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Achieving Independence: The Challenge for the 21st Century

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

A Report to the President and Congress

from the

**National Council on Disability
Marca Bristo, Chairperson**

**a product of the
National Summit on Disability Policy
Dallas, Texas
April 27, 28, 29, 1996**

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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We have an outdated system of public policy based on outdated attitudes toward people with disabilities.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
1988**

In 1986, the National Council on Disability 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 last decade.

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

A National Summit on Disability Policy

In keeping with the values of empowerment and consumer directed policy making, the 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 to participate in the Summit. Three hundred participants were chosen (see Appendix C for a list of all participants) utilizing 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 the NCD and the Summit Advisory Committee after reviewing 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.

With some trepidation and the sense of undertaking a risky, daunting, complex and potentially controversial challenge, the NCD proceeded into a great experiment in democracy. People gathered in Dallas from April 27-29 from each of the 50 states and the District of Columbia. People with all types of disabilities were represented as well as parents and family members. About 20% of 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 (see list in Appendix C) provided technical assistance and background information. A special emphasis was placed on youth with disabilities. Twenty young people with disabilities from age 13-22 participated fully, providing a glimpse of tomorrow's leadership and invigorating today's

dialogue.

Inspired by opening remarks from NCD Chair, Marca Bristo and disability rights leader, Justin Dart (see Appendix D and Appendix E for remarks), Summit participants met in policy working groups for three days. Led by volunteer facilitators who were chosen from among the participants, the groups brainstormed about their policy area -- 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. While they were reviewed and amended by the NCD, they remain true to the thinking and deliberations of the people who attended the Summit -- and are thus reflective of a cross-cutting set of people with disabilities and disability leaders throughout the nation.

Summit participants had the opportunity to organize additional groups to discuss topics that they felt were not addressed within the 11 topic areas. XX of these "Emerging Issues" groups were formed. A summary of these discussions appears in Appendix B.

The experiment in Dallas proved to be a great success of democracy in action. The diversity of people participating -- in terms of their disabilities, their ethnic/racial backgrounds, their geographic homes, their genders, their ages, and their viewpoints was remarkable. To our knowledge, such an event has never before occurred. When provided with the opportunity to change policy, people with disabilities are effective and thoughtful analysts and contributors. The NCD counts this event, in and of itself, as an important outcome of the Achieving Independence initiative.

Conclusions

The 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.

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 the ADA and many other laws listed in this report in the last decade are 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, challenges the progress of the past decade.

2) Most public policy affecting people with disabilities does not yet promote the goals of the

ADA — equality of opportunity, full participation, independent living and economic self-sufficiency.

Public policy continues to send mixed messages to people with disabilities about independence, on the one hand stating it 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 of 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 disabilities and their minority status.

4) 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 at some point in time. Thus, creating an accessible and inclusive society is important for all of us, not just for some of us.

5) When Americans with disabilities achieve independence, the benefits to society are compelling.

When Americans with disabilities are employed, educated, participating, tax-paying citizens living in the community contributing to the economic and social fabric, all Americans benefit. When federal funds become an investment in independence, rather than a trap of dependence, the economy and the culture prosper.

Overarching Themes of Recommendations

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

1. Existing laws should be more vigorously enforced.

Virtually every policy workgroup of the Summit discussed the need for greater enforcement of existing law. Lack of adequate resources dedicated to enforcement limits the impact of disability laws. A commitment to full enforcement by both the Congress and the Administration is imperative.

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 1990's is evidence of such lack of understanding and widespread mis-information. Public understanding can prevent needless lawsuits and needless mistakes, such as inaccessibly constructed buildings. 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 of full participation. Incentives to business, industry, state and local government, employers and other sectors of society to promote inclusion will support progress toward full citizenship.

5. Principles of universal design should be universally applied.

Most families will experience disability in their lifetimes. Ensuring that technology, housing, transportation and other aspects of community life are designed to accommodate the range of individual function and will ensure a more inclusive 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 in order to fully participate are not available to them. Too often those supports are only available 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 is 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 the ADA and achieving independence.

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, non-profit 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.

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Introduction

The National Council 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, the technology revolution 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 using computer programs. Computer literacy is becoming a basic skill for elementary school children. Card catalogues at public libraries are increasingly being replaced by on-line listings. The future promises expanded utilization of the information superhighway and 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, 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 flex-time, 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 nation's 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 true in the disability community as much as it is in other sectors of society.

It is in the context of these general societal trends that the National Council embarked on an assessment of the progress in the last decade in disability policy and agenda setting for the future. The goals of the 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 from the progress in disability policy. Native Americans with disabilities and Indian tribes are sometimes not covered by the laws and programs described in this report, or covered in part. Since tribal governments are separate government entities, the application of federal law is unique and often unclear. For example, the extent to which the ADA applies to Indian tribes is still being determined.

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

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.

The NCD intends this report to address all people with disabilities, no matter what their disability or their other characteristics. People with disabilities are a distinctively 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 purposes of this report.

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

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 died at birth now live. People injured in car accidents, diving accidents and war now live, when once they did not. 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.

A Profile of People with Disabilities

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% of the population less than age 18 has a disability, 84.2% of those age 85 and over have a disability. Of those age 18-44, 13.6 % have a disability, while of those age 45-64, 29.2% 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% of Whites had severe disabilities, compared to 12.7% of African Americans, 11.7% of American Indians, Eskimos or Aleuts, 9.1% of those from

Hispanic origin and 4.5 % of Asian or Pacific Islanders. Males had a disability rate of 18.7% and a severe disability rate of 8.1%. For females, the corresponding rates were 20.2% and 11% (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, while only 14% of people without disabilities have less than a high school education; 34% 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% to 22.4% between 1986-87 and 1991-92. Between 1984-5 and 1991-2, the percentage of students with disabilities completing high school rose from 55% to 64%. (U.S. Department of Education 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 post-secondary education programs, less than half the rate of youth in general (U.S Department of Education 1993). However, in 1991 almost 9% of college freshman were students with disabilities, whereas in 1978, less than 3% were students with disabilities (U.S. Department of Education 1995a).

Among people with disabilities, minorities are less educated than non-minorities. For example, while 30.7% of whites with disabilities have less than a high school education; 43.3% 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% of people with work disabilities had incomes below the poverty level, compared to 10.2% of the working age population without work disabilities. Of those with severe work disabilities, 35.8% had incomes below the poverty level (LaPlante et. al. 1996).

While the average family income for all families was \$46,478 in 1995, 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% 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% of whites with disabilities were employed in 1995, only 19% of non-whites were working (Yelin 1996).

According to polls of 1000 people with disabilities 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%) than in 1986 (24%) (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.

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 rights 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.

Sen. Ted Kennedy
Senate passage of the 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 Rep. 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 1960's and 1970's 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 anti-war movement of the 1960's, the black civil rights movement of the 1960's and the feminist movement of the 1970's, 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 1960's 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 Judy 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 was formed to monitor and influence legislation, the American Coalition of Citizens with Disabilities.

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 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 ten 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 1996).

The Disability Rights Perspective

The disability rights perspective views people with disabilities as a minority group which has been subject to discrimination and unfair treatment -- in legal terms, a class of people. It stands in contrast to a charitable perspective 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 stands in contrast to a rehabilitation perspective, which involves viewing people with disabilities as in need of an expert or professional who can provide services to enhance the functioning of the individual. During the 1980's, the disability rights perspective has become the dominant perspective adopted by people with disabilities and reflected in public policy. One commentator has described the evolution of regard for people with disabilities as moving from "caste to class" (DREDF 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 of 1990 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. These include the Disability Rights Education and Defense Fund (DREDF), the National Council on Independent Living (NICL), the National Association of Protection and Advocacy Systems (NAPAS), the National Parent Network on Disabilities (NPND) and the Consortium for Citizens with Disabilities (CCD), which is based in Washington and comprised of over 100 national organizations.

The Disability Vote

With 35 million voting age Americans, the disability community constitutes a significant voting block. 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. A drive is underway within the disability community to register people with disabilities to vote.

Disability Culture

The past decade has witnessed the evolution of the notion of 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 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 world view, 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. Much in the same manner 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. Described as the study of the lived cultures and experiences of individuals with disabilities, disability studies is in its early stages of development.

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**

...I wanted to do that as a sort of a special way of thanking a very special person in my life who taught me at a very early age that people with disabilities could do anything that they set their minds to do and that people should be judged on the basis of their abilities and not on the basis of their disabilities.

In sign language, I just wanted to say to my brother Frank that today was my proudest day in 16 years of Congress; that today Congress opens the doors to all Americans with disabilities; that today we say no to fear, that we say no to ignorance, and that we say no to prejudice.

**Sen. Tom Harkin
Senate Passage of the ADA
July 13, 1990**

Society's formal methods for dealing with people with disabilities can be summed up in two words: segregation and inequality. As a society we have treated people with disabilities as inferiors and made them unwelcome in activities and opportunities generally available to other Americans.

**Former Sen. Lowell P. Weicker
1990**

The discriminatory nature of policies and practices which exclude and segregate disabled people has been obscured by the unchallenged equation of disability with incapacity and by the gloss of "good intentions." The innate biological and physical "inferiority" of disabled people is considered self-evident. This "self-evident" proposition has served to justify the exclusion and segregation of disabled people from all aspects of life.

Arlene Mayerson
DREDF Amicus Brief
Darrone Supreme Court Case
1982

Congress acknowledged that society's accumulated myths and fears about disability and disease are as handicapping as are the physical limitations that flow from actual impairment.

Arline Supreme Court Decision
1987

If society today allows wrongs to go unchallenged, the impression is created that those wrongs have the approval of the majority.

Former Rep. Barbara Jordan
1990

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 the 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

I think about at this moment many of the major bills that have gone through this House in the last 10 years....I remember the passage of the Americans with Disabilities Act when people in this country with all sorts of disabilities were thought somehow in some way to be second-class citizens...you ask the disabled have their lives changed as a result of the Americans with Disabilities Act, and most would say they have.

Former Rep. Kweisi Mfume
Farewell address to the House of
Representatives
February 1, 1996

The ADA has made me feel like a real American!

Gregory Dugan
Washington, DC
Voices of Freedom
National Council on Disability
1995

I wish I could say that racism and prejudice were only distant memories...and that liberty and equality were just around the bend. 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

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 justifications for their subordination in the same manner 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 that of other civil rights movements, has generated numerous civil rights laws over the last

twenty five years, beginning with Section 504 of the Rehabilitation Act in 1973 prohibiting discrimination against people with disabilities when federal funds are involved. Other legislation built on this foundation to expand the anti-discrimination 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, the Americans with Disabilities Act of 1990 (ADA).

The Americans with Disabilities Act

People with disabilities are now protected by comprehensive anti-discrimination legislation comparable to that for women, racial and ethnic minorities and the elderly. Modeled after the Civil Rights Act of 1964, the 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 the Americans with Disabilities Act was the key recommendation made by the National Council on Disability in the landmark report of 1986, Toward Independence.

The benefits of the ADA have been documented in detail elsewhere (Blanck 1994a; Blanck 1994b; Blanck 1996; Gostin & Beyer 1993; National Council on Disability 1995; U.S. Government Accounting Office 1994; West 1991; West 1996a; West 1996b). People with disabilities have experienced increased access to many types of environment and service, including town halls, public libraries, child care centers, court houses, 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 SAT exams. 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 the 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.

People with disabilities have increasingly come to identify themselves as a minority group and be identified as a minority group in public policy. The Harris Polls of people with disabilities revealed a 14% increase in the number of individuals feeling a sense of common identity with other people with disabilities between 1986 and 1994 (Harris polls 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.

The ADA is creating positive changes in American society and culture, enhancing the national tradition of celebrating diversity among our citizens. Notions of accessibility, accommodations and universal design are increasingly becoming a part of how America does business. People without disabilities are also finding benefits of the ADA, looking forward to a more accessible society as they age. Businesses have reported unexpected positive impacts by expanding their markets and tapping 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 the ADA.

The federal government has supported the provision of technical assistance to both entities covered by the 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 (DBTACs), 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 the ADA, including education, transportation, state and local government services, public accommodations and telecommunications. In 1994, thirty percent of working age people with disabilities indicated they had encountered job discrimination, up 5% from 1986 (Lou Harris and Associates 1994). People with disabilities continue to report obstacles to full participation in housing, transportation, education and access to public accommodations. People who are deaf and hard of hearing cite ongoing communication access barriers.

While the ADA has had some impact on the provision of health insurance, its comprehensive anti-discrimination mandate exempts many health insurance practices. Pre-existing condition exclusions, underwriting practices and caps on benefits continue to be commonly used practices that negatively effect 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 communications access to health care providers through the provision of sign language interpreters.

People who are labeled "mentally ill" are frequently subject to legal interventions applied only to them and on the basis of the label of "mental illness." Such interventions are blatantly discriminatory and 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 or substantial limitations on personal choice/freedom by the judicial system.

Federal Enforcement

Every relevant agency of the federal government has initiated activities to implement the Americans with Disabilities Act 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. The EEOC is slow in processing complaints; the Department of Justice is not investigating all the complaints it receives and the Department of Transportation is unable to track the complaints it receives. Despite a twenty percent increase in workload resulting from the enactment of the ADA, the EEOC received no additional resources to carry out the additional responsibilities. Both Republican and Democratic Administrations have requested additional funds from the Congress for ADA enforcement, yet they have not been forthcoming. Without the infusion of additional resources, federal agencies will remain unable to use their full authority to enforce the law. The ADA is at risk of being accorded lower priority than it had initially (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 people with disabilities and covered entities are unaware of the requirements of the law. For example, a 1994 survey found that only 40% 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. The media has highlighted "fringe" ADA cases and characterized the ADA as an example of government over-regulation. People with disabilities have often been portrayed as malingerers, using the ADA as a mechanism to avoid responsibility. People with disabilities see the ADA as a ticket into the workforce, into the marketplace and into the community, not 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 IDEA. Awards under IDEA were authorized so that they are parallel to those authorized under other civil rights laws.

The Civil Rights Restoration Act of 1987 (P.L. 100-259) amended section 504 and other anti-discrimination laws to over turn the Supreme Court "Grove City College v. Bell" case clarifying that the phrase "program or activity" was intended to apply to an entire institution in 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.

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 anti-discrimination on the basis of disability into the private sector, paving the way for the 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.

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 one half of the first \$10,000 of eligible costs of complying with the ADA.

The Developmental Disabilities Act Amendments of 1990 (P.L. 101-496) authorizes 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 the Americans with Disabilities Act.

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 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. Implementation of civil rights policies has too often been lackluster. Expansion in some areas is needed. In particular, minorities with disabilities face multiple and unique forms of discrimination and disadvantage that restrict full participation.

ENFORCEMENT

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 include not only significantly increased funding dedicated for enforcement of disability laws by the Department of Justice, the EEOC and other relevant federal agencies, but also empowering and encouraging the United States Attorneys, 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.

The Department of Justice and the EEOC are currently backlogged with numerous complaints from individuals with disabilities seeking to assert and exercise their rights under the ADA. The DOJ routinely returns complaints to complainants noting that they are 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 reshaped to be compatible with

recent Supreme Court decisions and fully implemented. Such implementation should not include the common practice of targeting only certain disabilities for such efforts. The National Council is opposed to the practice of targeting one or two specific disabilities. Instead, the entire class of people with disabilities should be targeted.

The Department of Justice should more vigorously enforce the Motor Voter Law, ensuring that people with disabilities are provided with voter registration services at appropriate locations.

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

STRENGTHENING CIVIL RIGHTS LAWS

2. Congress should enact legislation to strengthen current civil rights laws so that

- a) a private right of action is guaranteed to redress all violations and is not subject to waiver;**
- b) 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;**
- c) collection of costs and full attorneys fees is authorized without statutory limitation;**
- d) 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 rate of a particular group of people. Affirmative action requirements should be compatible with recent court decisions. They should not include quotas, reverse discrimination or preferences for unqualified individuals.

- e) public communications and telecommunications law is expanded to include the provision of captioning and audio description for all materials available to the public;**
- f) consistent standardized universal building codes are developed, implemented and required.**

MEDICAL DIRECTIVES AND PERSONAL CHOICE

3. The federal government should act to protect children and adults with disabilities by restricting the imposition of “do not resuscitate” and “no cardiopulmonary resuscitation” orders, or similar medical directives or treatments made on the basis of quality of life judgments. This policy should in no way limit the rights of adults with disabilities to make their own personal choices and exercise unrestricted control regarding medical orders and treatment for themselves. Individuals with disabilities who are considering such medical directives and/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 which are consistent with the Americans with Disabilities Act, to help eliminate discrimination, ensure equality of opportunity, full participation, independence and inclusion.

Nondiscrimination, independence, and inclusion should be the norms throughout the United States and the 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 public fund-raising or licensing. In other cases, violations of these standards would be a basis for revocation of professional licenses or disbarment of a corporation.

TECHNICAL ASSISTANCE

5. Congress should appropriate significant amounts of 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 the ADA. Agencies should collect information and develop a data base about effective implementation strategies.

6. The Congress and relevant federal agencies should ensure that organizations funded to provide technical assistance and training related to the Americans with Disabilities Act, including the Disability Business and Technical Assistance Centers (DBTACs), 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 the National Council on Disability. All training and technical assistance provided should be fully accessible in the broadest sense and reflect multicultural and cross-disability diversity.

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 education, 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 distribute materials directly as well as through federal, state and local governments and territorial authorities.

TRAINING FOR FEDERAL AGENCIES AND RECIPIENTS OF FEDERAL FUNDS

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, such as a task force, to provide for the development and administration of standards for such education and training programs. Such a mechanism could be a task force comprised of 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 multimedia 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 multi million 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

Separate educational facilities are inherently unequal. This inherent inequality stems from the stigma created by purposeful segregation which generates a feeling of inferiority that may affect their hearts and minds in a way unlikely ever to be undone.

Earl Warren
Chief Justice
United States Supreme Court
May 17, 1954

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

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.

Sen. Bill Frist
1996

All children with disabilities need access to integrated experiences where they can learn to function effectively. Correspondingly, non-disabled people need to learn to function with disabled people through such experiences.

Oberti v. Board of Education of the
Borough of Clementon School District
August 17, 1992

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.

Sen. Tom Harkin
1996

For youngsters with disabilities, like 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 non-disabled peers. Like people without disabilities, people with disabilities experience benefits in employment and economic well-being when they are well educated. Like people without disabilities, people with disabilities experience education as a life-long endeavor. The NCD believes that education of 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, has assured access to a free appropriate public education for elementary and secondary level students with disabilities since 1975. Before the enactment of the law, one million children with disabilities were excluded from school and another 3.5 million did not receive appropriate programs in public schools. Many were housed in large state institutions. Today 5.3 million students with disabilities receive special education services, 12 percent of the elementary and secondary school population.

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% of students with disabilities are in educational placements in regular school buildings, 40% are in regular school classes. During the last five years, the percentage of general education classroom placements has increased by about ten percent, while the use of resource rooms has decreased. Placements in separate classes and separate facilities have remained about the same. (U.S. Department of Education, 1995b.) IDEA authorizes the federal government to pay up to 40% of the cost of educating students with disabilities. The current federal contribution is approximately seven percent, with 12% being the maximum reached since the law's enactment.

The Americans with Disabilities Act and Section 504 of the Rehabilitation Act prohibit discrimination against students with disabilities in 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 ages birth to 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, 1995a). 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, 1995b). Because of individualized early intervention service, these students reach school better equipped to learn and participate.

Transition from School to Adult Life

By the mid-1980's, a number of studies and reports had documented high levels of unemployment, economic instability, dependence and social isolation among young adults with disabilities. These findings prompted the development of transition from school to work initiatives intended to assist students with disabilities in making successful transitions to adult life when they leave high school. Planning for transition takes place while students are still in high school, often emphasizing participation in work sites and other community based settings prior to graduation. Evaluations of transition initiatives in states are currently underway.

Post-secondary Education

Students with disabilities are increasingly participating in post-secondary education and higher education, however they remain behind their peers without disabilities. Section 504 of the Rehabilitation Act and the Americans with Disabilities Act 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 3 to 5 years, fewer than one-third had enrolled in post-secondary education programs, less than half the rate of youth in general (U.S. Department of Education 1993). However, there is some evidence of progress. In 1991, almost 9% of college freshman were students with disabilities, whereas in 1978 less than 3% were students with disabilities (U.S. Department of Education, 1995a.). The 1994 Lou Harris Survey indicated that the percentage of adults with disabilities who had completed some or all of college increased from 29% in 1986 to 44% in 1994.

Section 504 of the Rehabilitation Act and the Americans with Disabilities 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 1984-5 and 1991-2, the percentage of students with disabilities completing high school rose from 55% to 64%. The drop out rate decreased for high school students with disabilities from 27.4% to 22.4% between 1986-87 and 1991-92 (Department of Education 1994). Graduates out of school up to five years report employment rates about 18% higher than school dropouts (U.S. Department of Education, 1995a). However, students with disabilities remain less educated than students without disabilities in terms of high school graduation.

Despite this progress, students with disabilities still lag behind their peers without disabilities in educational outcomes. While both high school and college graduation levels have increased for students with disabilities, they remain lower than for those without disabilities.

There is a strong association between educational attainment and work disability. Twenty-two percent of people with less than a high school education report being unable to work. Two percent of those who have completed college report being unable to work. The explanation for this relationship is not straight forward. People with lower education levels are more likely to have jobs involving physical labor that put them at greater risk of developing a disability through accident. They may have less access to adequate health care, resulting in disproportionate long term chronic illness. Jobs that require higher levels of education often are more flexible for people with disabilities, frequently offering greater control over the pacing of work and options such as working at home. Thus, those with lower education levels may be at a disadvantage in the employment marketplace (LaPlante, 1995b).

School Reform and Students with Disabilities

Inclusion of students with disabilities in school reform efforts across the country has been of considerable concern to the National Council for several years. Historically, students with

disabilities have been excluded from school reform efforts. 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. Currently underway, the study will issue its final report in 1996.

Current Issues of Concern under IDEA

The NCD 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 (May 9, 1995). Key issues addressed in that report include the following.

Inclusion

While the principle of educating students with disabilities alongside their non-disabled 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 financial incentives promote the placement of students with disabilities in separate facilities. Placing students in segregated settings solely on the basis of their disability is clearly prohibited by law. However, when students with disabilities are placed in regular education classrooms without the support and services they need, their rights are also being violated. 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. Pressure from school reform to be accountable for student achievement may act as a further deterrent to general education teachers instructing students with disabilities in their classrooms.

Many schools, however, do serve students with disabilities quite effectively in general education classrooms. Where school districts throughout the country 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, over identifies children from minority backgrounds as disabled, 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 are over represented in special education. While about 12% of the general population of students are African American, about 24% of secondary special education students are African American (SRI International 1993). One researcher found 85% of students in special education programs in Chicago to be African American (National Council on Disability 1993). An analysis of Department of Education data found tremendous variation by state of the percentage of African American students in special education. While 47% of special education students labeled mentally retarded were African American in Alabama, only 6% were African American in New Jersey (Shapiro 1993).

Developing methods and safeguards to assure non-discrimination and equal access for minority students with disabilities is of critical importance. The impact of inadequate and/or inappropriate educational services extends well into the child's adulthood, where the employment rate of minorities with disabilities is less than that for non-minorities with disabilities.

Parent Participation

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 (IEP) meetings only to be presented with a completed plan. 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. While IDEA precludes the violation of the due process rights of students with disabilities, the vast majority of school districts have determined how to effectively discipline students without violating their rights.

In fact, there is considerable evidence that students with disabilities are inappropriately excluded/removed from school based on behaviors associated with their disabilities. A study of suspensions and expulsions in the state of Minnesota found that while 8-12 percent of the student enrollment was students with disabilities, between 16.5% and 33.3% of the suspensions were of students with disabilities (Minnesota Department of Children, Families and Learning 1996). A Delaware study found that students with disabilities accounted for the same proportion of suspensions as a result of weapon possession as students without disabilities (LRP Publications 1995). A Kansas study found no educationally relevant differences between acts leading to the suspension or expulsion of students with disabilities and those committed by other students. It also found that students with disabilities are more than twice as likely to be suspended/expelled as other students (Kansas State Board of Education 1995).

Many instances of disciplinary problems are the result of inappropriate, inadequate or non-existent 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. The NCD is greatly concerned about efforts to weaken the requirements of IDEA that would 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, assisting 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 assure that all children with disabilities between ages 3 and 5 were receiving appropriate services, as well as transition programs for adolescents.

The 1990 Amendments renamed the Education for All Handicapped Children Act (P.L. 100-630) the Individuals with Disabilities Education Act (P.L. 102-119), required transition services to be provided beginning 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.

School-to-Work Opportunities Act of 1994 (PL 103-239) authorizes funds for programs to assist students, including students with disabilities, in 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.

Recommendations

Despite progress in the last decade in educating students with disabilities, for too many students current federal and state laws have failed to deliver a free and appropriate public education for students with disabilities. Students with disabilities often still find themselves in forced and inappropriate isolation, separated from their non-disabled peers. Lack of accountability, poor enforcement and systemic barriers have robbed too many students of their educational rights and opportunities and 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 systems of education or 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 of teachers, systems change and training for parents and students about the new education policies. The following features should be included.

A) Placements

- 1) Unified educational or training systems shall presume that every child is capable of learning in an integrated classroom setting. Each classroom shall be assigned sufficient personnel to meet the needs identified in each student's Individual Education Plan. Individual students may challenge this presumption and seek a placement more suitable to their individual disability.**
- 2) Funding for education should be modified to eliminate the incentive for segregating students with disabilities. Placements should be based on educational need, not driven by funding mechanisms.**
- 3) Effective practices of inclusion of students with disabilities in general education should be expanded. ***
- 4) All students should have a right to an individualized education plan.**

B) Teaching

- 1) All teachers who are trained and certified should have the skills to teach students with disabilities alongside students without disabilities.**
- 2) The training and certification programs for all teachers should include general knowledge of disability education. .**

3) Specialists in particular areas, such. as braille, sign language instruction, and computer technology should be part of a cadre of resource personnel available to support the generic instructional program for students with a range of special needs as specified in their Individual Education Programs.

C) Curriculum

1) Curriculum and textbooks for all students shall be culturally sensitive and include the study of disability culture and disability rights.

2) Publishers of text books should include accurate portrayals of people with disabilities in textbooks and in photographs and illustrations.

3) All students, including those with disabilities, should be included in school reform initiatives

TECHNOLOGY

2. 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 in service and preservice

b) requiring the individual educational plan for each student with a disability to address assistive technology and other technology for use at school and at home as a part of the educational program

c) requiring schools to notify students with disabilities and their parents of assistive technology and technology funding options available for educational programs and to provide them as needed

d) maximizing the use of technology in order to promote participation by all students in the learning process

e) ensuring adequate funding for assistive technology

ACCOUNTABILITY

3. The Secretary of Education and Governors should enhance accountability for compliance with federal and state education laws and be held accountable for student outcomes. Specifically:

a) Principals, teachers and other staff should 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, extra-curricular and non-academic programs and activities.

b) School systems and state agencies should 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 should establish the same educational expectations for all students and be accountable for the results of student learning.

d) School systems shall presume that all students, including those with disabilities shall be included in statewide and other standardized testing programs. A small number of students may need alternative testing methods.

e) Personal and systemic sanctions should be imposed for violations of the Individuals with Disabilities Education Act, Section 504 of the Rehabilitation Act of 1973 as amended, the Americans with Disabilities Act and other relevant federal and state laws.

ACCESSIBILITY OF SCHOOLS

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

HIGHER EDUCATION

5. The President and the Congress should insist on strong enforcement of the ADA and the Rehabilitation Act in higher education settings and develop mechanisms to expand access and support services for students with disabilities seeking to enter or participating in post-secondary education.

CAREER PLANNING

6. The Secretary of Education and the Secretary of Labor should expand initiatives to promote effective transition from school to work and/or post-secondary education for all students including those with disabilities, including a career plan as a part of every special education student's IEP and a clear expectation that work is the ultimate goal.

*** 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 to transportation for students with disabilities.**
- 2) Schools should design student's schedule with their disabilities in mind, for example taking into account mobility needs when students are expected to change classes.**
- 3) Access to existing buildings, e.g more ramps elevators and accessible restrooms, should be increased.**
- 4) Students should have more time available to them for 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 curriculum that covers:**
 - a) the Americans with Disabilities Act**
 - 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 the 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
April 25, 1995
Indiana
(NCD ADA Report, p. 85)

Before the 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. We face many challenges ahead in assuring income security for those who cannot work and also encouraging employment for those who can work.

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% of federal funds spent on people with disabilities are targeted for supporting dependency. Little is spent on supporting people in pursuing and maintaining employment. Health insurance is too often only accessible by people with disabilities 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 work remain significant and working is too often an irrational choice. Entry level minimum wage jobs rarely pay enough for an individual with significant disability needs to be able to live on the income and meet those disability related needs. Essential services, such as personal assistance and assistive technology, are often only subsidized through public health insurance which is generally only available to people who are not working. Private health insurance often precludes coverage for

pre-existing 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 to support 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% in 1986 and 79% 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% of the 16.8 million working age non-institutionalized Americans with a work disability were employed, while 75% of working age Americans without a disability were employed.

Women and minorities with disabilities face dual discrimination and employment challenges. Their employment rates have consistently been lower than those for whites and for men with disabilities. In addition, African Americans represent a significantly larger proportion of working age people with disabilities when compared with whites or Hispanics, and as a group are more severely disabled. While the full time employment rate for whites with disabilities was 15.9% in 1992, it was 7.2% for African-Americans and 8.2% for Hispanic Americans (Braddock & Bachelder 1994). The earnings of women with disabilities with full time jobs were only 65% of earnings of men with disabilities 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 are less available to women than men in sheltered employment (Blanck 1991), as are promotion opportunities (Blass & Elliott 1993).

Employment Statistics

The Bureau of Labor Statistics in the Department of Labor 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 comparably collected or reported about 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 worker's

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 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 through the nation and offered training, job placement, re-education 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 work force.

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 1970's, the largest decline has been among disabled men age 55-64 (Yelin 1993). Women have increased their labor force participation steadily since the 1970's, however women with disabilities have experienced less of an increase than 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 non-disabled workers, though it has increased more for workers with disabilities (Yelin and Katz 1994)

The changing nature of work and economic restructuring provides both opportunities and challenges for people with disabilities. The increasing use of telecommunications via fax machines and the internet has led to more liberal work-at-home policies by employers and an impetus for 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 9-5 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 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, pre-existing 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 than they used to be, 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 worksites, discrimination and lack of opportunities for career advancement (Braddock and Bachelder 1994).

Vocational Rehabilitation and Other Federal Employment Programs

The federal/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 VR 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 \$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 Department of Labor 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 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 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 four percent reported that special programs for people with disabilities assisted them in finding employment, while five percent reported that generic employment

services assisted them in finding a job.

Supported Employment

The concept of supported employment emerged in the early 1980's as a response to the dissatisfaction with the unemployment and segregation of people with developmental disabilities 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 roles. Systems change efforts in states have not produced widespread changes, but rather 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 CEO's and Human Resource Managers in Fortune 5000 companies found that 73% of the top industries across the country are currently hiring people with disabilities. Most reported that the ADA has had a positive impact on corporations with only 16% believing it has had a negative effect (PCEPD 1995). Lou Harris and Associates surveyed employers in 1986 and again in 1995 and found strong support for the employment of people with disabilities and the Americans with Disabilities Act. The employment anti-discrimination provisions of the 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% to 81% between 1986 and 1995 (Harris poll, 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% reporting no increase. The Job Accommodation Network (JAN) operated by the President's Committee on Employment of People with Disabilities 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 1994) found that 97% 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 employer. (Burkhauser, Butler & Kim 1994; Daly & 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 surveys 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% to 64%. The most commonly cited reason for not hiring people with disabilities, both in 1986 and 1995, was a lack of qualified applicants.

Additional concerns expressed by businesses about hiring people with disabilities include fear of increased costs for health insurance, for workers' compensation, and for accommodations; concern about liability for safety of an employee with a disability and co-workers, fear of ADA litigation, discomfort interacting with people with disabilities in the workplace and confusion about the overlap and potential conflicts between federal employment laws, such as the Family Medical Leave Act, the ADA and the Occupational Safety and Health Act.

One incentive in the tax code for employers intended to promote the employment of people with high levels of unemployment is the targeted Jobs Tax Credit (TJTC). 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% in 1987). No data are available about the impact of TJTC on the employment rate of people with disabilities or on employers of people with disabilities.

Shortly after the 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.

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

The Rehabilitation Act Amendments of 1992 (P.L. 102-569) require state VR agencies to provide for the individual's choice of services and service providers, 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, 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 40% 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

The lack of progress in the employment rate of people with disabilities in the last decade is a grave failure of public policy. While the ADA has been a great policy success of the last decade, it is an exception. Furthermore, it is not realistic to expect the ADA to reverse, in a few years, an employment level that has been far too low for decades. The ADA continues to be the exception in public policy. Most public policy continues to support barriers to employment for people with disabilities rather than minimize them. The goals of the ADA will not be realized while public policy allows so many people with disabilities to live in poverty, be unemployed and underemployed and function outside of the mainstream economy.

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 rather remaining 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 assure 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 impacting 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. Needed 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 and hard of hearing. An overhaul of federal/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

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 President's Committee on Employment of People with Disabilities, to add people with disabilities as a group within the national labor force statistics reported monthly and monitor reasons people with disabilities report for not working. This information should be available by type 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 of 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 expectation that people with disabilities are part of the workforce.

RESEARCH

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.

HEALTH INSURANCE

6. 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. Since long term services, such as personal assistance services and assistive technology, are not readily available, they too act as obstacles 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

7. The President, executive agencies and the Congress should vigorously support full enforcement of the 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

8. The Secretary of Labor, in conjunction with the President's Committee on Employment of People with Disabilities, 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. 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

9. 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 support on benefits or dependence.

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

10. 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 in the 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.

LABOR MARKET TRENDS

11. The Secretary of Labor and the President's Committee on Employment of People with Disabilities, 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; and provide recommendations for maximizing the employment of people with disabilities by the year 2006.

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 integrated 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.

Former Cong. Tony Coelho
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 being elderly 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

Social Security represents the federal government's largest expenditure on people with disabilities at \$63 billion annually. 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 rolls for SSI automatically confers Medicaid coverage in most states. Acceptance on the rolls for SSDI 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 SSI and/or SSDI beneficiaries 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/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 43 percent between 1989 and 1993.

A number of provisions have been enacted to promote the return to work of beneficiaries. Those are outlined below. In addition, the Social Security Administration (SSA) reimburses state vocational rehabilitation agencies for the rehabilitation of SSI/DI 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 one 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 too ill or too severely disabled to work, social security programs for people with disabilities have had an unintended effect of trapping people with disabilities in lifetimes of poverty.

It is unlikely that any reforms within the social security system alone will be effective in yielding a significantly increased employment level of 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 of AFDC household 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% 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, which is usually in the form of cash. These programs have become quite costly over the last decade and reforms in many states are underway. In too many instances, support for 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 on to 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 a well established system for providing cash compensation, people with disabilities may have no choice except to retire and accept the cash.

Key Legislation in the Past Decade

Since the early 1970's advocates and policy makers have worked to develop incentives for people on SSI/DI 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 9 months without losing benefits.

Extended Period of Eligibility. Cash benefits are reinstated for any month earnings are below the substantial gainful employment level for 36 months following the Trial Work Period.

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 39 months of premium free Medicare ends, Medicare can be purchased at the same monthly cost which uninsured retired beneficiaries pay.

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. Earnings which a blind person uses to work, such as transportation, taxes, or special equipment, is not counted in figuring SSI payments.

Plans for Achieving Self-Support (PASS). Beneficiaries can set aside income or resources for a period of time to meet expense 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 earning 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 (IRWE). 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 at 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

The National Council 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 with significant disabilities and those who are terminally ill. Cash benefits are the difference between sustenance and destitution for many recipients. However, for many others, SSI and SSDI 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 spider web than 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.

The National Council 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 to employment from benefits 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 which is based on employment, not accessing benefits, and that includes the supports, services and civil rights protections necessary to attain and maintain employment, that decreases 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 as support on the path toward employment, not early retirement. National policy should ensure that employment provides a genuine economic advantage over benefits. Currently, income maintenance policy may require a choice between a job or a personal attendant. It may require a choice between getting married or having health insurance. It may require a choice between an income or enrolling in higher education. Economic security policy should always support maximal employment and independence and recognize investments in the future, such as higher education.

ECONOMIC SUPPORT

2. Congress should enact legislation, including amendments to the Social Security Act, that assures a fundamental level of support for working age adults with disabilities who are in economic need and that leads 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;

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.

c) flexibility in the system so they 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 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 assure independent living and self-determination;

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

g) service and support brokers that facilitate the attaining and maintaining of employment by individuals with disabilities who are capable of working. The broker is a service coordinator whose job is to support the economic security and return to work efforts of people with disabilities. The brokers routinely provide information on employment options and supports to people with disabilities. These brokers could be private agencies run by people with disabilities.

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 which are covered by public health insurance. The Disability Tax Credit, which could function in a manner similar to the Earned Income Tax Credit, the Personal Assistance 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 notion 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 President's Committee on Employment of People with Disabilities 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 when a person becomes disabled, is the point he/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.

TAX INCENTIVES FOR EMPLOYERS

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 Care and Health Insurance

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.

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

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

Justin Dart
Disability Advocate

People with disabilities have increasingly identified the lack of access to adequate health care and health insurance as a major obstacle to equal opportunity and independent living. Some progress has been made in challenging discriminatory practices under the ADA. People with disabilities participated actively in the health care reform debates of the early 1990's, 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.

Designed to address acute health conditions rather than chronic health conditions, our health care

system rarely provides for long term services and supports which 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 have escalated, people with disabilities have increasingly found it difficult to meet their needs through private insurance. About 4.6 million people with disabilities of working age, or 15% of all working age people with disabilities, lack any health insurance (McNeil 1993) and millions more are not insured for pre-existing 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 SSI or 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 pre-existing condition exclusions, minimal benefit packages and benefit caps. Durable medical equipment, assistive technology and personal assistance services are common needs of people with disabilities which are rarely fully covered by health insurance plans.

Like people who are elderly, people with disabilities generally utilize more health care services than people without disabilities. For example, in 1993, 15% of Medicaid beneficiaries (those with disabilities) accounted for 39% of expenditures (NCD 1995). The significant expansion of Medicaid and Medicare has occurred to some extent because escalating restrictions from private insurers have pushed high-risk, high utilization people with disabilities increasingly into public sector programs. In addition, high health care costs and limited access to private health insurance encourage participation in the SSI/DI 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 for either an employer's group coverage or 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. A 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-invoking 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 or facing financial ruin from attempting to pay for the needed medical services themselves.

People with mental illness and their advocates have effectively articulated the need for parity in mental health coverage in health insurance policies during the last decade. 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 chief 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 all together. Practices in the private insurance market, such as pre-existing condition exclusions, limits on benefits and caps on payments present problems for people with disabilities. Public health insurance is generally only available 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 trend of an increasing number of people who work part time 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-pocket when 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 the ADA

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

The ADA has been used by some to effectively challenge discriminatory practices in the provision of health care and health insurance. In the early 1990's 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 the ADA. People with disabilities have successfully used the 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 the 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 the 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 ever increasing trend toward the provision of health care in a managed care, rather than a 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 pre-paid 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 saves health care dollars by creating a network of providers who agree to discount their fees in exchange for a certain volume of patients and by limiting access to specialty care through the use of primary care "gatekeeper" physicians. With a limited network of providers, consumers are restricted in their choice of doctor and other providers. Capitation arrangements provide further incentives to underserve high users of care because these plans are designed to serve "average" patients who infrequently need health services. In addition, providers in the plan may financially benefit from restricting services to beneficiaries.

Managed care generally creates incentives to underserve individuals who may require costly and/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 the 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 utilized is no longer available through their workplace. 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 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 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 people with disabilities below age 65. Most people with disabilities have generally opposed efforts to dramatically reduce Medicare expenditures to date 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 area of assistive technologies, home and community based care and complimentary 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 debate 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 to the value of the life of a person without a disability. One commentator has characterized the public debate as asking the question "Can we afford disabled people?" (Gallagher 1995).

Central to the formulation of the Oregon Medicaid waiver was a "quality of life" assessment which evaluated medical services in terms of their impact on the quality of life of those who received them. In their most basic form, such assessments relegate people with disabilities to lower quality of life status than those without disabilities. Such computations can result in denials of health related services to people with disabilities, because they will not necessarily improve their quality of life, i.e. "cure" 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 anti-discrimination 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/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. The 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/DI roles 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 the Americans with Disabilities Act, significant reforms are necessary throughout the next decade in the health policy arena. Recent trends in publicly-subsidized and privately-funded programs that comprise the health care delivery system in this country are of great concern to people with disabilities. The existing health care system disproportionately and negatively impacts 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. The corporatization and consolidation of medicine continues to syphon 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 private market. Long-entrenched systemic

biases continue to reward 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 socio-demographic 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 pre-existing 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.

Calls for incrementalism 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 co-payments. Medical savings accounts should not be pursued as they encourage segmentation of the health insurance market based on risk.

CONSUMER DRIVEN SYSTEM

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

a) adequate consumer information that will empower consumers to make informed decisions when making a health plan or a provider choice;

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 that enable consumers to challenge health plans and health provider decisions including arbitration mechanisms, ombudsmen independent of health plans and private rights of action; and

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 standard setting, monitoring and compliance of Medicare and Medicaid sponsored managed care health plans. In the market-based 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.

A strong federal role in standard setting, monitoring and compliance 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 to choose from 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. These managed care plans should be required to expend at least 90% of the premium collected on health services.

All managed care plans, including those which 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.

ANTI-DISCRIMINATION

5. The Department of Justice should develop regulations for the Americans with Disabilities Act 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).

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 the ADA. Private health plans, which perform the quasi-state function of servicing Medicaid beneficiaries, should be required to meet the standards of Title II of the ADA which applies to state and local governments. Private health plans that service Medicaid and Medicare patients should also be required to meet the on-discrimination provisions of Sections 503 and 504 of the Rehabilitation Act of 1973, which apply to federal contractors and recipients of federal funds. The National Council on Disability should establish an advisory committee to work with the U.S. Department of Justice to consider these issues and promulgate regulations clarifying the application of Titles II and III of the 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 4 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 this same time period. Despite attempts to address work disincentives 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. Resource 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 to a system that presumes 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 a 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. The definition of "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. Congress should define "medical necessity" 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 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 their representative.

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 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, 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 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. Promotion of clean air and use of non-toxic substances in public places (such as industrial cleaners) are of particular concern to people with multiple chemical sensitivities and should be addressed within the public health agenda.

RESEARCH

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 anti-discrimination law and access to health insurance for people with disabilities should also be studied.

EDUCATION AND TRAINING

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 methods to avert and manage secondary health conditions, how to make the most effective use of health care services in a managed health care plan, how 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 resident of Brandon Training School from
age 3 until she was a teenager
Ceremony marking the closing of Vermont's
Brandon Training Center
Rutland Daily Herald December 10, 1993
(Cameron now lives in a supervised group
home in Burlington, Vt. The property of the
Brandon Training School is for sale.)
(In Smith and Gettings, p. 7)**

I was in a nursing home for thirteen 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 only access long term services 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 need are not available to them. The NCD believes, and the ADA affirms, that every individual with a disability should live in the community

of their choice as a participating member of society.

There is no nationally organized community based system of long term services for people with disabilities. When an individual needs long term services, she/he 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 (ICF/MRs). 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 (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 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 1990's 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 2 million recipients with disabilities. Devolution of responsibility to states from the federal government for Medicaid 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 (PAS)

People who need PAS 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 PAS. Among PAS users living in the community, 10% use paid PAS only; 11% use both paid and volunteer PAS; and 79% use

volunteer or informal PAS only (World Institute on Disability and Rutgers University Bureau of Economic Research 1990).

A 1987 survey of attendant services in the U.S. 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 & Zukas 1987). Approximately 2 million people received some or all PAS services from public programs in 1988 with Medicaid and the Social Service Block Grants serving as the key federal sources of funding. Some PAS programs are solely state funded (Litvak 1991a).

The Personal Care Option under Medicaid was used by 23 states in 1988 to provide PAS. These programs have been criticized for being overly expensive, medically oriented, not allowing PAS 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. The NCD is concerned about proposals currently under consideration that might eliminate or curtail the federal Medicaid entitlement. States may or may not chose to provide long term community based services to people with disabilities under current proposals. Without the Medicaid support for long term community based services, people with disabilities would risk institutionalization.

De-institutionalization

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 community residences than in 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 in 1992, 52% lived in settings with 15 or fewer residents. By contrast, in 1977 only 14% of people with developmental disabilities who lived in residential settings with 15 or fewer residents (Braddock, Hemp, Bachelder, Fujiura 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 1980's and have continued. One study determined that 94 institutions were scheduled to or had completed closure in 29 states. (Braddock et.al. 1995) Since 1992 three states (New Hampshire, Vermont and Rhode Island) and the District of Columbia 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 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 16+ bed settings. In 1992, 57% 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 increased steadily since 1981 so that 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 (CSLA) 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 with state/federal expenditures projected to be \$60 million by the end of the program (Minnesota). Almost 75% of participants were supported living in their own homes. As the program terminates in the fall of 1995, it leaves an important legacy in most states, having planted "seeds" of supported living through out the country. These seeds will likely promote supported living approaches through out state service system. (Braddock et. al. 1995)

Despite the substantial progress, continued challenges remain. Thousands of individuals continue to live in large institutions and nursing homes when they could live in smaller community settings. Furthermore, states vary dramatically in their use of institutional services. For example, while New Hampshire supports 97% of residents in 15 bed or less settings, Mississippi supports 90% of residents in large congregate care 16+ bed facilities (Braddock et. al. 1995). State differences in spending on the developmental disabilities population are also significant. For example, in FY 1994 New York spent more than \$100 per state resident for medical services for people with MR/DD while California spent less than \$25 (Prouty & Lakin 1995).

Key Federal 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.

Older Americans Act Amendments of 1987 (P.L. 100-175) authorizes funds for state and community programs including non-medical 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 standardized services common to the ICF/MR program.

RECOMMENDATIONS

While there has been considerable progress in de-institutionalization, 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, inconsistent from one locality to another, and too often directed by agencies rather than by people with disabilities who are using the services. The Council'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/SUPPORTS POLICY

1. Congress should enact legislation that establishes a national long term services/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 services on both an ongoing and episodic basis. 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 services are the expected service setting and institutions are the last resort;**
- b) personal assistance services grounded in the values of consumer choice, consumer direction and community participation accommodating needs which change over time;**
- c) mechanisms to ensure access to long term services by those who, because of their disability, are unable to make their own decisions;**
- d) consumer direction in selecting, managing, training and dismissing PAS workers regardless of the employer of record;**
- e) amendments to the tax code that promote maximum consumer direction in PAS 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 the 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/her living environment in order to determine the level of need for personal assistance services;

Individual need must take into account the individual'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/family support system in place.

k) a study of how long term community services might be de-medicalized, directed by the Secretary of Health and Human Services 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 to end the entitlement to nursing homes and home health care and replace it with a priority for home and community services such as HCBS and CSLA for all Medicaid and other public funds with institutions being 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 PAS 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;**

THE FEDERAL ROLE/ THE STATE ROLE

3. Congress should ensure that the federal role and the state roles are clearly delineated in the provision of long term services/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 which co-develops 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 the provider is;**
- e) developing guidelines for consumer and worker protection;**
- f) developing administrative procedures.**

TRANSITION TO NEW LONG TERM SERVICES/SUPPORTS POLICY AND SYSTEM

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. Features of the team include:

- a) an active role in developing policy for new systems, reporting to state legislatures and Congress and monitoring any pilot programs;**
- b) use of current funding from existing Developmental Disabilities planning councils and statewide Independent Living councils;**
- c) members appointed by the Governor for five years with a composition of:**
 - 51% users of long term services 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 non-profit community,**
 - representatives from the Independent Living Council,**
 - representatives from organizations representing older Americans such as the American Association of Retired Persons(AARP),**
 - members of both legislative bodies from both political parties,**
 - one team member who attends a national body that monitors activities and innovation in all states.**
- d) maintaining a central registry on current pilot programs, including complaints and positive feedback;**
- e) developing policy guidelines to be used by state agencies, providers, Health Maintenance Organizations and Managed Care Organizations;**
- f) developing a time line for de-institutionalization in the first year and monitoring its implementation;**
- g) working with the Department of Labor and JOBS programs to develop PAS worker capacity;**
- h) developing draft regulations for both a direct pay/voucher model and a consumer directed agency model;**
- i) developing a universal assessment tool to determine if an individual will use vouchers or agencies; ensuring that resource allocation for the service models is based on these assessments;**

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

DE-MEDICALIZATION 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 and 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 shall 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. Non-medical assistants can and should perform many procedures that are currently considered to be medical and, thus, only allowed to be performed by medical professionals. Laws in many states, such as nursing practice laws, prohibit the performance of many procedures by lay persons, thus unnecessarily increasing the costs of PAS. Such laws will need to be amended.

RESEARCH AND DATA COLLECTION

6. Congress should direct the National Institute on Disability and Rehabilitation Research (NIDRR) 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 services being studied;**
- b) utilization of designs and methodologies that include people with disabilities in all aspects of the research/data collection processes, such as participatory action research;**
- c) a focus on data related to the interaction between the individual with a disability, including the physical, mental and emotional levels of functioning, with the individual's particular environment;**
- 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 need;**

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

h) longitudinal studies;

i) a priority on cross disability issues, functional issues and environmental issues as they relate to the need for PAS.

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, Cambridge, MA**

All Americans regularly and increasingly rely on technology to enhance functioning and perform routine tasks. From eyeglasses, to the telephone to remote controls for televisions, daily American life is 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 a computer 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 ADA, telecommunications relay services provide 24 hour access to the telephone for people who are deaf and 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, make 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 NIDRR and the National Center for Health Statistics co-sponsored 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% 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 were used 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 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.

The National Information Infrastructure (NII)

The development of the 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 (Vanderheiden & Kaine-Krolak 1995).

Potential barriers to the NII include socio-economic barriers experienced by many Americans and high levels of complexity requiring considerable skill to utilize information technologies. While these barriers are present for all 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 (Vanderheiden & Kaine-Krolak 1995).

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 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 the 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 (Vanderheiden & Kaine-Krolak 1995). However, some recent progress is evident. For the last year, the NCD has worked with the Microsoft Corporation on ensuring accessibility of their 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 the notions of universal design by seeking acceptance widely 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) (Tech Act) supports state efforts to implement consumer-responsive, comprehensive, statewide programs of technology-related assistance 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.

Television Decoder Circuitry Act of 1990 (P.L. 101-431) This legislation requires new television sets with screens 13 inches or larger to have built-in decoder circuitry in order

to display closed-captioned television transmission 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 by people who are deaf or hard of hearing 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 readily achievable. Closed captioning is required when it is readily achievable.

Recommendations

UNIVERSAL DESIGN

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 and/or production of technology which is particularly effective in meeting the needs of people with disabilities;**
- c) enacting a Universal Design Statute and/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 clearing house, 4) gather data on the need for and use of accessibly designed products, systems, practices and environments and assistive technology and 4) 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 audio visual 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, 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 which would be usable by individuals with multiple disabilities and/or which would be effective in a broad range of environments;

b) supporting research to develop assistive technology to address new and emerging audio-visual information and devices/systems such as research in 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

- 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 the Americans with Disabilities Act;**
- 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.**

AFFORDABILITY

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 and/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 the increased funding or better delivery of assistive technology to people with disabilities who are poor and/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.**

STRENGTHENING AND ENFORCING EXISTING LAW

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 beyond “readily achievable” so that 100% content access will be achieved.**

INFORMATION DISSEMINATION

6. Congress and the federal government should promote a range of activities intended to further disseminate information about accessible/assistive technology by urging public libraries 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 include the following features:

- a) accessible formats as required by Section 504 of the Rehabilitation Act and Titles II and III of the Americans with Disabilities Act;**
- b) universal key words relating to assistive technology as a discrete item in various library, professional and other research indices including the Library of Congress Cataloguing system, other major public library cataloguing systems, the National Library of Medicine index, the West Legal Research Key Number System, the National Information and Referral Taxonomy as well as World Wide Web indices and others as may be determined to be relevant to the dissemination of information about assistive technology.**

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 affordable housing is key to living in the community. Historically, people with disabilities resided in isolated institutions segregated from the mainstream and "out of sight, out of mind." Despite progress in de-institutionalization, 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 (1994) noted that 47% of non-elderly individuals with disabilities had "worst case needs" in housing. 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 the U.S. Department of Housing and Urban Development (HUD). The rural housing programs are administered by the U.S. Department of Agriculture. All Public Housing Agencies (PHAs) are managed by HUD. Since the 1970's they have been required to provide at least 5% fully accessible and 2% deaf/blind accessible apartments throughout their programs. Many of the accessible apartments have been located in elderly/disabled buildings. Congress recently authorized PHAs to make those buildings available only to people age 62 and older.

Both the Department of Agriculture and HUD administer rental certificate and voucher programs which 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 age 62 and older, with and without disabilities. The 811 program is directed specifically to people with disabilities under age 62. HUD has recently requested authorization from Congress to spend 25% of the 811 funds for vouchers. They plan to increase the request to 50% 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 underway in a number of communities exploring affordable housing models such as mutual housing associations and limited equity cooperatives to produce accessible housing in integrate 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 of the U.S. 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 thirteen states and intends to initiate coalition building among housing and disability advocates in 23 states by the end of the decade.

Support Services

The choice of where to live by people with disabilities 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 ICF/MR 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 foregone because the individual would risk losing the support services she/he needs if she/he moves. 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 and HIV/AIDS. Despite numerous government programs intended to assist them, their numbers continue to grow.

Neighborhood Resistance to Group Homes

Resistance in communities to group homes for people with mental illness and mental retardation remains prevalent, despite anti-discrimination 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 hand rails, 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 care giving easier and forestall or prevent institutionalization, there is no national policy or service system guiding the funding or delivery of home modifications supports and repairs or of 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 door knobs are not usable by people with limited use of their hands, however lever handles are usable by almost everyone, including people with no hands. Universal design address 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 (The Center for Universal Design undated.)

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% of Section 202 funds for use in developing housing for non-elderly persons with disabilities and separated 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) prohibits 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 (HOPE) 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 the Department of Housing and Urban Development, 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 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 (NOFA) 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

In the past disability rights organizations have been ineligible from such competition because they did not meet a requirement to have experience in housing activities. 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 maximum penalties for retaliation that are available under the law;

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

f) requiring builders/owners of housing to be certified for compliance with accessibility codes and other provisions of law by designers, builders, developers and owners, not lay people from the disability community full compliance with accessibility codes and other provisions of disability rights law by designers, builders, developers and owners, not lay people from the disability community;

In many communities builders and developers call on lay people with disabilities to advise them as to the accessibility of their buildings. While such a practice often enhances accessibility and builds positive community relations, it is not a 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. It is the builder/designer who is ultimately accountable for compliance, not the disability community.

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 include components that promote sensitivity to the discrimination experienced by people with disabilities, and to the impact of all types 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.

DE-LINKING SERVICES FROM HOUSING

2. The Congress should enact legislation prohibiting The Department of Housing and Urban Development 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. The opportunity to obtain and retain housing should be based on the need for shelter, not the need for particular services. 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 the Department of Housing and Urban Development and other relevant federal agencies to fund housing programs for people with disabilities on the basis of need, not diagnosis or label, and based on 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 and/or substance abuse, housing for people with HIV/AIDS, "202" and "811" programs and apartment buildings for people with mental illness would be replaced with housing programs targeted to individual need and based on individual choice. Section 8 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 with programs flexibly designed to accommodate individual need and choice.

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) home modification programs, such as IRS deductions, that promote individuals with all types of disabilities in eliminating barriers and enjoying the full use of dwellings, such as 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% of the units developed under the affordable housing formula for people whose income is below 30% 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 non-physical 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 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 or FHA guarantees, for single family dwellings which are inaccessible**
- 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, home offices and multiple chemical sensitivity needs to isolate toxic products within dwellings.

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 and are disseminated routinely through a variety of readily accessible communication mediums including:

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

b) research 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

To have less than adequate accessible public transportation services ... is analogous to throwing an eleven foot rope to a drowning man twenty feet offshore and proclaiming you are going more than half way.

Harold Russell
1989

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.

Rep. Cardiss Collins
House passage of the 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 resolved the decades-old debate by requiring an accessible fixed route system with paratransit available for those who, because of their disability, 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 the 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 the ADA, about one third of fixed route vehicles were accessible. In 1996, 60% of all buses meet ADA standards. Rural systems lag behind urban systems in accessibility where only 35% of fixed route vehicles are accessible. Projections for urban areas indicate that by 1997 seventy percent will be lift-equipped and by 2003 one hundred percent will be lift-equipped (Project Action 1995).

In 1989, prior to the enactment of the 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 (Project Action 1995). Some portion of the increase in usage 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. 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 TTY's are required for people with hearing disabilities. Detectible 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 utilize fixed route transportation. Many state and local governments complained that they were unable to meet the deadline for compliance of installation of curb cuts at existing pedestrian walkways. As a result, the Department of Justice has proposed extending the time period for compliance 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 auditory-based. Pay phone access at airports remains at minimal levels, thereby making private transportation arrangements by phone extremely difficult for people with hearing disabilities. 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, it has increased. Today about 20% of aircraft are equipped with movable armrests on 50% 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, inaccessible public announcement systems on airplanes for people with hearing disabilities, lack of captioning access 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 the ADA to change compliance dates to two and three years respectively, after issuance of final Department of Transportation 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 and 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, 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. Some times people with disabilities are unaware of their rights in relation to airline travel and complain that the Department of Transportation 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 on is to improve public transit systems generally. Additional funding from the 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.

ENFORCEMENT OF CURRENT LAW

2. The Department of Transportation 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) on-going 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 the drivers who don't 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, even if politically difficult, so that paratransit is available to those users with disabilities who will never be able to use fixed route services (including eligibility and service area requirements).**
- 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, but not limited to intercity rail.

COORDINATION

4. The Department of Transportation, 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 the current set of transportation systems by promoting initiatives such as agreements between urban and rural providers to pick up passengers in each others' 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. The Department of Transportation and the Department of Justice should enhance enforcement of the Americans with Disabilities Act 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 such as changes in times of departures or gates, seating upgrades, weather or mechanical problems and calling 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) which accept all forms of payment (including coin) in every phone bank within each concourse at airports, highway stops, street corners, on airplanes, trains etc. 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 the equivalent of text form communication; and

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

TRAINING

6. The Department of Transportation 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 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 making most appropriate use of the modes of transit that are available to them.

PARATRANSIT

7. The Department of Transportation should enforce the paratransit provisions of the Americans with Disabilities Act 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 utilizing 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 the ADA and Section 504 of the Rehabilitation Act for:

a) automobiles, in order to promote usability by people with disabilities such as

access to load folding wheelchairs into cars;

b) advance 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 utilize flashing lights when emergency vehicles are approaching.

AIR TRAVEL

10. The Department of Transportation 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.

ISSUANCE OF REGULATIONS AND STANDARDS

11. The Department of Transportation and the Architectural and Transportation Barriers Compliance Board (ATBCB) should issue all pending disability civil rights regulations and standards in final form.

Program and Policy Coordination

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

Ed Roberts
World Institute on Disability
1988

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

Sen. Tom Harkin
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
1989
"Universalizing a Disability Policy"

The Americans with Disabilities Act 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 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 the 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 only receive the support services they need if they live in segregated settings. While the federal government spends about \$175 billion per year on people with disabilities, most of it 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 the Americans with Disabilities Act. Yet there is no mechanism for these committees to jointly address the conflicts or promote co-ordination 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. Legislation to block grant discretionary programs under the Individuals with Disabilities Education Act is pending. 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 governments 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, 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 strong consumer and community focus. a set of consumer-centered values were 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 & Riley 1995).

The Customer's Perspective

The customer with disabilities seeking services faces a maze of programs, requirements and bureaucratic hoops to jump. 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 decision-making about the services she/he will receive. Duplication and conflict are commonplace. a customer in one state was reported to have 12 different case managers (Scully, Snow & 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 utilize 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 is often gathered from survey questions that were not intended for the purpose that they are used. 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 (SIPP) and the Current Population Survey (CPS).

There has been considerable discussion in the last decade about the limitations of these data bases and the need for a data base 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 SSI and SSDI rolls have experienced so much growth. Survey results should be released in 1997.

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

Little improvement in data collection about people with disabilities is evident in the last decade. Limited data about people with disabilities continue to thwart policy analysis and promote an "out of sight, out of mind" viewpoint.

Recommendations

There has been little progress in the last decade in enhancing the coordination of programs and policies for people with disabilities. Limited data collection and analysis about people with disabilities has served as an impediment to more effective coordination. Discrepancies and outright conflicting purposes remain the rule rather than the exception. The goals established by the ADA do not yet drive policies that effect people with disabilities, nor are they used to drive budget and spending priorities and allocations. People with disabilities seeking services from the many service systems are too often frustrated by the maze they must negotiate to try to meet their needs.

GOALS OF THE 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 the Americans with Disabilities Act. 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.

FULL PARTICIPATION IN THE COMMUNITY

2. Congress should revise federal laws and agencies should revise regulations (and require/encourage states to do the same) to ensure that all supports/services are provided to all people with disabilities in the most integrated setting. Revisions should foster independence/interdependence rather than dependence. a national clearinghouse of

successful approaches should be established and supported.

CONSUMER CONTROL

3. Congress and the President should ensure that people with disabilities direct the development and implementation of policies that affect them.

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 a token fashion. People with disabilities must play the central role in directing policy that is so critical to their empowerment.

4. Congress, in consultation with the NCD, should a) establish policy that people with disabilities and their families control resources necessary to obtain services/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.

CUSTOMER SATISFACTION

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

EQUITY

6. 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 under represented is critical to ensure equitable access for all people with disabilities, no matter what their disability and no matter what their ethnic/racial other characteristics.

FUNCTIONAL NEED, NOT DIAGNOSIS OR LABEL

7. Congress and the administration should base policies and services for people with

disabilities on needs rather than on disability category or label.

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/services should be made available regardless of personal resources while others might be means tested. Individual should not be required to impoverish themselves to have access to publicly funded supports.

FUNDING

8. Congress should establish funding mechanisms to promote the establishment of private businesses to generate income to fund services/supports for people with disabilities.

Current fiscal realities lead to the conclusion that creative approaches need to be taken to offset shrinking public dollars. It is neither appropriate nor sufficient to rely on charities to meet the needs of people with disabilities. The notion of government establishment of private businesses, sometimes called Community Wealth Enterprises, is discussed in the book Revolution of the Heart. Such businesses establish guidelines for the percent of profits that go to funding programs, perhaps 100%. In the case of people with disabilities, such businesses should operate with affirmative action policies for hiring people with disabilities. They should not be required to be owned or operated by people with disabilities. The primary goal would be to raise money, not to provide jobs. However, they all should have an active effective affirmative action plan in place to recruit and hire qualified disabled workers.

ACCOUNTABILITY

9. All federal and state government agencies should ensure that all of their communications are available in accessible media and portray people with disabilities in a manner that is consistent with the empowerment and inclusion goals of the Americans with Disabilities Act.

THE FEDERAL ROLE

10. If the federal government grants greater authority to states, it must retain responsibility and authority for ensuring rights and protections, standards for eligibility, supports/ benefits/services and meaningful outcomes for people with disabilities.

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 the Americans with Disabilities Act.

Federal agencies that sponsor research and data collection that affects people with disabilities should re-evaluate the economic assumptions that are implied in typical cost-benefit analysis in light of the new disability paradigm embodied by the 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 the ADA. All federal agencies conducting surveys should ensure that people with disabilities are self-respondents rather than utilizing 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 special 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 is relevant to the goals of the 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 the 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 from the 1994-95 Disability Supplement to the Health Interview Survey.

TRIBAL GOVERNMENTS/INDIGENOUS PEOPLES

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

Many federal policies, such as the Americans with Disabilities Act, 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..

International

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....

Sen. Robert Dole
Testimony before the Commission
on Security and Cooperation in Europe
Sept. 21, 1994

...our foreign aid dollars...should go towards 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
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 U.N. 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 of the inaccessible conditions at
the 4th World Conference on Women in
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 policy 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 U.N. 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. The law continues to serve as a model in countries everywhere. Ironically, the U.S. too often ignores the very tenets of the law in its international leadership role.

U.S. Foreign Policy

The National Council on Disability has been designated by the Department of State as the international 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 programs because of barriers and/or lack of outreach to them (National Council on Disability 1994).

The manner in which U. S. disability rights laws apply outside of the United States is still being determined. Some applications, such as the employment provisions of the 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 anti-discrimination mandate that applies to federal government activities in the U.S. applies to federally sponsored activities abroad continues to evolve (National Council on Disability 1994).

Ensuring accessibility and accommodations in American embassies is important so that people with disabilities can work in them and utilize 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.

The AID distributes about \$6 billion per year for economic assistance overseas, targeted to those at the lowest socio-economic levels. Recent persistent efforts of the disability community 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.

The 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 among official United States delegations to other countries. The first official representative with a disability was Marca Bristo, chair of the NCD, to the World Summit on Social Development. The recent U.N. Conference on Women in Beijing, China offered another notable exception. Judith Heumann, Assistant Secretary for Special Education and Rehabilitative Services of the U.S. Department of Education, was a delegate.

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 U.N. to insure 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 U.N. 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 U.N. 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 U.N. 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 and UNESCO) have adopted numerous conventions, recommendations, declarations, principles and guidelines that relate to the rights of people with disabilities (Degener & Koster-Dreese 1995). The impact of these activities on the lives of people with disabilities throughout the world is not known.

In the early 1990's, 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. Named "Disability-Adjusted Life Years" (DALYs), it statistically establishes a measurement for the value of life lived with a disability. It was devised with virtually no input from the disability community. The DALYs appears 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 the

ADA.

The International Classification of Impairments, Disabilities and Handicaps (ICIDH)

In 1980 the World Health Organization developed a system called the International Classification of Impairments, Disabilities and Handicaps (ICIDH) to classify and track disabilities and their impacts on people's lives. It is utilized by many countries to gather data and plan for service delivery programs. The World Health Organization has undertaken a revision of the 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 the ICIDH is likely to be completed by the turn of the century. If utilized by the U.S., it 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 Country Practice Reports on Human Rights.

The Foreign Relations Authorization Act for FY 94 and FY 95 (P.L. 103-236) directs the United States Information Agency 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 U.S. 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 U.S. 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 the Americans with Disabilities Act by a)

requiring full accessibility of all programs, activities, services and facilities of governmental and non-governmental entities involved with international activities; b) promoting the principles of the Americans with Disabilities Act throughout all aspects of international operations of U.S. companies; c) enforcing full accessibility as required by the 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 and 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 the Americans with Disabilities Act 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 a) microenterprise development b) business development credit c) business development loans d) integrated education for children with disabilities and e) 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 programs 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 non-governmental 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, non-profit 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 non-profit private sectors, including, but not limited to:

- 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) teachers 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.**

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Appendix A

Recommendations for the National Council on Disability

The following are recommendations provided by the policy work groups at the National Summit on Disability Policy in Dallas in April, 1996. They are recommendations for actions and activities to be undertaken by the National Council on Disability.

INTERNATIONAL

- 1. The 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 to make them available to Native American populations.**
- 2. NCD should promote the development of a curriculum on international disability policy issues which should be an integral part of post-secondary programs with an international focus.**
- 3. The 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.**

HEALTH INSURANCE AND HEALTH CARE

- 4. The NCD should assemble an advisory committee to work with the Department of Justice to develop ADA regulations that clarify that a) discrimination in the provision of health insurance under Title II and Title III is prohibited and b) discrimination in health service delivery solely on the basis of diagnosis or impairment is prohibited.**
- 5. The NCD should develop a direct working relationship with the disability related institutes at the National Institutes on Health to ensure that the views of Americans with disabilities guide and support NIH policies and funding.**

POLICY AND PROGRAM COORDINATION

- 5. The NCD should develop principles to guide Congress in a) establishing policy that people with disabilities and their families control resources necessary to obtain services/supports of their choice; and b) hold states accountable for implementing policy.**
- 6. The 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.**

7. The NCD should take responsibility for promoting and facilitating communication across disabilities and between policy makers and the grassroots.

These efforts should be coordinated with other national leaders from entities such as NCIL, PCEPD and state governors' committees. NCD should hold annual or bi-annual 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.

8. With appropriate funding from the Congress, the NCD should take responsibility for identifying and working toward elimination of contradictory and conflicting laws, regulations and programs and promoting coordination and commonality of goals across agencies for both those that are specifically targeted to people with disabilities and those that are not specifically so targeted.

9. NCD should develop and propose to Congress an approach/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) services provided regardless of age, ethnicity, type of disability or geographic region;**
- e) recognition of individual's changing needs over time;**
- f) ensuring regular evaluation of the services by obtaining consumer opinion and measuring outcomes;**
- g) confidentiality;**
- h) common data, definitions, forms;**
- i) reduced resources spent on intake and eligibility determination;**
- j) federal, state, local, tribal roles and responsibilities clearly delineated;**
- k) provisions requiring all governments to abide by these responsibilities. (?)**

10. The 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.

11. The 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 the NCD fellowship program; and**
- e) encouraging federal agencies, international exchange organizations and other agencies and organizations to include youth with disabilities in their internship programs and events.**

12. With adequate funding from the Congress, the NCD should develop strategies which will result in greater enforcement of existing laws which affect people with disabilities that are consistent with the philosophy of the 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.

13. The NCD should provide an exemplary model of accommodating people with disability to the rest of the nation in the ways in which it conducts its own business.

In cooperation with the PCEPD and NCIL, the NCD could develop the capacity needed to run truly universally accessible conferences. With this capacity, the 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

14. The NCD, or a consumer controlled task force, should develop standards for required education and training of all federal agencies and recipients of federal funds. The NCD, or the task force, should monitor compliance with the training requirement.

15. The NCD should convene national forums four times per year to develop strategies to guide enforcement of civil rights laws.

16. The NCD should 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.

17. The NCD should develop a task force to consider and determine strategies to address managed care as it affects people with disabilities.

18. The NCD should work with the American Bar Association to encourage attorneys to undertake pro bono disability rights cases.

19. The NCD should celebrate the anniversary of the enactment of the ADA by launching a "Barrier Buster Campaign" that would yield a report card on the status of America's accessibility.

20. The NCD should seek to develop additional enforcement strategies for the ADA beyond litigation and other current ones.

21. The NCD should undertake research on the development and management of sign language interpreter resources.

MULTIPLE CHEMICAL SENSITIVITIES

22. The NCD should catalyze action on multiple chemical sensitivities among the appropriate federal agencies to expand and enhance the rights of those with these disabilities.

23. The 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 Group Summaries

The following are brief summaries of the "emerging issues" group meetings held during the National Summit. NCD identified numerous emerging and ongoing issues that did not fit easily into the eleven major topic areas, or were issues identified as needing further study. Summit participants were invited to attend any of the meetings on a voluntary basis. All meetings took place on Sunday, April 28, 1996.

Multiple Chemical Sensitivity

Discussion led by Mary Lamielle

The flex discussion group on chemical sensitivities and related disabilities highlighted the critical need for action on the part of the National Council on Disability, appropriate federal agencies, and Congress. Efforts to educate the government and the private sector as to the nature of environmental disabilities and to provide adequate services for this population have been stalled due to the complex nature of the condition and failure to comprehend and address the chemical and environmental barriers that preclude access and accommodations for persons with multiple chemical sensitivities (MCS) and others. Most people with these disabilities find it difficult to achieve a reasonable quality of life because 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 ability to secure basic goods and services due to environmental exposures. The nature of these barriers and their impact on this population must be integrated into any policy response to this disability.

Complementary Medicine

Discussion group 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. According to a 1993 study reported in *The New England Journal of Medicine*, one in three U.S. citizens use complementary therapies, and a majority of these people do not inform their primary care physician.

Those who attended the discussion group were people who are part of the complementary medicine movement. It's value is widely known, especially in prevention of secondary disabilities. The consensus of the group attending the discussion was that 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 but, (according to people who use these therapies) complementary medicine can save lives when orthodox medicine is not effective.

Native Americans

Discussion group led by Ela Yazzie-king and Marca Bristo

Representatives from different tribal nations attended this meeting. A major concern was differences among various tribal governments, including differences in attitudes and treatment of people with disabilities. Each tribal government has its own unique structure and there is no uniformity for the rights of Native Americans with disabilities. Another major concern among participants is 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. Strong statements were expressed about the minimal services provided by Indian Health Services (IHS). However representatives stated that the climate is generally positive toward more inclusive services for Native Americans with disabilities.

The group suggested that NCD pay for a series of conference calls among representatives of Native Americans with disabilities from various tribal groups as well as to hold an NCD quarterly meeting in an area central for many tribal groups' location. Native American representatives requested that language be inserted into Summit recommendations that related to Native Americans with disabilities that reflects their unique cultural issues. Marca Bristo indicated that a statement would be included in the report's preamble.

Cross-over Between Health Care and Long-term Services

Prepared by Bob Griss

The discussion group session on acute and long-term services raised issues which had not been addressed in either the health care or the long term services work groups. The biggest concern is that the cost containment strategies of managed care plans would 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 combine acute and long-term services by the higher capitation payment that long-term services would bring. Some advocates of specialized managed care believe that non-profit specialized providers might be more sensitive to the ideology of consumer-directed services. Critics of managed care believe equally strongly that non-profit 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 over-medicalization and the problem of coordination have been overshadowed by political strategies to protect existing Medicaid dollars for persons who have been benefitting 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 adjusters are still in their infancy. An alternative, which has begun to appear in Medicaid programs across the country, is to "carve-out" certain populations who have frequent or ongoing specialized health care needs. Other alternatives include "carve-outs" where health plans would be responsible for all of the specialized health needs of a population but would receive extra payments for such care.

The "emerging issue" group expressed significant concern that targeted approaches to the care of people with disabilities will lead to further segmentation of the market. The argument was made that over the long term, targeted approaches could be very damaging to the concept of cross-subsidization which high users of care rely upon to have their needs met. Others believed that capitated systems were not designed for people with extensive or ongoing specialized services and that targeted approaches offered promise to ensuring appropriate health care for people with disabilities. The "emerging issue" group agreed that people with disabilities must quickly address this issue, study the existing programs that utilize targeted approaches and agree to a position before these programs proliferate. The U.S. Health Care Financing Administration (HCFA) 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.

Research

Discussion group led by Mitch LaPlante

A small number of participants who are involved in disability research and data collection attended this discussion group meeting; therefore their discussions centered around suggestions for more disability-specific research initiatives to be sponsored by the federal government. This disability-related research should ensure that people with disabilities are included in all aspects of the research process, including setting the research agenda, developing research questions, collecting information, analyzing information. Such research must be grounded in the policy and orientation of the ADA. The economic assumptions that are implied in typical cost-benefit analysis should be re-evaluated in light of the new disability paradigm embodied by the ADA.

With regard to data collection, the group discussed that the Administration should ensure that all federal statistical activities include data collection and reporting for categories such as minorities, women, and people with disabilities, use a definition based on the ADA. A recurring longitudinal study was discussed similar to the Survey of Income and Program Participation. The study would routinely collect and report data relevant to the goals of the ADA and the needs of the disability community.

Another discussion item centered around the federal government sponsoring methodological analysis that will develop new measures and survey questions, and review existing surveys that have questions related to disability and update those questions to reflect the paradigm of disability embodied in the ADA. Agencies conducting surveys should ensure that people with disabilities are self-respondents rather than utilizing proxies. This will require alternate formats, adaptation of telephone surveys for people with cognitive impairments, and training of surveyors in how to interview people with particular needs.

Regarding data analysis, the group agreed that all federal agencies should promote further analysis of existing data related to people with disabilities, particularly from the 1994-95 Disability Supplement to the Health Interview Survey, and the federal government and Congress should ensure that questions about disability are adequately included in the 2000 Census.

Disability Culture

Discussion led by Bruce Curtis

Bruce Curtis, the facilitator of the "emerging issue" group discussion on disability culture, requested that the following document be used as the basis for the historical background statement on this topic, preceding the summary of the "emerging issue" group discussion. The author is Steve Brown from the Institute on Disability Culture in New Mexico.

More than thirty years ago, during the 1960s, the modern disability rights movement began when people with disabilities around the world successfully challenged dominant social stereotypes. Ed Roberts, a post-polio ventilator-using person with quadriplegia, broke U.S. educational barriers when he became the first person with such a significant disability to enroll at college. Roberts entered the University of California at Berkeley in 1962 and during a lifetime of fighting for equality for people with disabilities became an international representative of human rights and overthrowing oppression.

But Ed did not act alone. At Berkeley, other significantly disabled individuals enrolled and coalesced into a group they named the Rolling Quads. Providing a sounding board for each other, the Rolling Quads quickly determined that their life experiences shaped a group understanding of the condition of disability and societal oppression.

People with disabilities recognized that they shared a similar, but unique, history based solely on the condition of disability. Since the most apparent trait of this history was a legacy of oppression, the overwhelming need for political change took precedent over other endeavors.

While political activism remained the most visible arena of disability rights into the 1970s and 1980s, other avenues of expression took shape. A significant discussion about language and its meaning raged throughout the 1980s in a new outlet: the disability press. Magazines like *Mainstream*, the *Disability Rag*, and the older *Accent on Living*, discussed these changes and published articles written by disabled individuals.

One of the most important results of these debates was an (r)evolution in the perception of disability from weak and discounted to strong and valued. A traditional antipathy to identification as an individual with a disability turned into pride in both individual and group strength.

The pervasiveness of this change could be seen from grassroots efforts, such as the development of independent living centers and organizations like ADAPT to academic interest best personified in the multi-disciplinary Society for Disability Studies.

All of these activities have contributed to the development of disability culture, but it is the artists of various stripes who have made the culture most accessible. Fittingly, it is the San Francisco Bay Area of California, the home of the independent living movement, that has birthed the most prominent artists, such as dancers Bruce Curtis and the Axis Dance Troupe; performance artists like Cheryl Marie Wade, Wry Crips Women's Theatre, and Frank Moore; and playwright Neil Marcus. But it may be musicians, such as Cleveland's Jeff Moyer, Canada's Jane Field, and England's Johnny Crescendo who signify the worldwide development of the Disability Culture Movement.

All of these individuals and groups represent the tip of an enormous iceberg called Disability Culture which might be defined in this way: "People with disabilities have forged a group

identity. We 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. We claim our disabilities with pride as part of our identity. We are who we are: we are people with disabilities." (Brown, 1996)

The group initially reacted to the section on disability culture in the background summit report. It felt that disability culture should not be seen as a reaction to negative stereotypes, but as a positive, proactive proclamation.

It is an expression of pride in our struggle. It is being debated more by "ablebodies" and professionals than by "crips." Disabled kids often grow up without any exposure to disability culture.

Participants discussed the question: is it a double message to want both mainstream inclusion and a disability culture? Consensus was that these objectives were not incompatible: we can want inclusion and our own identity as well. Disability culture needs to be valued within the disabled community.

The group identified various aspects of disability culture. We have a culture because of our common experience such as sports, rehab, oppression, humor, civil rights demonstrations, crip camps, hospitals, etc. We use language that is specific to us, e.g., terms like "crips." Disability culture has artifacts, rituals, humor, history, and shared experience. It is not a U.S. phenomenon, but a world-wide emergence.

We need to recognize various subgroups in disability culture, including women, lesbians, and people with various religious and ethnic affiliations. Parents of disabled kids also share part of a disability cultural identity. Different disabilities create and experience disability culture differently. It can foster self pride, self advocacy, and community organizing. The disability movement can nurture disability culture.

Art, within a disability cultural context, means creating art from a disabled person's perspective. Adding the particular life experience of the disabled person to the artistic statement takes the art form in a new direction and redefines it. Disability culture needs to have its own critical analysis of disability art. The arts and culture are crucial to the identity of all humans. Disability culture is a direct reflection of the life struggle of disabled people.

Knowledge of our history is especially important to young disabled people in order to have positive role models.

We need to archive our disability culture. It should be part of high school and university curricula. We need to make disabled people more aware about disability

culture.

Is there a problem with disabled artists who use self debasing humor? No, self humor has helped us survive. In fact, using humor shows our new level of self confidence.

The group made the following recommendations. NCD should promote, nurture, and fund disability culture through the arts, including projects of the National Endowment for the Arts. It should include disability culture as an integral part of its 10 year agenda. It should sponsor research on disability culture, including what characterizes it and how it is perceived. So far, very little research has been done.

Physician Assisted Suicide

Discussion led by Diane Coleman

The group shared perspectives on the issue of physician assisted suicide, which has recently been declared a constitutional right in the 2nd and 6th Circuits--thereby affecting twelve states. Some participants felt 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.

APPENDIX C

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