.9 percent among those with a disability that was not severe, and 26.1 percent among those with a severe disability. Data collected three years earlier for people in the same age group showed employment rates of 80.5 percent for those with no disability, 76.0 percent for those with a disability that was not severe, and 23.3 percent for those with a severe disability. The statistically significant increase in the employment rate of people with severe disabilities between 1991 and 1994 is noteworthy.
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> Within the working population, the Census Bureau data showed an association between the presence of a disability and lower earnings, and showed that women with disabilities earned less than men with disabilities.
>
> Among people 22 to 64 years old with no disability, 79.9 percent were covered by private health insurance, while 3.0 percent had only government coverage. In contrast, among people with a severe disability in the same age group, only 43.7 percent had private health insurance coverage, while 39.6 percent had government coverage only.
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> According to data from the disability supplement to the National Health Interview Survey, 10.5 million to 12.6 million children in the United States have disabilities and/or special health care needs. That number represents approximately 15 to 18 percent of the total population of children in the United States.

Disability Data Collection and Analysis

In *Achieving Independence*, NCD recommended that "all federal statistical activities that include data collection and reporting for other groups, such as minorities and women, include the category of people with disabilities, using a definition based on ADA."[4] Two of the key

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[4] National Council on Disability, *Achieving Independence: The Challenge for the 21st Century* (1996) at 30. *See also* p. 31 (recommending that questions about disability be

federal statistical activities are the decennial census and the Current Population Survey used by the Bureau of Labor Statistics (BLS) to track national labor force statistics on a monthly basis.

> A multi-agency working group with significant participation from agencies with disability expertise, including the National Institute on Disability and Rehabilitation Research at the Education Department, the Office of the Assistant Secretary for Planning and Evaluation at the Department of Health and Human Services (HHS), NCD, and others, worked with key staff from the Census Bureau to develop and test a new question set to measure disability status as part of census 2000. The group developed a consensus set of disability questions that represents a significant improvement over the questions that were asked on the 1990 census. In particular, the new questions ask about a broader range of functional limitations, including seeing, hearing, walking, climbing stairs, reaching, lifting carrying, learning, remembering, and concentrating. Also, the new questions deemphasize the correlation between disability and inability to work. *NCD commends the Census Bureau for recommending the inclusion of the new questions in census 2000 and recommends that Congress approve the inclusion of the new disability question set in census 2000. Moreover, NCD encourages the interagency workgroup that developed the new questions to continue to meet, in consultation with disability community stakeholders outside government, to develop additional questions that are more likely to capture the full spectrum of the disability community and completely delink disability status questions from ability to work questions. These new questions should be added to the Current Population Survey and to the next census.*
>
> BLS, encouraged by the President’s Committee on Employment of People with Disabilities and others inside and outside the government, has agreed to work with other agencies with disability expertise to develop and test questions about disability status for possible inclusion in the Current Population Survey. BLS reports that it is in the process

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adequately included in the 2000 census) and pp. 67–68 (recommending addition of people with disabilities as a group to national labor force statistics reported monthly).

of testing questions and has agreed to have its draft questions reviewed by statisticians with disability expertise. *NCD recommends that this process continue expeditiously, building on the experience of the interagency group that worked on the disability questions for census 2000.*

In general, there remains a need to orient disability data collection activities to the post-ADA paradigm of thinking about disability, focusing on the societal and environmental barriers to full participation rather than the functional impairments of the individual. Along these lines, federal researchers should operationalize and track progress made in achieving the nation's goals for people with disabilities, as articulated in ADA— equality of opportunity, full participation, independent living, and economic self-sufficiency. For example, federal research and data collection should attempt to capture and track the percentage of elementary schools that are physically accessible, the number of professional licensing examinations that ask questions about history of treatment for mental illness, or the number of new software products or government web sites that are inaccessible to people with sensory disabilities.

Removing Barriers to Work in Social Security Disability Programs

While the lion's share of federal spending for disability is in Social Security Administration (SSA) programs (according to some estimates, well over 95 percent of federal spending targeted to people with disabilities occurs in Social Security income-maintenance programs and accompanying health coverage), these programs have been virtually unchanged by significant disability policy changes in other arenas, such as civil rights, independent living, and advocacy. As President Clinton noted when he met with disability community leaders on September 10, 1997, the United States must develop new markets for consumer products if we want to sustain the economic growth and prosperity we are currently experiencing. One good way to develop new markets is to increase the economic self-sufficiency of people with disabilities currently receiving Social Security disability benefits. On September 24, 1997, NCD presented the President and congressional leaders a list of action proposals to remove barriers to work that continue to discourage Supplemental Security Income (SSI) recipients and Social Security Disability Insurance (SSDI) beneficiaries from participating in rehabilitation and job training programs and reentering the workforce.[5] These proposals, designed to transform Social Security programs from a lifelong entitlement to an investment in employment potential for thousands of individuals, were developed after broad consultation with people with disabilities, their families, advocates, and policy experts. The proposals reflect the emerging bipartisan emphasis on personal responsibility by removing some of the complex and burdensome federal requirements that prevent many people with disabilities from taking charge of their own lives and becoming employed. Some of the key recommendations in NCD's report are listed below.

> *Make work pay by providing medical coverage for workers with disabilities, replacing the SSDI income cliff with gradual benefit reductions, ensuring that people do not lose eligibility solely because they work, compensating for disability-related work expenses, removing marriage penalties, waiving no-fault overpayments, and raising resource limits.*
>
> *Increase consumer access and choice in vocational rehabilitation by instituting a "ticket" or "voucher" program that enables SSI recipients and SSDI beneficiaries to select and buy services leading to employment, providing access to investment funding by simplifying the Plan for Achieving Self-Support program and making it available to both SSI recipients and SSDI beneficiaries, and eliminating the scholarship penalty.*
>
> *Increase employment opportunities for people with disabilities by reimbursing employers for disability-related expenses like sign language interpreters, on-the-job personal assistance, and job coaches; and instituting a tax credit for disability/diversity training.*

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[5] National Council on Disability, *Removing Barriers to Work: Action Proposals for the 105th Congress and Beyond*," September 24, 1997.

The Balanced Budget Act of 1997 (BBA) included a new program that gives states the option of allowing workers with disabilities to buy into Medicaid. To be eligible for this new program, workers must meet the SSI definition of disability, and total family income must be less than 250 percent of poverty. *While this new program is a step in the right direction, NCD strongly encourages Congress and the Administration to remove the income cap for the Medicaid buy-in. For workers with significant disabilities like Assistant U.S. Attorney Holly Caudill, a job that pays below 250 percent of poverty will not make economic sense. A Medicaid buy-in program with a sliding-scale premium schedule would be more attractive to a wider range of workers with disabilities whose health care and long-term service needs are not being met adequately in the private market.*

NCD strongly encourages congressional leaders in both parties to work with stakeholders in the disability community and the newly confirmed commissioner of the Social Security Administration, Kenneth Apfel, to transform the Social Security disability programs so that they promote independence and economic self-sufficiency for recipients and beneficiaries without sacrificing basic economic security for those who are unable to support themselves.

Welfare Reform

The welfare reform initiatives being carried out pursuant to the Personal Responsibility and Work Opportunity Reconciliation Act (PRWOR) of 1996 will have a significant impact on individuals with disabilities who participated in the former AFDC (Aid to Families with Dependent Children) program, as well as people who will lose benefits as a result of changes in the SSI and SSDI programs. It is critical that the federal and state entities charged with overseeing the implementation of this new law recognize that the law’s goals will not be achieved if people with disabilities transitioning to work are not able to maintain adequate health insurance coverage and do not have access to appropriate supports and accommodations in the job training and job placements that grow out of welfare reform efforts.

Moreover, the heightened emphasis on personal responsibility and work that characterizes federal and state welfare initiatives has the potential to create opportunities for people with disabilities seeking to leave the benefit rolls, provided that the new initiatives are open to and accessible by people with disabilities in the target populations. Unfortunately, much of the rhetoric of welfare reform has focused on the need for "able-bodied" people on welfare to get a job, implying that "non-able-bodied" recipients need not seek employment. Given the high prevalence of disability among the existing welfare population, the success or failure of welfare reform will likely turn on the ability of states to meet the needs of welfare recipients with disabilities. *Moreover, the influx of workers that the welfare reform initiative will produce, if appropriately conceptualized, could be used to provide services for people with disabilities, including sign language interpreting, reading for blind or visually impaired people, personal assistance, child care for children with disabilities, or respite care for primary caregivers.*

> According to the Department of Health and Human Services, approximately 50 percent of AFDC recipients are individuals with disabilities or parents of disabled children.[6]
>
> Without identification and access to proper interventions and reasonable accommodations, welfare recipients with disabilities are not likely to achieve self-sufficiency within the time limits provided under the new law. *NCD encourages federal entities to work with states to ensure that welfare recipients with disabilities are identified to the extent possible and appropriately accommodated.*

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[6] "An Interim Report on HHS Accomplishments on Behalf of People with Disabilities," submitted to NCD October 3, 1997 (hereinafter "HHS Interim Report"), at 5. Many welfare recipients with disabilities have impairments such as specific learning disabilities, attention deficit disorder, major depression, and other mental and physical disabilities that are not always visible and have not been identified in the education system or other systems. It is worth noting that women with disabilities are disproportionately represented in the unidentified disability category. While there is no gender differential in the prevalence of neurological disabilities, for example, public education programs are identifying boys with these disabilities at a rate three times that for girls.

Although PRWOR specifically provides that states are responsible for complying with ADA and Section 504 of the Rehabilitation Act in implementing the law’s provisions, there has been little federal effort to ensure that states are in fact making their programs accessible to all people with disabilities in the population eligible for services and making reasonable accommodations for persons who require them.

NCD is concerned that states may be steering people with disabilities away from job training and employment by using their ability to exempt up to 20 percent of their former AFDC population from PRWOR’s work requirements and by referring individuals with known disabilities to the SSI program.

Title II of PRWOR has resulted and will result in loss of cash assistance for some people who are SSI recipients or SSDI beneficiaries. *At a minimum, NCD recommends that self-sufficiency support programs similar or identical to the programs being developed and offered to people leaving Temporary Assistance for Needy Families (TANF) under Title I of PRWOR be offered to people losing cash assistance under SSI and SSDI..*

Similarly, incentives being made available to employers (including public employers) who hire former AFDC recipients should be extended to employers who hire persons losing cash assistance through the SSI/SSDI eligibility changes and the more rigorous continuing disability review process.

Likewise, along the lines of our return-to-work recommendations, NCD recommends that Medicaid eligibility be decoupled from eligibility for TANF, SSI, or SSDI, so that people with disabilities are not forced to forgo working in order to maintain vital medical and long-term services and supports. To the extent that this recommendation is adopted, it is critical that current Medicaid recipients not lose health coverage solely as a result of the recommended decoupling.

> NCD commends the President and Congress for taking some steps to delink health coverage from cash assistance in the Balanced Budget Act (BBA), signed by the President in August 1997, which allows certain SSI recipients who become employed to continue their health coverage by purchasing Medicaid. Likewise, BBA ensures that children who lose benefits as a result of the new children's SSI eligibility definition will retain Medicaid coverage, even if their families are not otherwise eligible for the program. *NCD urges Congress and the Administration to ensure that states implement this important provision for children and families consistently so that no child experiences an unintended lapse or loss of health care coverage as a result of changes in SSI eligibility.*

> NCD commends the Department of Health and Human Services (HHS) for establishing a workgroup on welfare reform and disability, which is charged with developing materials and a structure to provide technical assistance to states in helping TANF recipients with disabilities to become productive workers and advising policy makers regarding TANF issues as they relate to disability. The workgroup includes members from the Departments of Education, Labor, and Justice, and the President's Committee on Employment of People with Disabilities. *Although NCD applauds HHS for recognizing the need for this workgroup, we remain concerned that welfare reform is proceeding at a pace that is leaving the workgroup behind. There is a need for policy makers throughout government to recognize and address the fact that the disability issues in welfare reform are core issues that will determine the success or failure of the entire initiative.*

Family Support

One of the themes of early welfare reform emphasized the importance of child care for parents seeking to leave the welfare rolls and enter the workforce. Child care issues can be compounded when either the child or the parent has a disability or special health care need. Child care should be viewed as a critical family support for families where the child or parent has a disability. Nonetheless, to the extent that child care issues are addressed by policy makers, the unique issues facing families of children with disabilities and parents with disabilities, particularly when family income is below poverty, rarely receive adequate attention.

NCD encourages the Administration and Congress to take steps to ensure that children with disabilities and parents with disabilities will benefit from administrative and congressional efforts to improve child care options for working parents.

As former welfare recipients and others are trained to become child care workers, it is critical that training programs prepare workers to meet the needs of children and parents with a range of disabilities in a culturally competent manner.

Part I of IDEA, enacted in 1994, created a national family support systems change program that is scheduled to sunset at the end of FY 1998. *NCD strongly encourages Congress and the Administration to authorize and fund ongoing family support programs in freestanding legislation or as part of other legislation before the sunset date. These programs play an important roll in ensuring that public policy does not overlook the needs of families of children with disabilities and special health care needs.*

Cuts in SSI Program for Children

Pursuant to Title II of PRWOR, the childhood eligibility standard for SSI was tightened, putting hundreds of thousands of low-income children and their families at risk of losing critical cash assistance and health coverage. These changes were made because many in Congress and some vocal critics outside Congress believed that the old childhood eligibility standards were subject to fraud and abuse, despite the fact that studies by the General Accounting Office (GAO) and Social Security were unable to document any systemic problems. Social Security proceeded to issue regulations interpreting the new standard that the *New York Times* described in an editorial as appearing "unduly harsh."[7] The Administration estimated that approximately 260,000 children will have their eligibility to continue to receive SSI benefits reviewed under the new standards, and that over half of these, or 135,000 children, will have their benefits terminated as a result of these reviews.[8] Several key senators in both parties, including John Chafee (R-RI) and the minority leader, Tom Daschle (D-SD), have indicated a desire to have fewer children made ineligible. As of October 31, Social Security Commissioner Kenneth Apfel was conducting a "top to bottom" review of how the agency is implementing the new rules.[9]

> As of October 18, 1997, more than 138,000 children had been terminated from SSI pursuant to the new eligibility standards.[10]
>
> There are large differences in the rates at which children are losing benefits in different states. In Mississippi, for example, 82 percent of the children whose cases had been reviewed by early September had their benefits terminated, compared with about 38 percent in Minnesota and 36 percent in the District of Columbia.[11]
>
> According to a September article in the *Washington Post*, SSA figures show that, of 2,200 cases that had been appealed and reached the first step of review, 67 percent had been overturned with benefits restored.[12] It is likely that many of the families who have been terminated have not filed appeals on behalf of their children. Accordingly, even if reversals on appeal are common, many children who may have been terminated improperly will never seek review of the termination decision.

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[7] "Disabled Children Get a Needed Review," *New York Times*, September 13, 1997.

[8] Id.

[9] "Quick Review Promised for SSI Rules," *Washington Post*, September 11, 1997.

[10] Social Security Administration, Office of Disability.

[11] "Quick Review," supra note 9.

[12] Id.

As of 1996, there were approximately one million children with disabilities receiving SSI that qualified them for Medicaid. Many of these children are at risk of losing or experiencing a gap in health insurance coverage as a result of changes in the SSI eligibility standard for children. Moreover, as new children and families apply for SSI and experience denials, many of the new childhood applicants will be forced to go without health coverage while they challenge the denials on appeal because they were without coverage when they applied for benefits. Lack of coverage can mean lack of access to critical services and supports such as outpatient rehabilitation, asthma care, or preventive care, resulting in irreversible adverse health outcomes, including premature death, for some of these children. *As mentioned above in the section on Welfare Reform, NCD urges the Administration and Congress to ensure that states implement BBA provisions preserving Medicaid eligibility for children losing SSI consistently so that no child experiences an unintended lapse or loss of health care coverage as a result of changes in SSI eligibility. Moreover, NCD encourages Congress to require the Social Security Administration to refer the families of new child applicants who are turned down for SSI to the appropriate entity for separate determination of Medicaid eligibility.*

NCD is concerned that the promised 30-day review will not undo the damage that is occurring as a result of an unnecessarily narrow eligibility standard for SSI for children. Although much of the recent advocacy and criticism has focused on SSA's interpretation of the new law, and there appears to be room for improvement in how the new law is being implemented, NCD remains concerned that a basic support program for low-income children with disabilities and their families was significantly cut by Congress and the President without a well-reasoned and well-documented policy rationale for moving away from an eligibility standard that had grown out of a decision of the U.S. Supreme Court. *NCD strongly encourages SSA, HHS, Education, and the rest of the federal and state policy and research communities to evaluate the impact of the recent cuts on children and families. For example, how are the cuts affecting educational outcomes, health outcomes, and functional outcomes for these children? To what extent are the* *cuts making it more difficult or impossible for low-income families to continue to care for their children at home in integrated community settings? What is the breakdown by race and ethnicity of the denial rates? Are the cuts having a disproportionate impact on children and families from minority racial or ethnic backgrounds? Are they having a disproportionate impact on children and families in rural communities, who may have more difficulty gaining access to free legal advocacy services?*

The Office of Management and Budget (OMB) and the Congressional Budget Office (CBO) estimated significant cost savings to the Federal Government to be realized as a result of the recent narrowing of eligibility for SSI for children. *To the extent that significant cost savings are being realized as a result of the recent cuts, NCD encourages policy makers to use these new funds to expand other programs and services offered to low-income children with disabilities and their families.*

Particularly in light of the expressed desire of many of the Senate authors of the new eligibility standard for children's SSI to see fewer children terminated from the program, NCD encourages SSA and the White House Office of Management and Budget to reexamine and revise the new administrative standard for children's SSI eligibility in a manner that will result in smaller and more consistent termination and denial rates.

Immigrants, Minorities, and Rural Residents with Disabilities

In addition to the changes outlined above, PRWOR mandated that current and future legal immigrants be barred from receiving SSI and food stamps, with some limited exceptions. Likewise, with limited exceptions, PRWOR gave states discretion to determine whether or not legal immigrants would continue to be eligible for federal assistance under TANF, services under the Social Services Block Grant, and Medicaid. In a number of states, where eligibility to receive Medicaid depends on eligibility to receive SSI benefits, Medicaid would be discontinued to existing recipients when SSI benefits were cut off, unless the state laws were changed. Moreover, the law provided that immigrants who arrived legally in the United States after enactment of PRWOR would not be eligible for federal means-tested public benefits for five years after their date of entry, again with some limited exceptions. CBO estimated that PRWOR would result in denial of SSI benefits to approximately 500,000 legal immigrants, and of food stamps to approximately 1 million of the roughly 1.5 million legal immigrants who were receiving federal assistance.

BBA undid some of the damage of PRWOR with respect to legal immigrants. The two major changes will continue benefits for noncitizens receiving SSI on August 22, 1996, and allow eligibility if they were in the United States on August 22, 1996, and are “disabled.” These changes allow for continued SSI and Medicaid eligibility for noncitizens with disabilities who were in the United States as of August 1996, but leaves the general bar to eligibility for food stamps in effect. Likewise, PRWOR restrictions on SSI eligibility still apply to immigrants with disabilities entering the country on or after August 22, 1996.

> *Although NCD commends Congress and the President for softening the effect of some of BBA’s cuts in benefits for legal immigrants with disabilities, we remain concerned about the public policy direction of the remaining cuts in PRWOR with respect to immigrants. Denying basic subsistence benefits to disabled legal immigrants, many of whom have worked and paid taxes, is unjust and violates common principles of fairness and compassion. No disabled person legally in this country, whether immigrant or American born, should be faced with the threat of losing his or her only means of financial support or medical services. Removing basic federal supports for this population puts their lives at risk, and states and private charities do not have the resources or the political will to pick up the slack. Put simply, it is NCD’s position that the budget should find its balance elsewhere.*
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> *As we recommended with respect to changes in childhood eligibility for SSI, NCD recommends that the federal research community track the impact of the cuts in federal assistance for immigrants with disabilities. Also, NCD recommends that employment and*

training services being made available to people leaving the TANF rolls be made available to immigrants losing federal assistance as well.

NCD encourages Congress to restore basic benefits to people with disabilities who cannot be naturalized because they are unable to take the required oath.

In an effort to stave off the impending loss of their sole means of support, many legal immigrants with disabilities who have held their green cards long enough to be eligible to file for citizenship have commenced the process of becoming naturalized U.S. citizens. Unfortunately, understaffing at Immigration and Naturalization Services offices has resulted in long lines for naturalization and people with disabilities are finding themselves at the end of these long lines as they seek to become naturalized. By raising the importance of becoming a citizen, PRWOR highlighted a fundamental problem with the immigration laws in this country—the inability of many individuals with severe disabilities to become U.S. citizens. Despite some recent changes exempting immigrants with “physical and developmental disabilities” or “mental impairments” seeking citizenship from requirements that they prove their English proficiency and knowledge of U.S. civics, all immigrants are still required to take the citizenship oath and renounce their former citizenship. These remaining requirements have the potential to make it impossible for people with the most severe mental impairments, such as people with Alzheimer’s, some people who have had strokes, and people with severe mental retardation, to become citizens because of questions about their competence to understand the meaning of the citizenship oath and renunciation of former citizenship. In an effort to address these remaining barriers, legislative measures have been introduced to give naturalization officials the flexibility to accommodate the needs of individuals with disabilities in their process. NCD applauds recent efforts to facilitate the naturalization of immigrants with the most severe disabilities and makes the following recommendations with respect to the naturalization process:

Naturalization must be afforded to all qualifying individuals with disabilities, regardless of the severity of their disability.

> *The naturalization process must be sensitive to the unique needs of individuals with disabilities and the naturalization examiners must receive adequate training to evaluate when the English and civics tests and oath requirements should be waived or modified.*
>
> *The naturalization process should be in accord with the requirements of ADA.*

In addition to the issues facing immigrants discussed above, people with disabilities from minority and rural communities face a range of challenges and barriers to full enjoyment of their rights as citizens with disabilities. In an effort to identify and address some of these challenges and barriers, NCD convened a roundtable discussion in Atlanta, Georgia, in August on outreach to minorities with disabilities and persons with disabilities living in rural communities. NCD is currently in the process of responding to the recommendations that were suggested by roundtable participants for how the Federal Government could do a better job of meeting the unique needs of such persons. Some of the recommendations have made their way into other sections of this report, and NCD will include a longer list of recommendations in our 1998 progress report. *In the interim, NCD makes the following two recommendations:*

> *NCD encourages the President's Advisory Commission on Race to include people with disabilities and their families in the national dialogue on race, paying particular attention to the unique issues posed by the intersection between disability and minority racial/ethnic status.*
>
> At the August roundtable discussion, several people called attention to the need for federal enforcement and technical assistance entities to focus resources and initiatives on educating people in minority communities about the requirements of ADA and other federal disability civil rights statutes and how to bring claims under these laws. Targeted outreach to minority communities, particularly isolated communities in rural areas, would be a worthwhile follow-up to much of the urban-focused training conducted by the Department of Justice (DOJ) and the U.S. Equal Employment Opportunity Commission (EEOC) in the years after ADA was passed. *NCD encourages the federal enforcement*

> *and technical assistance entities, along with the protection and advocacy network, to work together to develop strategies to reach minorities, people in rural communities, and other underserved groups as part of their ongoing outreach and technical assistance plans.*

Education Policy

On June 4, 1997, President Clinton signed into law the Individuals with Disabilities Education Act Amendments of 1997 (IDEA '97). This law, which represents a bipartisan compromise and culminated a prolonged and at times controversial reauthorization, includes some significant improvements in education policy for students with disabilities. An important theme of the 1997 amendments, based on 20 years of experience with special education, was to reduce the dissonance between regular education and special education, looking at the whole school and the whole education system to the greatest extent possible.

> IDEA '97 strengthens academic expectations and accountability for the nation's 5.8 million children with disabilities and attempts to bridge the gap between what those children learn and the regular curriculum.
>
> Beginning July 1, 1998, each disabled student's individualized education program (IEP), the plan that sets out a student's educational goals as well as the instruction and services the student will receive, must relate more clearly to the general curriculum that students in the regular classrooms receive. Also, the student's regular classroom teacher must participate in meetings where the student's IEP is developed.
>
> IDEA '97 also includes provisions for strengthening parental involvement. In all states, parents are now included in groups making eligibility and placement decisions about children with disabilities. In addition, the new law requires that the state advisory panel, which provides policy guidance for states on the provision of special education and

related services for children with disabilities in the state, must include as a majority of its membership individuals with disabilities or parents of children with disabilities.

Consistent with the importance of holding students with disabilities to high standards, IDEA '97 requires that students with disabilities be included in state and district-wide assessments given to all other children, with the provision of appropriate accommodations where necessary. The Department of Education has given major support to research projects and to a center that provides technical assistance to states to ensure that students with disabilities can be offered appropriate accommodations to facilitate their participation in assessments.

This year, for the first time, the Department of Education has introduced accommodations for including more children with disabilities in the nation's report card, the National Assessment of Educational Progress (NAEP), which it administers. NAEP is designed to assess the progress of our nation's schools based on a representative sample of students. Although NAEP has been in existence for the past 25 years, the progress of students with disabilities has not properly been included in past assessments.

The 1997 amendments made the old "Part H" early intervention program for infants and toddlers into "Part C." The new Part C places greater emphasis on the use of natural environments in provision of early intervention services; places greater attention on children at risk of developing disabilities in the individualized family support plan (IFSP); and expands the Federal Interagency Coordinating Council overseeing early intervention to include officials with Head Start and child care responsibilities. *NCD supports these important reforms for early intervention, yet NCD remains concerned that the Administration should ensure that issues related to infants and toddlers with disabilities are also included in some of the broader generic system initiatives dealing with child care and early brain development.*

One of the most controversial issues in the recent reauthorization of IDEA was that of school discipline. In an effort to address the concerns voiced by school officials that the law's "stay put" provisions were making it difficult to discipline disruptive or violent students being served under IDEA, the new law permits schools to remove students with disabilities from the classroom for up to 45 days if they are caught with weapons or illegal drugs or if they are substantially likely to injure themselves or others. Under the old law, children could be removed for up to 10 days. The requirement that children be kept in their placement pending an opportunity to challenge the proposed discipline was intended to protect students participating in IDEA from unilateral changes in placement by the school. While the compromise was likely necessary to address the concerns of school officials, NCD is concerned that the discipline issue received undue attention from Congress, given the documented scope of the problem. *As President Clinton noted when he signed IDEA '97 into law, "young people with disabilities drop out of high school at twice the rate their peers drop out of high school, and into less certain futures." Rather than making it easier for schools to wash their hands of students with disabilities, federal policy must look for ways to address the needs of all students with disabilities so that they stay in school and succeed.*

In the FY 1997 and FY 1998 appropriations for the Office of Special Education Programs, Congress allocated and the President signed increases of approximately $750,000 and $700,000, respectively, for special education services under Part B of IDEA. *NCD applauds Congress for recognizing the importance of increasing the federal financial commitment to the education of children with disabilities, and strongly encourages Congress and the Administration to build on these increases in special education budgets for FY 1999 and later years.*

While NCD commends the Administration and Congress for the improvements noted above, we remain concerned that the civil rights vision of a free and appropriate public education embodied in IDEA has frequently been ignored by schools struggling with inadequate funds and multiple challenges. Monitoring of compliance with IDEA by *federal authorities is simply not adequate, and students with disabilities continue to be ill-served by a separate and segregated special education system in too many of our school districts. NCD strongly encourages the Department of Education and the Department of Justice to strengthen their compliance monitoring under Part B of IDEA, Section 504 of the Rehabilitation Act, and ADA, including the use of appropriate sanctions for noncompliance.*

NCD also remains concerned about fewer deaf students learning how to communicate in sign language and fewer blind and visually impaired students learning how to read braille as two unintended side effects of the increased emphasis on mainstream instruction. Public school systems must find ways to continue instruction in these vital skills for deaf students and blind and visually impaired students, and explore integrating instruction in American Sign Language and braille awareness as part of the core curriculum available to all students.

NCD also remains concerned that the history of the disability rights movement is not receiving adequate attention in most American history texts, and that students are leaving the public education system with little knowledge of federal disability civil rights laws and the civil rights movement that led to their development. Similarly, although there has been some progress in higher education, disability issues and disability culture continue to receive short shrift in the course offerings of our colleges and universities. Moreover, key professional schools such as law schools, medical schools, architecture schools, and education schools have shown little leadership in making knowledge about disability issues and the requirements of civil rights laws like ADA, IDEA, and the Fair Housing Act a basic part of professional education. *NCD recommends that curriculum developers and textbook writers throughout the education system make a concerted effort to include the history of the disability rights/independent living movements and their federal legislative and policy legacy as part of mainstream curricula so that all students will be exposed to disability civil rights as they are exposed to other areas of civil rights.*

> *Finally, as the government seeks to help local schools access the Internet and other information technologies in the classroom, NCD strongly encourages the officials involved to ensure that access issues for students with disabilities, particularly students with sensory disabilities, are addressed (e.g. multimedia CD-ROMs often are not accessible for such students) so that these students may benefit from the increased emphasis on technological literacy at school and in the workplace.*

Technology

As the American population ages, sensory disabilities and lack of fine motor skills will become more and more prevalent. These conditions represent the greatest bar to computer use with present technology. Federal efforts to help a child with visual impairments use technology in the classroom should also contribute, over time, to the ability of the child's grandparents to check their Social Security or health insurance benefits, bank and pay bills, or send an e-mail message. Moreover, federal and private efforts to ensure universal design of technology as it is developed will ultimately mean an infrastructure for business that can tap into the productive capacity of all workers.

> The Telecommunications Act of 1996 requires providers of telecommunications services and manufacturers of customer premises equipment to make such services and equipment accessible, if this is readily achievable. This is the first time the telecommunications industry has been required broadly to address accessibility issues. The Telecommunications Act requires the United States Architectural and Transportation Barriers Compliance Board (the "Access Board") to develop, in conjunction with the Federal Communications Commission (FCC), guidelines for access for telecommunications equipment. In April 1997, the Access Board issued a Notice of

Proposed Rulemaking. Official guidelines are awaiting clearance by OMB and are expected by the end of this calendar year.

FCC has not yet announced or issued proposed regulations on the accessibility of telecommunications services. Moreover, it has not yet announced the process by which it will address complaints about inaccessible services or equipment under the Telecommunications Act. *The legislative history of this law indicates a clear intent by Congress that FCC develop and enforce regulations in this area. The significant delay in doing so, while new, inaccessible technologies emerge each week, is of serious concern to NCD. NCD strongly encourages FCC to act promptly in this area.*

In August 1997, FCC issued regulations related to closed captioning under the Telecommunications Act. *These regulations, though not completely in accord with the expectations of many in the deaf community, will result in important improvements in access to video programming by people with hearing disabilities if they are implemented appropriately and if video programmers are monitored to ensure compliance with the regulations.*

In April 1997, the Web Accessibility Initiative (WAI) was launched as a partnership among the World Wide Web Consortium, the U.S. government (the White House, National Science Foundation, and Department of Education) and other interested governments. Based at the Massachusetts Institute of Technology, WAI is intended to promote Internet access for people with disabilities on both a policy and technical level. *NCD applauds this initiative and encourages appropriate U.S. entities to support the work of the initiative.*

In June 1997, the House passed HR 1385, which includes language to strengthen the implementation of Section 508 of the Rehabilitation Act by transferring enforcement responsibility for ensuring that federal equipment and data are accessible from the U.S. General Services Administration to OMB. Language in a draft Senate bill would transfer such responsibility to the Access Board instead. *NCD supports the Senate proposal because of the Access Board's commitment and expertise in developing accessibility guidelines under ADA and the Telecommunications Act.*

In May 1997, Microsoft Corporation released a long-awaited technology called “Active Accessibility,” which provides a standard way for Windows applications to communicate with adaptive equipment such as screen reader programs used by blind persons. Although Microsoft encountered some deserved criticism when it failed to incorporate Active Accessibility in a Microsoft web browser that was released in late September,[13] NCD commends Microsoft for releasing technology that addressed graphical user interface access. This new technology responded to the crisis that people with disabilities, particularly visual disabilities, were facing as a result of the rapid deployment of graphical user interfaces to computing. *Moreover, NCD encourages Microsoft to incorporate accessible technology in its Windows 98 operating system and other related applications. Under its obligations under Sections 504 and 508 of the Rehabilitation Act, the Federal Government should be favoring procurement of software that supports accessibility. Accordingly, NCD encourages federal procurement officials to make it clear to Microsoft and other vendors that it will not purchase technology that is not accessible.*

NCD also commends IBM and Sun Microsystems for their public commitment in fall 1997 to making Java-based applications accessible to people with disabilities. *As NCD encouraged Microsoft, so NCD encourages IBM and Sun Microsystems, along with other technology vendors not mentioned in this report, to incorporate accessibility in the design stage of all emerging products.*

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[13] The problem with the web browser was subsequently addressed by Microsoft after the period covered in this report.

NCD encourages the Health Care Financing Administration (HCFA) and other sources of public financing for assistive technology to recognize that high cost can make technology inaccessible for people with disabilities, and to address to dearth of publicly subsidized assistive technology under Medicaid, Medicare, Rehabilitation, and other federal, state, and local programs. The upcoming reauthorization of the Technology-Related Assistance for Individuals with Disabilities Act would be a good opportunity to increase the federal commitment to subsidizing access to assistive technology.

NCD is aware that many election officials are considering moving to a system of voting that would enable people to vote by computer or through other remote technologies. *To the extent that these proposals are implemented, NCD encourages the Federal Election Commission, the Department of Justice, and other interested federal, state, and local entities to ensure that the new voting system is accessible for all people with disabilities, particularly for people with visual disabilities and people who do not have easy access to computers or other remote technologies.*

ADA Enforcement and Implementation

Having recently celebrated its seventh birthday, ADA continues to enjoy widespread support in the disability community and mixed reactions from the broader society. NCD, the National Institute on Disability and Rehabilitation Research, and the U.S. Commission on Civil Rights have all begun studies on how ADA is being enforced, the results of which should be available next year. However, without the benefit of the systematic review that is currently under way, NCD will take this opportunity to call attention to some significant developments in ADA implementation.

One of the most disturbing trends in the case law interpreting Title I of ADA, which prohibits employment discrimination on the basis of disability, is the tendency to narrow the definition of disability and thereby narrow the group of people who are able to benefit from the law’s protections. Although the ADA definition was designed to be broad so that it would encompass the full range of people who experience discrimination based on fears, myths, and stereotypes about disability, many courts have interpreted the definition in a way that excludes people with a broad range of impairments from the law's protections.[14] Federal courts have found people with various forms of cancer, diabetes, epilepsy, HIV disease, mental disorders, and other common conditions that often provoke prejudice to fall outside the law's definition of disability. In a recent case involving a bank employee who was HIV positive but asymptomatic, the majority of the Fourth Circuit sitting en banc found that asymptomatic HIV disease was not a disability for purposes of statutory protection.[15] *NCD strongly encourages EEOC, DOJ, and the Office of Federal Contract Compliance Programs at the Department of Labor (OFCCP) to work together to develop a federal enforcement strategy to address the disturbing trend in the courts narrowing the definition of disability under ADA and Title V of the Rehabilitation Act.*

A related trend has been the tendency of federal courts to find people not to be "qualified" for a particular job based on evidence they submit in support of their applications for disability benefits or evidence simply supporting their claim that they have a "disability" for purposes of ADA protection. Some courts have gone so far as to prevent people from bringing an ADA claim against a former employer based solely on the fact that they submitted an application for disability benefits asserting they were unable to work. EEOC issued guidance in February 1997 clarifying that an application for disability benefits should never act as a bar to an ADA claim, and Social Security has filed at least one amicus brief concurring with EEOC's position, but the federal courts continue to be split on this issue. *NCD strongly encourages EEOC, DOJ, SSA, OFCCP, and other interested federal entities to work together to address court decisions*

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[14] For a recent analysis of the case law interpreting the definition of disability in ADA, see Steven S. Locke, *The Incredible Shrinking Protected Class: Redefining the Scope of Disability Under the Americans with Disabilities Act*, 68 Colo. L. Rev. 107 (1997).

[15] Runnebaum v. Nations Bank, 7 A.D. Cases 217, 1997 WL 465301 (4th Cir. 1997).

improperly requiring people to choose between their civil rights and their ability to support themselves.

EEOC issued important guidance in March 1997 discussing the application of Title I of ADA to individuals with psychiatric disabilities. Although the guidance itself largely restated long-standing EEOC policy, the reaction to the guidance from the media and the employer community was surprisingly negative. Many journalists called into question the need for civil rights protections for people with psychiatric disabilities, and much of the reaction to the guidance played out many of the fears, myths, and stereotypes about mental illness that ADA was designed to address. An editorial cartoon prompted by the guidance, for example, depicted a caricature of a person with a psychiatric disability wielding an axe and wearing a hockey mask, a reference to the homicidal character "Jason" from horror films.

More recently, EEOC has brought a number of lawsuits challenging distinctions between mental and physical disabilities in long-term disability insurance coverage. Many policies in the long-term disability insurance area limit coverage to one or two years if the disability is "mental" or "emotional," but provide lifetime wage replacement if the disability is "physical." *NCD commends EEOC for taking on this issue, and for making the long-term disability insurance industry justify its long-standing second-class treatment of people who are forced to stop working because of mental disabilities.*

On July 26, 1996, DOJ launched an ADA home page at www.usdoj.gov/crt/ada/adahom1.htm. The page, which includes all of DOJ's technical assistance documents and many settlement agreements and model policies, gets approximately 35,000 hits a week. DOJ also operates an ADA information line, which receives over 75,000 calls a year. In addition, DOJ has implemented a fax-on-demand system whereby technical assistance documents can be faxed 24 hours a day.

DOJ’s Civil Rights Division is working with U.S. attorneys throughout the country on ADA enforcement. DOJ is also part of a disability task force under which state attorneys general are working with DOJ on disability civil rights issues across the country.

DOJ has continued to build its mediation program to the point where it now has approximately 350 professional mediators in 42 states who have received ADA training and mediate complaints referred from DOJ on a pro bono basis. Approximately 90 percent of DOJ ADA complainants are opting for mediation, and 82 percent of these complaints are being mediated successfully. The majority of cases being referred to mediation include issues such as architectural barrier removal when readily achievable; failure to modify policies such as excluding a person with a service animal; failure to provide effective communication such as a sign language interpreter when appropriate; and failure of a government entity to provide program access.

At an NCD hearing in August 1997 on disability issues in minority and rural communities, several people called attention to the need for federal enforcement and technical assistance entities to focus resources and initiatives on educating people in minority communities about the requirements of ADA and other federal disability civil rights statutes and how to bring claims under these laws. *Targeted outreach to minority communities, particularly isolated communities in rural areas, would be a worthwhile follow-up to much of the urban-focused training that DOJ and EEOC conducted in the years after ADA was passed. NCD encourages the federal enforcement and technical assistance entities, along with the protection and advocacy network, to work together to develop strategies to reach minorities, people in rural communities, and other underserved groups as part of their ongoing outreach and technical assistance plans.*

NCD is concerned that resources for ADA enforcement, particularly at EEOC and DOJ, are inadequate to address the discrimination people with disabilities face throughout the country. EEOC, for example, received no new resources when it was given ADA to enforce, and it continues to struggle with a large pending inventory of cases waiting for investigation, which often translates into long delays for charging parties. Also, although the President requested an increase in the ADA enforcement budget for DOJ in FY 1997, Congress did not approve the increase. *NCD strongly recommends that Congress and the President allocate substantial new financial resources to EEOC and DOJ to facilitate effective enforcement of ADA.*

NCD recommends that DOJ exercise greater leadership in addressing the growing use of inaccessible information kiosks by state and local governments, which are prohibited by Title II of ADA. Moreover, NCD strongly encourages DOJ to become more proactive in addressing a range of technology access issues under Titles II and III of ADA, including the issue of inaccessible web sites, automated teller machines, and transportation-related technologies.

Transportation

Like housing, health care, and technology, transportation must be affordable and accessible if people with disabilities are to be able to live independently and participate fully in their communities. As a follow-up to *Achieving Independence*, NCD representatives met with Secretary of Transportation Rodney Slater on May 1, 1997, to present NCD's transportation-related recommendations and begin a dialogue to improve transportation policy for people with disabilities.

In the regulatory arena, Secretary Slater committed first to address pending proposals to improve the Department of Transportation's (DOT's) rules under the Air Carrier Access Act. Then, DOT plans to develop its proposed rule on over-the-road bus accessibility. *NCD is very concerned that DOT act promptly in both these areas to address the substantial deficiencies in access for people with disabilities to air travel and over-the-road bus travel. The continuing inaccessibility of over-the-road buses, combined with the high cost of air and rail travel, means that many people with disabilities cannot* *afford to travel between cities. NCD strongly encourages DOT to act promptly in these areas.*

Secretary Slater also acknowledged that the Access Board was working, in cooperation with the Federal Highway Administration, to issue guidance concerning public rights-of-way, and DOT is considering referencing this guidance in its Section 504 rules. Likewise, Secretary Slater committed to continuing to work with the Department of Health and Human Services to improve coordination between transportation services funded by the two agencies and to continue to coordinate with the Civil Rights Division at DOJ on transportation-related enforcement matters.

Finally, Secretary Slater reported that the Federal Transit Administration had recently added a toll-free number for filing transit-related ADA complaints to facilitate a prompt response to concerns about transit service for individuals with disabilities. The number is 1-888-446-4511.

In response to ADA requirements, fixed-route transit bus accessibility doubled (about 60 percent of the total fleet is lift-equipped or ramp-equipped), and more low-floor buses and accessible light-rail cars are in use. The new light-rail systems recently opened in St. Louis, Dallas, and Denver are all fully ADA accessible. Likewise, annual aggregate paratransit trips increased from 45 million in 1992 to 54 million in 1995. Although much of the progress referenced in this paragraph occurred before the period covered in this progress report, it is included here because DOT announced much of the information during the covered period.

In November 1996, DOT issued regulations that require airlines and airports to contract for the purchase and use of lifting devices for boarding commuter aircraft with 19 to 29 seats that are not served by jetways. The regulations required that such contracts be in place by August 1997 and gave large airports two years and small airports three years to obtain the necessary devices.

> *More broadly, NCD encourages Congress, the Administration, state and local partners, and outside stakeholders to fund programs that will increase opportunities for people with and without disabilities to access affordable mass transit.*

Housing

As it does with everyone else, housing plays a central role in the lives of people with disabilities. It is where they live, sleep, bathe, dress, conduct significant parts of their family and social lives, and conduct other core life activities. Without accessible, useable, and affordable housing, people with disabilities are severely hampered as they try to become independent, productive members of their communities. Like transportation and personal assistance, the availability or absence of real housing options for people with disabilities dramatically affects their independence and economic self-sufficiency.

Since the publication of *Achieving Independence*, people with disabilities have seen both positive and negative developments in housing policy.

> Through the FY 1997 appropriations process, the Department of Housing and Urban Development (HUD) experienced severe funding and staffing reductions as a result of an almost $8 billion cut in its appropriations. In addition, Congress and the President repealed a set of preferences that directed communities to make housing available to people who were homeless, a significant percentage of whom are people with disabilities, particularly people with mental illness.
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> The 104th Congress and the President also made it easier for housing authorities to designate public housing “elderly only.” *NCD is concerned that the housing that has been designated “elderly only” will exclude people with disabilities below age 62 and thereby reduce the availability of accessible public housing for this population.*

The FY 1997 appropriations for HUD also included a $50 million allocation for Section 8 tenant-based rental assistance specifically for people with disabilities who lost housing because of elderly-only designation. *Although these additional resources have the potential to expand housing options for people with disabilities and fill the hole left by any "elderly-only" designations, the requirement that the money go to people who have lost housing as a result of elderly-only designation may have the unintended effect of encouraging elderly-only designation by public housing authorities seeking to tap into the new money. In addition, these certificates and vouchers have limited utility for people with significant mobility impairments because of the great dearth of physically accessible housing in the community.*

The 104th Congress and the President reduced protections against arbitrary evictions of residents with a history of alcohol or substance abuse disorders. *NCD is concerned that these changes have the potential to result in unfair evictions of people based on fears, myths, and stereotypes about their disabilities.*

In the area of fair housing enforcement, this year HUD announced a landmark $1.3 million new component of its Fair Housing Initiatives Program (FHIP) that will target fair housing enforcement for people with disabilities. As of October 31, 1997, this new money had been awarded to a range of qualified disability community organizations and others throughout the country. Entities selected to participate in this program will be eligible to compete for additional fair housing enforcement dollars in HUD's Fair Housing Administration Program (FHAP) after two years of participation in the FHIP. Accordingly, for the first time, HUD has deliberately expanded the pool of entities charged with fair housing enforcement to include organizations from the disability community. *In the current climate of shrinking resources for fair housing enforcement, HUD is to be commended for recognizing the need to expand its efforts in this critical area for people with disabilities.*

In FY 1997, 25 percent of the funds in HUD's Section 811 program, which targets people with disabilities, was set aside for tenant-based rental assistance (i.e., certificates and vouchers). *NCD applauds this important step away from project-based, segregated housing for people with disabilities.*

In its Notices of Funding Availability for its Section 811 program, HUD prohibited mandatory acceptance of services as a condition of housing. In addition, in December 1996 Secretary Henry Cisneros sent a notice to providers and residents of Section 202 housing that made clear that residents may not be required to accept services as a condition of living in Section 202 housing. These important developments are consistent with NCD's recommendation in *Achieving Independence* that HUD cease funding programs that require an individual to live in a particular setting in order to receive services that are not related to housing. *NCD encourages HUD to continue to delink housing from services in other programs it administers. Also, NCD urges HUD to continue to recognize that people with disabilities should have a range of housing choices comparable to that available to people without disabilities.*

This year HUD created a "People with Disabilities" web site to showcase best practices in making housing accessible for people with disabilities.

Long-Term Supports and Services

As the case of Holly Caudill recounted at the beginning of this report illustrates, the United States has yet to develop consistent federal policies that support people in need of long-term services and supports when they choose to live independently in the community. If Caudill chose to check herself into an institution, her needs would be met at taxpayer expense. The ongoing institutional bias in our long-term service system simply cannot be squared with ADA's emphasis on "equality of opportunity, full participation, independent living, and economic self-sufficiency."[16] Two bills currently pending in Congress attempt to expand access to home- and community-based long-term services and supports.

> The Medicaid Community Attendant Services Act of 1997 (H.R. 2020/MiCASA), introduced by Speaker Newt Gingrich (R-GA), would amend Title XIX of the Social Security Act (Medicaid) and create a new and mandatory Medicaid service—Qualified Community-Based Attendant Services (QHCBS). Under this bill, each state would be required to develop a long-term care services transition plan, with major participation by the state Independent Living Council and the state Developmental Disabilities Council and Council on Aging, which must have specific action steps and timetables to increase the proportion of home- and community-based services provided in the state. Under this bill, funding currently earmarked for institutional care would be available for people choosing QHCBS. In addition, $2 billion would be appropriated over six years to help states transition from institutional to community-based services.
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> The Long Term Care Reform and Deficit Reduction Act (S. 879), introduced by Senator Russell Feingold (D-WI), would add a new optional home- and community-based long-term services and support program funded through a combination of federal and state funds that is similar to the long-term care provisions of the Administration's Health Security Act introduced in 1993. Home- and community-based services would continue to be optional, as they are under current law in state Medicaid plans. If states opt to offer home- and community-based services, the Feingold bill allows states to determine which services they will offer. The Feingold bill contemplates new federal funding to be phased in over nine years starting in 1999 reaching $5 billion in 2007. This new funding would occur outside the Medicaid program and be earmarked solely for community-based long-term supports and services for people of all ages with the most significant level of impairments, regardless of income or impairment type.

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[16] ADA Section 2(a)(8).

NCD urges policy makers to ensure that services and supports offered under any new or existing federal legislation meet the needs of all *people with disabilities.*

As a follow-up to a meeting between disability community leaders and President Clinton on September 10, 1997, the President has asked Robert Williams, deputy assistant secretary, Office of Disability, Aging and Long-Term Care, Office of Assistant Secretary for Planning and Evaluation, HHS, to head up a personal assistance working group for the Administration that will develop proposals for expanding access to consumer-directed, home- and community-based long-term supports and services. *NCD commends the President for creating this working group, which has begun meeting under the leadership of Robert Williams and Sally Richardson, Deputy Administrator of HCFA, and strongly encourages the Administration to show leadership in this critical area as it did during health care reform by coming forward with its own proposal and working with congressional leaders to address this critical issue.*

Health Care

In addition to the provisions in BBA described above preserving Medicaid coverage for children losing SSI and creating an optional Medicaid buy-in for workers with disabilities, other incremental measures have been taken since *Achieving Independence* was published that plug some of the gaps in the private and public health insurance systems for people with disabilities. Also, it is worth noting that Medicaid was maintained as an entitlement and not block granted or capped, as some in Congress and the Administration had originally proposed.

BBA created a new federal block grant program for the states called the State Children's Health Insurance Program. This new program, funded at $24 billion, would expand health services for children who live in families with incomes below 200 percent of the federal poverty line in most states. The program, which is provided for under a new Title XXI of the Social Security Act, does not require any specific package of benefits for children participating in the program. States are given flexibility on whom to cover and what benefits to provide. *NCD commends Congress and the President for this significant new investment in health outcomes for children from low-income families. NCD is concerned, however, that the needs of children with disabilities who may benefit from this new program will not be met if the eligible population defined at the state level excludes children with disabilities or if the benefits package defined by particular states does not include critical services to maximize functioning, such as outpatient rehabilitation, durable medical equipment, prosthetics, orthotics, pediatric specialty care, and mental health services. Also, NCD is concerned that low-income families of children with special health care needs will be expected to pay more than they can afford to access the new program. NCD encourages states to use the new federal funding to invest in a comprehensive affordable statewide system that seeks to maximize functioning for children with special health care needs who are not well served by existing systems and to use the program to expand their existing Medicaid programs with the comprehensive package of benefits required under the Early and Periodic Screening, Diagnosis and Treatment program.*

The budget reconciliation law eliminated a Medicaid requirement for prior institutionalization for certain services under the Home and Community Based Waiver program. It also included an exemption from mandatory managed care without a waiver for children with special needs. This exemption includes children under age 19 who are eligible for SSI, children with special needs eligible for Maternal and Child Health block grant services, children eligible under the Katie Beckett (Tax Equity and Fiscal Responsibility Act) waiver option; and children receiving foster care or adoption assistance. Also exempted are qualified Medicare beneficiaries and American Indians in certain circumstances. *NCD supports these changes*.

BBA also included language requiring HCFA to develop safeguards to ensure that Medicaid managed care entities meet the needs of individuals with special needs, including individuals with disabilities. *NCD commends Congress for seeing the need for this language, and encourages HCFA to act promptly to develop and implement the* *required standards, working with the disability community and other stakeholders in this process.*

Although it made children with special needs exempt from mandatory managed care, BBA made it easier for states to move other Medicaid beneficiaries into managed care plans by eliminating the need for federal waivers. *This change lifts the federal oversight provided by the waiver process and puts adult Medicaid recipients with disabilities at greater risk of being moved to managed care arrangements that can threaten their access to appropriate specialists and services. For example, adults with HIV disease often have their care managed by a specialist, yet many managed care companies refuse to allow specialists to serve as care coordinators. Also, people with rare or unstable medical conditions often have particular physicians and allied health professionals with whom they have developed a relationship over many years, and these relationships are not always respected by managed care companies, which sometimes require a change in providers to accommodate their network of preferred providers. Accordingly, the need for HCFA to develop and implement the new standards for populations with special needs is particularly important.*

The 104th Congress passed legislation mandating that private insurance plans not discriminate between mental health and physical health care in lifetime or annual reimbursement caps. As enacted, this provision applies only to employers with 50 or more employees, does not take effect until January 1998, and sunsets in October 2001. Further, the provision does not apply at all if its costs result in an increase of 1 percent or more in a plan’s premiums. These provisions, though significant, do not amount to parity for people seeking mental health services, in part because they do not address the critical issue of forced treatment.

The 104th Congress also passed legislation improving portability as people move from job to job or from group to individual coverage. This legislation generally prohibits insurers from denying coverage based on preexisting conditions, and it protects small groups by requiring insurers to provide them with coverage, although a higher fee may be charged to groups with higher health care costs. The law covers not just traditional insurance companies but also companies that self-insure, which cannot be regulated under state insurance laws. The law also includes a provision stating that access to insurance cannot be denied solely because someone has a history of using mental health benefits. Once again, the health portability legislation takes important steps toward plugging the holes in the current system, but several significant holes still remain. For example, the legislation did not attempt to address affordability of health coverage or require a comprehensive benefits package that would meet the needs of all people. Also, perhaps most significantly, millions of people in the United States continue to have no health insurance coverage, including many people with disabilities. *NCD commends Congress and the President for these important first steps toward a private health care system that meets the needs of people with disabilities and encourages them to go further and fill the remaining holes in our health care system for people with disabilities and others.*

International Issues

ADA continues to serve as model civil rights legislation for countries throughout the world. Accordingly, there is strong international interest in how ADA implementation is proceeding. NCD is confident that there will be great interest in the results of our ADA monitoring project. In the meantime, three significant developments in the international arena are worthy of mention.

On September 12, 1997, the U.S. Agency for International Development (USAID) issued a policy paper articulating its commitment to pursue advocacy for, outreach to, and inclusion of people with "physical and cognitive disabilities," to the maximum extent feasible, in the design and implementation of USAID programming. The policy paper includes guidance for making the commitment operational. The paper outlines the fundamental principles on which the USAID disability policy is based, including (1) need for a comprehensive and consistent approach to considering people with disabilities, being sure to include women and children, within USAID and in USAID-assisted activities; (2) outreach to and early consultation with persons with disabilities and the community of organizations concerned about them as part of ongoing participatory processes; (3) intent to work as development partners with U.S. and foreign private voluntary organizations and nongovernmental organizations committed to persons with disabilities and to facilitate relationships among these entities; and (4) encouragement of U.S. interagency collaboration and networking among donors and other diverse entities concerned about persons with disabilities with a view to increasing impact and sustaining these efforts. NCD commends USAID for its leadership in issuing the new policy paper, which can serve as a model for other agencies throughout the government. *NCD encourages USAID to make a technical amendment to its policy paper to change references from "physical and cognitive" impairments and disabilities to "physical and mental" impairments and disabilities, which would accomplish the agency's stated intention of tracking the definition of disability in the Rehabilitation Act.*

The Organization of American States (OAS) is currently considering the "Inter-American Convention on the Elimination of All Forms of Discrimination by Reason of Disability." This Convention, when passed, will create an opportunity for OAS to carry out a great responsibility to ensure that all its State Members observe the Convention. *NCD encourages the U.S. Permanent Mission to the Organization of American States (USOAS) to work to see that the Convention is adopted with strong antidiscrimination provisions and to advocate that the Convention be fully implemented by each State Member when it is passed. In addition, NCD commends the Department of State, including USOAS, for its efforts to involve NCD and other disability community stakeholders in reviewing draft policies.*

On June 15–20, 1997, the International Leadership Forum for Women with Disabilities was held in Bethesda, Maryland, as a follow up to the United Nations Fourth World Conference on Women, held in Beijing in 1995. The Forum, which was attended by more than 500 participants from 80 countries, included sessions and workshops on exemplary practices and projects in the areas of leadership development, health services, education, employment, technology, advocacy and public education, and electronic networking. Secretary of State Madeleine K. Albright spoke at the Forum, reaffirming her commitment to increase employment opportunities for people with disabilities in the Foreign Service and to address access barriers at U.S. embassies. *NCD strongly encourages the Department of State, working with the Access Board and other stakeholders in the disability community, to act promptly and in a systematic manner to address the access barriers at U.S. embassies and other government-owned buildings abroad.*

Physician-Assisted Suicide

Physician-assisted suicide and related issues received significant judicial, media, and scholarly attention in the past year, much of which did not acknowledge the disability policy issues raised by the debate. On March 24, 1997, NCD issued a position paper opposing assisted suicide. In it, NCD acknowledged the substantial benefits of permitting physician-assisted suicide, including respect for individual autonomy, liberty, and the right to make one's own choices about matters of personal welfare; affording the dignity of control and choice to a patient who otherwise has little control of her or his situation; allowing the patient to select the time and circumstances of death rather than being totally at the mercy of the terminal medical condition; safeguarding the doctor/patient relationship in making this final medical decision; giving the patient the option of dying in an alert condition rather than in a medicated haze during the last hours of life; and, most important, giving the patient the ability to avoid severe pain and suffering.

Having acknowledged these benefits, NCD nonetheless found that the countervailing arguments against permitting physician-assisted suicide outweighed its benefits. In making this finding, NCD noted that the benefits of physician-assisted suicide only apply to the small number of people who actually have an imminently terminal condition; are in severe, untreatable pain; wish to commit suicide; and are unable to do so without a doctor's involvement. Moreover, NCD noted the substantial dangers of permitting physician-assisted suicide, including the already prevalent pressures on people with disabilities to choose to end their lives and the insidious appropriation by others of the right to make that choice for them, compounded by the growth of managed care and "rationing" of health care services and health care financing. NCD also noted the societal devaluing of the lives of people with disabilities, the historical experience in the Netherlands of coercion and involuntary "euthanasia" for people with disabilities, the difficulty of crafting adequate procedural safeguards, which inevitably would place unacceptable control in the hands of medical and legal "experts," and the many societal barriers that continue to limit life choices for people with disabilities. As NCD noted, "[s]ociety should not be ready to give up on the lives of its citizens with disabilities until it has made real and persistent efforts to give these citizens a fair and equal chance to achieve a meaningful life."[17]

On June 26, 1997, the U.S. Supreme Court upheld the constitutionality of state laws that prohibit physician-assisted suicide. Although the Court refused to recognize a constitutional right to assistance in committing suicide, the Court left open the possibility of states passing laws that make physician-assisted suicide available. More recently, the Court refused to review an Oregon law that would make physician-assisted suicide available to residents of that state. Accordingly, the dangers that physician-assisted suicide poses for people with disabilities recounted in NCD's position paper continue to be present, and the Supreme Court decision will likely let the policy debate play out at the state level. *NCD strongly encourages states and their federal partners to consider the likely impact on residents with disabilities of any legislative proposals in this area.*

Genetic Discrimination

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[17] "Assisted Suicide: A Disability Perspective," NCD, March 24, 1997 (Executive Summary).

As the Human Genome Project continues to make remarkable progress in mapping the human genome, the potential for discrimination based on genetic information in employment, health care, and other areas becomes greater. NCD is pleased that Congress and the Administration are considering legislation that would prohibit discrimination in employment and health care on the basis of genetic information. *Given that a number of disabilities have genetic links and given the great potential for discrimination based on access to genetic information about the existence of a disability or the propensity to develop a disability, NCD strongly encourages the President to work with Congress to enact legislation that will restrict access by employers, insurance carriers, and others to such information and will outlaw discrimination based on such information.*

Wilderness Accessibility

Section 507(a) of ADA required that NCD identify important issues relevant to wilderness accessibility for people with disabilities. On December 1, 1992, NCD issued a report entitled *Wilderness Accessibility for People with Disabilities,* which included recommendations developed after a hearing and comprehensive study of the issue. A key recommendation in the report was that the federal agencies responsible for wilderness management should better coordinate their policies and management practices regarding disability access and make them consistent with the requirements of federal nondiscrimination laws. In October 1997, a memorandum of understanding was signed by the federal wilderness management agencies and a nonprofit organization called Wilderness Inquiry, Inc. (WI), to coordinate their policies to "establish a general framework of cooperation between the agencies and WI for increased opportunities for people of all abilities to use and enjoy the programs, facilities, and activities of the agencies." NCD commends the National Park Service, the U.S. Forest Service, the Bureau of Land Management, the U.S. Fish and Wildlife Service, the Bureau of Reclamation, and the U.S. Army Corps of Engineers for recognizing the importance of coordinating their efforts to ensure access for people with disabilities to this country's rich wilderness resources.

Currency Accessibility

In 1997, the U.S. Department of Treasury issued a new $50 bill with features designed to make it accessible to people with low vision. The size and coloring of the $50 denomination make it considerably easier for people with partial sight to identify. *NCD commends the Department of Treasury for taking this important first step toward an accessible U.S. currency. We remain concerned, however, that the new $50 bill is completely inaccessible for blind people. Moreover, NCD urges the Department to issue subsequent bills under its counterfeit reduction initiative that are tactually identifiable for people who are blind. Such an action would increase the independence and expand employment options for blind people in this country.*

CONCLUSION

The past 18 months have included many significant accomplishments and some troubling setbacks in public policy as it affects people with disabilities. Although overall the country continues to move forward and expand opportunities and inclusion for Americans with disabilities, the rate of progress is slower and less steady than many in the disability community had hoped when ADA was enacted into law. Federal policy remains rife with inconsistent messages and unrealistic requirements. For people with disabilities truly to accomplish the vision of ADA and achieve independence, empowerment and inclusion in all aspects of American society, it is critical that the current Administration work with leaders in this Congress to forge a disability agenda that supports and rewards people with disabilities when they choose to work and pay taxes, and avoids punishing people with disabilities when they are unable to find a job.

This disability agenda, which might be framed as an opportunity agenda for all people, must address the numerous barriers to employment and self-sufficiency for people with disabilities that have been identified in this report and in *Achieving Independence*. In addressing these barriers, the agenda would include more complete and timely data about people with disabilities and a need for a new research agenda grounded in the ADA paradigm; return-to-work legislation for Social Security disability benefit recipients that addresses health care, makes work pay, and gives recipients a choice in vocational rehabilitation and other employment and training services; an unwavering commitment to accommodate people with disabilities seeking to leave the welfare and Social Security rolls; renewed efforts to expand family support for families that have children with disabilities, including appropriate child care; a reexamination of the recent cuts in the children's SSI program and immigrant programs to ensure that federal policy is consistently applied and not moving backward with respect to this vulnerable population; a concentrated effort to bring immigrants, minorities, and rural residents with disabilities into the mainstream of disability policy through targeted outreach, education, technical assistance, and inclusion; building on the recent reauthorization of IDEA to maximize outcomes and integration for students with disabilities, without overlooking the unique issues facing deaf students, blind students, and minority students, and without diluting civil rights protections in the name of discipline; a technology agenda that ensures access to the information superhighway for all people; a coordinated, aggressive, well-funded ADA enforcement and implementation strategy that addresses disturbing trends in the case law and educates underserved groups about their rights under ADA; a transportation agenda that addresses accessibility, cost, and enforcement in air travel, over-the-road bus travel, and all other forms of mass transit; a housing agenda that expands options for people with disabilities within their budgets and does not force them to live in group settings to receive services; new long-term services and supports legislation that shatters the institutional bias in our publicly administered long-term care programs once and for all; ongoing attempts to fill the many holes in our health care system so that people with disabilities are not forced to accept publicly funded second-rate health care, to enroll in inappropriate managed care arrangements, or to forego employment to have access to health coverage at all; an international agenda that empowers people with disabilities throughout the world and makes ADA’s message global; and a flexible approach to emerging issues such as physician-assisted suicide, genetic discrimination, wilderness accessibility, and currency accessibility in a manner that is consistent with the vision of ADA.

APPENDIX

MISSION OF THE NATIONAL COUNCIL ON DISABILITY

OVERVIEW AND PURPOSE

The National Council on Disability (NCD) is an independent federal agency led by 15 members appointed by the President of the United States and confirmed by the U.S. Senate.

The overall purpose of NCD is to promote policies, programs, practices, and procedures that guarantee equal opportunity for all individuals with disabilities, regardless of the nature or severity 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, in order to assess the effectiveness of such policies, programs, practices, procedures, statutes, and regulations in meeting the needs of individuals with disabilities.
>
> Reviewing and evaluating, on a continuing basis, new and emerging disability policy issues affecting individuals with disabilities at the federal, state, and local 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 operate 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, respecting 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, 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 (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 with respect to the policies and conduct of the Rehabilitation Services 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 persons 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 the purposes of NCD to promote 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.*

Preparing and submitting to Congress and the President an annual report containing a summary of the activities and accomplishments of NCD.

INTERNATIONAL

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

CONSUMERS SERVED AND CURRENT ACTIVITIES

While 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, status as a veteran, 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 persons 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, it was NCD that originally proposed what eventually became the Americans with Disabilities Act (ADA). NCD's current list of key issues includes improving personal assistance services, promoting health care reform and Social Security 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 persons with disabilities who are members of minority groups fully participate in society.

STATUTORY HISTORY

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