Achieving Independence:

The Challenge for the 21st Century

A Decade of Progress in Disability Policy
Setting an Agenda for the Future

NATIONAL COUNCIL ON DISABILITY
July 26, 1996

National Council on Disability

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LETTER OF TRANSMITTAL

The White House
Washington, D.C. 20500

Dear Mr. President:

Today, as we commemorate the sixth anniversary of the signing of the Americans with Disabilities Act (ADA), I am pleased to submit to you the National Council on Disability's (NCD) report, *Achieving Independence: the Challenge for the 21st Century*. This is done in accordance with Section 401(b)(1) of the Rehabilitation Act of 1973, as amended.

In 1986, NCD published *Toward Independence: An Assessment of Federal Laws and Programs Affecting People with Disabilities--With Legislative Recommendations*. That report provided careful analysis and recommendations for improving federal laws and programs affecting people with disabilities. *Toward Independence* has had a profound impact on the way the country views people with disabilities and brought the need for equal opportunity to the fore. Most notably, ADA began as an NCD recommendation for a "comprehensive law requiring equal opportunity for individuals with disabilities."

Achieving Independence is not "government as usual." It calls for real change by and for real people. It is the result of recommendations developed by a diverse group of 300 participants at NCD's National Summit on Disability Policy, which took place in Dallas, April 27-29, 1996. At this historic gathering, people with disabilities representing the grassroots and national leaders alike, developed recommendations that build on two major accomplishments of the last decade--the passage of ADA and the empowerment of people with disabilities, both of which embody your people first principles of inclusion, independence, and empowerment.

In this era of social change, there is bipartisan support for increasing the role of the citizen in government. This report is a major step in that direction. NCD urges you to listen to the voices of democracy. For only in so doing, can this nation end its legacy of exclusion, dependence, and paternalism, and create an America which values and empowers all of its people.

Sincerely,

Marca Bristo
Chairperson

NATIONAL COUNCIL ON DISABILITY MEMBERS AND STAFF

Members

ACKNOWLEDGMENTS

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EXECUTIVE SUMMARY

We have an outdated system of public policy based on outdated attitudes toward people with disabilities.

Ed Roberts
World Institute on Disability

In 1986, the National Council on Disability (NCD) issued *Toward Independence*, a report now considered a milestone in the history of disability policy. It set the agenda for the decade, proposing the enactment of the Americans with Disabilities Act (ADA). The adoption of this law in 1990 was certainly the watershed event for individuals with disabilities in the past decade.

Achieving Independence is a follow-up to *Toward Independence*. Fueled by the collective empowerment and self-determination of the disability community, it is proof of the impact of ADA. It offers an assessment of the nation's progress in achieving equal opportunity and empowerment in the last decade (1986–1996) and sets the agenda for the next decade by offering more than 120 recommendations for change.

A National Summit on Disability Policy

In keeping with the values of empowerment and consumer-directed policy making, NCD decided to convene a summit of people with disabilities to discuss how to achieve independence in the next decade. Over 1100 grassroots disability leaders from around the country were asked to complete nomination forms for participation in the summit. Three hundred participants were chosen on the basis of the following criteria: disability and cross-disability representation; geographic representation; ethnic, racial and other diversity; policy area expertise and breadth of knowledge in disability policy. Eleven policy areas were determined by NCD and the Summit Advisory Committee after a review of the topics addressed in *Toward Independence* and the

priorities reported by the President's Committee on Employment of People with Disabilities in *Operation People First*. These are the policy areas that are addressed in this report.

Politicians in both the Congress and the administration have increasingly called for "people first" government, for direct participation by Americans in decision making. There is less interest in hearing from intermediaries, such as professional advocates, and greater interest in hearing the views and ideas of Americans "outside the Beltway." The National Summit on Disability Policy provided a forum for just such views—it was an event at which knowledgeable people from around the country met to provide input directly into the federal policy-making process.

With the sense of undertaking a complex and potentially controversial challenge, NCD proceeded into this experiment in democracy. From April 27 through April 29, 1996, people from each of the 50 states and the District of Columbia gathered in Dallas. People with all types of disabilities were represented, as well as parents and family members. About 20 percent of the participants were minorities, including Native Americans, African Americans and Hispanic Americans. Participants were from disability organizations, service-providing organizations, academia, and federal, state, and local government. Federal officials provided technical assistance and background information. A special emphasis was placed on youth with disabilities. Twenty young people with disabilities, aged 13–22, participated fully, providing a glimpse of tomorrow's leadership and invigorating today's dialogue.

NCD chairperson Marca Bristo and disability rights leader Justin Dart opened the Summit, challenging participants to be both practical and visionary. Led by volunteer facilitators chosen from among the participants, Summit participants met in policy working groups for three days. The groups brainstormed about their policy areas, assessing the current state of affairs and debating how future policy could best promote the goal of independence.

The recommendations in this report were generated by these working groups and supplemented by suggestions from disability leaders who could not attend the Summit. Although the working groups' original recommendations were reviewed and amended by NCD, the recommendations presented here remain true to the deliberations of the people who attended

the Summit and are thus reflective of the thinking of a cross-section of disability leaders and people with disabilities throughout the nation.

Summit participants had the opportunity to organize additional groups to discuss topics that they believed were not sufficiently addressed within the 11 policy areas defined by NCD and the Summit Advisory Committee. Discussions of nine of the "emerging issues" groups are summarized in Appendix B.

The experiment in Dallas proved to be a great success of democracy in action. The diversity of the men and women who participated—in terms of their disabilities, their ethnic/racial backgrounds, their geographic homes, their ages, and their viewpoints—was remarkable. To our knowledge, the only similar event that has occurred was the 1977 White House Conference on Handicapped Individuals, where people from around the country assembled in Washington to determine recommendations for disability policy. When provided with the opportunity to change policy, people with disabilities are effective and thoughtful analysts and contributors. NCD counts this event, in and of itself, as an important outcome of the Achieving Independence initiative.

Conclusions

NCD draws the following conclusions about the current state of disability policy as a result of dialogue at the Summit, internal deliberations and a review and analysis of current law and programs. These conclusions provide the basis for the recommendations in the report.

1. Disability policy has made steady progress in the last decade in empowering people with disabilities; however, this progress is threatened, compromised, and often undermined by lack of understanding and support in the Congress and among particular segments of society.

The enactment of ADA and many other laws in the last decade is evidence of considerable progress toward independence. The sense of empowerment experienced by people with disabilities is an important outcome of this policy progress. However, repeated attacks on the fundamental liberty and freedom of people with disabilities by those who do not understand

the need for and the requirements of disability rights laws challenge the progress of the past decade. The media backlash against people with disabilities, fueled by special interest segments of society, is evidence of the residue of stereotypes about people with disabilities that remains pervasive in some quarters.

2. Most public policy affecting people with disabilities does not yet promote the goals of ADA─equality of opportunity, full participation, independent living, and economic self-sufficiency.

Public policy continues to send mixed messages to people with disabilities, on the one hand stating independence as a goal and on the other hand constructing significant obstacles to its achievement. The recommendations in this report are intended to change public policy so that it promotes the achievement of independence.

3. Most Americans with disabilities remain outside the economic and social mainstream of American life.

Despite notable progress in the last decade, people with disabilities continue to be less employed, less educated and poorer than other Americans. Barriers to the tools of economic empowerment remain significant. Minorities with disabilities are particularly disadvantaged by barriers unique to them because of their dual-minority status.

Overarching Themes of Recommendations

Most Americans will experience disability at some point during their lives, either themselves or within their families. Disability is not the experience of a minority of Americans. Rather, like aging, it is an experience that will touch every American family. Thus, creating an accessible and inclusive society is important for all of us.

When Americans with disabilities achieve independence, the benefits to society are compelling. People with disabilities want to be employed, educated, participating, tax-paying citizens living in the community and contributing to the economic and social fabric of American

life. Federal funds should be an investment in those goals, an investment in independence, rather than a trap of dependence.

The recommendations provided in this report are offered in the context of balancing the national budget, with a priority on investment in human capital. In the long run, investments in the productivity and mainstream participation of people with disabilities are essential to achieving a balanced budget, a maximally productive society, and an America that is able to continue to provide economic leadership in an increasingly competitive world marketplace.

The following are overarching themes of the recommendations in this report.

1. Existing laws should be more vigorously enforced.

While they are aware of the dedicated commitment of officials and employees at federal enforcement agencies, virtually every policy working group at the Summit discussed the need for greater enforcement of existing law. The lack of adequate resources dedicated to enforcement limits the impact of disability laws. The Congress and the administration must commit additional resources to enforcement.

2. People with disabilities should direct policy and decision making when they are affected by the outcome.

As the Summit in Dallas demonstrated, people with disabilities are knowledgeable, effective decision makers. However, policies are frequently developed and carried out with little involvement of people with disabilities. Too often the outcome is that people with disabilities have little choice about the services, programs, supports or accommodations they may receive. Decisions have already been made for them. The empowerment of choice is a key to achieving independence.

3. Outreach and awareness campaigns must be launched to educate the public about the human and societal benefits of achieving independence for people with disabilities and the important role that civil rights and community-based supports play in promoting independence.

Most Americans do not understand the barriers faced by people with disabilities, the concept of disability rights or the need for disability rights laws. The backlash of the mid-1990s is evidence of this lack of understanding and widespread misinformation. Public understanding

can prevent needless lawsuits and needless mistakes, such as the construction of buildings without access. Public support is critical to furthering the independence of people with disabilities.

4. Incentives for the inclusion of people with disabilities in all aspects of society must be further developed and implemented.

Disability policy must continue to open doors to full participation. While business, industry, state and local government, employers, and other sectors of society must meet their legal compliance obligations, they should also be provided with incentives to go beyond minimal compliance.

5. Principles of universal design should be universally applied.

Universal design involves developing and producing products that are usable by people with a wide range of functional capacity. Most families will experience disability in their lifetimes. Ensuring that technology, housing, transportation and other aspects of community life are designed to accommodate people with disabilities will ensure a more inclusive and productive society for all Americans.

6. Systems, services, and supports for people with disabilities must be further developed as a part of the mainstream of community life.

Too often people with disabilities face unnecessary barriers to full participation, such as employment, because the supports they need to fully participate are not available to them. Too often those supports are available only in segregated settings or for those who are not working. Community-based services and supports are critical to independence.

7. Accurate data about people with disabilities should be regularly collected, analyzed and reported.

Policy development and implementation are inhibited by a lack of statistical information about people with disabilities. Regular reporting of statistics, such as employment rates, will promote policy development, implementation and public understanding. Without such data, people with disabilities and policy makers are unable to accurately assess the nation's progress in meeting the goals of ADA and achieving independence for people with disabilities.

The Challenge for the Future

People with disabilities are well aware of the tools they need to achieve independence. Advances in policy, science and technology are available to support independence as never before. The challenge of achieving independence is a challenge of mustering the political will to move forward. Progress requires a dedicated commitment from all sectors of society─policy makers, people with disabilities and their allies, state and local government officials, nonprofit organizations, the private sector and the media. The achievement of independence for people with disabilities is a test of the very tenets of our democracy. It is a test we can pass.

INTRODUCTION

NCD undertook this examination and analysis with awareness that the world has changed significantly in the past decade—politically, socially and economically. Specifically, we note four trends that served as a context for reflections about the last decade in disability policy and discussions about the future disability policy agenda.

First, technology has evolved to such a point that the very nature of American life is changing. Americans increasingly exchange information and messages by E-mail; we surf the Internet for entertainment; we have conference calls by computer; we talk on cellular telephones from our cars; we balance our budgets and pay bills with computer programs. Computer literacy is becoming a basic skill for elementary school children. Card catalogs at public libraries are increasingly being replaced by on-line listings. The future promises expanded utilization of the information superhighway and the approaching obsolescence of routine hard-copy information exchange and communication.

Second, work has changed. Corporate trends of downsizing, merging and decreasing middle management have escalated. Job security is limited. Rarely does an individual stay with the same job, or career, for a lifetime. Benefits, such as health insurance and retirement plans, are of greater concern as job changing increases. People now expect to have several careers in a lifetime and must retrain to be prepared and remain marketable. Fewer jobs require physical labor and more require the provision of services. Self-employment is increasingly an option as technology minimizes geographical barriers. The workplace has become more flexible and more family-friendly as flextime, family and medical leave, and day care have become standard fare.

Third, the role of government is changing. Americans are frustrated with the ever-increasing federal deficit and its corollary—a large Federal Government. The current trend of a decreasing federal role and a concomitant increasing state role is likely to continue. The private sector may come to play a larger role in addressing problems that used to be the domain of government. The nature of government programs is increasingly being defined as one of "helping individuals to help themselves" with a wariness about the potential dependence that

extended government support may engender and a hesitance to intrude in private sector decision making.

Fourth, our world has increasingly become a global community. No more are nations separated by geography and borders. Mass telecommunications, the development of a global economy, and increased interdependence bring the world's citizens closer together. Domestic developments have international ramifications. This is as true in the disability community as it is in other sectors of society.

It is in the context of these general societal trends that NCD embarked on an assessment of the progress made in the last decade in disability policy and agenda setting for the future. The goals of the Americans with Disabilities Act (ADA) and the principles of independent living provided the touchstones for our deliberations as we considered how they should guide disability policy into the next millennium.

While this report addresses all people with disabilities, it is important to point out some subgroups of the disability community who continue to be disenfranchised. Minorities with disabilities, including African Americans, Hispanic Americans, and Asian Americans, face dual discrimination and a unique set of barriers compounded by their membership in two minority groups. Likewise, women with disabilities face dual barriers.

Native Americans with disabilities and Indian tribes sometimes are not covered by the laws and programs described in this report or are covered in part. Since tribal governments are separate government entities, the application of federal law to Indian tribes is unique and often unclear. For example, the extent to which ADA applies to Indian tribes is still being determined.

Some disabilities are less acknowledged and less understood than others. For example, people with multiple chemical sensitivities have a particularly difficult time securing recognition for their disability. Most people do not understand the chemical and environmental barriers that preclude such persons' access to the most basic and essential areas of life, such as housing and education.

NCD intends this report to address all people with disabilities, no matter what their disabilities or their other characteristics. People with disabilities are a diverse group of

Americans with as diverse a set of needs as any other group of Americans. The common experience of disability is what defines us for the purposes of this report.

This report is organized in the following manner. Two background sections—Disability Demographics and Independent Living, Disability Rights and Disability Culture—begin the report to provide a context for the policy discussion and recommendations that follow. Eleven discrete policy areas are then addressed, providing an overview of progress in the last decade, current issues, a list of significant relevant legislation enacted in the last decade, and recommendations for the future. The report is intended to provide a summary of each policy area rather than a comprehensive analysis. Appendix A provides recommendations made by participants at the National Summit on Disability Policy to NCD for NCD activities and initiatives. A summary of discussions held about emerging issues at the Summit appears in Appendix B. Other appendices list Summit participants, give the text of remarks made by Marca Bristo and Justin Dart at the Summit, and provide a description of NCD.

This report will reveal that while much progress has been made in disability policy in the last decade, much remains to be done to shape public policy so that it promotes the achievement of independence for people with disabilities.

DISABILITY DEMOGRAPHICS

Disability used to signal the end of active life. Now it is a common characteristic of a normal lifespan. Sooner or later it will occur in the lives of most people, surely in the life of every family.

Justin Dart
"Fallacy and Truth About the ADA"
The Washington Post, July 18, 1995

Similarly deceptive is the now-popular figure of "43 million people with a disability"...for it implies that there are over 200 million Americans without a disability. We in the independent living/disability rights movement have coined the term TABS—Temporarily Able-Bodied. But the metaphor of being but a banana-peel slip away from disability is inappropriate. The issue of disability for individuals...is not whether but when, not so much which one but how many and in what combination.

Irving K. Zola
"Disability Statistics, What We Count and What It Tells Us"
Journal of Disability Policy Studies,
Vol. 4, No. 2, 1993

Disability, like aging, is increasingly an artifact of American society. Advances in public health, medical treatment, and technology enable people to live longer lives. The longer one lives, the more likely one is to develop a disability. Premature infants who once would have died at birth now live. People injured in car accidents, diving accidents, and war now survive, when once they would have died. The increasing presence of people with disabilities in society, like the increasing proportion of elderly people in society, is a testament to the success of modern science.

As a group, people with disabilities are older, poorer, less educated and less employed than people without disabilities. The most widely accepted estimate of the number of people with disabilities is 49 million non-institutionalized Americans (McNeil 1993). As such, people with disabilities constitute the single largest minority group identified in the United States, surpassing the elderly (about 33.2 million) and African Americans (about 32.7 million) (Bureau of the Census 1995).

Data from the 1990 Census indicate that about 2.3 million residents of institutions have disabilities, most of these residing in nursing homes. Others live in mental hospitals, correctional institutions and mental retardation facilities. Mental disability is the most frequent impairment cited among those living in institutions (LaPlante 1991). In the last decade, the number of people with disabilities who are homeless has increased, particularly those with mental disabilities.

The percentage of people with a disability increases with age. While 5 percent of the population less than age 18 has a disability, 84.2 percent of those age 85 and over have a disability. Of those age 18-44, 13.6 percent have a disability, while of those age 45-64, 29.2 percent have a disability (McNeil 1993). As the baby boom generation advances in age, the number of people with disabilities will likewise increase.

There are differences in the prevalence of severe disability among races, ethnicity groups and sexes. For the population aged 15-64, 7.4 percent of Whites had severe disabilities, compared to 12.7 percent of African Americans, 11.7 percent of American Indians, Eskimos or Aleuts, 9.1 percent of those from Hispanic origin and 4.5 percent of Asian or Pacific Islanders. Males had a disability rate of 18.7 percent and a severe disability rate of 8.1 percent. For females, the corresponding rates were 20.2 percent and 11 percent (McNeil 1993).

Education

People with disabilities have a lower level of educational attainment than people without disabilities. While improvements in the last decade have been documented, a gap between people with and without disabilities remains in terms of both high school and college graduation.

For example, only 14 percent of people without disabilities, but 34 percent of people with disabilities, have less than a high school education (Yelin 1996).

The dropout rate for high school students with disabilities decreased from 27.4 percent to 22.4 percent between 1986–87 and 1991–92. Between 1984–85 and 1991–92, the percentage of students with disabilities completing high school rose from 55 percent to 64 percent (U.S. Department of Education [DOED] 1994).

Few students with disabilities go on to postsecondary school; however, the number is increasing. One study found that when students with disabilities had been out of high school 3 to 5 years, fewer than one-third had enrolled in postsecondary education programs, less than half the rate of youth in general (DOED 1993). However, in 1991 almost 9 percent of college freshmen were students with disabilities, whereas in 1978 less than 3 percent were students with disabilities (DOED 1995a).

Among people with disabilities, minorities are less educated than non-minorities. For example, while 30.7 percent of Whites with disabilities have less than a high school education, 43.3 percent of minorities have less than a high school education (Yelin 1996).

Income Status

People with disabilities are poorer than people without disabilities. In January 1995, 30 percent of people with work disabilities had incomes below the poverty level, compared with 10.2 percent of the working-age population without work disabilities. Of those with severe work disabilities, 35.8 percent had incomes below the poverty level (LaPlante et al. 1996).

While the average family income for all families in 1995 was $46,478, it was only $28,067 for families of people with disabilities. Among families with disabilities, those who were White had an average family income of $30,216, while those who were minorities had an average family income of $20,587 (Yelin 1996).

Employment

People with disabilities are twice as likely as people without disabilities to be unemployed. In 1995, 10.1 percent of the population aged 16–64, or 16.9 million people, had a work disability. Of these, 11.4 million had a severe work limitation and were not participating in the labor force, with a cost to society of about $150 billion (LaPlante 1995). People with disabilities who are minorities are less likely to be employed than people with disabilities who are not minorities.

Among people with disabilities, those who are minorities are less likely to be working than those who are White. While 31.2 percent of Whites with disabilities were employed in 1995, only 19 percent of non-Whites were working (Yelin 1996).

According to polls of 1000 people with disabilities taken in 1986 and again in 1994, there was virtually no change in the proportion of people with disabilities who are working. Both polls found about two-thirds of working-age people with disabilities not working. Somewhat fewer adults with disabilities were working full-time in 1994 (20 percent) than in 1986 (24 percent) (Lou Harris and Associates 1986, 1994). This lack of increase in the employment rate of people with disabilities persists despite an increase in their overall education level.

Note: As this report went to press, the President's Committee on Employment of People with Disabilities notified NCD that it would soon release new employment figures for people with disabilities that are more encouraging than the information cited above. These figures are based on a new survey by the Census Bureau.

INDEPENDENT LIVING, DISABILITY RIGHTS
AND DISABILITY CULTURE

In its broadest implications, the independent living movement is the civil rights movement of millions of Americans with disabilities. It is the wave of protest against segregation and discrimination and an affirmation of the right and ability of persons with disabilities to share fully in the responsibilities and joys of our society.

>   Ed Roberts
>   1977

The dignity of risk is the heart of the independent living movement. Without the possibility of failure, the disabled person lacks true independence and the ultimate mark of humanity, the right to choose.

>   Gerben DeJong
>   1983

The key force behind a rethinking of policy toward persons with disabilities has been the independent living movement.

>   Judith E. Heumann
>   "Building Our Own Boats"
>   1993

For generations, society has viewed people with disabilities as citizens in need of charity. Through ignorance we tolerated discrimination and succumbed to fear and prejudice. But our paternalistic approach did no more to improve the lives of people with disabilities than labor laws restricting women in the workplace did to protect women. Today we are shedding these condescending and suffocating attitudes—and widening the door of opportunity for people with disabilities....People with disabilities are here today to remind

us that equal justice under the law is not a privilege but a fundamental birthright

in America.

> Senator Ted Kennedy, during the
> Senate's passage of ADA
> July 13, 1990

America's mission was and still is to take diversity and mold it into a

cohesive and coherent whole that would espouse virtues and values essential to

the maintenance of civil order. There is nothing easy about that mission. But it is

not Mission Impossible.

> Former Representative Barbara Jordan
> 1993

A hallmark of the past decade has been the growth of the disability rights movement and the independent living philosophy. Just as civil rights movements for African Americans and women propelled political, social and legal changes in society, so too has the disability rights movement.

During the 1960s and 1970s people with disabilities began to organize themselves to gain greater access to society and to challenge widely held stereotypic beliefs and attitudes about them. Influenced by the antiwar movement of the 1960s, the Black civil rights movement of the 1960s and the feminist movement of the 1970s, disability leaders began to articulate an agenda and engage in activities to promote their civil rights. Although there is no one defining event marking the birth of the independent living movement, the determination of a group of students with disabilities to attend the University of California at Berkeley in the 1960s is often considered the pivotal effort that began the disability rights movement. Those students were led by Ed Roberts, at the time a young man with significant disabilities who was determined to go to college (Shapiro 1993).

Other people with disabilities began organizing groups around the nation. For example, in 1971, Judith E. Heumann formed a group called Disabled in Action to advocate for disability rights in New York. Grassroots organizations in communities around the country organized to

seek community-based services that supported their independence in lieu of institutions and services that fostered dependence. In Washington, a national coalition—the American Coalition of Citizens with Disabilities—was formed to monitor and influence legislation.

Independent Living Philosophy and Services

The three cornerstones of the independent living philosophy are consumer sovereignty, self-reliance, and political and economic rights. The philosophy rejects the supremacy of professionals as decision makers and views disability as an interaction with the society and the environment rather than as a medical condition or physical or mental impairment (DeJong 1979). Essential features of the independent living service model include consumer control, a cross-disability emphasis (inclusion of people with all types of disabilities—mental, physical, sensory), a community-based and community-responsive approach, peer role modeling, provision of a wide range of services, a community advocacy orientation and open and ongoing access to services (Lachat 1988).

Beginning in 1978, funding for independent living services was authorized through Title VII of the Rehabilitation Act. These funds were authorized to promote the development of service programs operated by and for people with disabilities. In 1979, 10 independent living center were funded throughout the country. Today there are over 200 centers throughout the states, providing information and referral services, peer counseling, independent living skills training, and individual and systems advocacy (Smith, Frieden and Richards 1995).

The Disability Rights Perspective

The disability rights perspective views people with disabilities as a minority group that has been subject to discrimination and unfair treatment—in legal terms, a class of people. It stands in contrast to a charitable perspectives which views people with disabilities as unfortunate and deserving of pity and care. Likewise, it stands in contrast to a medical model, which views people with disabilities as needing to be "cured." It also stands in contrast to a rehabilitation perspective, which views people with disabilities as needing experts and professionals who can provide services to enhance the functioning of the individual. During the 1980s, the disability

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rights perspective has become the dominant perspective adopted by leaders of the disability community and reflected in their approach to public policy. One commentator has described the evolution of regard for people with disabilities as moving from "caste to class" (Disability Rights and Education Defense Fund 1981).

The tenets of other civil rights perspectives apply to the disability rights perspective. The defining aspect of the perspective is that people with disabilities, as a group, have been subject to pervasive and persistent discriminatory treatment. The remedy for such treatment is a prohibition against discrimination, protection of civil rights, and heightened empowerment of people with disabilities. Beginning with the passage of Section 504 of the Rehabilitation Act of 1973, people with disabilities were acknowledged by the Congress as a class of people subject to pervasive discrimination. The Americans with Disabilities Act (ADA) affirmed this view. Disability policy has increasingly acknowledged that—like race, ethnicity, gender, and age—disability is a characteristic that invites discrimination.

The notion of disability rights is a relatively new concept, yet to be widely understood by the public. While people generally acknowledge racism and sexism as realities to be challenged, discrimination against people with disabilities often goes unperceived. Furthermore, paternalistic acts and attitudes toward people with disabilities are often expected and accepted, when in fact they are acts and attitudes of discrimination and should be so labeled.

Many organizations have evolved over the last couple of decades to promote and defend the rights of people with disabilities such as the Disability Rights Education and Defense Fund, Americans for Disabled Attendant Programs Today, the National Council on Independent Living, the National Association of Protection and Advocacy Systems, the National Parent Network on Disabilities and the Consortium for Citizens with Disabilities, which is based in Washington and comprises over 100 national organizations.

The Disability Vote

With 35 million voting-age Americans, the disability community constitutes a significant voting bloc. The impression of the disability community as a silent and overlooked minority, a "sleeping giant," is changing. Data from a study of the 1988 presidential election strongly suggest that George Bush gained votes among voters with disabilities because of his outreach efforts. It is likely that the disability vote helped win the election for President Bush (National Organization on Disability 1996). Disability rights advocates are currently working aggressively within both major political parties to attract the disability vote for the next presidential election. Efforts are under way within the disability community to register people with disabilities to vote.

Disability Culture

The past decade has witnessed the evolution of the notion of what some have described as disability culture, a corollary to the self-identification of people with disabilities as a minority group. As people with disabilities have increasingly come to identify with each other, and to express themselves artistically through graphic arts, performing arts and participation in the cultural life of society as a whole, they have increasingly identified their own cultural affiliation, which, as with other minority groups, may mitigate the effects of social devaluation. A function of disability culture is a celebration of the uniqueness of disability and a sense of belonging in a world that is often rejecting. Key aspects of disability culture have been identified as unique communication, disability humor, a sense of shared history in society, evolving language and symbols, a common worldview, and shared strategies for surviving and thriving (Gill 1995).

Disability Studies

As the disability community has grown, its researchers and academics have sought to develop a home in academia. In much the same way that the civil rights movement for African Americans generated departments of African American studies and the feminist movement generated departments of women's studies, the disability community has promoted the notion of developing disability studies as a discrete area of academic inquiry. The field of disability

studies, described as the study of the lived cultures and experiences of individuals with disabilities, is in its early stages of development.

ASSESSMENT OF DISABILITY POLICY

Policy Coordination

We must forge a national disability policy that is based on three simple creeds—inclusion, not exclusion; independence, not dependence; and empowerment, not paternalism.

President Bill Clinton
1996

...an exclusively special needs approach to disability is inevitably a short-run approach. What we need are more universal policies that recognize that the entire population is "at risk" for the concomitants of chronic illness and disability....Without such a perspective we will further create and perpetuate a segregated, separate but unequal society—a society inappropriate to a larger and older "changing needs" population.

Irving K. Zola
"Universalizing a Disability Policy"
1989

The Americans with Disabilities Act (ADA) is the most comprehensive policy statement ever made in American law about how the nation should address individuals with disabilities. Built on the principles of equal opportunity, full participation, independent living and economic self-sufficiency, the law reflects the disability community's convictions and determination to participate as first class American citizens and to direct their own futures.

Yet little progress has been made in ensuring that the various federal programs for people with disabilities are grounded in the principles of ADA. People with disabilities receive conflicting messages from national disability policy. While national policy promotes employment, national policy does not ensure access to health insurance unless an individual with a disability is not working. While full participation in the community is a national goal, many

people with disabilities can receive the support services they need only if they live in segregated settings. While the Federal Government spends about $175 billion per year on people with disabilities, most of this amount continues to support dependence rather than independence. Decisions about the services people with disabilities will receive continue to remain largely in the hands of service providers, rather than people with disabilities.

Progress in ensuring that people with disabilities are considered and included in generic policy areas has begun. For example, there has been a concerted effort to ensure that the National Information Infrastructure will be accessible to and usable by people with disabilities. President Clinton's AmeriCorps program explicitly included people with disabilities as both volunteers and recipients of volunteer services. Yet national employment and labor policy, as well as foreign policy, have done little to acknowledge people with disabilities.

The Federal Level

There are multiple federal programs for people with disabilities, administered by different federal agencies. The programs differ in their eligibility criteria and foci, depending on their purposes and their target populations. The largest federal disability programs are Social Security and Medicaid/Medicare.

Disability programs are distributed through a number of committees and subcommittees in Congress that rarely consult with each other during policy development. For example, in the Senate the $63 billion Social Security programs and the $43 billion Medicaid and Medicare programs are under the jurisdiction of the Committee on Finance. The Subcommittee on Disability Policy of the Committee on Labor and Human Resources has jurisdiction over vocational rehabilitation, special education and ADA. Yet there is no mechanism for these committees to jointly address the conflicts or promote coordination of the disability policies under their respective jurisdictions.

The current climate in Washington is one of consolidation, downsizing, block grants and performance partnerships. Legislation intended to consolidate vocational rehabilitation with other federal employment programs was introduced and almost enacted in 1995. Congress is considering transforming the Medicaid entitlement into a state block grant.

While consolidation offers increased flexibility in service delivery, it also brings the risk of loss of services altogether as potential recipient groups are left to battle for a fair share at the state level. Many people with disabilities believe they may lose funding and services under state block grants, as they are often put in a position of competing with other groups who have historically been more successful in staking their claims at the state level.

The State Level

Much of the consolidation impetus has been generated by states that are frustrated trying to implement so many federal programs with disparate requirements. State programs generally reflect the categorical nature and complexity of programs at the federal level. There is no single point of entry or access point for people with disabilities to receive information or services.

A number of states have attempted to address these problems by consolidating programs at the state level. The state of Wisconsin developed a county-administered program, the Community Options Program, designed and funded to divert and relocate people with significant disabilities from institutions. The state of Oregon enacted legislation authorizing the state to set up a comprehensive health and social service system for people with disabilities.

A recent report examined the states' experiences in administering disability programs and recommended the consideration of consolidation at the federal level with a strong consumer and community focus. A set of consumer-centered values was recommended to drive reform with a common intake process and a consumer-centered individualized plan for each customer who receives services under the consolidated system (Scully, Snow and Riley 1995).

The Customer's Perspective

The customer with disabilities seeking services faces a maze of programs, requirements and bureaucratic obstacles. Separate intake systems and eligibility determination processes are frustrating and wearing. Furthermore, even after being determined to be eligible by an agency or service provider, the customer is empowered with little leverage to participate in decisionmaking about the services she or he will receive. Duplication and conflict are commonplace. A

customer in one state was reported to have 12 different case managers (Scully, Snow and Riley 1995).

Waiting lists are another common problem. Rarely do states provide services to all eligible recipients in any service area. For example, state vocational rehabilitation agencies now use an order-of-selection process because the demand for their services is so much greater than their resources. Lack of adequate resources is usually the explanation for waiting lists.

Data Collection

Lack of detailed and current data about people with disabilities remains an obstacle to effective policy development and analysis. Major national surveys do not routinely collect or report data about people with disabilities the way they collect and report data about other protected groups, such as women, the elderly, and racial and ethnic minorities. Disability statistics lag well behind many areas of health and social statistics. There is neither a national survey that regularly gathers information about the nation's population with disabilities nor an agreed-upon definition of disability. Data about people with disabilities are often gathered from survey questions that were not intended for this purpose. Survey questions often reflect a medical orientation to disability rather than an independent living orientation. The major national surveys used are the National Health Interview Survey (NHIS), the Survey of Income and Program Participation and the Current Population Survey.

There has been considerable discussion in the last decade about the limitations of these databases and the need for a database specifically designed to answer policy- relevant questions about people with disabilities. One outcome of this discussion has been the creation of the most comprehensive national survey on disability ever undertaken in this country—the 1994/1995 Disability Survey, a supplement to the NHIS. Questions for this survey were extensively reviewed by the federal disability community, advocacy groups, and academics. In addition, the questionnaire was voluntarily tested by people with disabilities and their families. It is intended to address key policy questions, including why employment among people with disabilities is so low and why the Supplemental Security Income (SSI) and Social Security Disability Insurance (SSDI) rolls have experienced so much growth. Survey results should be released in 1997.

There are currently no plans to repeat this survey later. It is scheduled as a one-time, snapshot event; thus it does not appear to be a vehicle for examining trends over time in employment, income, and other areas important to monitoring the status of people with disabilities.

Little improvement in data collection about people with disabilities has been evident in the last decade. The limited availability of data about people with disabilities continues to thwart policy analysis and promote an "out of sight, out of mind" viewpoint.

Recommendations

During the last decade, public policy discussions have increasingly focused on enhancing the consistency and coordination of programs and policies for people with disabilities. Even though discrepancies and conflicting purposes remain the rule rather than the exception, efforts are under way at both federal and state levels to bring consistency and coordination to benefits and services. However, the goals established by ADA do not yet drive policies that affect people with disabilities, nor are they used to drive budget and spending priorities and allocations. In most states, people with disabilities seeking services from the many service systems are still too often frustrated by the maze they must negotiate to try to meet their needs.

Goals of ADA

1. All federal agencies involved with policies or programs that affect people with disabilities should ensure that such policies and programs promote the goals of ADA. In cases where there is conflict, changes should be initiated, including drafting legislative proposals if required.

All policies and programs should support empowerment, independence, economic self-sufficiency, full participation and equal opportunity. Many programs and policies continue to present obstacles to the achievement of these goals rather than creating opportunities.

Coordination and Collaboration

2. The Federal Government and the Congress should develop mechanisms to ensure consistency, collaboration and coordination among federal agencies that administer policies that affect people with disabilities and among Congressional committees with jurisdiction over policies and programs that affect people with disabilities.

The goal of such mechanisms should be to ensure that programs and policies interact in such a manner as to promote independence for people with disabilities rather than to create obstacles. Such mechanisms, which may be interagency committees in the case of the Federal Government, should also work to avoid duplication and to maximize use of existing resources.

3. Federal agencies should work to reduce the redundancy and duplication imposed upon people with disabilities when they are seeking to participate or are participating in programs or services and should seek to maximize customer satisfaction with entry into, participation in, and exit from programs and services.

The Federal Role

4. If the Federal Government grants greater authority to states, it must retain responsibility and authority for ensuring rights and protections; standards for eligibility for supports, benefits, and services; and meaningful outcomes for people with disabilities.

Full Participation in the Community

5. Congress should revise federal laws and agencies should revise regulations (and require or encourage states to do the same) to ensure that all supports and services are provided to all people with disabilities in the most inclusive setting. Revisions should foster independence and interdependence rather than dependence. A national clearinghouse of successful approaches should be established and supported.

Consumer Control

6. Congress and the President should ensure that people with disabilities are significantly involved in the development, direction and implementation of policies that affect them.

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Policy development continues to take place without the participation and involvement of people with disabilities. Sometimes people with disabilities are involved in a minor or token fashion. People with disabilities must play the central role in directing policy that is critical to their empowerment**.**

7. Congress, in consultation with NCD, should a) establish a policy that people with disabilities and their families will control resources necessary to obtain services and supports of their choice and b) hold states accountable for implementing this policy.

Such a policy should include the provision of guidance and support in assisting people with disabilities and their families in making informed choices. Self-advocacy training, focusing on skills, should be authorized. The customer service principle so common in the private sector, with a focus on customer satisfaction, should be paramount. Marketing and outreach strategies should be used to inform potential consumers of the services and supports that are available.

Equity

8. Congress and the administration should establish equitable policies that address the needs of all people with disabilities (including appropriating funds as needed to include those with emerging disabilities and recently recognized disabilities) regardless of disability diagnosis or label, age, gender, ethnic/cultural background, religion, familial status or sexual orientation.

Outreach to those who are often underrepresented is critical to ensure equitable access for all people with disabilities, no matter what their disability and no matter what their race, ethnicity, or other characteristics.

Functional Need, Not Diagnosis or Label

9. Congress and the administration should base policies and services for people with disabilities on needs rather than on disability categories or labels.

The needs of people with disabilities change over time and are a function of the interaction between disability-related limitations and environmental factors. Some supports and services should be made available regardless of personal resources while others might be means tested. Individuals should not be required to impoverish themselves to have access to publicly funded supports.

Accountability

10. All federal and state government agencies should ensure that all of their communications are available in accessible formats and that they portray people with disabilities in a manner that is consistent with the empowerment and inclusion goals of ADA.

Data Collection and Analysis

11. The administration should ensure 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.

Federal agencies that sponsor research and data collection that affect people with disabilities should reevaluate the economic assumptions that are implied in typical cost-benefit analysis in light of the new disability paradigm embodied by ADA. The Federal Government should review existing surveys that have questions related to disability and update those questions so that they reflect the paradigm of disability embodied in ADA. All federal agencies conducting surveys should ensure that people with disabilities are the respondents, rather than using proxies. This will require alternate formats, adaptation of telephone surveys for people with cognitive impairments, training of surveyors in how to interview people with particular needs, etc.

12. The Federal Government should design and carry out a recurring longitudinal study (with a design comparable to that of the Survey of Income and Program Participation) that routinely collects and reports data that are relevant to the goals of ADA and the disability community.

The Federal Government should sponsor methodological analysis and development that will develop new measures and survey questions appropriate to the new paradigm of disability as reflected in ADA.

13. The Federal Government and the Congress should ensure that questions about disability are adequately included in the 2000 census.

14. All federal agencies should promote further analysis of existing data related to people with disabilities, particularly data from the 1994-95 Disability Supplement to the National Health Interview Survey.

<u>Tribal Governments and Indigenous Peoples</u>

15. Federal and state governments should invest resources in working with tribal governments and indigenous people with disabilities to ensure that all policies affecting people with disabilities are culturally appropriate and extend beyond the federal or state government to include tribal governments.

Many federal policies, such as ADA, were not developed in conjunction with tribal governments; thus their applicability to indigenous people and tribal governments is still being delineated. In the future, Congress and federal and state governments should work together to ensure appropriate applicability of disability laws to tribal governments and Native Americans.

Civil Rights

Discrimination occurs in every facet of our lives. There is not a disabled American alive today who has not experienced some form of discrimination. Of course, this has very serious consequences. It destroys healthy self-concepts and slowly erodes the human spirit.

I. King Jordan
President, Gallaudet University
1989

As a former mental patient (who now prefers to use the term psychiatric survivor) who has been active for many years in the movement to develop self-help and empowerment, I have seen the crippling effect that stigma has on people who carry the mental illness label....Indeed, this prejudice may be the most powerful barrier that persons with psychiatric labels face, keeping us out of the mainstream in the same way that the lack of ramps hampers people in wheelchairs from fully participating in community life.

Judi Chamberlin
"Psychiatric Disabilities and the ADA"
1993

Today's legislation brings us closer to that day when no Americans will ever again be deprived of their basic guarantee of life, liberty and the pursuit of happiness....This historic act is the world's first comprehensive declaration of equality for people with disabilities.

President George Bush
Statement at the signing ceremony
for ADA
July 26, 1990

America is reaping the benefits of a more inclusive society. Employers have a larger pool of qualified workers. Businesses are opening doors to new customers. State and local governments are enjoying broader citizen

participation. Most important, individuals are being judged not by their disabilities, but by their abilities.

President Bill Clinton
July 18, 1995

ADA has made me feel like a real American!

Gregory Dougan
Voices of Freedom
National Council on Disability
1995

Throughout history, people with disabilities have been subject to prejudice, stereotyping and discrimination (Mayerson 1982; DREDF 1981). Beliefs about the inferiority of people with disabilities have offered justification for their subordination in the same way that erroneous but widely held beliefs resulted in the oppression of women and African Americans. Disability policy, like policy for other oppressed groups, has both guided and reflected changes in attitudes over time. Over the last century disability policy has evolved from an orientation of care and charity to an orientation of medical treatment and rehabilitation to its current orientation of empowerment and civil rights. The growth and determination of the disability rights movement, like those of other civil rights movements, have generated numerous civil rights laws over the last 25 years, beginning with Section 504 of the Rehabilitation Act of 1973 prohibiting discrimination against people with disabilities when federal funds are involved. Other legislation built on this foundation to expand the antidiscrimination mandate—the Voting Accessibility for the Elderly and Handicapped Act of 1984, the Air Carriers Access Act of 1986, the Fair Housing Amendments Act of 1988, and the most comprehensive civil rights legislation to date for people with disabilities, ADA.

The Americans with Disabilities Act

People with disabilities are now protected by comprehensive antidiscrimination legislation comparable to that for women, racial and ethnic minorities and the elderly. Modeled after the Civil Rights Act of 1964, ADA has contributed significantly to equal opportunity for

people with disabilities. With a legal prohibition against discrimination and enforceable sanctions established, people with disabilities have begun to experience the empowerment of first-class American citizenship and the benefits of full participation. Enactment of ADA was the key recommendation made by NCD in its landmark report of 1986, *Toward Independence*.

The benefits of ADA have been documented in detail elsewhere (Blanck 1994a, 1994b, 1996; Gostin and Beyer 1993; NCD 1995; U.S. General Accounting Office 1994; West 1991, 1996a, 1996b). People with disabilities have experienced increased access to many environments and services, including town halls, public libraries, child care centers, courthouses, retail stores, restaurants, hotels, parks, 911 emergency services, university programs and telecommunications services. Employment opportunities have increased with the provision of reasonable accommodations. Students with learning disabilities can receive additional time to take the SAT. Applicants with visual impairments can take the bar exam in large-print versions. People who are blind or deaf can serve as jurors. People with mobility impairments are traveling independently, some after years of staying at home being imprisoned by the lack of access to the environment and society.

People with disabilities feel differently about themselves as a result of ADA. They are empowered and more confident in approaching employers or entering public places. They are traveling places they have never been before, shopping in stores they never had access to, and attending dramatic arts and musical performances at theaters that used to exclude them. They are experiencing the pride of independence and the satisfaction of full participation.

Following the passage of ADA, people with disabilities have increasingly come to identify themselves as a minority group and to be identified as a minority group in public policy. The Harris polls of people with disabilities revealed a 14 percent increase in the number of individuals feeling a sense of common identity with other people with disabilities between 1986 and 1994 (Lou Harris and Associates 1986, 1994). The last decade has also witnessed a broadening of the disability community. People with HIV and AIDS now identify with the disability community. The presence of people with mental illness advocating for themselves has grown notably.

ADA is creating positive changes in American society and culture, enhancing the national tradition of celebrating diversity among our citizens. Notions of accessibility, accommodation and universal design are increasingly becoming a part of how America does business. People without disabilities can look forward to a more accessible society as they age. Businesses have reported unexpected positive impacts as they have expanded their markets and tapped new employee pools.

Programs and Services Supporting Civil Rights for People with Disabilities

Key federal programs that advocate for and protect the rights of people with disabilities have grown steadily over the last decade. The Protection and Advocacy Systems and their affiliate programs (Client Assistance Programs, Protection and Advocacy for Individuals with Mental Illness, Protection and Advocacy for Individual Rights, Protection and Advocacy for Technology) are active in every state serving over 600,000 individuals annually. Centers for Independent Living are also active in every state promoting effective implementation of the law. In addition, there has been an increase in participation in disability rights litigation by members of the private bar and legal services organizations. State and local laws and ordinances barring discrimination on the basis of disability have facilitated compliance with ADA.

The Federal Government has supported the provision of technical assistance to both entities covered by ADA and people with disabilities whose rights are protected by the law. Technical assistance centers in every region of the country, called Disability and Business Technical Assistance Centers, answer questions, provide training and develop and disseminate materials.

Ongoing Discrimination

Despite the remarkable progress in civil rights, people with disabilities still encounter discrimination frequently, and access cannot be taken for granted. Between July 26, 1992, and March 31, 1996, 63,000 employment discrimination complaints were filed with the Equal Opportunity Commission. Discrimination complaints have been filed by people with disabilities in virtually all areas covered by ADA, including education, transportation, state and local

government services, public accommodations and telecommunications. In 1994, 30 percent of working-age people with disabilities indicated they had encountered job discrimination, up 5 percent from 1986 (Lou Harris and Associates 1994). People with disabilities continue to report obstacles in housing, transportation, education and access to public accommodations. People who are deaf and hard of hearing cite ongoing communication access barriers.

While ADA has had some impact on the provision of health insurance, its comprehensive antidiscrimination mandate does not address many health insurance practices. Preexisting-condition exclusions, underwriting practices, and caps on benefits continue to negatively affect people with disabilities and disadvantage them in both access to health care and access to private health insurance policies. In addition, people who are deaf have noted considerable difficulty in gaining communication access to health care providers through the provision of sign language interpreters.

People who are perceived to be "mentally ill" are frequently subject to legal interventions applied only to them on the basis of the label of "mental illness."   Such interventions would not be tolerated if applied to people without the label of mental illness. Such interventions include forced treatment, involuntary commitment, forced or coerced medication and substantial limitations on personal freedom imposed by the judicial system.

Federal Enforcement

Every relevant agency of the Federal Government has initiated activities to implement ADA in good faith and in keeping with the spirit of the law. However, the Federal Government has yet to use its full authority to enforce the law. Both Republican and Democratic administrations have requested additional funds from the Congress for ADA enforcement, yet such funds have not been forthcoming. Without the infusion of additional resources, federal agencies will remain unable to use their full authority to enforce the law. With a 20 percent increase in workload resulting from the enactment of ADA, the Equal Employment Opportunity Commission (EEOC) is slow in processing complaints. The Department of Justice (DOJ) is not investigating all the complaints it receives and the Department of Transportation (DOT) is unable

to track the complaints it receives (West 1995). People with disabilities have repeatedly urged the Federal Government to play a stronger role in enforcement (NCD 1994; PCEPD 1994).

Despite the technical assistance provided by the Federal Government, many covered entities and people with disabilities are unaware of the requirements of the law. For example, a 1994 survey found that only 40 percent of people with disabilities were aware of the law (Lou Harris and Associates 1994). Outreach to small businesses and people from ethnic and racial minorities with disabilities is lacking (West 1994).

The Backlash

Just as other disenfranchised groups have experienced backlashes against their efforts to empower themselves, so too have people with disabilities. Although some in the media have taken the time to understand the issues and provide fair and balanced coverage, unfortunately, too often the media have highlighted "fringe" ADA cases and characterized ADA as an example of government overregulation. People with disabilities have often been portrayed as malingerers, using ADA as a mechanism to avoid responsibility. People with disabilities see ADA as a ticket into the workforce, into the marketplace and into the community, not as a route to avoid responsibility. This basic message is rarely communicated by the press.

Key Legislation in the Past Decade

The Voting Accessibility for the Elderly and Handicapped Act of 1984 (P.L. 98-435) requires that registration and polling places for federal elections be accessible to people with disabilities.

The Air Carriers Access Act of 1986 (P.L. 99-435) prohibits discrimination against persons with disabilities by all air carriers.

The Handicapped Children's Protection Act of 1986 (P.L. 99-372) overturned a Supreme Court decision and clarified that courts may award attorneys' fees to parents who prevail in administrative or judicial proceedings brought under the Individuals with Disabilities Education Act (IDEA). Awards under IDEA were authorized so that they are parallel to those authorized under other civil rights laws.

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The Civil Rights Restoration Act of 1987 (P.L. 100-259) amended Section 504 and other antidiscrimination laws to overturn the Supreme Court *Grove City College v. Bell* decision, clarifying that the phrase "program or activity" was intended to apply to an entire institution of which any component or part was receiving federal funds.

The Protection and Advocacy for Individuals with Mental Illness Act of 1986 (P.L. 99-319) authorizes advocacy on behalf of people with mental illness, focusing on freedom from abuse and neglect in institutions and for a period of time after discharge from such facilities.

The Fair Housing Amendments Act of 1988 (P.L. 100-430) amended the Fair Housing Act of 1968 to extend the protections afforded by the legislation to people with disabilities, adding disability to race, color, religion, sex and national origin as a prohibited basis for discrimination. This legislation represented the first extension of legislation prohibiting discrimination on the basis of disability into the private sector, paving the way for ADA.

The Americans with Disabilities Act of 1990 (P.L. 101-336) prohibits discrimination on the basis of disability in employment, state and local government services, transportation, public accommodations and telecommunications.

The Revenue Reconciliation Act of 1990 (P.L. 101-508) includes a provision called the "access credit" that enables small businesses to claim credit against taxes for half of the first $10,000 of eligible costs of complying with ADA.

The Developmental Disabilities Act Amendments of 1990 (P.L. 101-496) authorize Protection and Advocacy Systems in every state.

The Civil Rights Act of 1991 (P.L. 102-166) reversed nine U.S. Supreme Court decisions that restricted the protections available to covered workers in employment discrimination cases and authorized compensatory and punitive damages under Title V of the Rehabilitation Act of 1973 and ADA.

The National Voter Registration Act of 1993 (P.L. 103-31) requires states to provide enhanced voter registration services through driver's license, public assistance and disability agencies.

The Telecommunications Act of 1996 (P.L. 104-104) requires telecommunications manufacturers and service providers to ensure that equipment is designed, developed and

fabricated to be accessible to and usable by individuals with disabilities, if this is readily achievable.

Recommendations

While there has been considerable policy development in the area of civil rights for people with disabilities in the last decade, enforcement, education and empowerment are lagging. Expansion in some areas is needed. In particular, minorities with disabilities face multiple and unique forms of discrimination and disadvantage that restrict full participation.

<u>Enforcement</u>

1. Congress and the President must take action to ensure that all civil rights laws affecting individuals with disabilities are more vigorously upheld, implemented and enforced. Such measures would not only include significantly increased funding dedicated to enforcement of disability laws by DOJ, EEOC and other relevant federal agencies, but would also empower and encourage state attorneys general, state and local governments, public interest and legal services organizations, and members of the private bar to provide the means to redress discrimination against individuals with disabilities.

DOJ and EEOC are currently backlogged with numerous complaints from individuals with disabilities seeking to assert and exercise their rights under ADA. DOJ routinely returns complaints to complainants, saying that the Department is unable to investigate due to a lack of resources. Enforcement controlled and funded by a limited segment of the Federal Government cannot alone be expected to reverse the history of unequal treatment, pervasive discrimination and unjust stereotypical assumptions that have oppressed individuals with disabilities for decades. More expansive efforts are required in addition to increased effort by the Federal Government to see that all civil rights laws affecting individuals with disabilities are fully enforced.

The affirmative action requirements of Section 501 and Section 503 of the Rehabilitation Act that apply to the Federal Government and federal contractors should be fully implemented. Such implementation should not include the common practice of singling out only certain disabilities for such efforts. NCD is opposed to the practice of targeting one or two specific

disabilities. Instead, the entire class of people with disabilities should be included in affirmative action programs.

DOJ should more vigorously enforce the National Voter Registration Act, ensuring that people with disabilities are provided with voter registration services at appropriate locations.

NCD should regularly convene forums to develop strategies that would guide enforcement.

Strengthening Civil Rights Laws

2. Congress should retain current civil rights laws ensuring that standards promulgated under ADA are not lowered and should, where necessary, enact legislation to strengthen current civil rights laws so that

> **a) a private right of action is guaranteed to redress *all* violations;**
>
> **b) employment and other contracts may not be construed to waive or supersede procedural safeguards and remedies contained in law;**
>
> **c) violators of civil rights laws are subject to liability for compensatory and**

punitive damages in all cases, with or without the intervention of the Federal

Government;

Federal agencies violating Section 504 of the Rehabilitation Act and other disability rights laws should be liable for compensatory and punitive damages.

> **d) collection of costs and full attorneys' fees is authorized without statutory**
>
> **limitation;**
>
> **e) affirmative action is required for all individuals with disabilities, including those**
>
> **working in the private sector;**

The persistent high level of unemployment and underemployment of people with disabilities warrants the application of affirmative action as a policy remedy. This recommendation would expand the existing affirmative action requirements for the Federal Government and federal contractors to the private sector. Even those who are not proponents of affirmative action acknowledge that it can have a positive impact on increasing the employment

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rate of a particular group of people. Affirmative action requirements should not include quotas, reverse discrimination or preferences for unqualified individuals.

> **f) public communications and telecommunications law is expanded to include the provision of captioning and audio description for all materials available to the public;**

> **g) consistent standardized universal building codes are developed, implemented and required, at the level of standards promulgated under ADA or a higher level;**

> **h) discrimination on the basis of genetic information is prohibited using the standards currently used to prohibit discrimination on the basis of disability.**

Medical Directives and Personal Choice

3. The Federal Government should act to protect children and adults with disabilities by ensuring that "do not resuscitate" and "no cardiopulmonary resuscitation" orders and similar medical directives are carried out in a manner consistent with the standards of nondiscrimination set out in civil rights and other statutes. This policy should in no way limit the rights of adults with disabilities to make their own personal choices and to exercise unrestricted control regarding medical orders and treatment for themselves. Individuals with disabilities who are considering such medical directives or limitations on their own treatment should, however, be provided with complete information on the ramifications of their decisions and the full range of community support and medical resources available to them.

Implementation

4. The Federal Government should encourage state, tribal, county and municipal governments; regulatory agencies; territorial and regional authorities; public licensing agencies; public schools; zoning boards; accreditation groups; and private organizations and entities to adopt disability policies, standards and requirements that are consistent with ADA to help eliminate discrimination and ensure equality of opportunity, full participation, independence, and inclusion.

Nondiscrimination, independence, and inclusion should be the norms throughout the United States, and ADA provides a minimum national standard. Individual litigation based on federal law is not and should not be the only means for effective elimination of discrimination and the implementation of the civil rights of people with disabilities. For example, for certain industries and activities compliance audits could be a condition of licensing permission for public fund-raising. In other cases, violations of nondiscrimination standards would be a basis for revocation of professional licenses or disbarment of a corporation.

Technical Assistance

5. Congress should appropriate significant funds to agencies responsible for enforcing civil rights laws so that they can develop and fund innovative collaborative efforts and partnerships of traditional and nontraditional entities to ensure the effective implementation of ADA. Agencies should collect information and develop a database about effective implementation strategies.

6. The Congress and relevant federal agencies should ensure that organizations funded to provide technical assistance and training related to ADA, including the Disability Business and Technical Assistance Centers, are controlled by people with disabilities. Additional funds should be appropriated to expand such technical assistance.

Technical assistance can be an effective tool to avoid litigation. After six years of the provision of technical assistance, effective models can be identified and expanded. Standards for technical assistance should be developed by an interagency disability committee or NCD. All training and technical assistance provided should be fully accessible in the broadest sense and should reflect multicultural and cross-disability diversity.

Effective technical assistance must involve both people with disabilities who are knowledgeable about disability issues and people with technical expertise. Sometimes people with disabilities have both disability expertise and technical expertise. Usually people with disability expertise and people with technical expertise (such as architects, builders and attorneys) must form partnerships to ensure that the technical assistance is accurate and effective. Care needs to be taken to ensure that technical assistance is not provided by organizations that do

not have expertise in both areas. Too often one or the other prevails and the outcome is less than optimal. Too often people with disabilities are not in leadership positions.

Education and Training

7. Congress should authorize and fund education and training programs to promote greater independence and empowerment of all individuals with disabilities, including elementary and secondary students with disabilities, those with traditional disabilities, and those with disabilities that are less widely recognized. The mission and funding of independent living centers should be expanded to carry out such education and training for this broader population.

Materials and training must inform people with disabilities about their rights under state, local and federal laws as well as how to exercise them and how to utilize complaint mechanisms when they are violated. All such educational, training and informational materials should be developed and reviewed under the direction of people with disabilities. The training should utilize peer training and emphasize cross-disability issues. Materials should be accessible in format and available in various languages as well as to people of diverse ethnic and cultural backgrounds. Materials should be targeted to various age groups, including youth. The Federal Government should provide such training directly and should distribute materials directly as well as through federal, state and local governments and territorial authorities.

8. Congress should require all federal agencies and recipients of federal funds, including those based abroad, to undergo training about civil rights laws that affect people with disabilities.

A mechanism should be established to provide for the development and administration of standards for such education and training programs. Such a mechanism could be a task force comprising a majority of people with disabilities. The task force could also audit compliance with education and training requirements.

Media Campaign

9. The Congress and the administration should allocate resources to develop a national media campaign to educate the public about issues, concerns and civil rights of all people with disabilities.

The Federal Government and Congress have funded and launched several effective national media campaigns designed to increase public awareness about important social issues. A multimillion-dollar HIV/AIDS awareness and education campaign utilizing television, printed materials and mailings, and technical assistance for the workplace has had a significant impact on Americans' understanding of HIV/AIDS. Similarly, campaigns to educate citizens about drug abuse and to promote a drug-free culture have had an important impact on the American consciousness.

Education

We must continue to be courageous in our commitment to improve the lives of our citizens with disabilities, most especially children, and in making American schools the best they can be for all of our children. For the sake of America's future, we can do no less.

Senator Bill Frist
1996

Laws like IDEA are investments in the future of our families and our nation. IDEA is designed to help ensure that our nation's disabled children can grow up and lead proud, productive independent lives.

Senator Tom Harkin
1996

When kids with special needs were first given the opportunity to go to school, they were separated. That's how it was done because that's what we thought was best. Now we know that it's better for kids with and without disabilities to grow up and learn alongside one another. We need to start out when they are young so that these kids, when they are our community leaders, will

accept people who are different and give them the opportunities to succeed that
everyone deserves.

Kathy Martin, parent
Florence, Alabama
20 Years of IDEA in America
1996

IDEA has made a difference for Maddie, a difference that translates into
her attendance at our public elementary school a half a block from our home with
other first and second graders in her neighborhood. Her regular presence in
school means that kids of all ages greet her on the playground, acknowledge her
in stores, and expect that she is a part of the community.

Joe Wild Crea, Parent
Denver, Colorado
Improving the Implementation of the IDEA:
Making Schools Work for All of America's
Children
National Council on Disability
1995

For youngsters with disabilities, as for youngsters without disabilities, education is the
key to the future. Historically denied access to elementary and secondary school as well as
higher education, people with disabilities remain less educated than their nondisabled peers.
Like people without disabilities, people with disabilities are more likely to experience benefits in
employment and economic well-being when they are well educated. Like people without
disabilities, people with disabilities experience education as a lifelong endeavor. NCD believes
that quality education for our youngsters—those with and without disabilities, side by side—holds
great promise for increased integration in future generations.

Access to Elementary and Secondary Education

The Individuals with Disabilities Education Act (IDEA), enacted in 1975, promised
access to a free appropriate public education for elementary and secondary level students with
disabilities. Before the enactment of the law, one million children with disabilities were

excluded from school, and half of those who were being educated were not receiving appropriate programs in public schools. Many were housed in large state institutions. Today 5.3 million students with disabilities—12 percent of the elementary and secondary school population—receive special education services.

Early landmark Supreme Court decisions established that the responsibility of states and local school districts to educate youngsters with disabilities is derived from the equal protection clause of the Fourteenth Amendment to the Constitution. IDEA was guided by the principles of these court decisions in ensuring a free appropriate public education for every child with a disability, determined on an individualized basis and delivered in the least restrictive environment. The rights of children with disabilities and their families are protected through procedural safeguards.

The law requires that students with disabilities be educated in general education settings alongside their peers without disabilities to the maximum extent appropriate. While 94 percent of students with disabilities are in educational placements in regular school buildings, 40 percent are in regular school classes. During the last five years, the percentage of general education classroom placements has increased by about 10 percent, while the use of resource rooms has decreased. Placements in separate classes and separate facilities have remained about the same (Department of Education [DOED] 1995b.) IDEA authorizes the Federal Government to pay up to 40 percent of the cost of educating students with disabilities. The current federal contribution is approximately 7 percent; 12 percent is the maximum reached since the law's enactment.

ADA and Section 504 of the Rehabilitation Act (when federal funds are involved) prohibit discrimination against students with disabilities in public and elementary and secondary private schools.

Early Intervention and Preschool Services

Public policy has increasingly acknowledged the efficacy of providing services as early as possible to youngsters with disabilities and their families. The family-centered focus of early intervention services is often cited as a particularly effective and beneficial service delivery approach. As of December 1, 1993, early intervention programs served approximately 150,000

infants and toddlers from birth to age three. As of October 1, 1994, every state in the nation was participating in the early intervention program authorized under Part H of IDEA (National Early Childhood Technical Assistance System 1995b). The number of preschool children (aged three to five) with disabilities receiving services has increased from 261,000 in 1986 to 528,000 in 1995 (National Early Childhood Technical Assistance System 1995a). Because of individualized early intervention services, these students reach school better equipped to learn and participate.

Transition from School to Adult Life

By the mid-1980s, a number of studies and reports had documented high levels of unemployment, economic instability, dependence and social isolation among young adults with disabilities. Youth with disabilities were not being admitted into vocational education programs. These findings, coupled with an increased emphasis on independent living for persons with disabilities, prompted the development of school-to- work initiatives intended to assist students with disabilities in making successful transitions to adult life when they leave high school. Planning for the transition takes place while students are still in high school and often emphasizes participation in work sites and other community-based settings prior to graduation. Evaluations of transition initiatives in states are currently under way. Recently enacted school-to-work legislation further extends transition activities for students with and without disabilities.

Postsecondary Education

Students with disabilities are increasingly participating in postsecondary education and higher education; however, they remain behind their peers without disabilities. The Americans with Disabilities Act (ADA) and Section 504 of the Rehabilitation Act and ADA include institutions of higher education in their anti-discrimination prohibitions. Colleges and universities are required to make accommodations for students with disabilities and to provide auxiliary aids and services.

One study found that when students with disabilities had been out of high school three to five years, fewer than one-third had enrolled in postsecondary education programs, less than half the rate of youth in general (DOED 1993). However, there is some evidence of progress. In

1991, almost 9 percent of college freshmen were students with disabilities, whereas in 1978 less than 3 percent were students with disabilities (DOED 1995a). The 1994 Harris poll indicated that the percentage of adults with disabilities who had completed at least some college increased from 29 percent in 1986 to 44 percent in 1994.

ADA and Section 504 of the Rehabilitation Act also prohibit discrimination in trade and vocational technical schools.

Results for Students

Results for students with disabilities have improved in the last two decades. Between 1984−85 and 1991−92, the percentage of students with disabilities completing high school rose from 55 percent to 64 percent. The dropout rate for high school students with disabilities decreased from 27.4 percent to 22.4 percent between 1986−87 and 1991−92 (DOED 1994). Despite this progress, students with disabilities still lag behind their peers without disabilities in educational outcomes. Graduates out of school up to five years report employment rates about 18 percent higher than school dropouts (DOED 1995a); however, students with disabilities remain less likely than students without disabilities to graduate from high school. Although college graduation levels have increased for students with disabilities, they remain lower than for those without disabilities.

Relationship between Education and Employment

There is a strong association between educational attainment and the future employment achievement of people with disabilities. Twenty-two percent of people with disabilities with less than a high school education report being unable to work. In contrast, 2 percent of those with disabilities who have completed college report being unable to work. Jobs that require higher levels of education are often more flexible for people with disabilities, frequently offering greater control over the pacing of work and options such as working at home (LaPlante 1995b).

School Reform and Students with Disabilities

Inclusion of students with disabilities in state-initiated school reform efforts across the country has been of considerable concern to NCD for several years. Historically, students with disabilities have been completely or partially excluded from school reform efforts in all but a few states. The federal Goals 2000 school reform legislation (see below) assumes that all children are ready to learn and specifically includes students with disabilities in its coverage.

Issues such as the appropriate inclusion of students with disabilities in state-wide performance testing have raised questions among educators and the disability community. Concern over issues such as these prompted the Congress to mandate a study by the National Academy of Sciences on school reform and students with disabilities. The Academy will issue its final report in 1996.

Current Issues of Concern under IDEA

NCD (1995b) presents an in-depth analysis of current issues related to the education of students with disabilities in its recent report *Improving the Implementation of the Individuals with Disabilities Education Act: Making Schools Work for All of America's Children*. Key issues addressed in that report include the following.

Least Restrictive Environment

While the principle of educating students with disabilities alongside their nondisabled peers has been well-established for over two decades, too many students with disabilities still must fight to be a part of general education classes and the general education curriculum. In some school districts, state funding methods provide financial incentives for placement of students with disabilities in separate facilities. Placing students in separate settings solely on the basis of their disability and without regard to their individual needs is clearly prohibited by law. However, it is equally inappropriate to place students with disabilities in regular education classrooms without the supplemental aides and services they need. General educators often lack training in providing instruction for students with special needs. They often lack paraprofessional or auxiliary staff to assist them in making accommodations or delivering services.

Many schools, however, do serve students with disabilities quite effectively in general education classrooms. When school districts have made a concerted effort to meet the needs of students with disabilities in general classroom settings, they have been quite successful.

Assessment and Labeling

The current system of identifying students as eligible for special education sometimes results in the stigmatizing of children, fails to identify some needy students as eligible, overidentifies minority children as disabled in some situations, underidentifies minority children as disabled in other situations, and often employs assessment criteria that are inappropriate for students or insensitive to their cultural and communication backgrounds. Children continue to be misdiagnosed and mislabeled and tests are sometimes administered in a language other than the student's native language or mode of communication.

African-American students and non-English-speaking students are overrepresented in special education. While about 12 percent of the general population of students are African American, about 24 percent of secondary special education students are African American (SRI International 1993). An analysis of DOED data found tremendous variation by state in the percentage of African-American students in special education. While 47 percent of special education students labeled mentally retarded in Alabama were African American, only 6 percent of those in New Jersey were African American (Shapiro 1993).

Developing methods and safeguards to ensure nondiscrimination and equal access for minority students with disabilities is of critical importance. The impact of inadequate or inappropriate educational services extends well into adulthood: the employment rate of minorities with disabilities is lower than that for nonminorities with disabilities.

Parents' Perspective

Parents report deep frustration in their efforts to access appropriate services for their children. Resistance from school personnel is pervasive, according to many parents. Some describe their efforts as "battling" with the system to secure what has been guaranteed by law for over two decades.

In spite of provisions mandating parent participation in decision making, parents in many parts of the country remain excluded from the process. Many report arriving at individualized education program meetings only to be presented with a completed program. Many parents, particularly those with low incomes or those who are minorities, remain uninformed or ill-informed of their rights under the law.

Discipline

The current reauthorization of the IDEA has generated considerable controversy over the issue of disciplining students with disabilities in school. It has been alleged that students with disabilities are subject to more lenient disciplinary procedures than students without disabilities.

IDEA precludes the violation of the due process rights of students with disabilities, and the vast majority of school districts have determined ways to effectively discipline students without violating their rights. However, there is considerable evidence that students with disabilities are inappropriately excluded or removed from school because of behaviors associated with their disabilities. A study of suspensions and expulsions in the state of Minnesota found that while students with disabilities constituted 8 to 12 percent of the student enrollment, between 16.5 percent and 33.3 percent of the suspended students were students with disabilities (Minnesota Department of Children, Families and Learning 1996). A Delaware study found that students with disabilities accounted for a disproportionate number of suspensions for weapon possession ("Educators Find" 1995). A Kansas study found that students with disabilities are more than twice as likely to be suspended or expelled as other students (Cooley 1995).

Many instances of disciplinary problems are the result of inappropriate, inadequate or nonexistent programming for students with disabilities, often due to lack of training of professionals or limited resources for support services for students. Few regular education teachers are trained in special education. NCD is greatly concerned about efforts to weaken the requirements of IDEA that would allow or invite increased suspensions and expulsions of students with disabilities. Disciplinary action has historically been used as a means of excluding students with disabilities from public school.

Key Legislation in the Past Decade

The Handicapped Children's Protection Act of 1986 (P.L. 99-372) overturned a Supreme Court decision and clarified that courts may award attorneys' fees to parents who prevail in administrative or judicial proceedings brought under IDEA.

The 1986 Amendments to the Education for All Handicapped Children Act (P.L. 99-457) established Part H, an early intervention formula grant program that assists states in developing a coordinated, comprehensive statewide network of early intervention services for infants and toddlers with disabilities. The amendments also expanded the preschool program to ensure that all children with disabilities between the ages of three and five were receiving appropriate services, and they expanded transition programs for adolescents.

The 1990 Amendments (P.L. 100-630) renamed the Education for All Handicapped Children Act the Individuals with Disabilities Education Act (P.L. 102-119), required transition services to be provided at age 16 or younger if appropriate, revised the definition of "children with disabilities" to create separate categories for autism and traumatic brain injury, and included provisions for the preparation and retention of personnel who are racial and ethnic minorities.

The Americans with Disabilities Act of 1990 (P.L. 101-336) prohibits discrimination on the basis of disability in private elementary and secondary schools as well as institutions of higher education.

The School-to-Work Opportunities Act of 1994 (P.L. 103-239) authorizes funds for programs to assist students, including students with disabilities, in the transition from school to work.

The Goals 2000: Educate America Act of 1994 (P.L. 103-227) provides a framework for meeting national education goals by promoting coherent, nationwide, systemic education reform and improving the quality of learning and teaching in the classroom and in the workplace. Students with disabilities are explicitly included in Goals 2000 programs and activities.

The 1996 Amendments to the Individuals with Disabilities Act were pending in Congress as this report was printed.

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Recommendations

Despite progress in the last decade in educating students with disabilities, current federal and state laws have failed to ensure the delivery of a free and appropriate public education for too many students with disabilities. Students with disabilities often still find themselves in forced and inappropriate isolation, separated from their nondisabled peers. In other situations, students with disabilities are in regular education classrooms with teachers with little or no training in how to educate students with disabilities and without the supports they need. Lack of accountability, poor enforcement and systemic barriers have robbed too many students of their educational rights and opportunities and have produced a separate system of education for students with disabilities rather than one unified system that ensures full and equal physical, programmatic and communication access for all students. Parents and students across the country express a high level of frustration with the continued barriers they face to full participation and effective instruction.

A Unified System

1. The Congress and state governments should mandate a unified system of education and training that will ensure equal physical, programmatic and communication access to all education programs, facilities and related benefits of education for all students while meeting the individual needs of all students, including those with disabilities. The mandate should include a firm timetable for retraining teachers, changing systems, and training parents and students about the new education policies. A single system of education should include the following features:

    a) Placements

        i) Educational or training systems would presume that every child is capable of learning in a regular classroom setting. Special education should assume the role of a supportive service within the context of regular education. Each classroom should be assigned sufficient qualified personnel to meet the needs identified in each student's individualized education program. Students and their parents who believed that their educational needs could not be met in a

regular classroom setting could challenge this presumption and seek a placement that would meet their educational needs.

ii) Funding for education would be modified to be placement neutral. Services should be provided where the student could best be educated.

iii) Information about effective practices for inclusion of students with disabilities in general education would be collected and disseminated nationally.

iv) All students, with or without disabilities, would benefit from an individualized education plan.

b) Teaching

i) All teachers who were trained and certified would have general knowledge about educating students with disabilities.

ii) Specialists in particular areas, such as braille, sign language instruction, and computer technology, would be part of a cadre of resource personnel available to support students with a range of special needs in the general instructional program as specified in their individual education programs.

c) Curricula

i) Curricula and textbooks for all students would be culturally sensitive and include the study of disability culture and disability rights.

ii) Publishers of textbooks would include accurate portrayals of people with disabilities in textbooks and in photographs and illustrations.

iii) All students, including those with disabilities, would be included in school reform initiatives.

iv) The content of all curricula, including written, verbal, and computer-based materials, would be accessible to all students. Especially, students with sight, hearing and learning disabilities would be taught with methods and materials that met their communication requirements.

Due Process Protections

2. The Congress and the Federal Government should ensure that current due process protections for students under IDEA are not weakened and that they are fully enforced.

Technology

3. The Congress, the Secretary of Education, state education agencies and educational organizations should promote the maximal use of modern technology in education by

> **a) requiring training in the availability and use of assistive technology (both equipment and software) as a part of teacher education programs, both inservice and preservice;**
>
> **b) requiring that the individualized educational plan for each student with a disability address the need for assistive technology at school and at home as a part of the educational program;**
>
> **c) requiring that schools notify students with disabilities and their parents of assistive technology and technology funding options available for educational programs ;**
>
> **d) maximizing the use of technology to promote participation by all students in the learning process;**
>
> **e) ensuring adequate funding for assistive technology.**

Accountability

4. The Secretary of Education and state governors should enforce compliance with federal and state education laws. Local education agencies should be held accountable for student outcomes. Specifically:

> **a) Principals, teachers and other staff must be held accountable to the same extent they are held accountable for all students for ensuring the full physical, programmatic and communication access of all students to all curricular, extracurricular and nonacademic programs and activities.**

b) School systems and state agencies must be held accountable for providing a fully unified education system that includes a full range of placement options suitable to meet the unique individual needs of each child .

c) Schools must establish high educational expectations for all students and be accountable for the results of student learning.

d) School systems must be required to provide all students with disabilities with the accommodations and/or alternative assessment methods they need to effectively participate in statewide testing programs.

Accessibility of Schools

5. The President and heads of relevant Cabinet agencies should more strongly enforce the accessibility provisions of ADA and the Rehabilitation Act and state governments must enforce state accessibility laws to ensure better accessibility in schools for students, parents, teachers, staff and members of the public with disabilities.

Postsecondary Education

6. The President and the Congress should insist on strong enforcement of ADA and the Rehabilitation Act in higher education settings and should develop mechanisms to expand access and support services for students with disabilities who seek to enter or who are participating in postsecondary education.

Career Planning

7. The Secretary of Education and the Secretary of Labor should expand initiatives to promote effective transition from school to work or postsecondary education for all students, both with and without disabilities, with a clear expectation that work is the ultimate goal.

Additional Recommendations

The following recommendations related to effective inclusion were made by the caucus of students with disabilities who attended the National Summit on Disability Policy in Dallas.

1. More funding should be designated for transportation for students with disabilities.

2. Schools should design students' schedules with their disabilities in mind, for example, taking into account mobility needs when students are expected to change classes.

3. Access to existing buildings should be increased (e.g., by providing more ramps, elevators and accessible restrooms.

4. Students should receive more time and assistance from instructional aides.

5. If students with disabilities decide to form peer groups or clubs, school administrations should support them.

6. All students should participate in a curriculum that covers:

   a) ADA,

   b) the history of disability culture,

   c) positive attitudes,

   d) listening skills,

   e) patience,

   f) appropriate terminology.

7. Teachers should participate in student advocacy training and make use of group projects and student-assisted academics so that the abilities of all students can be demonstrated.

Employment

The company accommodates me so I can feed my two children and pay my taxes.

David Vice, Mechanic
Indiana
1995
(NCD ADA Report, p. 85)

Before ADA, I could go to a job interview and the employer could say, "We won't hire you because you're disabled," and I had no legal recourse.

Tim Harrington
Ohio
1995
(NCD ADA Report, p. 13)

Together with exciting new technology, improved rehabilitation techniques, better education and changing public attitudes, real work for real wages is more than a dream; it can be a reality.

Susan M. Daniels
Social Security Administration
1995

People with disabilities want to work. When people with disabilities work, the economy benefits. When people with disabilities work, our society is enriched. However, the overriding message sent to people with disabilities through our public policies is that they are not expected to work. Public policy most often creates a path to premature retirement for people with disabilities, not one to rehabilitation and work. Over 95 percent of federal funds spent on people with disabilities are targeted for supporting dependency. Little is spent on supporting people in pursuing and maintaining employment. Too often, health insurance is accessible for people with disabilities only if they do not work. The national employment policy agenda has never included people with disabilities.

Despite accomplishments in medical rehabilitation, technology, education, and civil rights, it should not come as a surprise that the employment rate among people with disabilities

has not increased in the last decade. For most people with disabilities, the barriers to working remain significant and working is too often an irrational choice. Entry-level minimum-wage jobs rarely pay enough for an individual with significant disability-related needs to be able to live on the income and meet those needs. Essential services, such as personal assistance and assistive technology, are often subsidized only through public health insurance, which is generally available only to people who are not working. Private health insurance often precludes coverage for preexisting conditions and offers minimal coverage for mental health needs and long-term supports and services. While there is a well-established and well-funded system to support people with disabilities in dependency, there is relatively little support for their efforts to be independent.

Employment Rate

People with disabilities remain significantly less employed than they would like to be, and significantly less employed than other Americans. Polls conducted by Lou Harris and Associates in 1986 and 1994 reveal that two-thirds of working-age people with disabilities are not working. An overwhelming majority who are not working (66 percent in 1986 and 79 percent in 1994) indicate that they want to work. Data from the Current Population Survey of 1995 confirm that the employment rate of people with disabilities has remained consistently low over the last decade. In 1995, only 28 percent of the 16.8 million working-age noninstitutionalized Americans with work disabilities were employed, while 75 percent of working-age Americans without disabilities were employed.

Women and minorities with disabilities face dual discrimination and employment challenges. Their employment rates have consistently been lower than those for men and Whites with disabilities. African Americans represent a significantly larger proportion of working-age people with disabilities than do Whites or Hispanics, and as a group they are more severely disabled. While the full-time employment rate for Whites with disabilities was 15.9 percent in 1992, it was 7.2 percent for African Americans and 8.2 percent for Hispanic Americans (Braddock and Bachelder 1994). The earnings of women with disabilities with full-time jobs were only 65 percent of the earnings of men with disabilities who were employed full-time

(Bowe 1992). Women with disabilities are more frequently employed part-time, rather than full-time, than men with disabilities. Integrated employment opportunities in sheltered employment are less available to women than men (Blanck 1991), as are promotion opportunities (Blass and Elliott 1993).

Employment Statistics

The Bureau of Labor Statistics in the Department of Labor (DOL) and the Census Bureau in the Department of Commerce regularly collect, analyze and disseminate employment data aggregated on the basis of gender, race, ethnicity, age and geography. No such data are collected or reported for people with disabilities. The most frequently cited data about the employment of people with disabilities are gathered from the March supplement to the Current Population Survey. These data are collected only once a year, whereas for other groups they are collected and reported monthly. Furthermore, the question used to determine the employment status of people with disabilities was not designed for the purpose of tracking employment.

Public Policy: Too Often a Path to Premature Retirement

The vast majority of adults with disabilities become disabled as adults, many while they are working. The response to this adult onset of disability generally comes through the state workers' compensation system or the private disability insurance system (car insurance, short-term and long-term disability insurance). Too often these systems emphasize compensation for the acquisition of a disability and retirement from the workforce. Retirement is sometimes inadvertently promoted by emphasizing the extent of an impairment and the residual dysfunction. There is rarely motivation to assess the individual's functional capacity and productivity with appropriate accommodations. There is little sustained long-term focus on returning to work or retaining the individual at work. As gatekeepers to most benefit-providing systems, medical doctors focus on medical assessments and documentation of disability. Little attention is given to long-term vocational assessments or accommodations that would enable employment. By focusing on the disability rather than the ability, our national disability policies and programs leave many employment opportunities unrealized.

Throughout the years, national employment policies and initiatives have often promoted full employment throughout the nation and offered training, job placement, reeducation programs, employment services, unemployment services, etc. People with disabilities have never been routinely considered as a potential part of the labor force and as part of large-scale training, education and employment initiatives for the general workforce. Disability is poorly understood and communicated in the nation's larger employment policy agenda. The implicit assumption is that people with disabilities are not expected to be part of the workforce.

Labor Market Trends

People with disabilities are disproportionately affected by labor market trends. While the labor force participation of men has declined steadily since the 1970s, the largest decline has been among disabled men aged 55–64 (Yelin 1993). Women's labor force participation has steadily increased since the 1970s; however, the increase has been less for women with disabilities than for women without disabilities (Yelin 1991). The level of full-time employment for workers without disabilities has remained relatively constant over the last several years, while it has decreased for workers with disabilities. Part-time employment has increased for both disabled and nondisabled workers, though it has increased more for workers with disabilities (Yelin and Katz 1994) .

Economic restructuring and the changing nature of work provide both opportunities and challenges for people with disabilities. The increasing use of telecommunication via fax machines and the Internet has led to more liberal work-at-home policies by employers and an increase in entrepreneurship and self-employment. Such developments hold promise for people with disabilities who are skilled and educated. They are appealing to people who find the rhythm of the traditional 9 to 5-work setting incompatible with their disability-related needs. However, such trends may also reduce job opportunities for less skilled workers (Lewin–VHI 1995).

Barriers and Disincentives to Work

The factors that contribute to the low employment rate for people with disabilities are many. Access to private health insurance is increasingly cited as the key obstacle to employment, particularly in light of the increase in part-time work, which rarely brings access to health insurance. With underwriting practices, preexisting-condition exclusions and limits on benefits acting as critical disincentives, many people with disabilities seek Social Security benefits in order to gain access to public health insurance. However, current discussions about revising Medicaid and Medicare may result in closing this route of access to public health insurance. As jobs become increasingly less secure, because of downsizing and merging trends, people with disabilities may find the relative security of benefits even more appealing.

Other barriers to work cited by people with disabilities include loss of benefits; disincentives to work in benefit programs; lack of access to personal assistance services; lack of access to assistive technology; inadequate education, work experience and vocational rehabilitation; inadequate transportation; inadequate housing; negative attitudes; inaccessible transportation, housing and work sites; discrimination; and lack of opportunities for career advancement (Braddock and Bachelder 1994).

Vocational Rehabilitation and Other Federal Employment Programs

The federal and state vocational rehabilitation program has been the government's key response to the employment of people with disabilities since 1920. Over the years smaller discretionary programs, such as supported employment and projects with industry, have been developed to further target employment for people with disabilities. The 1992 Amendments to the Rehabilitation Act required state vocational rehabilitation agencies to provide for the individual's choice of services and service providers; to focus on careers, not just entry-level jobs, and to presume that most individuals with disabilities are employable. Because resources are not sufficient to serve all who apply, priority is given to those with the most severe disabilities. In addition, states develop an order-of-selection priority, which determines who will be served in each state. With approximately $2.3 billion in federal funds, targeted employment services programs for working-age adults with disabilities serve about 1 million individuals per

year, placing about 200,000 per year in employment. Despite their successes, targeted employment programs for people with disabilities have never made a noticeable impact on the employment rate nationwide.

Generic employment and training programs in the DOL report that they serve thousands of people with disabilities every year through the Job Training Partnership Act, the Employment Services Office and veterans programs. Despite the fact that these programs are covered by the Americans with Disabilities Act (ADA), many people with disabilities report that they have difficulty accessing services through generic programs. They report that the services they need may not be available or accessible and that the programs do not see it as their role to serve people with disabilities.

The 1994 Lou Harris poll of 1000 people with disabilities reported that employed adults with disabilities were much more likely to have found their jobs through personal contacts than through structured services. Only 4 percent reported that special programs for people with disabilities had assisted them in finding employment, while 5 percent reported that generic employment services had assisted them in finding a job.

Supported Employment

The concept of supported employment emerged in the early 1980s as a response to dissatisfaction with the unemployment of people with developmental disabilities or their segregation in day activity programs and sheltered workshops with low or no wages. As evidence emerged about the capabilities of people with significant developmental disabilities to work and live successfully in the community, people with disabilities, their advocates and progressive policy makers developed a national initiative to promote jobs in the community with individualized support. After a decade of investment and implementation, over 110,000 people have had access to supported employment, with an annual federal investment of over $40 million (Mank in press). The majority of individuals with significant developmental disabilities remain placed in segregated facility-based sheltered workshops and adult day programs. Supported employment has often become an "add-on" to these services. The extended supports are not available to enable Social Security beneficiaries to use supported employment as a route to

leaving Social Security benefit rolls. Efforts to change systems in states have produced only modest local changes.

The Private Sector

Polls repeatedly indicate that employers support the employment of people with disabilities and experience people with disabilities as good employees. A 1995 poll of 300 chief executive officers and human resource managers in Fortune 5000 companies found that 73 percent of the top industries across the country are currently hiring people with disabilities. Most reported that ADA has had a positive impact on corporations; only 16 percent believed it has had a negative effect (President's Committee on Employment of People with Disabilities [PCEPD] 1995). Lou Harris and Associates surveyed employers in 1986 and again in 1995 and found strong support for ADA and the employment of people with disabilities. The employment antidiscrimination provisions of ADA apply to 666,000 businesses employing about 86 million people.

The percentage of companies reporting that they have made accommodations in the workplace increased from 51 percent to 81 percent between 1986 and 1995 (Lou Harris and Associates 1995). Furthermore, the costs of accommodations did not appear significant, with about half of employers saying costs increased a little between 1986 and 1995 and 32 percent reporting no increase. The Job Accommodation Network operated by PCEPD to assist employers in developing specific work accommodations has consistently reported that the majority of accommodations cost less than $500. One case study of Sears, Roebuck and Co. (Blanck 1994a) found that 97 percent of accommodations involved little or no cost.

Analysis of one national data set indicates that between one-fourth and one-third of workers who become impaired on the job are accommodated following onset of disability. Those who are accommodated at work are more likely to stay employed than those who are not. Most who continue to work after the onset of disability remain with their current employers. (Burkhauser, Butler and Kim 1994; Daly and Bound 1994).

Despite the positive attitudes of many employers and the effectiveness of job accommodations, many companies are still not hiring people with disabilities. Lou Harris and

Associates (1986, 1995) found that the percentage of companies that had hired people with disabilities within the last three years changed only slightly between 1986 and 1995—from 62 percent to 64 percent. The most commonly cited reason for not hiring people with disabilities, both in 1986 and 1995, was a lack of qualified applicants.

One incentive in the tax code intended to promote the employment of people with high levels of unemployment is the Targeted Jobs Tax Credit. Enacted in 1977 and renewed periodically since that time, the provision allows a credit to employers for hiring members of specific disadvantaged groups. People with disabilities are one of several targeted groups, representing a small portion of those hired under the credit (about 7 percent in 1987). No data are available about the impact of the credit on the employment rate of people with disabilities or on employers of people with disabilities.

Shortly after ADA was enacted, a disability access credit was enacted, amending the tax code to provide tax relief to small businesses that incur eligible costs in complying with the law. The credit was an addition to the Section 190 deduction, which has been available to businesses since 1976 for expenses incurred in removing barriers. No data are available about the use by employers or businesses of either of these tax code provisions (Schaffer 1991).

Key Legislation in the Past Decade

The Rehabilitation Act Amendments of 1986 (P.L. 99-506) amended the definition of "severe handicap" to include functional as well as categorical criteria and clarified that part-time work and supported employment are viable outcomes of rehabilitation services. States were required to plan for individuals making the transition from school to work.

The Americans with Disabilities Act of 1990 (P.L. 101-336) prohibits discrimination on the basis of disability in businesses with 15 or more employees. Qualified individuals with disabilities are protected by the law. Employers are required to provide reasonable accommodations so long as they do not impose an undue hardship on the business.

The Revenue Reconciliation Act of 1990 (P.L. 101-508) amends the tax code with an "access credit" intended to provide tax relief to small businesses that incur eligible costs when complying with ADA.

The Rehabilitation Act Amendments of 1992 (P.L. 102-569) require state vocational rehabilitation agencies to provide for the individual's choice of services and service providers; to focus on careers, not just entry-level jobs; and to presume that most individuals with disabilities are employable. Initiatives to ensure participation of minorities were authorized.

The Family and Medical Leave Act of 1993 (P.L. 103-3) allows workers to take up to 12 weeks of unpaid leave from work every year to care for newborn or adopted children, to care for family members with serious health conditions, or to recover from serious health conditions.

The Targeted Jobs Tax Credit (P.L. 74-271) allows employers to claim a credit equal to 40 percent of the first $6000 in wages of a person hired in a category of chronically unemployed workers. This credit has been intermittently renewed over the last decade, but has lapsed at the time this report is being written.

Recommendations

We know definitively that people with disabilities, including those with severe disabilities, can be effective workers and contribute to the economy. It is not the capacities of people with disabilities that limits their employment, but outdated attitudinal, organizational, societal and policy barriers.

General Employment Policy

1. The President, the Congress and federal agencies should ensure that all generic employment and labor policy and programs presume that people with disabilities are part of the American workforce.

As long as people with disabilities are viewed as outside of the labor force, they will never fully join the mainstream of American life. The appropriate role of all federal policy is to support people with disabilities in maximizing their employment.

Inclusion of People with Disabilities

2. The Congress and the President should ensure that all policy initiatives and programs having an impact on educational attainment and employment opportunities are designed and implemented to meet the needs and maximize the talents of all individuals, including those with disabilities.

Employment and training programs for people with disabilities should be integrated with employment and training programs for all other Americans. Accommodations and specialized services and supports should be provided as needed in the generic programs to people with disabilities. For example, direct communication access should be ensured for people who are deaf or hard of hearing. An overhaul of federal and state systems may be required to achieve a generic system that provides accommodations and access in order to successfully meet the needs of people with disabilities.

Employment Goals

3. The President should issue an executive order directing the Secretary of Labor to promote the employment of people with disabilities and to establish employment goals for people with disabilities to be reached by the year 2006.

Establishing national goals is an effective way to galvanize public attention, build broad support and provide a public mechanism for policy accountability. The nation has effectively used this process in campaigns to improve the health of the nation's citizenry and decrease infant mortality. The secretary of labor should work in conjunction with other relevant federal agencies and the disability community to establish employment goals.

Employment Statistics and Research

4. The President and the Congress should direct the Departments of Labor and Commerce, through the Bureau of Labor Statistics and the Bureau of the Census and in consultation with the chairman of PCEPD, to add people with disabilities as a group within the national labor force statistics reported monthly and to monitor reasons people with disabilities report for not working. This information should be available for types of

disability, state and local areas, and diverse cultural and racial groups. These statistics should be used to monitor progress toward the employment goals for people with disabilities established in the previous recommendation.

Availability of these data will enable public monitoring of progress toward meeting the employment goals. It will provide the same level of visibility for the employment rate of people with disabilities as that provided for other protected groups, such as women and ethnic and racial minorities, when their employment rates are reported. It will promote a public assumption that people with disabilities are part of the workforce.

5. The Department of Labor, in conjunction with the National Institute for Disability and Rehabilitation Research in the Department of Education, should establish research priorities consistent with achieving the targeted employment goals for the year 2006.

Labor Market Trends

6. The Secretary of Labor and the chairman of PCEPD, in conjunction with representatives from business, labor, people with disabilities and labor market economists, should assess our nation's efforts to employ people with disabilities in the context of current and future labor market trends, both nationally and locally, and should provide recommendations for maximizing the employment of people with disabilities by the year 2006.

Health Insurance

7. Congress should enact legislation ensuring that adequate health care and long-term supports—including personal assistance services and assistive technology—will be available to people with disabilities who are employed, are seeking employment or are changing jobs.

The most often cited barrier to employment for people with disabilities is lack of access to adequate health care. For many people with disabilities, the only route to secure health care is through cash benefit programs. If they work, they risk losing those cash benefits and the health insurance that accompanies them. The unavailability of long-term services, such as personal

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assistance services and assistive technology, is also an obstacle to achieving and maintaining employment. Furthermore, people with disabilities—even those who are highly educated with strong work histories—may find it difficult to secure jobs with salaries that are high enough to enable them to pay for the support services they require.

Enforcement of Civil Rights Laws

8. The President, executive agencies and the Congress should vigorously support full enforcement of ADA, the Rehabilitation Act and other federal civil rights laws, supporting this enforcement with adequate funding, culturally appropriate outreach and accessible technical assistance services.

Incentives for Employers

9. The Secretary of Labor, in conjunction with the chairman of PCEPD, should establish a working group of employers and people with disabilities to identify and expand meaningful financial incentives for employers to meet the needs of their employees with disabilities for workplace access, accommodations, and family support and to promote the use of existing incentives.

Many employers are unaware of or do not utilize existing incentives to employ people with disabilities, such as the disability access credit. In addition, employers have expressed a need for financial incentives to cover costs for employees with disabilities that may be beyond the bounds of the "reasonable accommodation" requirement.

Youth

10. The Secretary of Labor, the Secretary of Education and the Commissioner of Social Security should work together to ensure that generic policies and programs that target youth include youth with disabilities, sending the clear message that the goals for their adult lives are employment and independence, not lifetimes of dependence or support on benefits.

The importance of work and individual responsibility should be woven into the educational programs of youth with disabilities, including effective transition planning for students in special education and real work experiences in middle school and high school. The assumption should be that all students with disabilities have the capacity to work and should be given every opportunity to prepare for a lifetime of work.

Media Campaigns

11. The President and the Congress should provide funding for and direct federal agencies with employment and/or ADA enforcement responsibilities to initiate and carry out national, state and local media campaigns designed to change public attitudes to support the vision of inclusion, empowerment and independence set out in ADA, thereby promoting employment opportunities of people with disabilities.

Such a media campaign should be a part of the media campaign called for in recommendation 9 of the Civil Rights section of this report.

Employment of People with Significant Disabilities

12. The President and the Congress should ensure that people with significant disabilities, including those with developmental disabilities, are provided with opportunities and programs to support them in working in inclusive settings at real jobs for real wages.

Despite some progress in employing people with developmental disabilities in real jobs for real wages, many remain in sheltered workshops with sub-minimum wages and few options. Strategies such as supported employment have promoted competitive employment for people often overlooked by mainstream employers. More initiatives to ensure real jobs for people with the most significant disabilities need to be developed.

Entrepreneurship

13. The Congress and the President should develop and fund initiatives to promote innovative employment and entrepreneurship among people with disabilities.

Social Security and Other Income Maintenance

Dependency increases the costs of entitlements, lowers our gross national product, and reduces revenue to the Federal Government....People with disabilities want to work...to be productive, self-supporting and tax- paying participants in society.

Tony Coelho
Chairman, PCEPD
1990

Now, in the interlude between the baby boom and its echo, is the time for us to create constructive alternatives to people declaring themselves "unable to engage in substantial gainful activity." Now is the time for a new approach toward people with disabilities. Such an approach will help to alleviate the coming labor shortage, and it will do much to reduce the "disability crunch" that should arrive within a few years.

Edward Berkowitz and David Dean
May 9, 1989

The concept of income maintenance historically is one of providing income to individuals when they are unable to generate it themselves by working. Retirement because of age is the most common reason for the provision of income maintenance. Increasingly, people with disabilities have become recipients of income maintenance through both welfare and Social Security.

Social Security

At $63 billion annually, Social Security represents the Federal Government's largest expenditure on people with disabilities. When Medicaid and Medicare expenditures are added, the figure is over $120 billion.

Social Security manages two programs that provide income support (cash) to people with disabilities: Supplemental Security Income (SSI) and Social Security Disability Insurance (SSDI). Beneficiaries for both programs are those who are determined to be "too disabled to

work." Children are deemed eligible for SSI when they are determined to be substantially limited in their ability to function appropriately for their age. SSI is an income maintenance program serving poor people with disabilities. SSDI is a social insurance program available to those who have worked and contributed to the Social Security trust fund. Acceptance on the SSI rolls automatically confers Medicaid coverage in most states. Acceptance on the SSDI rolls automatically confers Medicare coverage after a two-year waiting period.

Both programs have expanded considerably in the last decade. From 1984 to 1994, the number of beneficiaries of the two programs combined has grown from 4.5 million to 8.5 million. Expenditures have increased from $25.3 billion to $54.9 billion. Despite this considerable federal expenditure, most people on the rolls live at or below the poverty level. The average SSI federal payment as of September 1995 was $334 per month. The average SSDI payment was $662 per month.

Most people with disabilities who become Social Security beneficiaries remain on the rolls for their entire lives. The younger an individual is who comes on the rolls, the longer she or he is likely to stay on the rolls. For example, a 9-year-old SSI beneficiary, on average, will stay on the rolls about 27 years. The percentage of young beneficiaries, those under the age of 30, has increased by 43 percent between 1989 and 1993.

A number of provisions have been enacted to promote the return to work of beneficiaries. These are outlined below. In addition, the Social Security Administration (SSA) reimburses state vocational rehabilitation agencies for the rehabilitation of SSI and SSDI beneficiaries. SSA is currently implementing a program to reimburse private providers for rehabilitation services to beneficiaries. While these incentives have yielded increased employment by those who utilize them, they have not been effective in enabling people to actually terminate their benefits and return to employment. Less than one-half of 1 percent of beneficiaries, or about 6000 people annually, leave the rolls to return to work as a result of rehabilitation efforts. This percentage has been consistent over the life of the programs.

Designed as a safety net for people who are terminally ill or too severely disabled to work, Social Security programs for people with disabilities have had the unintended effect of trapping people with disabilities in lifetimes of poverty.

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It is unlikely that any reforms within the Social Security system alone will be effective in yielding a significantly increased employment level for people with disabilities. Issues such as access to adequate health insurance and wages that are high enough to meet expenses need to be addressed.

The Social Security system is based on the notion that a person can be determined to be "too disabled to work." Evolution in knowledge, policy and practice in the last decade has challenged the concept of being "too disabled to work." We now know that individuals with severe disabilities can work if they have access to appropriate support services, accommodations and health care.

The Social Security system does not encourage people with disabilities to maximize their capabilities and competencies toward the achievement of independent living. While multiple work incentives have been enacted, their results are limited.

Other Income Maintenance Programs

The other key federal income maintenance program for people with disabilities is administered by the Department of Veterans Affairs. Veterans with disabilities receive about $18.6 billion in cash per year.

While there are substantial knowledge gaps regarding the number of recipients of Aid to Families with Dependent Children (AFDC) who have disabilities, there are studies that suggest that the prevalence of disability among heads and members of AFDC households is significant (Zill et al. 1991; Doyle et al. 1990; Adler 1993). One estimate found that over one in three AFDC households includes someone with a disability and almost 20 percent of women on AFDC have a disability (Adler 1993). The disability-related needs of these individuals are rarely identified or addressed by the programs that serve AFDC recipients.

Every state runs a workers' compensation program, whereby workers who become disabled as a result of an on-the-job injury receive compensation, usually in the form of cash. These programs have become quite costly over the last decade and reforms in many states are under way. In too many instances, support for a return to work is lacking.

The other major source of income maintenance is private long-term disability insurance, most often provided to employees through employers. Often employees who stop working because of an illness or disability begin drawing payments from their employers and eventually shift onto SSDI, either as a supplement or when private payments end.

Too frequently these systems provide incentives for people with disabilities to stop working when they are capable of continued work with additional supports or modifications. Because there is no well-established or well-funded system to provide supports to maximize employment and there is a well-established system for providing cash compensation, people with disabilities may have no choice except to leave the workforce and accept the cash.

Key Legislation in the Past Decade

Limiting Eligibility for Benefits

The Contract with America Advancement Act of 1996 (P.L. 104-121) prohibits the award of SSI, SSDI, Medicaid, and Medicare benefits to people who are disabled if drug addiction or alcoholism is a contributing factor material to the determination of disability.

Work Incentives

Since the early 1970s advocates and policy makers have worked to develop incentives for people on SSI and SSDI to work. Today a patchwork of over a dozen separate provisions operate with the goal of promoting employment. While many of these have been in place for longer than a decade, most have been amended and fine-tuned within the last decade in an ongoing effort to render them more effective.

Work Incentives for SSDI Beneficiaries

Trial Work Period. A beneficiary can work for nine months without losing benefits.

Extended Period of Eligibility. For 36 months following the trial work period, cash benefits are reinstated for any month in which earnings are below the substantial gainful activity level.

Substantial Gainful Activity. After the trial work period, a person can earn $500 ($880 for people who are blind) without losing any cash benefits.

Medicare Coverage. A beneficiary receives 39 months of hospital and medical insurance after the trial work period.

Medicare Buy-In. After the 39 months of premium-free Medicare, Medicare can be purchased at the same monthly cost paid by uninsured retired beneficiaries.

Work Incentives for SSI Beneficiaries

Section 1619(A) Benefit Offset. SSI beneficiaries working at or above the substantial gainful activity level receive an offset of $1 for every $2 earned.

Section 1619 (B) Continuation of Medicaid. Beneficiaries continue to receive Medicaid coverage when cash benefits are totally offset by earnings.

SSI Work Expenses for Blind Persons who Work. The portion of earnings spent by a blind person in order to work for transportation, taxes, special equipment, etc., is not counted in figuring SSI payments.

Plans for Achieving Self-Support. Beneficiaries can set aside income or resources for a period of time to meet expenses for reaching an occupational goal. The income or resources are not counted when determining the SSI payment amount.

Earned Income Exclusion. The first $65 of earnings in a month plus one half of the remainder is not counted when figuring SSI payments.

Student Earned Income Exclusion. A person under 22 who regularly attends school can exclude up to $400 in earnings per month (maximum of $1620 per year).

Work Incentives That Apply to Both SSI and SSDI

Impairment-Related Work Expenses. Beneficiaries can deduct the cost of certain impairment-related items or services needed to work (such as transportation or medical devices) from earnings.

Subsidy. The value of support a person receives on the job is deducted from earnings to determine if a person is engaged in substantial gainful activity.

Continued Payment Under a Vocational Rehabilitation Program. Beneficiaries who improve medically and are no longer considered disabled may continue to receive benefits if they are participating in any approved vocational rehabilitation program that will likely enable them to work permanently.

Recommendations

NCD concludes that the current set of policies and programs intended to provide economic security to individuals with disabilities is often a life preserver for people it serves. Cash benefits are the difference between sustenance and destitution for many recipients.

However, many features of the SSI and SSDI programs serve as obstacles to maximizing independence and self-sufficiency. Lack of access to health insurance and lack of flexibility supporting maximal employment often sentence people with significant disabilities to lifetimes of dependence. The current set of policies and programs too often functions more as a spiderweb than as a safety net, capturing people in poverty rather than supporting them to maximize their potential and their employment. The existing matrix of income maintenance and non-cash support programs is too complex, fragmented and punitive. These problems call for alternatives to reorient the program to assume and promote productivity, not dependence.

NCD envisions a system that serves as a trampoline, rather than a safety net, supporting people as they maximize their potential, catching them when they fall, and supporting their efforts toward independence again, always moving toward the goal of maximal employment. The system should function in a manner similar to our unemployment insurance system while addressing the unique needs of workers with disabilities who, due to the nature of their disability, may be unable to work continuously or at a consistent level of output. Key ingredients of this system include access to health insurance, tax credits to ensure that transitioning from benefits to employment does not produce financial disincentives, flexibility to accommodate disabilities that intermittently limit work capacity, and third parties with a vested interest in assisting people with disabilities in maximizing their employment.

Employment at the Core of Economic Security

1. The President and Congress should devise national policy that enables individuals with disabilities to develop economic security that is based on employment, not accessing benefits; and includes the supports, services and civil rights protections necessary to attain and maintain employment; and that decreases the dependency of people with disabilities.

For many people on benefits, Social Security represents their only opportunity for some degree of dignity while they are terminally ill. These individuals will never return to work. However, for the many who could work with appropriate support, both public and private income support programs must encourage work as the outcome of temporary benefits. Benefits must be constructed to provide on the path toward employment, not early retirement. The assumption that undergirds these programs should be one of productivity, not dependence. National policy should ensure that employment provides a genuine economic advantage over benefits. Currently, income maintenance policy may require a person with a disability to make a choice between a job and a personal attendant, between getting married and having health insurance, between having an income and enrolling in higher education. Economic security policy should always support maximal employment and independence and recognize investments in the future, such as higher education.

<u>Economic Support</u>

2. Congress should enact legislation, including amendments to the Social Security Act, that ensures a fundamental level of support for working-age adults with disabilities who are in economic need. This support should lead to employment as the desired outcome whenever possible. Key aspects of this legislation should include the following:

a) cash assistance at the poverty level that ends upon return to work but is immediately replaced by a Disabled Worker Tax Credit and a Personal Assistance Services Tax Credit, both of which are phased out as income rises;

This recommendation would be effective only if long-term services were available and if wages from employment are sufficient for self-support.

b) a de-linking of eligibility for cash benefits and other supports, including health insurance, personal assistance, housing subsidies and food stamps;

The de-linking of benefits will eliminate the current "cliff effect" that many people experience when they leave the Social Security rolls and simultaneously lose health insurance, long-term services (including personal assistance services), housing subsidies and food stamps. Such de-linking should not apply to the eligibility for Medicaid/Medicare that usually accompanies SSI/SSDI eligibility.

c) flexibility in the system so that people can be supported during intermittent periods when their disability may temporarily limit their ability to work;

d) health insurance coverage (including some long-term services) for individuals with disabilities who work or who return to work but who cannot obtain or afford health coverage;

e) supports and services, including housing, personal assistance services, assistive technology and vocational rehabilitation, that are necessary to ensure independent living and self-determination;

f) an accommodation fund that would pay for individual accommodations for Social Security beneficiaries that are beyond the reasonable accommodations required by ADA and that would enable these beneficiaries to leave the rolls and work.

g) service and support brokers to facilitate the attaining and maintaining of employment by individuals with disabilities who are capable of working;

A broker is a service coordinator whose job is to support the economic security and return-to-work efforts of people with disabilities. Brokers routinely provide information on employment options and supports to people with disabilities. These brokers could be private agencies run by people with disabilities;

h) maintenance of some cash support and full health insurance for those whose disabilities are so significant that they will not be able to support themselves by full-time employment.

This economic security package is intended to support independence and employment. Because many people leaving the Social Security rolls often take minimum-wage jobs, their

income from working is not sufficient to cover basic living expenses, in particular disability-related expenses that are covered by public health insurance. The Disabled Worker Tax Credit (which could function in a manner similar to the Earned Income Tax Credit), the Personal Assistance Services Tax Credit, and the continuation of health insurance are intended to ensure that working is economically more advantageous than cash benefits. Access to long-term support services based on need, not eligibility for cash assistance, is also intended to support employment and independence. The accommodation fund is intended to fund technological accommodations, such as expensive computer systems and lifts or hand controls on vehicles, that will enable employment. The use of a broker to support people with disabilities in their efforts to maximize independence and employment may take many forms. One possibility is to issue "tickets" to beneficiaries who may deposit their tickets with the broker of their choice, who, in turn, will be paid by Social Security or another funding source to assist the individual in finding and keeping a job.

Employment Retention

3) The Commissioner of Social Security, the Secretary of Labor, the Secretary of Education and the chairman of PCEPD should work with state and local governments, employers, organized labor and the disability community to initiate policies and programs and, if necessary, legislation amending programs such as workers' compensation to ensure prompt comprehensive intervention for workers who become injured or disabled while they are employed, with the goal of returning workers as quickly as possible to the workforce.

Most people with disabilities become disabled during their working years. The point at which a person becomes disabled is the point at which he or she is most vulnerable to long-term separation from employment. Too often workers' compensation systems, long-term private disability insurance and Social Security promote that separation rather than a return to work. Early intervention at the onset of disability can serve to prevent entry onto the long-term insurance rolls, including Social Security, and retain people in the workforce in a productive capacity as long as possible.

4) Congress should develop tax incentives for employers who hire people with disabilities who have been receiving SSI or SSDI for more than two years.

Health Insurance and Health Care

> *We have learned that our system of health care is not really committed to the concept of family, and further, is not really committed to the concept of health care for all. This system, instead, offers health care to some people, in some places, for some diagnoses, in some age groups, some of the time.*

<div align="right">

Abioses and Molly Cole, parents of
Mariyama, a child with a disability
Testimony before the National
Council on Disability
Hartford, Connecticut
June 17, 1991

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> *I am prepared to die for my country, but not for my insurance company.*

<div align="right">

Justin Dart, disability advocate

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People with disabilities have increasingly identified the lack of access to adequate health care and health insurance as a major obstacle to employment and independent living. Some progress has been made in challenging discriminatory practices under the Americans with Disabilities Act (ADA). People with disabilities participated actively in the health care reform debates of the early 1990s, securing provisions designed to meet their needs in both President Clinton's proposals and a number of bills introduced in Congress. The lack of significant progress in health care reform to date, the trend toward managed care and reforms proposed for Medicaid and Medicare, and the continued bias toward institutional, rather than community-based care, greatly concern people with disabilities and their families. (See NCD reports *Disability Perspectives and Recommendations on Proposals to Reform the Medicaid and Medicare Programs*, November 9, 1995 and *Sharing the Risk and Ensuring Independence: A*

Disability Perspective on Access to Health Insurance and Health-Related Services, March 4, 1993.)

All people are at risk of developing a disability at some time in their lives, from accident, injury, illness, or from the aging process itself. However, people are generally regarded by insurance companies as high risk, in terms of health care costs, when they become disabled or older or have a family history of disability. Our current health care system has increasingly sought to segregate those who are high health care users or potentially high health care users from those who are "low risk." Rather than spreading the risk equitably throughout the population, the current system has minimized the risk for some and made access to insurance virtually impossible for others.

Our health care system, which is designed to address acute rather than chronic health conditions, rarely provides for the long-term services and supports that are often needed by people with disabilities. In addition, little emphasis is placed on prevention and wellness in order to avoid more costly treatments in the future.

Access to Private and Public Health Insurance

As the cost of health care and health insurance has escalated, people with disabilities have found it increasingly difficult to meet their needs through private insurance. About 4.6 million people with disabilities of working age, or 15 percent of all working age people with disabilities, lack any health insurance (McNeil 1993), and millions more are not insured for preexisting conditions. People with disabilities are more likely to receive health care through public sector programs than people without disabilities. About 9.2 million people with disabilities receive Medicaid and/or Medicare, largely as a result of being on Supplemental Security Income (SSI) or Social Security Disability Insurance (SSDI). While the majority of people with disabilities have some private health insurance, few have adequate coverage that they can depend on to meet their health-related needs, due to preexisting-condition exclusions, minimal benefit packages and benefit caps. Durable medical equipment, assistive technology and personal assistance services are common needs of people with disabilities that are rarely fully covered by health insurance plans.

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Like people who are elderly, people with disabilities generally utilize more health care services than people without disabilities. For example, in 1993, 15 percent of Medicaid beneficiaries (those with disabilities) accounted for 39 percent of expenditures (NCD 1995). The significant expansion of Medicaid and Medicare has occurred to some extent because escalating restrictions from private insurers have increasingly pushed high-risk, high utilization people with disabilities into public sector programs. In addition, high health care costs and limited access to private health insurance encourage participation in the SSI and SSDI programs by people with disabilities in order to gain access to public health insurance.

While most people with disabilities have private health insurance, many receive it as a result of a family member's group policy through an employer. Working-age people with disabilities who are working full-time have the highest rate of private health insurance. Those who are working part-time are at considerable risk of being uninsured because they are likely to be ineligible both for an employer's group coverage and for public coverage, which is generally available only to those who are determined by Social Security to be "too disabled to work" (DeJong 1995).

Parents of children with disabilities are rarely secure in knowing that they will be able to provide for their children's health care needs. Private policies held by working parents may or may not cover children. When they do, annual caps and lifetime maximums may be met quickly. The complex array of public programs intended to assist parents is often overwhelming and baffling. High-risk pools established in some states may be very expensive and have long waiting lists. Parents may spend inordinate amounts of time trying to understand what is available and how to access it. They are often confronted with making guilt-inducing decisions requiring painful trade-offs between financial solvency, the needs of other family members and the health of the child with a disability. Some families have found themselves in the position of having to choose between relinquishing custody of their children to the state in order to become eligible for a program that would pay their child's medical bills and facing financial ruin from attempting to pay for the needed medical services themselves.

During the last decade, people with mental illness and their advocates have effectively articulated the need for parity in mental health coverage in health insurance policies. While little

policy progress is evident, the issue of parity has been well established as a part of the health care reform debate.

Health Insurance and Employment

People with disabilities frequently list the lack of access to adequate and affordable health insurance as a major barrier to employment. Discouraged by knowing that they are unlikely to have access to adequate health insurance through employers, they may eventually drop out of the labor market altogether. Private insurance market practices, such as preexisting-condition exclusions, limits on benefits and caps on payments present problems for people with disabilities. Public health insurance is generally available only to those who are not working, though there have been some legislative changes to provide incentives for those who go back to work after being on benefits to keep their health insurance. The increasing trend toward part-time work is also problematic, as part-time employment rarely brings access to health insurance.

Those who need personal assistance services and other long-term supports generally must pay for those services out of their own pockets when they are working. Medicaid is virtually the only source of reimbursement for long-term services and supports, and it is generally unavailable to those who are working. Virtually no private health insurance reimburses for long-term services such as personal assistance.

Discrimination and ADA

NCD's original draft of ADA in 1988 included an omnibus provision prohibiting discrimination in the provision of health insurance. This provision was subsequently significantly restricted so that practices such as preexisting condition exclusions and underwriting would not be affected. People with disabilities continue to face discrimination in obtaining health insurance and health care services.

ADA has been used by some to effectively challenge discriminatory practices in the provision of health care and health insurance. In the early 1990s the state of Oregon submitted a Medicaid waiver application to the Federal Government intended to redistribute Medicaid benefits in the state. The application was initially rejected on the grounds that it violated ADA.

People with disabilities have successfully used ADA to challenge caps on benefits specific to particular diseases, such as HIV/AIDS. Limitations on specific treatments for particular diagnoses have also been rejected as potential violations of ADA. For example, women with breast cancer have successfully challenged their exclusion from autologous bone marrow transplants by health insurance companies. Spouses and parents have prevailed in using ADA to secure health insurance through their employers for their husbands, wives and children with disabilities.

Managed Care

The past decade has ushered in an increasing trend toward the provision of health care in a managed care, rather than fee-for-service, delivery system. Although there are myriad types of managed care arrangements, managed care often provides access to health care services at a prepaid capitated rate of payment to providers. Managed care is increasingly being adopted in both the private and public sectors. Designed to stem the growing costs of health care, managed care has significant implications for people with disabilities.

Although some coordinated systems of care are effective in meeting the health care needs of people with disabilities and chronic illnesses, many managed care plans tend to underserve high users of care. Managed care is intended to save health care dollars by creating a network of providers who agree to provide all health services for a fixed per capita price known as a "capitation payment." Limiting access to specialty care through the use of primary care "gatekeeper" physicians is another managed care strategy intended to control costs. With a limited network of providers, consumers are restricted in their choice of doctor and other providers. Capitation arrangements provide incentives to underserve high users of care because these plans are designed to serve "average" patients who need health services infrequently. In addition, providers in the plan may benefit financially from restricting services to beneficiaries.

Thus, managed care generally creates incentives to underserve individuals who may require costly or frequent health care services. People with disabilities who need specialists may have a more difficult time accessing specialized services under managed care. Some have recommended that health plans and providers be "risk-adjusted," or compensated for the risk

profile of their subscribers, in order to minimize risk competition. In the absence of an adequate risk-adjustment methodology, others have suggested that people with disabilities and other higher-risk groups be "carved out" into separate managed care systems in order to reduce the incentive to underserve. The challenge for disability and health policy is to develop risk-neutral financing and service delivery systems that do not undermine the full participation and equal access principles of ADA while simultaneously meeting the ongoing health care needs of people with disabilities.

For people with disabilities and chronic illnesses, incentives built into managed care often run counter to effective rehabilitation, prevention of secondary disabilities and complications, and independent living. It is important to note that the savings generated from managed care are usually not reinvested in the plan to expand benefits or improve quality.

Some people with disabilities who have been treated by the same specialist for decades are finding that they must leave that specialist and seek a new provider because the fee-for-service plan they once used is no longer available through their employer. Whether or not they will have access to a specialist in a managed care plan is uncertain, and even if they do, they will have to start all over again with a doctor who does not know their history and may have little experience with their particular disability or chronic illness.

In acknowledgment of the potential shortcomings of managed care for consumers with disabilities and chronic illnesses, a number of bills have been introduced in Congress to establish federal consumer and provider protections.

Medicaid Reform

With the rising costs of the Medicaid program, dramatic proposals in the recent past have taken the form of block grants to states and caps on the federal contribution to this program. With over five million people with disabilities on Medicaid, many of whom receive long-term services and supports, these proposals are particularly troubling to the disability community. Some proposals even allow states to define who has a disability for eligibility in the program, with no federal standard. Proposals to grant states maximum flexibility in designing their own programs would allow states complete authority over the amount, duration and scope of benefits

provided. The funding formula under these proposals would severely restrict Medicaid service,

leading inevitably to decreased benefits for fewer people. Finally, important legal remedies

would be eliminated under some proposals, leading to limited recourse for consumers.

Medicare Reform

Proposals to dramatically scale back expenditures on the Medicare program have raised significant concerns about its future. Although Medicare covers approximately 35 million people over the age of 65, it also covers 4.2 million younger people with disabilities. Most people with disabilities have generally opposed efforts to dramatically reduce Medicare expenditures and are also concerned with proposals to shift large numbers of beneficiaries into private managed care plans. Of particular concern to people with disabilities is the outdated benefit package that Medicare offers its recipients, particularly in the areas of assistive technologies, home and community-based care, and proven complementary medicine. Many believe that the Medicare benefits package should be reviewed periodically to make it more consistent with contemporary health services and medical practice.

Cost Savings and Quality of Life

As the health care reform debate has proceeded in the last decade, some disturbing proposals and dialogue have emerged that greatly concern the disability community. Driven by escalating costs, the discussion has often been cast in the context of cost-effectiveness. Rationing proposals have raised questions about the value of the life of a person with a disability compared with the value of the life of a person without a disability. One commentator has characterized the public debate as posing the ethical question "Can we afford disabled people?" (Gallagher 1995). ADA answers this question by affirming that the lives of people with disabilities are as valuable as the lives of all other Americans.

The Oregon Medicaid waiver request raised such ethical questions. Central to the formulation of the original Oregon Medicaid waiver was a "quality of life" assessment that evaluated medical services in terms of their impact on the quality of life of those who received them. Depending on how such assessments are framed, they can relegate people with disabilities to lower quality-of-life status than those without disabilities. Such assessments can result in the denial of health-related services to people with disabilities on the grounds that these services will not necessarily improve their quality of life, that is, "cure" or significantly lessen their disability.

The challenge for disability policy is to develop cost-effectiveness criteria that do not put people with disabilities at a disadvantage in resource allocation or health care decision making.

Key Legislation in the Past Decade

The Americans with Disabilities Act of 1990 (P.L. 101-336). This broad antidiscrimination legislation includes a prohibition against discrimination in the terms and conditions of employment, including health insurance. Thus, if a person with a disability is hired, he or she must have equal access to the health insurance provided by the employer to other employees. Refusing to hire a person with a disability because of concerns about health insurance costs is prohibited; however, medical underwriting is specifically permitted. ADA requires the provision of auxiliary aids and services in public accommodations, including offices of health services providers.

Medicaid amendments. Numerous amendments to the Medicaid program over the last decade have promoted increased community-based services for people with disabilities, such as personal assistance, case management, supported employment and psychiatric rehabilitation.

Social Security work incentives. People with disabilities leaving the SSI and SSDI rolls may continue to participate in Medicaid or Medicare indefinitely under certain conditions.

Recommendations

The lack of access to health insurance for people with disabilities is one of the most significant contributors to the low employment rate and the dependence of people with disabilities. In order to truly achieve independence and meet the goals of ADA, significant health policy reforms are necessary throughout the next decade.

Recent trends in publicly subsidized and privately funded health care programs in this country are of great concern to people with disabilities. The existing health care system disproportionately and negatively affects users of frequent or specialized health services. Health care continues to be strictly defined in medical terms without regard to the importance of enhancing function and independence. Some allege that the corporatization and consolidation of medicine diverts vital resources away from broader coverage and comprehensive benefits and

toward investors' portfolios. The strong federal role in publicly subsidized health programs is increasingly being ceded to the states and the private market. Long-entrenched systemic biases continue to encourage congregate-care nursing home settings as the first option rather than the last resort. Rather than reforming the system to ensure the cross-subsidization necessary to provide appropriate health services to any individual in need, proposals are directed toward further segmentation of the market based on health risks.

Health Care as a Right

1. Congress should enact legislation that establishes health care as a right of all Americans without regard to a person's health, functional status or sociodemographic factors (e.g., age, race, employment, income).

Health care should be a right of all Americans and everyone should be able to access the health services they need when they need them. The success of such a system should be measured by a set of principles including accessibility, affordability, continuity, appropriateness, quality (based on outcomes), consumer control, comprehensiveness and equity.

Total Coverage by the Year 2006

2. In addition to limiting preexisting condition exclusions and improving portability and renewability of private insurance coverage, Congress should address the next series of health reforms designed to achieve a consumer-driven, risk-neutral health care system that covers everyone by 2006.

The calls for incrementalism heard during the defeat of comprehensive health system reform should now fuel a series of federal laws designed to achieve a health care system that spreads risk, is driven by consumers of health services and covers everyone. The next series of private insurance reforms should include community rating and limitations on premium increases, open enrollment mechanisms, a standard benefit package (to facilitate health plan comparisons), the elimination of lifetime aggregate insurance caps, meaningful choice of at least three health plans, portability in the individual private insurance market, the establishment of federal standards under plans that are subject to the Employment Retirement Income Security Act

(ERISA), and a sliding scale based on income for premiums and copayments. Medical savings accounts should not be pursued, as they encourage segmentation of the health insurance market based on risk.

Consumer Driven System

3. Congress should ensure that all health care reforms and changes, in both the private and public sectors, make health care more consumer driven and include the following features:

> **a) adequate consumer information to empower consumers to make informed decisions when choosing a health plan or provider;**
> **b) quality standards (e.g., health care report cards) that are developed in collaboration with people with disabilities and are responsive to the clinical and information needs of consumers with disabilities;**
> **c) adequate appeals and grievance processes to enable consumers to challenge health plans and health provider decisions, including arbitration mechanisms, ombudsmen independent of health plans, and private rights of action;**
> **d) consumer governance in which consumers and purchasers, not providers and payers, dominate the governing of the health care system through purchasing cooperatives and various oversight mechanisms.**

Managed Care

4. Congress should maintain a strong federal role in setting standards and monitoring compliance of Medicare- and Medicaid-sponsored managed care health plans. In the market-baseg system of managed care, Congress should establish a framework that will ensure a more risk-neutral, consumer-driven managed care system that does not underserve people with frequent or specialized health needs and allows consumers to choose from a range of options.

A strong federal role in standard setting and monitoring of managed care will ensure that health plans compete on price and quality, not on price and risk. All Medicare and Medicaid

beneficiaries should be given a choice of at least three viable health plans rather than being mandatorily assigned to a managed care plan. Each managed care plan that serves Medicare and Medicaid beneficiaries should be required to conduct an individual needs assessment at the time of enrollment. Such information must be acquired with the consent of the beneficiary and must remain confidential.

All managed care plans, including those that service only privately insured persons, should be required to meet federal standards to ensure access to specialty care, adequate grievance and appeals procedures including ombudspersons, and equitable utilization review criteria. Financing mechanisms should be studied (in a timely manner) to discourage underservice in all managed care plans, particularly capitated systems of care. These mechanisms may take the form of risk adjustments and other targeted approaches.

Antidiscrimination

5. The Department of Justice (DOJ) should develop regulations for ADA and the Rehabilitation Act of 1973 that clarify how disability discrimination laws apply to private health insurance companies and health plans as public accommodations (ADA Title III), instrumentalities of state and local governments (ADA Title II), federal contractors (Rehabilitation Act Section 503), and recipients of federal funds (Rehabilitation Act Section 504).

Many people believe that private health insurance companies and health plans should be considered places of public accommodation and therefore subject to Title III of ADA. Private health plans that perform the quasi-state function of servicing Medicaid beneficiaries should be required to meet the standards of Title II of ADA which applies to state and local governments. Private health plans that service Medicaid and Medicare patients should also be required to meet the nondiscrimination provisions of Sections 503 and 504 of the Rehabilitation Act of 1973, which apply to federal contractors and recipients of federal funds. NCD should establish an advisory committee to work with the DOJ to consider these issues and promulgate regulations clarifying the application of Titles II and III of ADA and Sections 503 and 504 of the Rehabilitation Act to private health insurance companies and health plans.

Medicare

6. Congress should reinvest in Medicare by periodically reviewing the benefit package to provide benefits (particularly assistive technologies) that accurately reflect contemporary health and medical practice and expand coverage to people with disabilities by removing work disincentives.

Although over four million people with disabilities below the age of 65 receive their health care through the Medicare program, the benefit package has been designed for the acute health care needs of senior citizens. In addition, the package of benefits provided by Medicare was established many years ago and has evolved slowly, while medical science, health interventions, and independent living have evolved dramatically during the same period. Despite attempts to address the work disincentives that are inherent in the program, many people with disabilities are not returning to the workforce for fear of losing indispensable health benefits through Medicare. Rather than cutting funding for Medicare over the next several years, Congress should reinvest in the program by updating the benefit package to more accurately reflect the health needs of people with disabilities, particularly in the areas of assistive technology and complementary medicine that has proven to be effective. Resources should also be reinvested in the Medicare program to eliminate work disincentives.

Medicaid

7. Congress should maintain the individual federal entitlement to Medicaid services and refrain from decreasing funding for this vital program for people with disabilities. If the states are to assume more control of the Medicaid program, a federal definition of "disability" and a federal private right of action should be maintained. Medicaid's institutional bias should be transformed into a presumption that long-term services and supports should be provided in the home and community.

Reforms that significantly transform the current Medicaid program with the goal of reducing Medicaid expenditures are most threatening to the large number of Americans with severe disabilities. Vastly increasing state control over the Medicaid program without adequate federal oversight and monitoring could be disastrous to many Medicaid recipients. Effective

reforms of the Medicaid program can be accomplished without eliminating the underpinnings of the program. Congress should not eliminate the individual federal entitlement to Medicaid and should not seek to reduce funding for this program. The Federal Government should maintain a strong role in standard setting and monitoring to ensure state compliance with quality and effective health care service delivery. "Disability" should be defined at the federal level and a private right of action should be maintained in federal court to provide states with an incentive to meet the health needs and long-term services needs of people with disabilities. Long-term services and support should be provided in the home and community, with congregate-care settings as the last resort.

Redefining "Medical Necessity"

8. The term "medical necessity" should be clarified to include the concept of maintaining and improving the functional capacity of the individual, taking into account consumer choice, consumer lifestyle, and the long-term cost-effectiveness of the intervention or equipment under consideration. Specifically:

a) Long-term cost-effectiveness should be evaluated from a societal perspective, not from a health plan perspective, since health plans are prone to evaluate need and outcomes using a more limited time horizon (e.g., time remaining in current enrollment period) and a more narrow range of cost considerations.

To facilitate the assessment of long-term cost-effectiveness, the Federal Government should support efforts to develop standardized data collection protocols that can be applied across various impairment groups.

b) Interventions designed to maintain function should include interventions that will slow functional losses among people with progressive conditions.

c) In individual instances, medical necessity should be determined by persons who are knowledgeable about the needs of people with disabilities in consultation with the person with a disability or that person's.

d) In determining medical necessity, health plans should also consider the impact of their decision on the safety and well-being of unpaid caregivers such as family

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members who may be called upon to assist a family member with functional limitations.

e) People with disabilities should be afforded an appeal and grievance process that will enable them to challenge decisions based on medical necessity.

f) A strong federal role, as opposed to a strong state role, in defining medical necessity is needed because self-insured organizations are exempt from state regulation under ERISA. Federal leadership is needed in establishing the scientific evidence and establishing consensus with regard to controversial interventions and therapies where clear scientific evidence may be limited.

Demonstration Projects

9. Congress should authorize and fund demonstration projects to test a variety of model primary care, fitness and wellness strategies for people with disabilities, including those from minority and low-income groups, that can be replicated in a variety of settings.

Demonstration projects should engage the participation of medical rehabilitation providers, primary care providers, sports medicine providers, health clubs and fitness centers, providers of nontraditional complementary medicine, independent living centers, and other provider and consumer entities knowledgeable about the health care needs of people with disabilities.

Public Health

10. Congress should establish a focal point of leadership within the Federal Government to define, implement and coordinate a public health agenda for individuals with disabilities.

Such an agenda should promote access for people with disabilities to mainstream public health services such as health education, nutrition counseling, and smoking cessation programs and should develop and implement targeted public health efforts to address the specific health concerns of people with disabilities, including those from minority and low-income groups. Prevention of secondary disabilities should be a component of the agenda, as well as primary prevention that does not demean or devalue people with disabilities. The promotion of clean air

and use of nontoxic substances (such as industrial cleaners) in public places is of particular concern to people with multiple chemical sensitivities and should be addressed within the public health agenda.

<u>**Research**</u>

11. Congress should fund a comprehensive research program on the efficacy of health services, health service delivery, and financing issues facing people with disabilities, including those related to the development of a more consumer-driven health care system.

The research program should evaluate various capitation and risk-sharing schemes and how they shape health plan and health provider behavior and the health outcomes of people with disabilities. It should develop quality indicators that are responsive to the clinical and information needs of consumers with disabilities seeking to make informed health plan and health provider choices. The efficacy of managed care approaches that are targeted to people with specific impairments or chronic health conditions should be studied. The development of risk adjusters that can be used to adjust health insurance premiums, provider payments, and quality of outcomes to more accurately reflect the clinical needs of enrollees with disabilities should be considered.

The incidence, prevalence, prevention and medical management of secondary health conditions among people with disabilities should be researched. New and existing interventions and strategies to meet the health care needs of people with disabilities should be studied in terms of their efficacy and cost-effectiveness. Practice guidelines that address the ongoing health care needs of people with disabilities should be developed. Prevention and health service delivery strategies targeted to minority and low-income people with disabilities should be developed. Model programs directed to meeting the primary and ongoing health care needs of people with disabilities should be evaluated and assessed for replicability. A health services research capacity that responds to the health care issues of people with disabilities should be developed.

Issues related to genetic screening should also be a part of the research agenda. The ethical implications and quandaries presented by new knowledge in genetic screening should be

examined. The interface of genetic testing practices with antidiscrimination law and access to health insurance for people with disabilities should also be studied.

<u>**Education and Training**</u>

12. The Federal Government and the private sector should develop and implement education and training programs that will sensitize health care providers to the ongoing health care needs of people with disabilities, with the federal and state governments awarding grants to help develop such model educational programs.

Such training should provide a better understanding about the independent living needs and self-determination aspirations of people with disabilities in order to minimize misinformation, stereotyping and ignorance about disability. The training should be largely the responsibility of medical schools, health professional schools, professional and trade organizations, and health care providers. A knowledge and understanding of disability-related issues should be required for professional licensure and certification and for provider accreditation.

13. The Federal Government and state governments should provide training grants to consumer organizations, health care institutions and educational organizations designed to enable people with disabilities to become more informed consumers of health plans.

Such training should include ways to avert and manage secondary health conditions, ways to make the most effective use of health care services in a managed health care plan, ways to obtain and use price and quality information in choosing a health care plan when such information becomes available, and graduate level training that will enable people with disabilities to become health service researchers and assume leadership roles on health policy issues that affect their lives.

Long-term Services in the Community

...true freedom of expression...is about power, to make clear our wants and opinions...to...control our health and well-being...to lead a lifestyle of our own choice and direction....The simple fact of the matter, however, is that millions

of Americans with varying disabilities of all ages still lack this fundamental

human power. Not because of their disabilities. But because they lack access to

personal assistance, assistive technology and other ongoing supports....

Bob Williams
1994

I was sitting here crying, remembering when I was a little teeny baby here

in Dorm K. Now I'm happy Brandon Training School is closing for good. I miss

some of the people from here and I'm happy to see them. But I don't want to be

back here. I don't ever want anyone to live here again—not even prisoners.

Cameron, a former resident of Brandon
Training School
(In Smith and Gettings 1994 p. 7)

I was in a nursing home for 13 years. I had to fight to get out. It was the

beginning of my life at 22.

Claude Holcomb
ADAPT Activist

People with disabilities often need long-term supports and services in order to live independently. Long-term services include personal assistance services to assist people with activities of daily living, readers for individuals who are blind, interpreters for people who are deaf, habilitation, rehabilitation, assistive technology support and supported employment services. Historically, many people with disabilities, particularly those with mental retardation or mental illness, could access long-term services only if they lived in institutional settings. Many people lived, and continue to live, away from their families and communities in institutions and nursing homes because the community-based long-term services they needed were not available to them. NCD believes, and the Americans with Disabilities Act (ADA) affirms, that every individual with a disability should live in the community of his or her choice as a participating member of society.

There is no nationally organized community-based system of long-term services for people with disabilities. An individual who needs long-term services must pursue them through

a complex, confusing and uncoordinated series of agencies and funding sources. Most frequently the services are provided as a part of medical services. Sometimes services are provided as a part of a supported living setting. In both cases, the services may be restrictive, failing to meet the full independent living needs of the consumer. Increasingly, consumers are advocating for community services that address a range of disabilities including mental illness, mental retardation and physical impairments.

Current Status of Long-term Services

Approximately 12.7 million people need long-term services. Of these, 2.4 million live in institutions such as nursing homes and intermediate care facilities for the mentally retarded. The majority of people who need long-term services are over age 65; however, 2 percent are children and 40 percent are working-age adults (American Association of Retired Persons [AARP] 1995). In 1991 America spent about $59.9 billion on nursing home care and $9.8 billion on home health care services. Medicaid paid $28.4 billion and Medicare paid $2.7 billion of the nursing home bill. Public funding for home health services, including Medicaid, Medicare and local governments, accounted for $7.1 billion of the home health care expenditure (AARP 1994).

People with disabilities have actively pursued the establishment of a national long-term services system, calling for the redirection of funds from nursing homes and institutions to community-based services. Disability organizations drafted personal assistance services legislation and actively participated in the health care reform debates of the early 1990s, crafting long-term services provisions that were included in both President Clinton's proposals and congressional proposals. Pressure to expand community-based services is likely to continue as people with disabilities increasingly move out of institutions into the community.

Current proposals to eliminate the federal entitlement to Medicaid threaten the major source of funding for community-based long-term services for approximately two million recipients with disabilities. Devolution of responsibility for Medicaid to states from the Federal Government is of great concern to people with disabilities who rely on Medicaid as the major source of funding for long-term services.

Personal Assistance Services

People who need personal assistance services have substantially lower personal incomes and are less likely to be employed than the general population. There is no private insurance coverage for long-term personal assistance services. Among personal assistance services users living in the community, 10 percent use paid services only; 11 percent use both paid and volunteer services; and 79 percent use volunteer or informal services only (World Institute on Disability and Rutgers University Bureau of Economic Research 1990).

A 1987 survey of attendant services in the United States concluded that such services are "fragmented, lack coordination, are usually medically oriented and burdened with work disincentives, are inequitably distributed across the United States and are most often delivered by personal assistants who are poorly paid" (Litvak, Heumann and Zukas 1987). Approximately two million people received some or all personal assistance services from public programs in 1988, with Medicaid and the Social Service block grants serving as the key federal sources of funding. Some personal assistance services programs are solely state funded (Litvak 1991a).

The Personal Care Option under Medicaid was used by 23 states in 1988 to provide personal assistance services. These programs have been criticized for being overly expensive, medically oriented, not allowing personal assistance services outside the home and allowing little consumer control or management of services (Litvak 1991a). However, Medicaid is the main funding source for long-term services for people with disabilities. NCD is concerned about proposals currently under consideration that might eliminate or curtail the federal Medicaid entitlement. Under current proposals, states may or may not choose to provide long-term community-based services to people with disabilities. Without Medicaid's support for long-term community-based services, people with disabilities would be at risk for institutionalization.

Deinstitutionalization

For the first time in history, more Americans with developmental disabilities (mental retardation and other significant impairments that require extended and multiple services) live in publicly supported community residences than in publicly supported congregate-care institutional settings. The institutional census peaked at 195,000 in 1967 and has diminished steadily since

that time. Between 1988 and 1992, the population in institutions dropped from 91,000 to 78,000.

Of the 347,000 individuals with developmental disabilities living in residential settings lived in

1992, 52 percent lived in settings with 15 or fewer residents. By contrast, in 1977 only 14

percent of people with developmental disabilities who lived in residential settings lived in

settings with 15 or fewer residents (Braddock et al. 1995). The number of individuals with

mental retardation residing in nursing homes has also declined, from 50,000 to 41,000, between

1988 and 1992 (Braddock et al. 1995).

Large institutions around the country began closing in the 1980s. A 1995 study

determined that 94 institutions were scheduled to close or had closed in 29 states (Braddock et al.

1995). Since 1992 three states (New Hampshire, Vermont and Rhode Island) and the District of

Columbia have completed closure of all institutions. The declining census, in conjunction with a

leveling budget, has caused escalating per diems in institutions. Between 1988 and 1992 per

diems rose from $154 to $212, ranging in various states from $124 to $435 (Braddock et al.

1995).

In 1989, for the first time in the nation's history, the amount of public funds supporting

people with developmental disabilities in community settings exceeded the amount of funds

allocated for institutions and other settings with 16 more beds. In 1992, 57 percent of funding

was supporting individuals in community settings with 15 or fewer beds (Braddock et al. 1995).

Historically, the primary source of federal funding for services for people with

developmental disabilities has been the Medicaid Intermediate Care Facilities for People with

Mental Retardation (ICF/MR) program. Because the program has been so heavily biased toward

institutional care, advocates urged Congress to enact a Home and Community-based Waiver

(HCBW) provision in 1981. This provision allows states to redirect institutional funds to

community programming. Participation in the program has increased steadily since 1981; 49

states currently participate. In 1995, for the first time, more individuals with developmental

disabilities will be served under the HCBW (approximately 155,000) than under the ICF/MR

program (Smith and Gettings 1994).

In 1990, Medicaid amendments were adopted that authorized Community supported

living arrangements, promoting individualized support services for people with developmental

disabilities as they designed their own living situations. Eight pilot states participated in this program, serving about 3500 individuals; state and federal expenditures were projected to be $60 million by the end of the program (Prouty and Lakin 1995). Almost 75 percent of participants were supported living in their own homes. As the program terminated in the fall of 1995, it left an important legacy in most states, having planted "seeds" of supported living through out the country. These seeds will likely promote supported living approaches throughout the state service system (Braddock et al. 1995).

Since the 1960s, people with mental illness have increasingly left institutional settings. However, the funding has rarely followed them to support community services. Many people who once resided in institutions have become homeless. The results of the deinstitutionalization movement are controversial, with some organizations calling for easier access to hospital-based treatment.

Despite the substantial progress, challenges remain. Thousands of individuals continue to live in large institutions and nursing homes when they could live in smaller community settings. Too many people with mental illness remain unserved or underserved in the community. States vary dramatically in their use of institutional services and in the amount of money they spend on alternative services.

Key Legislation in the Past Decade

The Medicaid Home and Community-based Waiver Program, Section 1915 (c) of the Social Security Act of 1981 (amended in 1986, 1987, 1988 and 1990), enables states to target a population of long-term care recipients to receive home and community-based alternatives to institutional care.

The Older Americans Act Amendments of 1987 (P.L. 100-175) authorize funds for state and community programs including nonmedical in-home services for the frail elderly such as homemaker and home health aides, chore services, in-home respite care, adult day care and minor modifications of homes (not to exceed $150 per person).

The 1990 Medicaid Amendment authorizing Community Supported Living Arrangements (P.L. 101-508) stresses individualized support rather than the standardized services common to the ICF/MR program.

Recommendations

While there has been considerable progress in deinstitutionalization, much remains to be done to build an effective long-term services system in the community. Ongoing biases toward providing services in institutional settings inhibit the continued development of such a system. People with disabilities continue to face a complex maze of fragmented services that are inconsistent from one locality to another and are too often directed by agencies rather than by people with disabilities who are using the services. NCD's recommendations provide the framework for a new system, a mechanism for its financing and a transition strategy for achieving it.

National Long-Term Services and Supports Policy

1. Congress should enact legislation that establishes a national long-term services and supports policy and unifies existing fragmented funding and services to establish a Long-Term Services System. The new system should be consumer driven, provide a range of home and community-based services, offer personal assistance services as the core service, and provide both ongoing and episodic basis services. The legislation should include the following elements:

a) a reversal of the institutional bias in Titles XVIII and XIX of the Social Security Act (Medicaid) so that home and community are the expected service settings and institutions are the last resort;

b) personal assistance services grounded in the values of consumer choice, consumer direction, and community participation, accommodating needs that change over time;

c) mechanisms to ensure access to long-term services by those who, because of their disabilities, are unable to make their own decisions;

d) consumer direction in selecting, managing, training and dismissing personal assistance services workers regardless of the employer of record;

e) amendments to the tax code that promote maximum consumer direction in personal assistance services;

f) a range of management and payment models including direct pay, vouchers and consumer-directed agency provision;

g) elimination of legal and regulatory barriers to the maintenance of dignity and independence of people with significant disabilities, including inappropriate medicalization of routine procedures;

h) funding of demonstration projects that test innovative approaches that honor the intent and spirit of ADA;

i) elimination of legal and regulatory barriers to the provision of functional supports that promote independence and inclusion;

j) establishment of a functional needs assessment instrument that assesses the person's functional capabilities in relation to the support in his or her living environment in order to determine the level of need for personal assistance services;

Individual need must take into account the individual's's environment. For example, a person with quadriplegia who lives in an accessible house, has appropriate assistive technology, including a lift-equipped van which the individual drives, and has a support system of family and friends is likely to have fewer personal assistance needs than a person with less significant disabilities who lives in an inaccessible house, has no assistive technology, does not drive and has no informal or family support system in place.

k) a study of how long-term community services might be demedicalized, directed by the Secretary of Health and Human Services (HHS) with the participation of people with disabilities and national medical and allied health organizations such as the American Medical Association and the American Nursing Association;

l) a requirement for consumer-directed oversight of a services system plan submitted to HHS by states that involves consumer participation in the development of the plan; a record of consumer comments, consumer participation in the design and evaluation of services; the rights of consumers to sign off on, refuse or approve a plan of services and ongoing assessment of the performance and efficiency of administering agencies;

m) ongoing training of consumers and providers that promotes meaningful consumer direction and evaluation.

Financing

2. Congress should amend the current Medicaid law and other relevant laws to establish a priority for home and community services and to establish that, for all Medicaid and other public funds, institutions are the placement of last resort. Provisions in the legislation should include

a) a combination of funds for institutional and community services;

b) an attachment of funding to individuals rather than providers so that the funds follow the person, not the service or the setting;

c) empowerment of people with disabilities and their families to decide how funds are allocated across available services;

d) assurances that providers of personal assistance services will receive wages and benefits commensurate with jobs of comparable skill and effort in the community;

e) the establishment of a task force to continue to study the financing of long-term services, which must include a majority of people with disabilities who use long-term services.

<u>The Federal Role and the State Role</u>

3. Congress should ensure that the federal role and the state role are clearly delineated in the provision of long-term services and supports. The federal role should include

> **a) integrating fragmented programs and funding streams into one organizational structure;**
>
> **b) defining eligibility and basic scope of services with guidelines for implementation within one year;**
>
> **c) appointing a consumer/user group to codevelop definitions of eligibility and scope of services.**
>
> **The state role should include**
>
> **a) mirroring the federal structure of integrating funding streams and programs;**
>
> **b) developing a state plan of action with significant participation by users of long-term services;**
>
> **c) reporting regularly on compliance with eligibility guidelines and scope of services;**
>
> **d) ensuring that users have the right to decide on services and who provides them;**
>
> **e) developing guidelines for consumer and worker protection;**
>
> **f) developing administrative procedures.**

<u>Transition to New Long-Term Services and Supports Policy System</u>

4. Congress should mandate a transition team in each state to ensure a smooth transition from an institutional/medical model to a home- and community-based consumer-directed model. These teams should

> **a) play an active role in developing policy for new systems, reporting to state and federal policy makers and monitoring any pilot programs;**
>
> **b) coordinate and integrate efforts with existing Developmental Disabilities Planning Councils and Statewide Independent Living Councils;**
>
> **c) consist of members appointed by the governor for five years, with a composition of 51 percent users of long-term services or representatives of such individuals,**

reflecting the minority and urban/rural demographics of the population, including Native Americans; representatives from the lead state Medicaid agency; representatives from the state department of labor; representatives from the nonprofit community; representatives from Statewide Independent Living Councils; representatives from organizations representing older Americans such as the American Association of Retired Persons; members of both legislative bodies from both political parties; and one team member who attends a national body that monitors activities and innovation in all states;

d) maintain a central registry on current pilot programs, including complaints and positive feedback;

e) develop policy guidelines to be used by state agencies, providers, health maintenance organizations and managed care organizations;

f) develop a time line for deinstitutionalization in the first year and monitor its implementation;

g) work with the state department of labor and JOBS programs to develop personal assistance services worker capacity;

h) develop draft regulations for both a direct pay/voucher model and a consumer-directed agency model;

i) determine whether individuals will use vouchers or agencies and ensure that resource allocations are based on these determinations;

k) holding statewide hearings to gather input from the broad cross-disability community.

Demedicalization of Services

5. Congress should direct the Secretary of HHS to develop a national policy which recognizes that disability does not necessarily connote illness or incompetence or the need for medically controlled services.

In the case of people with psychiatric disabilities, generic community services (e.g., housing, vocational training) should not be linked to compliance with "treatment plans." Personal freedom should be the benchmark of all community programs.

This policy must distinguish between acute and chronic conditions and recognize that acute needs for some are chronic conditions for others that should be approached as activities of daily living. Nonmedical assistants can and should perform many procedures that are currently considered to be medical and thus are allowed to be performed only by medical professionals. Laws in many states, such as nursing practice laws, prohibit the performance of many procedures by laypersons, thus unnecessarily increasing the costs of personal assistance services. Such laws will need to be amended.

Research and Data Collection

6. Congress should direct the National Institute on Disability and Rehabilitation Research and other relevant research and data collection agencies to establish a research agenda and data collection efforts with the following features:

a) a focus on priorities and perspectives of people with disabilities, including those who are consumers of the services being studied;

b) use designs and methodologies that include people with disabilities in all aspects of the research and data collection processes, such as participatory action research;

c) a focus on data related to the interaction between the individual with a disability and the individual's particular environment, including data on the person's physical, mental and emotional levels of functioning,;

d) a focus on data related to consumer satisfaction;

e) a focus on understanding the effects of racial, ethnic and gender characteristics in relation to various service models;

f) a focus on family structures, living arrangements and isolation as these factors relate to functional needs;

g) a study of the impact of gender inequities in long-term services in the public and private sectors;

h) use of longitudinal studies;

i) an emphasis on cross-disability issues, functional issues and environmental issues as they relate to the need for personal assistance services.

Technology

The disability access provisions in the Telecommunications Act of 1996 mark a high point in legislative advocacy for the disabled community....Universal design enhances the marketability of a new product or service.

Deborah Kaplan
1995

If we rely solely on market forces to drive the communications revolution, then people with disabilities will be disenfranchised in the communications revolution. Americans with disabilities then would be denied the basic tools necessary in the Information Age to get an education, to get a job, to share in our cultural experience, to be part of politics, to communicate.

Reed E. Hundt, Chairman
Federal Communications Commission
June 28, 1995

All Americans regularly and increasingly rely on technology to enhance functioning and to perform routine tasks. From eyeglasses to telephones to remote controls for televisions, the daily lives of Americans are significantly shaped by technological innovation. Over time, as the novel becomes the ordinary, the provision and cost of such technology becomes standard fare in American business and culture. Historically, technological progress has yielded both benefits and barriers for people with disabilities. Developed in an effort to enhance communication for people who are deaf, the telephone ironically served to isolate people who are deaf for many decades. To the extent that technological innovation proceeds in an accessible fashion, it holds great promise for people with disabilities.

Recent rapid and potent advances in technology have developed the potential for a level of independence and productivity for individuals with disabilities that was once only dreamed of.

Augmentative communication devices, almost unheard of only a decade ago, enable people without speech to program and activate computers to speak for them. Voice-activated computers enable people with limited motor capacity to write books. Assistive listening devices enable individuals who are hard of hearing to hear within the average range. With the enactment of the Americans with Disabilities Act (ADA), telecommunications relay services provide 24-hour access to the telephone for people who are deaf or hearing impaired. Television decoders and descriptive video services bring television to people with hearing and visual impairments. Assistive listening devices and descriptive video services have increased the accessibility of movies and the performing arts for patrons with disabilities.

The development of the National Information Infrastructure (NII), or "information superhighway," holds great promise for people with disabilities. All of these technological developments have the potential to significantly increase the employment rate of people with disabilities and to enhance educational opportunities.

Advances in telecommunications in the last decade have already had considerable impact on people with disabilities. A decade ago the term "E-mail" was virtually unheard of. For people with disabilities who can afford and use the technology, E-mail offers enhanced communication and increased access to information. A decade ago working at home was an oddity. The expansion of telecommunications options, including fax machines and E-mail, makes telecommuting more and more of a trend. For a person with a mobility impairment or a person with a disability in a rural area, technology can enable increased participation in the mainstream of American life.

Access to Assistive Technology

In 1990, the National Institute on Disability and Rehabilitation Research and the National Center for Health Statistics cosponsored a survey on assistive technology devices and homes with accessible features as part of the National Health Interview Survey of 1990. The survey found that more than 13.1 million Americans, about 5.3 percent of the population, were using assistive technology devices. Mobility devices were the most frequently used type of assistive technology, used by 6.4 million people. Hearing aids were used by 3.8 million people, walkers

by 1.7 million people, wheelchairs by 1.4 million people and back braces by 1.2 million people (LaPlante 1995a).

While the right assistive technology can make a monumental difference in the life of a person with a disability, many people who need the technology remain frustrated by persistent barriers in gaining access to the products and devices yielded by scientific research and development in a timely and usable manner. Advances in science and research simply are rarely readily available to people with disabilities. Barriers include limited dissemination of information about what technology is available and how to locate it and lack of third-party reimbursement or funding to purchase or utilize the technology (NCD March 4, 1994).

In addition, many assistive technology services are not consumer responsive. While the 1988 Technology Related Assistance for Individuals with Disabilities Act defines and requires consumer-responsive systems, barriers to implementation abound (Galvin 1995). People with disabilities have not yet been fully empowered to determine their service needs.

ADA should increase the availability of assistive technology for people with disabilities. The reasonable accommodation requirement may involve the purchase of equipment or devices by employers. Places of public accommodation are providing auxiliary aids and services which may involve assistive technology. For example, hotels are purchasing telecommunication devices for the deaf and television decoders for hearing-impaired guests. Libraries and schools are purchasing reading machines and other devices to allow blind people access to printed material.

The National Information Infrastructure

The development of NII has the potential to level the playing field in many areas of life for people with disabilities. It also has the potential to create new barriers to full participation if it is not developed to be accessible to and usable by people with disabilities. Potential advantages include increased access to information, increased communication with others, decreased personal isolation and increased opportunities to participate in distance learning, do shopping and receive medical services (NCD 1996).

Potential barriers to NII include socioeconomic barriers and the high levels of skill required to utilize complex information technologies. While these barriers are present for many

Americans, they may disproportionately affect people with disabilities who are poorer than the general public and less educated. Graphic user interfaces and touchscreen kiosks and products present barriers to people who are visually impaired or blind (NCD 1996).

Universal Design

People in the disability community have been articulating and promoting the notion of "universal design" for over a decade. This notion refers to designing buildings, transportation, technology, etc., so that it is usable by people with a range of abilities and disabilities. Such design offers accessibility to individuals with disabilities, but also to others. For example, a voice-activated computer may be used by individuals who want to avoid the risk of carpal tunnel syndrome or who simply prefer voice input.

When applied to NII, the notion implies access to newly emerging and developing technologies for people with disabilities. Because development in this area is so rapid, it has been difficult for third-party vendors to create access technologies to keep up with new information technologies (NCD 1996). However, some recent progress is evident. For the last year, NCD has worked with the Microsoft Corporation on ensuring accessibility of Microsoft's new products and technologies. The company has committed itself to addressing the needs of people with disabilities during all phases of product planning, development and support. The disability community has worked with Congress and representatives from the telecommunications industry over the last four years to ensure that telecommunications deregulation legislation will include disability access safeguards.

The challenge for the future will be to continue to promote universal design by seeking wide acceptance in the industry.

Key Legislation in the Past Decade

The Technology Related Assistance for Individuals with Disabilities Act of 1988 (P.L. 100-407) amended in 1994 (P.L. 103-218) (the Tech Act) supports state efforts to implement consumer-responsive, comprehensive, statewide programs of technology-related assistance, including technology centers, for individuals with disabilities of all ages.

The Americans with Disabilities Act of 1990 (P.L. 101-336) requires the establishment of telecommunications relay systems within every state and across states so that people who are deaf and hard of hearing have equal access to the telephone.

The Television Decoder Circuitry Act of 1990 (P.L. 101-431) requires new television sets with screens 13 inches or larger to have built-in decoder circuitry in order to display closed-captioned television transmissions for people who are deaf or hard of hearing. The legislation became effective July 1, 1993. This legislation will have the effect of phasing in increased accessibility to television over time.

The Telecommunications Act of 1996 (P.L. 104-104) requires telecommunications manufacturers and service providers to ensure that equipment is designed, developed and fabricated to be accessible to and usable by individuals with disabilities, if this is readily achievable. Closed captioning is required when it is readily achievable.

Recommendations

<u>**Universal Design**</u>

1. The President, the Congress and the private sector should develop initiatives to promote universal design through a combination of incentives, legislation, enforcement and research, including

> **a) developing a research agenda on universal design that includes market research, design research, research to develop guidelines and standards and descriptive research (e.g., the history of the use of technology, the type of technology used, the level of durability);**
>
> **b) establishing a Universal Design Award, modeled on the Baldrige Award for Innovation in Business, that would recognize outstanding innovation in the development, design or production of technology that is particularly effective in meeting the needs of people with disabilities;**
>
> **c) enacting a universal design statute or a new title to the Rehabilitation Act that would 1) promote the creation of more universally designed/accessible products, systems, practices and environments leading to enhanced employment of people**

with disabilities; 2) support research funding for interested industries, 3) establish an information clearinghouse; 4) gather data on the need for and use of accessibly designed products, systems, practices and environments and assistive technology; and 5) provide technical assistance to industry by developing a universal design support network modeled after the Job Accommodation Network;

d) establishing functional standards for accessible/universal design beyond telecommunications, including 1) incorporating captioning and audio description standards into audiovisual technologies; 2) encouraging development of telecommunication equipment standards that include the ability to present information in (at the user's option) audio, text or video and that are compatible with assistive technology add-ons; and 3) addressing copyright concerns without limiting the ability to add captions or descriptions;

e) charging or creating an interagency committee with addressing how different agencies can promote universal design, including consideration of 1) strengthening government purchasing policies, including Section 508 of the Rehabilitation Act, to give preference in purchasing to universally designed products and 2) requiring a disability impact statement in all proposals responding to requests for proposals for federal research and demonstration funds and establishing increased accessibility for people with disabilities as a criterion for funding;

f) creating tax incentives for Universal Design including a tax credit for companies engaged in basic research and development in universal design.

Assistive Technology Research and Development

2. Congress and the President should promote continued research and development of assistive technology and assistive technology services by

a) mandating and conducting a feasibility study regarding the creation of universally designed technologies that would be usable by individuals with multiple disabilities and effective in a broad range of environments;

b) supporting research to develop assistive technology to address new and emerging audiovisual information, devices, and systems, such as research on converting information into digital presentation–independent (sensory modality– independent) form;

c) supporting research to develop assistive technology to address new and emerging gestural/manipulative devices and systems;

d) supporting research to improve existing types of assistive technology, including the incorporation of new technologies and knowledge;

e) supporting consumer involvement in product design and testing activities;

f) broadening the funding support for these activities beyond the Department of Education to other federal agencies.

Incentives to Business and Industry

3. Congress and the President should develop a range of initiatives that offer incentives to business and industry to develop and utilize assistive technology and accessible technology, including

a) tax credits and deductions for entities that undertake housing and building construction and modification that incorporates accessible design, innovative facilities that transcend minimal accessible design requirements, and acquisition and maintenance of assistive technology for people with disabilities;

b) expanded tax credits and deductions now allowable under the access credit for compliance with ADA;

c) incentives for insurance carriers that cover the acquisition and maintenance of assistive technology for people with disabilities;

d) incentives to industry and business for donations of assistive technology to people with disabilities;

e) incentives to developers and manufacturers of universally designed products that meet established universal design functional standards.

<u>Affordability</u>

4. Congress and the President should develop a range of initiatives to enhance the affordability of assistive technology and accessible technology for people with disabilities, including

> **a) personal tax credits or deductions for individual expenses incurred in purchasing or maintaining assistive technology;**

> **b) expanded coverage for durable medical equipment and all assistive technology through Medicaid, Medicare, private health insurance and eventually through universal health care;**

> **c) widely disseminated studies of results of projects funded by the Tech Act that resulted in increased funding for or better delivery of assistive technology to people with disabilities who are poor or institutionalized;**

> **d) an expanded universal service fund under the Telecommunications Act to include telecommunications-related assistive technology for people with disabilities;**

> **e) a revolving low-interest long-term assistive technology loan fund designed to facilitate access to assistive technology for consumers for whom such technology would otherwise be unaffordable.**

<u>Strengthening and Enforcing Existing Laws</u>

5. Congress should strengthen existing laws and the administration should undertake stronger enforcement of existing laws, regulations and policies that address assistive technologies and universal/accessible design, including

> **a) extending Section 508 of the Rehabilitation Act beyond the Federal Government to ensure availability of accessible technology for people with disabilities who are employed in the private sector;**

> **b) increasing funding for enforcement;**

> **c) amending relevant laws to strengthen the standard of access ("readily achievable") so that total access will be achieved.**

6. Congress and the Federal Government should promote a range of activities intended to further disseminate information about accessible/assistive technology.

Public libraries should be urged to offer a range of information related to accessible/assistive technology, including information about services and funding resources for people with disabilities. This information should be in accessible formats as required by Section 504 of the Rehabilitation Act and Titles II and III of ADA. It should involve the establishment of universal key words relating to assistive technology as a discrete item in various library, professional and other research indices as well as World Wide Web indices.

Housing

The battle to secure the rights of people with mental illness to live in communities has taken place as policy emphasis has shifted from community residential facilities toward personal choice of where, how, and with whom to live.

J. Wolf
"Out of Mind, Out of Sight?" From Housing Discrimination to Public Accommodations Legislation
Journal of Disability Policy Studies, Summer 1990

Too often older or disabled people live limited lives or give up their homes and neighborhoods prematurely because standard housing of the past cannot meet their needs....The universal design concept...allows people to remain in their homes as long as they like.

Ron Mace FAIA
Architect and
product designer
Universal Design
1994

Living in the community is essential to independence and full participation for people with disabilities. Accessible, available, affordable housing is key to living in the community. Historically, people with disabilities have resided in isolated institutions, segregated from the mainstream and "out of sight, out of mind." Despite progress in deinstitutionalization, freedom of choice in where to live remains an unattained goal for people with disabilities.

The obstacles people with disabilities encounter in attempting to secure adequate housing in the community are multiple. Often low income levels exclude them from access to mortgage loans or render rental payments unaffordable. When people with disabilities do own or rent homes, the cost of modifications to make them fully accessible and usable may be prohibitive. Even if they are able to afford modifications, they may be forced to settle for inadequate ones because designers, contractors and rehabilitation professionals skilled in barrier-free and universal design are unavailable. Even when they gain access to government assistance, their housing needs are often unmet. A recent report by the U.S. Department of Housing and Urban Development (HUD) noted that 47 percent of non-elderly individuals with disabilities had "worst case needs" in housing (HUD 1994). Despite the relatively high rates of assistance reflecting their eligibility for rental programs, they are the group most likely to live in severely inadequate housing.

Federal Programs

All federally subsidized housing serves fewer than one third of all eligible applicants, with and without disabilities. The Federal Government's urban housing programs addressing the housing needs of people with disabilities are administered by HUD. The rural housing programs are administered by the U.S. Department of Agriculture. All public housing agencies are managed by HUD. Since the 1970s they have been required to provide at least 5 percent fully accessible and 2 percent deaf/blind accessible apartments throughout their programs. Many of the accessible apartments have been located in buildings designated for the elderly and people with disabilities. Congress recently authorized public housing authorities to make those buildings available only to people age 62 and older.

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Both the Department of Agriculture and HUD administer rental certificate and voucher programs that enable people with disabilities to locate their own housing in the community. The lack of accessible, affordable housing in many communities limits the effectiveness of the vouchers. In addition, HUD administers the "202" and "811" programs. The 202 program is directed toward people aged 62 and older, with and without disabilities. The 811 program is directed specifically to people with disabilities under age 62. HUD recently requested authorization from Congress to spend 25 percent of the 811 funds for vouchers and plans to increase the request to 50 percent in the near future.

Historically, HUD has emphasized providing service-connected housing for people with disabilities and placing people with disabilities into "disability only" or "disability and elderly only" housing. This approach is currently reflected in the McKinney programs, which specifically target homeless people with mental illness and drug and alcohol addiction histories, and in the Housing for People with AIDS Program. This emphasis has resulted in segregated housing and has provided little housing choice to eligible applicants.

Local Innovation

A number of efforts in local communities demonstrate creative financing for housing for people with disabilities that maximizes choice and autonomy. Atlantis Community, an independent living organization in Colorado run by people with disabilities, in conjunction with Northwest Bank, created a Disability Home Ownership Program that assisted more than 100 individuals in buying their own homes while generating more than $6 million in mortgage loans (Svaldi 1995). Experiments are under way in a number of communities exploring affordable housing models such as mutual housing associations and limited equity cooperatives to produce accessible housing in integrated settings. A number of home modification programs are also in operation, using Community Development Block Grants and state funds to support adaptations of homes and rental units for people with disabilities and elders. In 1993, the Administration on Developmental Disabilities in the Department of Health and Human Services funded the National Home of Your Own Alliance to promote home ownership opportunities for people with disabilities. The Alliance is currently working on local demonstrations in 13 states and intends to

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initiate coalition building among housing and disability advocates in 23 states by the end of the decade.

Support Services

For people with disabilities, the choice of where to live is often limited by program requirements of the government or service providers. Funding for support services is often tied to housing. For example, under the Intermediate Care Facilities for People with Mental Retardation program, Medicaid may pay for a group home and the services needed for a person who lives there. The option of living with a roommate at another location must be forgone because the individual would risk losing needed support services if she or he moved. When eligibility for support services is decoupled from eligibility for a housing subsidy, people with disabilities are not so restricted in where they might live. Developing a community-based support system independent of housing programs would require considerable redirection of funds, and in some communities, the development of an infrastructure where one currently does not exist.

Homelessness

The last decade has witnessed a continued increase in the number of homeless people, many of whom have disabilities such as mental illness or HIV/AIDS. Despite numerous government programs intended to assist them, their numbers continue to grow. Homeless shelters are frequently inaccessible.

Neighborhood Resistance to Group Homes

Resistance in communities to group homes for people with mental illness and mental retardation remains prevalent, despite antidiscrimination laws such as the Fair Housing Act Amendments of 1988. A number of studies indicate that group homes do not affect the value of residential property or the stability of neighborhoods (Lauber 1986), however, discrimination persists.

Accessible Housing Stock

A recent survey found that 7.1 million people were living in homes with accessible features, such as handrails, ramps, extra-wide doors and raised toilets (LaPlante 1995a). However, the availability of homes that are fully accessible to and usable by people with disabilities is inadequate. When people with disabilities seek single-family homes in the private market, they confront a lack of accessible and adaptable housing stock. While there is considerable evidence that home modifications and appropriate design can save service dollars, make caregiving easier and forestall or prevent institutionalization, there is no national policy or service system guiding the funding or delivery of home modifications and repairs or the design of housing that maximizes the independence of people with disabilities (Wilner 1994).

The concept of universal design has evolved during the last decade to mean buildings and items that are usable by most people regardless of their level of ability or disability. For example, round doorknobs are not usable by people with limited use of their hands, but lever handles are usable by almost everyone, including people with no hands. Universal design addresses the scope of accessibility and seeks to make all elements and spaces accessible to and usable by all people to the greatest extent possible. It need not increase costs or result in special or different-looking structures or features (Center for Universal Design n.d.).

Key Legislation in the Past Decade

The Housing and Community Development Act of 1987 (P.L. 100-242) requires the Secretary of HUD to earmark at least 15 percent of Section 202 funds for use in developing housing for non-elderly persons with disabilities and separate housing standards for people with disabilities and people who are elderly.

The Stewart McKinney Homeless Assistance Act of 1987 (P.L. 100-77) provides funds for transitional housing projects, with no less than $15 million for permanent housing for homeless people with disabilities.

The Fair Housing Act Amendments of 1988 (P.L. 100-430) (FHAA) prohibit discrimination against people with disabilities in the sale, rental or buying of private housing.

Dwellings having four or more units built for first occupancy after March 13, 1991, must be built in a manner that includes certain features of accessible and adaptable design.

The National Affordable Housing Act of 1990 (P.L. 101-402) authorizes the Home Ownership and Opportunity for People Everywhere program, which assists low-income people in purchasing apartments or single-family homes. The Shelter Plus Care program provides rental assistance and support services to individuals who are homeless and disabled. The legislation also authorizes the HOME Investment Partnerships program, which provides grants to help state and local governments expand the supply of affordable housing through new construction, rehabilitation of existing housing and rent subsidies to low-income families.

Recommendations

Enforcement of Existing Fair Housing and Civil Rights Laws

1. Federal agencies charged with enforcing civil rights laws related to housing, including HUD, the Department of Agriculture, and the Department of Justice, should strengthen enforcement efforts of the Fair Housing Act, Section 504 of the Rehabilitation Act, and Title II of the Americans with Disabilities Act (ADA) by

> **a) including knowledgeable people with disabilities, disability advocates and advocacy organizations in enforcement activities such as monitoring and testing in the housing, banking, real estate, design and construction industries;**
> **b) including knowledgeable people with disabilities, disability advocates and advocacy organizations in the Notification of Funding Availability process of selecting grantees under the Fair Housing Initiative Program (FHIP) and Fair Housing Administrative Program (FHAP) grant competitions;**
> **c) developing initiatives to ensure that entities controlled by people with disabilities, such as independent living centers, are eligible for funding under the FHIP and FHAP competitions and instituting application incentives, such as the allocation of bonus points on grant applications, for applicants that are organizations run by people with disabilities.**

Currently most disability rights organizations are ineligible for such competitions because they do not meet the requirement to be "qualified fair housing organizations." The ineligibility of disability rights organizations has precluded the active involvement of the disability rights community in enforcing fair housing laws. It is critical to have a disability perspective represented in these activities and to engage the disability community in the enforcement of housing rights laws.

> **d) designing mechanisms and strategies to strengthen the protection of complainants with disabilities against retaliation, such as aggressively prosecuting violators and seeking the maximum penalties for retaliation that are available under the law;**

> **e) redirecting housing funding away from separate housing or housing that requires special terms or conditions and toward housing in the most inclusive settings with maximal consumer control, in keeping with the tenets of FHAA, ADA and Section 504 of the Rehabilitation Act;**

> **f) requiring housing to be certified for compliance with accessibility codes and other provisions of law by designers, builders, developers and owners;**

In many communities builders and developers call on laypeople with disabilities to advise them as to the accessibility of their buildings. While there is no substitute for an assessment of accessibility by knowledgeable people with disabilities, neither is there any substitute for a professional determination of compliance with accessibility standards. Too often builders and developers believe that because someone with a disability determined that a particular aspect of a building was accessible, the entire building is in compliance with accessibility codes. Likewise, too often builders and developers have little or no knowledge about the extent to which or the manner in which accessible features are used by people with disabilities. While both sets of expertise are critical, it is the builder and designer who are ultimately accountable for compliance.

> **g) providing policy guidance, clarification, and interpretation of the FHAA by continually clarifying and disseminating information through published material in**

accessible formats, including the full participation of the disability advocacy community in the process;

h) ensuring that all federal, state and local officials with responsibility for fair housing enforcement are thoroughly trained in the disability provisions of relevant civil rights law and that such training includes components that promote sensitivity to the discrimination experienced by people with disabilities and to the impact of operational, architectural, communications and attitudinal barriers.

Sensitivity training components should be conducted by people with disabilities, including individuals with psychiatric, developmental, sensory and physical disabilities.

Delinking Services from Housing

2. The Congress should enact legislation prohibiting HUD from funding programs that require an individual to live in a particular setting in order to receive services that are not related to housing (e.g., long-term support services).

Housing for people with disabilities should be based on housing needs, not service needs. Requiring people with disabilities to accept services in order to live in a particular unit or to live in a particular unit in order to receive the services they need is inappropriate. Many people with disabilities do need services; however, the choice of services should be their own, not that of the housing provider.

Segregated, Set-Aside and Diagnosis-Specific Housing

3. The Congress should direct HUD and other relevant federal agencies to fund housing programs for people with disabilities on the basis of need, not diagnosis or label, and on the basis of an independent living model of individual control and choice with full integration.

Such an approach would end the funding of segregated or diagnosis-specific housing as well as set-asides for individuals with a specific diagnosis. Group homes, transitional housing for people with alcoholism or substance abuse problems, housing for people with HIV/AIDS, 202 and 811 programs, and apartment buildings for people with mental illness would be replaced by housing programs targeted to individual need and based on individual choice. Section 8

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vouchers for people with AIDS, funds for homeless individuals who are "dually diagnosed" with mental illness and substance abuse and "Shelter + Care" money for people with mental illness would also be replaced by programs flexibly designed to accommodate individual needs and choices.

Affordability

4. Congress and the administration should develop initiatives to ensure affordability of housing so that people with disabilities have choice in housing options, including

> **a) establishing home modification programs, such as tax deductions approved by the Internal Revenue Service, that would enable individuals with all types of disabilities to eliminate barriers and enjoy the full use of their dwellings (e.g., by installing flashing doorbells for people who are deaf, providing ramps and structural modifications for people with mobility disabilities, lowering cabinets and environmental controls for people of short stature and adding soundproofing for people with psychiatric disabilities);**

> **b) giving priority to those most in financial need, for example, allocating 50 percent of the units developed under the affordable housing formula to people whose income is below 30 percent of the federal poverty level;**

> **c) requiring rental agents and building owners to consider housing vouchers as income so that people holding vouchers will be assessed for eligibility in the same manner as applicants without vouchers;**

> **d) requiring banks and mortgage companies to consider housing vouchers as income so that people holding vouchers will be eligible for mortgage funding in the same manner as applicants without vouchers;**

> **e) ensuring that individuals with disabilities have equal opportunity to satisfy equity requirements for sweat equity home ownership programs, including acknowledgment of nonphysical labor;**

> **f) requiring that vouchers and Section 8 certificates be portable across state lines.**

Construction Practices

5. The Congress and the President should develop initiatives to promote the universal and accessible design of housing, including

a) replacing the notion of a percentage of set-aside accessible units or houses with a requirement for a basic level of access in all new dwelling units and in   all renovations;

b) until universal design can be fully achieved, promoting a level of accessibility which would enable people with disabilities to comfortably visit homes (called "visitability") in all single-family construction, even when no federal funds are involved, through tax credits, code changes, legislation and education;

c) ending federal support, including loans and Federal Housing Administration guarantees, for single-family dwellings that are not accessible;

d) requiring maximum feasible accessibility in renovations of single and multi-family dwellings funded or guaranteed by the Federal Government;

e) increasing the number of two-and three-bedroom units available to people with disabilities in order to support families that include members with disabilities and to accommodate individual needs such as equipment storage, attendants' rooms, home offices, and space to isolate toxic products within dwellings (for people with multiple chemical sensitivities).

Research and Data Collection

6. Congress and the administration should develop initiatives to expand research and data collection about housing for people with disabilities that involve the input and participation of the disability community. Research results and data collected as a result of these initiatives should be routinely disseminated through a variety of accessible communication mediums. Topics for research and data collection should include

a) information necessary to promote the replication of successful models and demonstration projects;

b) ways to expand the effective design of housing for people with   multiple chemical sensitivities;

c) research on the relationship of homelessness and disability and effective programmatic responses based on independent living principles;

d) research on compliance and enforcement of building codes;

e) data on the disability related characteristics of housing stock and markets, such as accessibility, ownership and affordability, and consumer satisfaction.

Transportation

Black people fought for the right to ride in the front of the bus. We are fighting for the right to get on the bus.

Mark Johnson
ADAPT

Accessible transportation is essential if people with disabilities, particularly persons who are severely disabled, are to live independently in the community. The development of transportation services has moved from a focus upon special and separate...programs to an emphasis upon making fixed-route, mainstream systems accessible.

Frank Bowe
"Transportation: Key to Independent Living"
Archives of Physical Medicine and Rehabilitation, Vol. 60, No. 10

There was a time in this country when I was required to ride in the back of the bus. I could not accept that kind of discrimination then, and I will not accept it now for any American....What disabled Americans seek with this legislation is the dignity which can only come with the full recognition of their civil rights.

Representative Cardiss Collins
House passage of ADA
May 22, 1990

Transportation is a linchpin to independence for people with disabilities. Despite important progress in increased accessibility, transportation remains a major obstacle to employment and participation in the community for people with disabilities.

Transportation policy for people with disabilities is a matter of both civil rights and services. The debate about transportation over the years has often pitted a civil rights view against a services view. Some researchers have concluded that rendering the transit system accessible is simply too costly. Some have argued that a separate system of vans and taxis—paratransit—is most effective, while others have argued for requiring the generic transit system to become accessible as a matter of equal access.

The Americans with Disabilities Act (ADA) resolved the decades-old debate by requiring an accessible fixed-route system with paratransit available for those who, because of their disabilities, are unable to use the fixed-route system. The strategy was to gradually render the fixed-route system more accessible so that more people with disabilities would use it and fewer would use the more expensive paratransit. Such a strategy is long-term and will likely take over a decade to implement.

Increasing Accessibility and Paratransit

Transportation access for people with disabilities includes the removal of physical, structural, communication and environmental barriers. For example, auditory information should be presented in visual formats (e.g., electronic messaging systems) for people with hearing disabilities. While full accessibility remains a long-term goal, the first five years of the implementation of ADA has witnessed an increase in both the accessibility of the generic system and the use of paratransit. In 1989, prior to the enactment of ADA, about one-third of fixed-route vehicles were accessible. In 1996, 60 percent of all buses meet ADA standards. Rural systems lag behind urban systems in accessibility—only 35 percent of rural fixed-route vehicles are accessible. Projections for urban areas indicate that 70 percent will be lift-equipped by 1997 and 100 percent will be lift-equipped by 2003 (Project Action 1995).

In 1989, prior to the enactment of ADA, paratransit was providing 16 million rides per year. By 1995 the number had risen to 37 million, and it is projected to be 48 million in 1997

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(Project Action 1995). Some portion of the increase in use is attributable to enhanced services'

generating a greater demand by both the disability community and the elderly community. A

portion is also attributable to transit authorities' implementation of an expansive definition of

eligibility. The disability community, transit authorities and governments are concerned about

the increasing use of paratransit, which is projected to cost over $700 million annually at full

service in 1997 (Project Action 1995). They are working together to address problems that have

arisen.

Rail Systems

Rail systems are increasing in accessibility, though slowly. At the end of 1995, 450 key

stations for rail systems were determined to be accessible by the Department of Transportation

(DOT). Over 200 were granted varying time extensions up to the year 2020. One hundred and

twenty-seven key stations are currently either in litigation or participating in compliance

negotiations with the Federal Transit Authority. The ADA requirement that one accessible car

be available on every train was met in 1995 (Project Action 1995). Expanded visual access (e.g.,

signage, electronic message boards) and teletypewriters (TTYs) are required for people with

hearing disabilities. Detectable warnings are required next to rails in order to warn people with

visual impairments of their proximity to the track. There has been considerable debate as to what

constitutes an effective detectable warning.

Curb Cuts

A common transportation obstacle for people with disabilities is lack of curb cuts from

sidewalks to streets. Without curb cuts, people who use wheelchairs cannot get from their homes

to bus stops or subway stops to use fixed-route transportation. Many state and local governments

complained that they were unable to meet the deadline for installation of curb cuts at existing

pedestrian walkways. As a result, the Department of Justice (DOJ) has proposed extending the

time period for compliance by several years. Without curb cuts, use of accessible fixed-route

systems will be limited for many people with mobility impairments, possibly resulting in greater

use of the more costly paratransit services.

Other Forms of Transportation

Other forms of transportation, such as private shuttle vans from hotels to airports and taxis, are increasingly accessible; however, a person with a disability certainly cannot take accessibility for granted when traveling. For example, information boards at airports remain visual. Pay phone access at airports remains at minimal levels, making it extremely difficult for people with hearing disabilities to make private transportation arrangements by phone. Cruise ships and other large boats used for recreational purposes have made some progress in becoming accessible.

Airplane accessibility is required by the Air Carriers Access Act of 1986. Over the last decade, accessibility has increased. Today about 20 percent of aircraft are equipped with movable armrests on 50 percent of aisle seats. Cabin wheelchairs are now provided on most planes with more than 59 seats. Accessible lavatories are required on new twin-aisle aircraft. Despite progress, persistent problems remain, including untrained or poorly trained attendants and other airline personnel, lack of accessible public announcement systems on airplanes for people with hearing disabilities, lack of captioning for TV monitors and airport channels at airports, and possible limits on the recovery of attorneys' fees for lawsuits.

The most common form of transportation for Americans is the private automobile, particularly in rural areas. Many people with physical disabilities can drive an automobile if it is adapted to meet their individual needs. Veterans are eligible for a subsidy for automobile adaptations under veterans' benefits programs; however, there is no such subsidy for others with disabilities. Some car manufacturers will subsidize adaptations for customers up to a set amount (such as $1000).

Key Legislation in the Past Decade

The Air Carriers Access Act of 1986 (P.L. 99-435) prohibits discrimination against people with disabilities by air carriers.

The Americans with Disabilities Act of 1990 (P.L. 101-336) sets standards for the design and delivery of accessible bus service, specifies requirements for accessible rail service,

establishes accessibility standards for vehicles and extends transportation access to the private sector.

The National Highway System Designation Act of 1995 (P.L. 104-59) amended ADA to change compliance dates to two and three years, respectively, after issuance of final DOT regulations for large and small over-the-road bus operators.

Recommendations

While the accessibility of public transportation has increased considerably in the last decade, numerous barriers remain. People with disabilities are far from being able to assume that the transportation they need will be accessible to and usable by them. Too often lifts on buses do not work or drivers will not operate lifts or call stops for people with visual impairments. Safety restraints for new-model wheelchairs are lacking and contrasts on steps for people with low vision are inadequate. People with hearing disabilities are frustrated by lack of communication access. Many people with disabilities do not live in areas served by public transportation and thus rely on private vehicles. Because of the additional expense of adapting a vehicle and the general low level of income of people with disabilities, buying a car may be difficult. Yet without a car, they are unable to get to a job or otherwise participate in community activities.

People with disabilities continue to confront discrimination on airlines. Lack of awareness of airline staff often contributes to problems. Sometimes people with disabilities are unaware of their rights in relation to airline travel and complain that DOT does little to enforce the Air Carriers Access Act.

General Public Transit Improvements

1. Federal, state and local governments should provide additional funding for public transit systems.

The level of access to public transportation for people with disabilities is directly related to the quality and expansiveness of the public transit system in general. Thus, the first step in enhancing access is improving public transit systems generally. Additional funding from the

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Federal Government should include both operating and capital funds, including flexible capital, in order to expand public transit in urban, suburban and rural areas, as well as tribal lands.

<u>Enforcement of Current Law</u>

2. DOT and relevant state and local government entities should aggressively enforce existing transportation statutes and regulations related to people with disabilities, by undertaking the following:

> **a) prompt referral of violators for appropriate action;**
>
> **b) systematic solicitation and utilization of input from the disability community when making decisions regarding funding, enforcement, paratransit planning and time extensions;**
>
> **c) ongoing meaningful public participation by people with disabilities in all projects and decisions of local transit agencies;**
>
> **d) improving fixed-route service through full compliance with ADA requirements such as calling out stops, providing textual/visual (print or electronic) access for people with hearing disabilities, not moving the bus until the person is seated, picking up all disabled people rather than passing them by, clearing priority seating when needed by someone with a disability, curbing the bus so people can get on, improving drivers' attitudes and disciplining drivers who do not comply;**
>
> **e) improved coordination by relevant entities to make bus stops more accessible, including removal of both permanent barriers and temporary barriers such as snow drifts;**
>
> **f) ensuring compliance with ADA requirements (including eligibility and service area requirements), even if politically difficult, so that paratransit is available to those users with disabilities who will never be able to use fixed-route services;**
>
> **g) ensuring that fixed-route information is provided in paratransit plans so these plans will constitute full ADA plans.**

Rural Transportation

3. The Congress and the Federal Government should fund more accessible rural transit services for the general public and for people with disabilities, including intercity rail services.

Coordination

4. DOT, in conjunction with other relevant federal agencies such as the Department of Health and Human Services, should develop a mechanism and a process to facilitate coordination of transportation resources at the federal, state and local levels.

Many human services agencies buy vans to transport clients, including those with disabilities, to and from services. These agencies rarely coordinate with transportation entities that provide related transportation services, such as paratransit. Human services vans sometimes sit idly for extended periods of time, while people with disabilities in the same community have difficulty accessing public transportation. In addition, Section 9 and Section 18 transportation providers─generally urban and rural providers─are prohibited from picking up residents outside their designated areas, even though they may drive directly through adjacent areas while transporting someone. Coordination efforts should seek to eliminate inefficiencies such as these in current transportation systems by promoting initiatives such as agreements between urban and rural providers to pick up passengers in each other's areas when logical to do so.

In addition, there are many people residing in "gray areas," or areas served by neither urban nor rural transit. These are most often communities in urbanized areas that have not signed on with the regional transit system. However, the regional transportation provider's funding allocation includes the population residing in the unserved areas. Coordination should ensure that these people are served by some public transit system.

Communications Accessibility

5. DOT and DOJ should enhance enforcement of ADA and the Air Carriers Access Act and develop additional initiatives to ensure communications accessibility in transportation facilities, services and vehicles, as well as on streets and highways, including

a) improved signage for people with visual impairments;

b) calling out bus stops for people with visual impairments;

c) identifying which bus is on which route for people with visual impairments;

d) ensuring the provision of way-finding information in transit stations, such as detectable warnings;

e) ensuring the provision of visual (text) public announcement/paging systems that provide information on changes in times of departures or gates, seating upgrades, and weather or mechanical problems, and that call out bus or train stops;

f) ensuring captioning of TV/video programming in areas such as airplanes, cruise ships and terminal waiting areas;

g) ensuring accessible public phones (voice and TTY) that accept all forms of payment (including coins) in every phone bank within each concourse at airports, at highway stops, on street corners, and on airplanes and trains, and that connect with other phone systems, including providing access to 411, relay services and emergency numbers;

h) ensuring accessible courtesy/emergency phones (voice and TTY) for vans, hotels, car rentals, in-transit facilities, satellite parking, call boxes, etc.;

i) ensuring flashing and audible emergency alarms in facilities and vehicles;

j) ensuring that radio-based advisories have equivalent text-form communication;

k) providing for research into color contrast needs of people with visual impairments.

Training

6. DOT should require and fund training of transit agencies, people who provide transit services and people with disabilities about laws and practices affecting accessible transit.

Training for service providers should include disability awareness and should be standardized across the country but also tailored to the unique needs of the community. People with disabilities, including those with mobility, vision and hearing disabilities, should be

involved in the design and delivery of the training. Training for people with disabilities should include training in their rights under the law, empowerment strategies to assist them in exercising their full rights, and orientation on how to use public transportation and making the most appropriate use of the modes of transit that are available to them.

Paratransit

7. DOT should enforce the paratransit provisions of ADA and local transit agencies should ensure that

> **a) eligibility for paratransit is uniform across all states and cities, including reciprocity from one locale to another;**
>
> **b) eligibility is determined by a functional model, not a medical model;**
>
> **c) trip-by-trip eligibility determination on the basis of comparable accessible public transit is an aspect of the process.**

Motor Vehicle and Transit Design

8. The Society of Automotive Engineers and relevant federal agencies should incorporate accessibility features in safety and design standards and ensure compliance with ADA and Section 504 of the Rehabilitation Act for

> **a) automobiles, in order to promote usability by people with disabilities;**
>
> **b) advanced car designs, such as electric cars, in order to provide audible and visual safety cues;**
>
> **c) new "intelligent transportation systems" currently under development.**

Highways and Streets

9. The Federal Highway Administration and other appropriate state and local agencies should ensure that highway call boxes are accessible and that traffic signals and poles show flashing lights when emergency vehicles are approaching.

<u>**Air Travel**</u>

10. DOT should improve access to air travel, particularly accessibility on airplanes, and, toward this end, should conduct research on ways to improve wheelchair storage, loading and service.

<u>**Issuance of Regulations and Standards**</u>

11. DOT and the Access Board should issue all pending disability civil rights regulations and standards in final form.

International Issues

> *Let me note that Americans have never shied away from challenges. The fight for full participation by the world's 500 million people with disabilities is one we accept willingly and with enthusiasm....*

>> Senator Robert Dole
>> Testimony before the Commission
>> on Security and Cooperation in Europe
>> September 21, 1994

> *[O]ur foreign aid dollars...should go toward building accessible, not inaccessible, structures and our technical assistance and bilateral aid should be inclusive of disabled persons. Foreign disability policy should reflect the American way.*

>> Judith Heumann
>> Assistant Secretary
>> Department of Education
>> Testimony before the Commission
>> on Security and Cooperation in Europe
>> September 21, 1994

> *In all societies of the world there are still obstacles preventing persons with disabilities from exercising their rights and freedoms, making it difficult for them to participate fully in the activities of their societies. It is the responsibility of states to take appropriate action to remove such obstacles.*

>> Standard Rules on the Equalization
>> of Opportunities for Persons with
>> Disabilities
>> United Nations
>> 1994

The world community should be as galvanized into working to see justice done for the disabled as it was to see apartheid ended. It is as much a moral issue as the struggle against apartheid ever was, and we must all take it up as a matter of religious and political conviction.

> Desmond Tutu
> Archbishop of Capetown, South Africa
> Keynote address
> Disabled Persons International World
> Assembly, 1994
> Sydney, Australia

If ever an event should have provided full access for persons with disabilities, it is a UN conference in a forum devoted to human rights. There is no excuse for what happened here. And if I have any say in the matter, it will never happen again.

> Madeleine Albright
> U.S. Ambassador to the United Nations
> Speaking at the Fourth World Conference on
> Women, 1995

There are about 500 million people with disabilities in the world, two-thirds of whom live in developing countries. Spurred by the growth of organizations founded and run by people with disabilities throughout the world, disability issues have continued to gain international momentum in the last decade. Organizations of people with disabilities have successfully influenced the way the international community views people with disabilities, shifting away from a medical orientation and toward an independent living orientation of personal empowerment.

The United States has one of the most progressive domestic disability rights policies in the world, yet it has not incorporated the goals and principles of that policy into its international role as the leader of the free world. U.S. participation in UN events related to disability rights

has been perfunctory rather than dynamic. Other countries, such as those in Scandinavia, have adopted progressive resolutions inserting full participation and independent living for people with disabilities into their foreign policy.

The world was captivated by our country's adoption of the Americans with Disabilities Act (ADA). The law continues to serve as a model in countries everywhere. Ironically, the United States too often ignores the very tenets of the law in its international leadership role.

U.S. Foreign Policy

NCD has been designated by the Department of State as the contact point within the U.S. government for disability issues. U.S. foreign policy is administered primarily through three agencies: the Department of State, the Agency for International Development (AID) and the U.S. Information Agency (USIA). The U.S. government spends about $22 billion annually on thousands of international programs. However, people with disabilities are often excluded from participation in such programs by barriers or lack of outreach (NCD 1996).

The manner in which U.S. disability rights laws apply outside the United States is still being determined. Some applications, such as the employment provisions of ADA in relation to U.S. citizens working for U.S. companies abroad, clearly apply directly. Courts have yet to rule on the applicability of the Rehabilitation Act abroad. The manner in which the antidiscrimination mandate that applies to Federal Government activities in the U.S. applies to federally sponsored activities abroad continues to evolve. (NCD 1996).

Ensuring accessibility and accommodations in American embassies is important so that people with disabilities can work in them and use their services. People with disabilities seeking to enter the Foreign Service continue to encounter considerable barriers, including an extensive medical screening that may result in limitations on career opportunities.

AID distributes about $1.6 billion per year for economic assistance overseas, targeted to those at the lowest socioeconomic levels. Recent persistent efforts of the disability groups to ensure that people with disabilities benefit from AID programs have yielded a greater commitment by the agency to ensure that the principles of full participation and empowerment

serve as underpinnings for AID programs. While some progress is evident, it has been slow and uneven and much remains to be done.

USIA operates educational and cultural foreign exchange programs, such as the Fulbright program. There is increasing evidence of the inclusion of people with disabilities in USIA programs, which is documented in annual reports by the agency. The agency is in the process of creating an accommodation policy.

The Peace Corps is the only U.S. international agency with a disability program area—special education. While the Peace Corps does place some volunteers with disabilities in other countries, there are limits on the extent to which it has accepted volunteers with disabilities.

Other countries have been more progressive than the United States in their international disability policies. For example, the Development Ministers of the Nordic Nations met in 1991 in Hanaholmen, Denmark, and adopted a resolution, known as the Hanaholmen Resolution, calling for the inclusion of disability issues as a core of the development activities of Nordic countries. Canada and the Nordic nations have funded disabled-directed organizations for years to conduct international development projects.

People with disabilities are rarely represented in official United States delegations to other countries. However, just recently this practice appears to be changing. The first official delegate with a disability was Marca Bristo, chair of NCD, to the World Summit on Social Development. The recent UN Conference on Women in Beijing, China, offered another notable exception. Judith Heumann, Assistant Secretary for Special Education and Rehabilitative Services of the Department of Education, was a delegate. In 1996, Marca Bristo was a U.S. delegate to Habitat II, the United Nations Conference on Human Settlements held in Istanbul, Turkey.

Recent increases in citizen diplomacy efforts by U.S. disability organizations to promote disability rights in other countries are having positive results.

Human Rights

The international disability community has had limited success in influencing the UN to ensure that people with disabilities are protected against human rights abuses. One significant

event was the United Nations appointment of a Special Rapporteur on Human Rights and Disability by the Sub-commission on Prevention of Discrimination and Protection of Disability in 1984. The final report of the Rapporteur in 1991 clearly reflects the input of the disability community and documents the pervasive and persistent violations of the human rights of people with disabilities all over the world. Violations are civil and political in nature, as well as economic, social and cultural. The report recommended the establishment of an ombudsman's position to monitor human rights implementation for disabled persons; however, the recommendation has not been followed (Degener 1995).

Despite the fact that people with disabilities constitute the largest minority in the world with serious human rights violations, they are not acknowledged by the UN as a minority. Without such acknowledgment, there is no binding human rights instrument explicitly protecting their rights. A draft convention intended to eliminate discrimination against disabled people was rejected by the UN in 1987. However, in 1993 the General Assembly adopted the Standard Rules on the Equalization of Opportunities for Persons with Disabilities (Standard Rules) intended to achieve full inclusion of people with disabilities in all aspects of society. The difference between the convention and the Standard Rules is that the Standard Rules are not legally binding (Degener 1995). The UN appointed Bengt Lindqvist as Special Rapporteur to monitor the implementation of the Standard Rules.

Over the years, the United Nations and other international entities (such as the International Labour Organization, the World Health Organization [WHO] and the United Nations Educational, Scientific, and Cultural Organization) have adopted numerous conventions, recommendations, declarations, principles and guidelines that relate to the rights of people with disabilities (Degener and Koster-Dreese 1995). The impact of these activities on the lives of people with disabilities throughout the world is not known.

In the early 1990s, the U.S. Congress directed the Secretary of State to expand human rights monitoring to include people with disabilities. To date, two reports, called Country Practice Reports on Human Rights, have been issued that include people with disabilities.

The World Bank

The World Bank recently developed a new methodology to assist ministers of health and development around the world to "better" determine how to allocate scarce health care and development dollars. "Disability-adjusted life years" (DALYs) statistically establish a measurement for the value of life lived with a disability. This methodology was devised with virtually no input from the disability community. DALYs appear to equate disability with lack of productivity and assume that investments in people with disabilities are poor investments (Groce 1996). Such methodologies are troubling to the disability community and fly in the face of the principles of ADA.

The International Classification of Impairments, Disabilities and Handicaps

In 1980, WHO developed a system called International Classification of Impairments, Disabilities and Handicaps (ICIDH) to classify and track disabilities and their impacts on people's lives. The system is used by many countries to gather data and plan for service delivery programs. WHO has undertaken a revision of ICIDH, in which the United States is actively participating. People with disabilities are participating in meetings and workshops all over the world to discuss the revision and promote a focus on social, physical and communications barriers that impede full participation. The revision of ICIDH is likely to be completed by the turn of the century. If used by the United States, the revised ICIDH will allow for comparative international data analysis.

Key Legislation in the Past Decade

The International Security and Development Cooperation Act of 1981 (P.L. 97-113) directs the Peace Corps to give particular attention to programs, projects and activities that integrate people with disabilities into national economies.

In 1993 and 1994 a number of legislative directives were included in various foreign aid and foreign operations bills with provisions such as requiring the Secretary of State to include reporting on people with disabilities in County Practice Reports on Human Rights.

The Foreign Relations Authorization Act for FY 94 and FY 95 (P.L. 103-236) directs USIA to issue an annual report on agency efforts to promote the inclusion of people with

disabilities in the general exchange activities of the agency and also requires exchanges specific to people with disabilities.

Recommendations

The accomplishments of the United States in the international disability policy arena are modest to date. The size of the population of people with disabilities throughout the world—500 million people—warrants a more substantial response from the United States. Indeed, we lag behind some other industrialized democracies in our outreach, development and international leadership. Developing the capacity of people with disabilities as leaders in their communities is vital to U.S. global interests.

Human and Civil Rights

1. The President and the Congress should ensure that all aspects of U.S. foreign policy and assistance recognize the individual human rights and civil rights of people with disabilities, reflecting current U.S. policy as articulated in ADA by

a) requiring full accessibility of all programs, activities, services and facilities of governmental and nongovernmental entities involved with international activities;

b) promoting the principles of ADA throughout all aspects of international operations of U.S. companies;

c) enforcing full accessibility as required by ADA and Section 504 of the Rehabilitation Act in U.S. embassies, consular offices and U.S. AID missions;

d) prohibiting the exclusion of people on the basis of disability in immigration policy;

e) collecting and reporting data on the demographics and the status of people with disabilities in U.S. government–generated country reports.

Foreign Assistance

2. The President and the Congress should develop initiatives to provide U.S. foreign assistance for programs that will strengthen and empower disability-directed organizations in other countries through exchanges, technical assistance, in-depth training, networking and funding, including the following:

a) technical assistance that enables people with disabilities to share information, resources and strategies, including, as appropriate, technology and in-depth training through bilateral and multilateral programs provided by disability-directed organizations;

b) translation of ADA and other disability rights legislation in a range of languages and accessible formats;

c) a directory of consultants with expertise in international disability programs and policies;

d) a comprehensive resource directory of disability-directed organizations in countries throughout the world.

Social and Economic Development

3. As a part of global economic and social development policy, the Congress and the President should develop initiatives to encourage the International Monetary Fund, the World Bank and other international entities to promote activities such as microenterprise development, business development credit, business development loans, inclusive education for children with disabilities, and public health initiatives for people with disabilities.

Inclusion of People with Disabilities

4. The President and the Congress should develop initiatives to ensure the inclusion of people with disabilities in all aspects of U.S. foreign policy and assistance, including

a) the participation of people with disabilities in the design, implementation and evaluation of program areas, utilizing participatory action research methodology;

b) requiring federal grantees to demonstrate how projects and activities will include people with disabilities as beneficiaries;

c) use of the extent to which people with disabilities are included in federal grants as a basis for evaluation of grants;

d) access to and inclusion of women and girls with disabilities in development projects serving women and girls;

e) hiring of people with disabilities at all levels of domestic and international operations by U.S. government agencies and nongovernmental organizations handling international activities;

f) hiring of people with disabilities by subcontractors assisting the U.S. government in international development projects;

g) internships sponsored by governmental, nonprofit and profit-making sectors to train people with disabilities in international issues;

h) presidential appointments of people with disabilities in foreign assistance and foreign policy arenas.

International Exchange Programs

5. The Congress and the administration should develop initiatives to increase the number of people with disabilities in all types of international educational exchange programs sponsored by the government and the for-profit and nonprofit private sectors, including

a) the Peace Corps;

b) international delegations such as international visitor programs, the world affairs council, and escort programs;

c) cultural exchange programs;

d) sports exchanges;

e) exchanges by U.S. independent living programs with similar disability-directed groups in other countries, with particular attention to developing countries;

f) leadership training;

g) youth, high school and university exchanges;

h) volunteer, intern and work-related exchanges;

i) family-to-family exchanges;

j) teacher and other disability-related professional exchanges;

k) international conferences;

l) business development exchanges for youth, such as Junior Achievement;

m) professional business delegation exchanges, such as those sponsored by the Department of Commerce.

IN CLOSING

I wish I could say that America has come to appreciate diversity and to see and accept similarity. But as I look around, I see not a nation of unity, but of division....We cannot play ostrich. Democracy cannot flourish amid fear. Liberty cannot bloom amid hate. Justice cannot take root amid rage. We must go against the prevailing wind. We must dissent from indifference. We must dissent from apathy....We must dissent because America can do better, because America has no choice but to do better.

> Thurgood Marshall
> Supreme Court Justice
> July 4, 1992

Human progress is neither automatic nor inevitable. Even a superficial look at history reveals that no social advance rolls in on the wheels of inevitability. Every step toward the goal of justice requires sacrifice, suffering, and struggle, the tireless exertions and passionate concern of dedicated individuals.

> Dr. Martin Luther King, Jr.

The recommendations in this report are intended to provide direction for public policy in order to facilitate the achievement of independence by people with disabilities. Many recommendations are long-term and will require a sustained collaborative effort by federal agencies and the Congress. The achievement of independence demands concerted efforts by virtually all sectors of society—state and local governments, the nonprofit and for-profit private sectors, the disability community, and others. NCD is committed to working with all relevant parties to implement these recommendations in a timely and effective manner.

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APPENDIX A

RECOMMENDATIONS FOR THE NATIONAL COUNCIL ON DISABILITY

The following are recommendations provided by the policy working groups at the National Summit on Disability Policy in Dallas in April 1996. They are recommendations for activities that Summit participants would like to see undertaken by NCD.

Policy and Program Coordination

1. With appropriate funding from the Congress, NCD should continue to develop initiatives to identify and work toward elimination of contradictory and conflicting laws, regulations and programs. NCD should promote coordination and commonality of goals across agencies, both those that are specifically targeted to people with disabilities and those that are not specifically so targeted.

2. With adequate funding from the Congress, NCD should work with other relevant federal agencies to develop strategies will result in greater enforcement of existing laws that affect people with disabilities that are consistent with the philosophy of ADA. These laws include Section 504 of the Rehabilitation Act, the Air Carriers Access Act, the Fair Housing Act Amendments and the Motor Voter Act.

3. NCD should develop and propose to Congress a model to achieve a seamless delivery system of benefits, supports and services for people with disabilities. The principles for the model include

    a) full participation by people with disabilities as program designers, qualified employees and service recipients;

    b) maximal opportunities for choice and control by people with disabilities;

    c) service eligibility based on individual need;

    d) provision of services regardless of age, ethnicity, type of disability or

geographic region;

e) recognition of individuals' changing needs over time;

f) regular evaluation of the services, ensured by obtaining consumer opinion and measuring outcomes;

g) confidentiality;

h) common data, definitions and forms;

i) reduction of resources spent on intake and eligibility determination;

j) clear delineation of federal, state, local and tribal roles and responsibilities;

k) provisions requiring all levels of government to abide by these responsibilities.

4. NCD should develop principles to guide Congress in a) establishing a policy that people with disabilities and their families will control the resources necessary to obtain services/supports of their choice and b) hold states accountable for implementing policy.

5. NCD should hold a summit/conference to identify methods to alter federal funding mechanisms to reward excellence and innovation in programs that affect people with disabilities.

These methods should build on connections with existing quality improvement/reinventing government initiatives and focus on consumer satisfaction.

6. NCD should continue to promote and facilitate communication across disabilities and between policy makers and the grass roots.

These efforts should be coordinated with other national leaders from entities such as the National Council on Independent Living (NCIL), the President's Committee of People with Disabilities (PCEPD) and state governors' committees. NCD should hold annual or biannual policy summits to continuously refine our national policies and have an opportunity to take up emerging issues in a timely manner. Existing and emerging computer technology should be used to promote timely sharing of information to broad audiences.

7. NCD should develop and implement a strategy to educate the philanthropic community about the disability rights philosophy and goals and work to shift their funding to support that philosophy and those goals.

8. NCD should continue to invest in developing the next generation of leaders with disabilities by

> **a) compiling resources;**

> **b) including youth events in national conferences;**

> **c) developing a task force to develop a plan for coordination with national organizations, exploring mentorship opportunities and coordinating with youth organizations;**

> **d) reinstituting NCD fellowship programs; and**

> **e) encouraging federal agencies, international exchange organizations and other agencies and organizations to include youth with disabilities in their internship programs and events.**

9. NCD should provide an exemplary model of accommodating people with disabilities to the rest of the nation in the ways in which it conducts its own business.

In cooperation with the PCEPD and NCIL, NCD could develop the capacity needed to run truly universally accessible conferences. With this capacity, NCD could provide training and technical assistance to other organizations on conducting universally accessible conferences and events.

In order to make conferences truly accessible, new technology will likely need to be developed. For example, without a braille printer available it is not possible for blind participants to have the same access to recently developed or up-to-date conference materials.

Civil Rights

10. NCD should seek to develop additional enforcement strategies for ADA beyond litigation and other current strategies.

11. NCD should regularly convene national forums to develop strategies to guide enforcement of civil rights laws.

12. NCD should work with the American Bar Association to encourage attorneys to undertake pro bono disability rights cases.

13. NCD should work with other relevant federal agencies to develop mechanisms to ensure that regulations and proposed regulations that affect people with disabilities are communicated to the communities that will be affected by them.

14. NCD, or a consumers-controlled task force, should develop standards for required education and training of all federal agencies and recipients of federal funds. NCD, or the task force, should monitor compliance with the training requirement.

15. NCD should celebrate the anniversary of the enactment of ADA by launching a "Barrier Buster Campaign" that would yield a report card on the status of America's accessibility.

16. NCD should develop a task force to consider and determine strategies to address managed care as it affects people with disabilities.

17. NCD should undertake research on the development and management of sign language interpreter resources.

Health Insurance and Health Care

18. NCD should assemble an advisory committee to work with DOJ to develop regulations for ADA and the Rehabilitation Act that clarify how disability discrimination laws apply to private health insurance companies and health plans as public accommodations (Title III), instrumentalities of state and local governments (Title II), federal contractors (Section 503), and recipients of federal funds (Section 504).

19. NCD should develop a direct working relationship with the disability-related institutes at the National Institutes of Health to ensure that the views of Americans with disabilities guide and support NIH policies and funding.

International Issues

20. NCD should explore ways to utilize the expertise, resources and skills that have been developed in the context of international development and technical assistance to persons with disabilities and make them available to Native American populations.

21. NCD should promote the development of a curriculum on international disability policy issues which should be an integral part of postsecondary programs with an international focus.

22. NCD should provide leadership to enforce full accessibility as defined by Section 504 of the Rehabilitation Act in U.S. embassies, consular offices and U.S. AID missions.

<u>**Multiple Chemical Sensitivities**</u>

23. NCD should catalyze action on multiple chemical sensitivities in the appropriate federal agencies to expand and enhance the rights of those with these disabilities.

24. NCD should engage in and urge Congressional authorization and funding for a comprehensive education, research and policy development agenda to address multiple chemical sensitivities and related disabilities.

APPENDIX B

EMERGING ISSUES

The following are brief summaries of the "emerging issues" group meetings held during the National Summit on Disability Policy. Issues that were beyond the scope of the 11 policy areas or that required further exploration were identified by Summit participants who then formed groups to discuss them. Summit participants were free to attend any group meeting they chose.

Multiple Chemical Sensitivities
Discussion led by Mary Lamielle

Decision makers are generally unaware of the disability called multiple chemical sensitivities and lack information about the chemical and environmental barriers that preclude access and accommodations for people with this disability. Most people with this disability find it difficult to achieve a reasonable quality of life because, owing to environmental exposures, they are frequently denied access and accommodations in the most basic and essential areas of their lives, including housing, employment, and education, and in their efforts to secure basic goods and services. The nature of these barriers and their impact on this population must be integrated into any policy response to this disability.

Complementary Medicine
Discussion led by Anne Seggerman

Complementary medicine and therapies include centuries-old treatments such as acupuncture, herbal medicine, chiropractic treatment, homeopathy, and European and Asian traditional medicine. A 1993 study reported that one in three U.S. citizens use complementary therapies, and a majority of these people do not inform their primary care physician.

The value of complementary medicine is widely known in the prevention of secondary disabilities. As the availability and benefits of complementary medicine become more widely known, more people will become advocates and users of these therapies. Complementary medicine has the potential to enhance the quality of life and, according to people who use these therapies, can save lives when orthodox medicine is not effective.

Native Americans
Discussion led by Ela Yazzie-King

Representatives from different tribal nations attended this meeting. Each tribal government has its own unique structure and there is no uniformity in attitudes toward Native Americans with disabilities, their treatment or their rights. It appears that the ADA does not cover Native Americans if they choose to live in tribal lands. Each tribal government has its own rules and regulations. Services provided by the Indian Health Service are frequently minimal. However, the climate is generally positive toward more inclusive services for Native Americans with disabilities.

Cross-over Between Health Care and Long-Term Services
Discussion led by Bob Griss

Cost containment strategies of managed care plans may be based on reducing utilization or increasing economies of scale, both of which are incompatible with consumer-directed services. The danger is that managed care plans will be attracted to combining acute and long-term services by the higher capitation payment that long-term services would bring. Some advocates of specialized managed care believe that nonprofit specialized providers might be more sensitive to the ideology of consumer-directed services. Critics of managed care believe equally strongly that nonprofit providers will be forced to resort to reductions in utilization or increases in economies of scale by the competitive process or the shrinking of public payments, especially in specialized Medicaid-only managed care plans. There are very few managed care plans that currently combine acute and long-term services. In states where this is being tried (as in Minnesota) the managed care plan has attempted to replace consumer-directed personal

assistance services with a contract to a Medicare-certified home health agency. If long-term services are combined with acute care, both may be overly medicalized; if they remain separate, coordination problems will remain. Ideally, long-term services should be structured to wrap around the limitations of the acute care benefit. Both the problem of overmedicalization and the problem of coordination have been overshadowed by political strategies to protect existing Medicaid dollars for persons who have been benefiting from them.

Targeted vs. Integrated Managed Care
Discussion led by Peter Thomas

One of the most contentious disability issues in the health policy arena concerns the manner in which managed care plans, particularly capitated arrangements, should be compensated for high users of care (e.g., people with disabilities who are ill and have chronic conditions). Because capitation relies on a set payment for a person's entire care, people with disabilities often experience underservice in these types of managed care plans. Risk adjustment mechanisms would resolve much of this problem but reliable risk adjustment is still in its infancy. An alternative, which has begun to appear in Medicaid programs across the country, is to "carveout" certain populations that have frequent or ongoing specialized health care needs. Other alternatives include carveouts in which health plans would be responsible for all of the specialized health needs of a population but would receive extra payments for such care.

Targeted approaches to the care of people with disabilities may lead to further segmentation of the market. Such targeting is dangerous because, over the long-term, it could damage cross-subsidization, which enables high users of care to have their needs met. On the other hand, capitated systems were not designed for people with extensive or ongoing specialized services; therefore, targeted approaches offer the promise of ensuring appropriate health care for people with disabilities. People with disabilities must study the existing programs that utilize targeted approaches and take a position before these programs proliferate. The U.S. Health Care Financing Administration should consider the potential implications of targeted managed care programs, before investing in such programs, which could have a long-term detrimental impact on people with disabilities.

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Research
Discussion led by Mitch LaPlante

Disability-related research and data collection have yet to be driven by the values of the ADA. Questions asked on surveys often reflect a medical model rather than an independent living model. Data collection and analysis efforts of the Federal Government are lacking in comparison to other protected groups, such as women and African-Americans. The economic assumptions that are implied in typical cost-benefit analysis need to be re-evaluated in light of the new disability paradigm embodied by ADA. There are too few researchers who are people with disabilities.

Disability Culture
Discussion led by Bruce Curtis

People with disabilities...share a common history of oppression and a common bond of resilience. We generate art, music, literature, and other expressions of our lives, our culture, infused from our experience of disability. Most importantly, we are proud of ourselves as people with disabilities.

> Steve Brown
> Institute on Disability Culture
> 1996

People who attended this session were interested in exploring the existence and nature of disability culture. They began by affirming that the concept of a disability culture is a positive, proactive proclamation of pride. The arts and culture are crucial to the identity of all humans. Participants concluded that pursuit of mainstream inclusion and development of a unique disability culture were not incompatible.

Disability culture exists because people with disabilities share common experiences, such as physical and mental rehabilitation, oppression, discrimination, and civil rights demonstrations. Disability culture has artifacts, rituals, humor, and history, as well as shared experience. It can foster self-pride, self-advocacy, and community organizing.

People who share disability culture also belong to other affinity groups or cultures. Women, gay men and lesbians and people with religious and ethnic affiliations enrich disability culture with their diverse experiences. Parents of children with disabilities also share part of a disability cultural identity.

Disability art adds the particular life experience of the disabled person to the artistic statement, taking the art form in a new direction and redefining it. Disability culture is a direct reflection of the life struggle of disabled people.

It is important to collect, archive and disseminate information about the history of the disability community and the development of disability culture. People with disabilities, particularly young persons with disabilities, will benefit from knowing about the struggles and successes of the disability community, including the identity of role models. Disability history and culture should be part of high school and university curricula.

Physician-Assisted Suicide
Discussion led by Diane Coleman

Physician-assisted suicide has recently been declared a constitutional right in the second and sixth Court Circuits─thereby affecting 12 states. Some participants in this discussion believed that individuals should have a right to assisted suicide, such as by lethal injection. Others, however, felt that the risk of abuse against people with disabilities is too great to condone such a practice.

Genetics Issues
Discussion led by Gina McDonald

The group expressed serious concern that many professional genetics counselors do not have enough knowledge about disability rights and pride to counteract the negative public reaction to the possibility of a baby's being born with a disability. Many counselors are overly cautious, tending to err on the side of telling prospective parents that they are likely to have a child with a disability.

The group called for training for all genetics counselors about disability rights, disability pride, and specific knowledge of possible quality-of-life outcomes for specific disabilities. Statistical information about the frequency of disability under various circumstances should be readily available. Parents who are told that there is a possibility of having a disabled child should be referred to community resources such as Centers for Independent Living and Parent Training Centers. The group noted that laws requiring that all fetuses be treated equally should be strongly enforced.

APPENDIX C

NATIONAL SUMMIT ON DISABILITY POLICY

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APPENDIX D

REMARKS BY MARCA BRISTO, CHAIRPERSON
National Council on Disability
National Summit on Disability Policy
April 27, 1996, Hyatt Regency Dallas

I look out at all of you and think what an absolutely incredible group of people we have here today. I think it's fitting that we are at Reunion Plaza. For me, this truly is a reunion. Just before I came in here, I was expressing my anxiety about the process, when I remembered that my artist friends tell me that the sloppier the process, the better the final product.

One of the people here turned to me and said, "It reminds me of the old Chinese proverb, 'Out of chaos, brilliance.'" You are the brilliance. We are the chaos. In any case, you are what brought us here. In my view, the greatest accomplishment of the National Council on Disability and its groundbreaking 1986 report, *Toward Independence*, has been the increased empowerment of people with disabilities—the heightened belief that we ourselves can make a difference. It is that commitment, that belief, and that principle that have gathered us here today.

Putting this summit together has been quite a journey. We started with *Toward Independence* as our foundation, an active advisory body, and a lot of dedication on the part of the people who have been working behind the scenes. We've looked at where we've been. We've looked at the progress of the last decade. We've looked at our achievements, and we've looked at the gaps and the problems that remain. We've begun to take a look at where we're going. That's why you are here. It requires an enormous leap of faith to take us from where we are today to where we hope we'll be Monday evening when we all go home.

The Council is committed to the principles of the Clinton administration—and we hope of all Americans—empowerment, independence, and inclusion. We challenge you to take those

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principles, apply them to the areas you'll be working in, and try to bring us closer to the values they represent. As we engage in this process, we need to remember the lessons of history and to consider the context in which we find ourselves today.

The world is changing rapidly. Budget pressures, economic pressures, globalization, the shrinking of the world's community, the change in politics in Washington, a shift in power from the Federal Government to the states, and the vast telecommunications revolution are but a few of the forces surrounding us.

We have changed also. How we in the disability community experience life today is quite different from the way we and our peers did only 15 short years ago. And most important, the attitudes toward our achievements have changed as well.

On the one hand, we see new hope and a new understanding of what our potentials and possibilities are. However, on the other hand, as with other political and social movements, just when we seem to be at the brink of achieving our goals, there is a backlash that comes along to stop us.

Our leaders, such as Ed Roberts, have challenged us to modify outdated attitudes and systems of public policy in order to force a paradigm shift. And as we do so, we cannot rest on our laurels. The post-euphoria period of the ADA has been a deep problem for us. We have not adequately prepared for the resistance we should have expected or the myths about the ADA that have persisted.

Leaders from other movements have taught us the lessons of backlash. Susan Faludi, a feminist author, refers to its subtle disguises. If we do not recognize them, they will divide and conquer us, breaking us up, pitting us against each other, isolating one disability group only to attack the next. We see that happening today: rewarding people who play the game and follow the rules of the good-old-boy network and punishing those who stand up for the new order.

Old myths are remarketed as if they were new truths, and we return again and again to face the very attitudes we have been working so hard to dispel. Backlash is at its worst when it goes within, challenging the sense of self that we, as individuals and as a group, have worked so hard to achieve. When we turn the backlash against ourselves and begin to accept those

discriminatory patterns, when we begin to believe that maybe we're asking just a little too much, we have to take a good, hard look at ourselves and each other.

Your presence here today strengthens our vision of a new world order that brings people with disabilities into the whole circle of life. It is also a testimony to your belief that we ourselves can be a significant force for change. Gloria Steinem calls this the "revolution from within."

That is your challenge today: to begin to paint a picture of where you want to be and to insist that, no matter what the odds, you will not give up. Ten years ago, who would have thought that the Berlin Wall would fall, that Nelson Mandela would be released from prison, or that the Soviet Union would break apart? Only those involved in these visions and struggles would have believed that such outcomes could be possible. We stand at a critical juncture where there are two paths: one embraces life, the other leads toward death. And folks, let me emphasize, these choices exist right now.

Consider the issue of health reform, the drive toward rationing and its potential impact on people with disabilities. We can only counteract this trend if we act together. Remember what happened in Oregon when the community used the ADA to reject the Oregon Medicaid waiver. Reflect on what happened in New York City where again the ADA was used to achieve similar ends. Recall the case of the young person who was denied a heart-lung transplant simply because he had a disability. In each case, the ADA and other tools we have fought so hard to win were used and the needs of the disabled community were not compromised.

My good friend Hugh Gallagher recently wrote a book that compares the priorities of the American health care system to the extermination of people with disabilities in pre-Nazi Germany. I share with you one section of that book to remind us of the stakes before us.

> *In Germany, treatment decisions regarding disabled patients were not made by attending physicians. Their roles were simply to provide information detailing the extent of disability, length of treatment, and the prognosis for recovery and return to useful employment. Completed questionnaires went to a committee of respected physicians who determined whether the patient was*

worthy of further medical treatment. These decisions were based on economic, social, and medical criteria.

Only when a majority of the committee favored "final medical treatment" was a patient's questionnaire forwarded for higher review. When the appeal board confirmed the original decision, the patient was sent to a euthanasia center.

At each stage of the process, responsibility was denied. "I simply filled out a form." "I only gave an opinion." "I only helped draft the guidelines." "I just carried out the order." "The decision was made by someone far senior than me."

Who is making such decisions for us today? The stakes are enormous. Therefore, I ask you today to accept the challenges we have put before you: to latch onto your vision, to test the limits, to believe in yourself. The Council believes in you. We have learned from our heroes in the civil rights movement that our goal must be not only to end segregation but to create and foster integration within a truly supportive community.

Martin Luther King reminded us of this when he said:

Desegregation will break down the legal barriers and bring men together physically. But something must touch the hearts and souls of men so that they will come together spiritually, because it is natural and right. A vigorous enforcement of civil rights laws will bring an end to segregated public facilities which are barriers to a truly desegregated society, but it cannot bring an end to fears, prejudice, pride, and irrationality. Those dark and demonic responses will be removed only as men are possessed of the invisible inner law which etches on their hearts the conviction that all men are brothers and that love is mankind's most potent weapon for personal and social transformation.

A few years ago, I had the opportunity to introduce Gloria Steinhem at a meeting. She expressed these thoughts in a different way. She said, "We can go nowhere until you can go everywhere." My dear friend Justin Dart, who has been my inspiration through this process, has

joined many others in reminding us that disability is a normal part of the human condition that is to be embraced and celebrated.

Let us dedicate our work today to the belief in ourselves and to our heroes Ed Roberts, Wade Blanck, Irv Zola, Tim Cook, Elizabeth Boggs, and many others who have given their lives to promoting changes in outdated attitudes and to charting a path that will alter world history. Let us also embrace the 25 young people who are here today to share and learn with us. They represent our future. You have a tremendous opportunity and responsibility to help pass on this vision. Thank you very much for being here.

APPENDIX E

REMARKS BY JUSTIN DART
National Council on Disability
National Summit on Disability Policy
April 27, 1996, Hyatt Regency Dallas

Our movement, our culture, stand at an historic crossroads.

Angry about a runaway national debt and other growing pains of democracy, well-meaning Americans are tempted by a politics of blame and retreat. The ADA and the IDEA are under attack. The public services that empower people with and without disabilities are under attack. Our very right to live is under attack.

On the positive side, science and democracy offer a golden age of human culture in the 21st century, if we, as a people, have the courage to act.

Frustrated by a dream so close, and yet so far, Americans cry out for a vision based on shared values, common sense and a record of practical solutions. You have created that record, that vision.

I propose a revolution of empowerment. A revolution that will empower every 21st century American to live his or her God-given potential for self-determination, productivity and quality of life. I propose a new vision of free enterprise─free enterprise that systematically includes all, in its process, in its fruits.

I congratulate Marca Bristo, Audrey McCrimon and all the members and staff of the National Council. At a time when others are retreating or defending, Marca is calling us forward, to create disability policy that fulfills the American dream.

How do we approach our task? An initial thought.

Common wisdom: Accept political reality. Don't suggest visionary changes. You might be accused of radicalism. You might not get anything. Don't rock the boat.

No. If you have no vision of your destination, how in the world are you going to get there? Fear of rocking the boat has killed great companies and great cultures. Thomas Jefferson, Thomas Edison, Ed Roberts, all the pioneers of 504, independent living, IDEA and the ADA

were all radicals who rocked the boat to victory. Practical politics, of course. Practical first steps, of course. Transcending vision, absolutely.

Before we create the policy, we've got to define the problem. And the potential. What is America's problem?

The politicians of retreat say socially responsible national government hasn't worked. They say go back to the good old days. They say pass social responsibility from the Federal Government to the states and cities, to the businesses, the charities and the families. They say the marketplace will provide rights, services and prosperity. They say ADA, IDEA, mainstreaming people with disabilities is too expensive, they say people with disabilities are a small minority of tragic victims that can be taken care of through minimal welfare and charity.

We say no!

Our vision: Socially responsible government is the heart, the soul, the success of America. We founded a new nation on a revolutionary new principle—all people are created equal—each human life is sacred.

All people are endowed by their creator with certain unalienable rights...life, liberty and the pursuit of happiness, that to secure these rights governments are instituted among men.

With government protecting, empowering wave after wave of oppressed people, America produced the greatest prosperity, the greatest quality of life in human history.

When people with disabilities are empowered America will be enriched again.

There's nothing wrong with responsible government. America's problems with debt, poverty, hostility, crime, the family, are the natural growing pains of our astounding success.

But however deserving they may be, are not people with disabilities, after all, a tragic minority that is only marginally relevant to the mainstream of culture? This monstrous fallacy is the foundation of most barriers.

We are not a tragic minority. We are a magnificent, triumphant majority.

Vision: Science and democracy have created a new human. The majority of Americans will triumph over death to live with a disability at some point in their lives. Every single American family will experience disability. Disability is a normal characteristic of the new

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human. Policy that does not meet the needs of people with disabilities does not meet the needs of anyone.

Vision: Science gives all the new humans, with and without disabilities, a new potential to be a hundred times more productive, to live immeasurably better than our strongest, smartest, richest ancestors of only 200 years ago. But we are not allowing old attitudes, old systems to limit the magnificent potential.

Vision: America's task now is not to go back, not to defend the adolescent status quo. Our task is to go vigorously forward, to focus the full force of science and free enterprise on creating a new culture that will enable the new humans to live their new potential.

We must learn the lesson of democracy in every nation: Success has resulted not from an unbridled free market, not from well-meaning socialism, but from government promoting and protecting the empowerment of the individual to exploit the power of free enterprise, and science, to produce and to live the good life.

We must eliminate the residue of pre-science, pre-democratic paternalistic culture that blocks progress, and complete the culture of empowerment.

Empowerment is when we say no to the primitive illusion that society, government, the free market, the public media, are some sort of paternalistic supergods that can give us truth, equality, and prosperity.

Empowerment is when we understand that society is nothing more than what we as individuals think and do every day. We are society. Only when we govern ourselves is there government. Only when we produce is there production. The legitimate purpose of society and its governments, therefore, is not to govern people and to provide the good life for them, but to empower them to govern themselves and to provide the good life for themselves.

Empowerment is when we understand that inalienable rights are inseparable from inalienable responsibilities. Each one of us is inescapably responsible to participate in democratic government, to invest all of our abilities and resources in producing lives of quality for ourselves and for all. Family values, absolutely! In interdependent modern society you cannot be responsible for the members of your own family without being responsible for the society in which they live and the air that they breathe.

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This is not a philosophy, it is a fact. It is not a new fact. It was clearly stated by Abraham, Jesus, Buddha and Mohammed.

Empowerment is when we understand that policy for an age of science and democracy cannot provide packaged solutions; it must provide a framework of principles and goals through which the trial and error of the scientific method can flow; it must enable all individuals to make the decisions, indeed to make the so-called mistakes, which are essential to the success of science and democracy.

Empowerment means choices.

These are some of the foundational concepts of a culture that empowers.

But what specific form will empowerment policies take? That is up to you, and to the trial and error of science.

Let me give you some random focuses. You will create more and better ones.

Vision: Our task is not to weaken government, it is to strengthen government. Our task is to cut the massive fat and the oppressive paternalism out of government, to eliminate the deadly domination of government by special interests. Our task is to greatly strengthen the ability of government to systematically empower all people to govern themselves and to produce the good life for themselves and for society. Our task is to infuse government with the best methods of independent living and free enterprise.

Vision: ADA and IDEA are cornerstones of the empowerment culture. They empower all Americans to participate, to produce. ADA and IDEA and other disability rights laws must not be weakened. They must be vigorously implemented.

Vision: No more billion-dollar Band-Aids on ghettoes and obsolete, high-overhead infrastructure. Government joins with free enterprise to create new communities where clogged highways, ghettoes, pollution and high taxes are replaced by compact, accessible, affordable environments. Accessible, affordable housing, commerce and recreation. Comprehensive systems of public transportation that take you where you need to go. Free enterprise gave us the shopping center. Now give us the shopping-living-working center.

Vision: All new technology for public use, required by law to be accessible and affordable to all. Accessible telecommunications makes every home, office, farm, hospital room and prison cell, into a university, a place of work, a shopping and commercial center.

Vision: Traditional public and private services, completely recreated, completely integrated, completely individualized, to foster empowerment. A computerized, one-stop, one-file continuum of services—from personal assistance, health care and employment, to economic aid and individualized counseling—available 24 hours a day to every person from birth to death. Guaranteed and coordinated by government, but with individuals making final choices from among the full spectrum of options provided by all levels of government and free enterprise. No forms. No waiting for offices to open. No bureaucrats telling you to call another number.

Vision: Lifetime education, a universal supermarket of educational choices, including higher education, guaranteed to every citizen. An educational Internet which opens the resources of Harvard, the Library of Congress, and the private sector to every person. A portable computer for every primary school child. Public service and private industry internships for all.

Vision: Comprehensive, quality, lifetime health care guaranteed to all. With complete choices for consumers. Including long-term, consumer-controlled personal assistance devices. Patient's rights, including the right to live, protected by law.

Vision: International policy characterized by a strong but reduced, streamlined military, and America as the world's most articulate voice for the rights and the empowerment of the individual. The disability community should be funded to play a leading role.

Vision: Balance the budget. Absolutely! And pay the national debt. In a bankrupt America, people with disabilities will be the first to suffer and die. The 225 billion dollar annual interest on the national debt will pay for the empowerment culture.

If every American carries his or her fair share of the load, we can balance the budget without depriving one single American of his or her federally guaranteed right to Medicaid, Medicare or any of the basic services that are essential to a life of productivity, dignity, and quality.

Vision: No tax cuts for anyone until we balance the budget, pay the debt and every person is receiving quality health care and empowerment services. Cutting investments in

productivity to provide short-term benefits for the wealthy violates the most fundamental principles of good business.

Vision: Government, the private sector and the disability community initiate a major campaign to educate America about the rights and the potential of people with disabilities, about the concepts and methods of empowerment. This will require presidential leadership and bipartisan leadership at every level of government. It will require substantial funding, including funding which empowers the disability community, business, education and the media to participate meaningfully.

This is an ambitious agenda with a magnificent potential. It is within our power to create a golden age of science for life, a quality of life for all Americans that exceeds the imagination of utopian fiction.

But can we afford to create the empowerment culture—to expand public services, to build new communities. We can't afford not to do it. The status quo is bankrupting us. Investment in empowerment will dramatically lower the overhead and increase the productivity and the quality of American life. It will create millions of new jobs. There will be an explosion of small business when guaranteed, portable, empowerment services liberate people to work where they choose. There will be an economic boom that will dwarf the industrial revolution. America will renew its economic and moral leadership of the world.

Nothing could be more Republican, nothing could be more Democratic, nothing could be more in harmony with family values, with reforming welfare, reducing the deficit and with the American heritage than empowering all Americans to participate in free enterprise democracy.

Empowerment in America is possible. We have the money. We have the technology. But do we as a nation have the will and the courage to change?

How can we possibly overcome the powerful lobbies for retreat—and for the status quo?

Even our oldest, strongest friends in government seem to be overcome by a tidal wave of hostile, escapist politics. Credible people are leaving public service.

Who will save the dream? Who will make the dream live?

Look around the room. The buck stops here.

We are responsible. We of the disability community are responsible to every American family, present and future, because every family will experience disability. We are responsible to every family in the world, because the world is watching the ADA and the IDEA. The world is watching American democracy.

The world will follow what we do. Failure is unthinkable.

No soldier ever died in a better cause.

You who have done so much—we together—have got to do more. We've got to win. Where do we start?

We start by getting off the defense and onto the offense.

Create the vision. Shout the vision. Build the new culture. Many of you are already doing it. But for every one of us, we've got to empower a thousand new leaders.

The elections of 1996 give us a once in a century opportunity to communicate our vision.

I believe this is the most important time of decision for America since the Civil War.

Will the United States of America maintain the authority to guarantee its citizens the basic rights and services of civilized society, or will that authority be passed to a confederacy of local governments, special interests and charities?

Get into politics as if your life depended upon it. It does.

We of the disability community must be represented, our message must be shouted in all campaigns. Yoshiko and I have made a decision of conscience—you will make yours. But whatever campaign we as individuals support—Clinton, Dole, Republican, Democrat, independent—we must not attack each other. We must remain united in the foundational values of the disability community—ADA, IDEA, empowerment.

United we win. Divided we lose.

Beloved colleagues, I've made a long speech. My words are inadequate. Listen to the heart of this old soldier.

As I face the defining battles in 1996—maybe the last great battles of my life—I agonize over my responsibility to you and to the life in the future. I raise my passionate prayer for the will and the wisdom to transcend my weaknesses and give all that I am.

And thank God for you. You have proved that the American dream can live. You have made miracles in thousands of lives like mine. I owe you so much. I love you so much.

My beloved mentors and peers in justice: Marca, Liz, Gina, Bob, Bruce, Michael, Howard, John, Rae, Nancy, Debbie, Marilyn, Max, Colleen, Gerben. My beloved colleagues in Justice for All, Becky, Fred, Mark.

I thank God for each and every one of you here today. I love you.

I reach out to each and every one of you. I ask your guidance and your inspiration. I ask for the privilege of fighting at your side once again.

Let us embrace and lift each other. Let us go forward in the great tradition of Washington, Lincoln, Martin Luther King, Wade Blank, Ed Roberts and Elizabeth Boggs. Let us greet intimidation with courage, hate with love, demagoguery with simple truth.

Let us overwhelm fear and fallacy with our vision of an America that includes all, that empowers all.

Let us embrace America, from sea to shining sea. Let us bring America together, men and women, young and old, people with and without disabilities, Republicans, Democrats, and Independents, business, labor, rich, poor, and middle class. Let us bring America together, Blacks, Whites, Browns, gays and lesbians, Christians, Muslims, and Jews, pro-lifers and pro-choicers. Every American has a valuable and unique contribution to make.

Let us shout together, each in our own way. President Clinton, Speaker Gingrich, Senator Dole, America, join us in creating empowerment USA. Free our people. Free enterprise for all.

America, join us in keeping the sacred pledge: One nation under God, indivisible, with liberty and justice for all.

Colleagues, I do love you. Together, we shall overcome.

APPENDIX F

DESCRIPTION OF THE NATIONAL COUNCIL ON DISABILITY

Overview and Purpose

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, the 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 the Congress, on a continuing basis, advice, recommendations, legislative proposals, and any additional information that NCD or the 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, the 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 the Congress an annual report titled *National Disability Policy: A Progress Report*.

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

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 ADA. NCD's present list of key issues includes improving personal assistance services, promoting health care reform, including students with disabilities in high-quality programs in typical neighborhood schools, promoting equal employment and community housing opportunities, monitoring the implementation of the Americans with Disabilities Act, 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.