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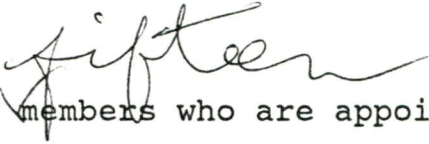
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Remarks by Sandra S. Parrino,
Chairperson, National Council on the Handicapped
Presented at an international conference on rehabilitation
legislation at Vienna, Austria, June 1986

I am very pleased to have the opportunity to describe the National Council on the Handicapped and several important initiatives which the Council has undertaken in recent months. The National Council on the Handicapped was originally established in 1978 in amendments to the Rehabilitation Act of 1973. At that time, the Council was an advisory body with limited powers located within the U.S. Department of Education. Since then, however, the Council has been reconstituted as a result of the 1984 amendments to the Rehabilitation Act, and we are now an independent federal agency functioning with a broad mandate and specific statutory responsibilities and authority.


The Council is made up of ~~members~~ fifteen who are appointed by the President and confirmed by the Senate. To summarize our responsibilities, the Council is charged with reviewing all laws, programs and policies of the federal government which affect people with disabilities, and we are responsible for making recommendations as necessary to the President, the Congress, the Commissioner of the Rehabilitation Services Administration, and the Director of the National Institute of

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Handicapped Research. Through our knowledge, we are the only federal agency which has a mandated responsibility to engage in the review and development of disability policy issues which cut across the entire array of federal agencies and a broad spectrum of disability types and concerns. Our perspective is not limited by age, disability type, perceived employment potential, perceived economic need, specific functional ability, status as a veteran, or other individual circumstances.

The Council realizes that we have a big, sometimes seemingly overwhelming, job to do, and comparatively little resources with which to do it; but we are motivated and driven by the challenge and the opportunity to improve the quality of life for 36 million Americans with disabilities, their families, and their friends. I have had the opportunity to work with many advisory committees and policy groups in the past, and I have never been associated with a group of people who are more dedicated, more knowledgeable, and more committed to a single purpose than the members of this Council. You might be interested to know that since I have been Chairperson of the Council, the attendance rate at the formal, scheduled meetings our Council and ad hoc work sessions by Council members is more than 93 percent. I think this is extremely remarkable when one considers that these people are busy with their own careers and families.

The Council formally became an independent agency on February 22, 1984. Since then, we have had the unique and sometimes *frustrating* ~~barsting~~ experience of setting up an agency from scratch. We have developed an organizational structure, operational

policies, working guidelines, personnel policies, agency regulations, interagency linkages, congressional linkages, and reams of reports.

Our Executive Director is Lex Frieden, whom many of you know. Our staff includes eight of the most proficient and knowledgeable people working in the field of disability today.

Structurally speaking, our Council is divided into four committees which address specific areas of Council responsibility according to law. These committees are research, adult services, children's services, and public affairs. At present, our research committee is developing a protocol which we will use to review the policies of the National Institute of Handicapped Research and other government agencies involved in disability-oriented research. The Council is mandated to set policies for NIHR, and we are in the process of doing this. Our adult services committee has just developed a critical analysis and recommendations on the Rehabilitation Act. Our report on this matter was delivered to Congress prior to the reauthorization of Public Law 93-112. Our children's services committee has been engaged in a parallel effort related to Public Law 94-142, the Education for All Handicapped Children Act. The Council provided advice on this law prior to its reauthorization this year. Finally, our public affairs committee has been responsible for arranging a series of consumer and provider forums during the past two years. These forums have involved more than 300 disabled people, family

members, advocates, and service providers from many communities around the United States. These forums provide an opportunity for the Council to maintain a meaningful dialogue with the general public. They have been the basis for many recommendations which were included in a special February 1986 report to the Administration and to Congress entitled Toward Independence.

I would like to discuss this important report with you for a moment. When Congress established the Council as an independent agency, it mandated the preparation of a special report to present legislative and administrative recommendations for enhancing the productivity and quality of life for disabled Americans. The Council saw the preparation of this report as its principal duty and function during 1985. Our objective was to provide the President and the Congress with a series of credible, meaningful, and do-able recommendations which, if followed, will result in removing disincentives and barriers that people with disabilities now face as they struggle to become independent, productive, contributing members of society. The Council's recommendations are aimed at facilitating independent living by people with disabilities and enhancing opportunities for them to be active participants in their own families and communities.

Our report contains some startling findings. Of 12.9 million disabled Americans of working age, approximately one-third are currently employed, one-third receive some sort of public assistance and one-third neither work nor receive public

assistance. These statistics should be considered in light of a recently released Harris Poll which indicates that more than half of persons with disabilities who are not working would like to work. They are now prevented from working, however, by a complicated array of structural, attitudinal and environmental barriers.

In the area of federal spending, the federal government spends over \$60 billion annually on disability-related services and programs, yet only \$2 billion of that is spent on vocational rehabilitation and educational programs designed to lead to employment and independent living.

Literally billions of dollars are spent each year on needless institutionalization, and the Council proposes ways by which disabled people can live independently and self-sufficiently in their communities, thereby reducing federal expenditures.

Among the 45 specific legislative recommendations are several pertaining to equal opportunity. The U.S. Constitution guarantees equal opportunity for all Americans, yet Americans with disabilities continue to encounter discrimination. The Council asserts that we have a moral obligation to ensure equal opportunity for and prevent discrimination against people with disabilities.

Thirty-six million disabled persons regard themselves as the forgotten minority. They, as a class, are undereducated,

underemployed, undervalued, overprotected, sometimes patronized and generally segregated from the mainstream of American life. The Council proposes a series of recommendations designed to eliminate both structural and attitudinal barriers and to provide cost-effective independence-oriented services to individuals with disabilities so that they may realize their full potential and become productive, contributing members of their families, communities and nation.

In the area of employment, the Council recognizes that millions of working age people with disabilities who have work skills are now unemployed. The Council proposed programs to increase the employment rate among this group.

The Council also recognizes that there are disincentives to employment. Many people with disabilities are afraid to leave entitlement programs to go to work for fear they will lose health insurance benefits. Many disabled people who are not employed would be required to assume inordinate risks associated with the loss of medical insurance benefits if they return to work. The Council proposes to remove such disincentives and refine outdated criteria used in the Social Security disability determination process.

The lack of suitable housing is one of the major barriers to community living for people with disabilities. The Council proposes a prohibition of discrimination against disabled persons in housing as well as continued development of the Administration's housing voucher programs to insure that

disabled people who require housing assistance can have the greatest degree of freedom in choosing their own living arrangements.

The Council regards accessible transportation as a prerequisite for achieving equal opportunity and independent living for persons with disabilities. The report recommends actions to achieve this including amending Section 16 of the Urban Mass Transit Act to require full accessibility to be achieved over a realistic period of time and amending the Federal Aviation Act to prohibit discrimination on the basis of disability by airlines.

The Council observes that an increasing number of Americans become disabled each year through preventable accidents and illnesses. The Council proposes a coordinated approach for the prevention of disabilities, thereby decreasing the eventual costs of disability in our society and the losses in quality of life associated with disability.

Data indicate that early intervention to assist families who have children with severe disabilities will increase the likelihood that disabled children may grow up to be self-sufficient members of their communities. The Council proposes to insure that families that desire pre-school educational assistance for their children will have such assistance.

Many people with disabilities are forced to live in nursing

homes and other institutional settings at great costs to the taxpayer because there is no national system for the provision of less expensive community-based personal care assistance (self-directed care provided by para-professionals in a home setting). The report recommends steps for creating such a cost-effective system.

President Reagan has described the "patchwork quilt" of existing policies and programs and has referred to the federal maze of programs that often work at cross-purposes. The Council proposes improved coordination of services and programs designed to aid people with disabilities. The Council suggests legislation to require states and local governments to develop plans for the coordinated delivery of services within their jurisdictions.

In preparing our report and recommendations, we have been struck by the often overwhelming, sometimes oppressive, and even demeaning environmental, attitudinal, and bureaucratic barriers which persons with disabilities must face in order to survive, let alone live a full and meaningful life in our society today. We are convinced that many of these barriers are artificial, moveable, changeable, and capable of being eliminated. We realize that many of these barriers have existed for a long time and that they are not easily surmountable, but we are certain that by addressing them at the level of national policy, perhaps even with the President's personal commitment, we can pave the way for dramatic improvements in the quality of life and take steps toward substantially increased self-sufficiency for

literally millions of people who are today and who will in the future be disabled.

The Council chose to focus on a select few recommendations which can predictably result in a meaningful changes rather than laying out a potpourri of suggestions which might never be considered seriously or appropriately prioritized. The Council believes that by establishing a good track record with this report, it will have the opportunity to address additional issues of importance and concern in the future.

In conjunction with the report, the Council initiated the first-ever Harris Poll which I mentioned before. The Harris Poll, "Disabled Americans' Self Perceptions," resulted from telephone interviews with 1,000 persons with disabilities from across the United States. The results of the study are fascinating and provide useful substantive information. The Council is now involved in analyzing the implications which the survey has for federal policies and programs affecting persons with disabilities. Among the findings are the following:

Disabled Americans have far less education, as a group, than do non-disabled Americans. Forty percent of all disabled persons did not finish high school. This proportion is nearly three times higher than in the non-disabled population, where only 15% of adults have less than a high school education.

Disabled Americans are much poorer than are non-disabled Americans. Half of all disabled persons (50%) report household

incomes for 1984 of \$15,000 or less. Among non-disabled Americans, only 25% have household incomes in this bracket.

There is a disturbing rate of poverty among elderly disabled persons. One-third (32%) of all disabled persons aged 65 and over report a household income of \$7,500 a year or less. Six out of ten elderly disabled persons report a household income of \$15,000 or less.

Being disabled means having less social life than non-disabled people and, for a majority of disabled persons, not being able to get around and socialize as much as they would like:

An 85% majority of non-disabled people socialize at least once a week with family and friends. Seventy-five percent of all disabled persons say that they socialize at least once a week, but this figure drops to 67% among very severely disabled persons.

A 56% majority of all disabled persons say that their disability prevents them from getting around, socializing outside of their home, or attending cultural or sports events as much as they would like. This majority rises to 67% among somewhat severely disabled persons, and to 79% among very severely disabled persons.

Disabled Americans participate much less often in a host of social activities that other Americans regularly enjoy, including watching movies, plays, and sports events, and going

to restaurants:

Nearly two-thirds of all disabled Americans never went to a movie in the past year. In the full adult population, only 22% said that they had not gone to a movie in the past year.

Three-fourths of all disabled persons did not see live theater or a live music performance in the past year. Among all adults, about 4 out of 10 had not done so.

Two-thirds of all disabled persons never went to a sports event in the past year, compared to 50% of all adults.

A 58% majority of non-disabled persons eat at a restaurant at least once a week, but only 1 in 3 disabled persons do. Another third of disabled persons say that they go to restaurants less than once a month, or never.

Disability also has a negative impact on vital daily activities, like shopping for food. Disabled persons visit grocery stores much less often than do non-disabled persons. About 6 out of 10 disabled persons visit a grocery store at least once a week, while 90% of non-disabled adults shop for food this often.

Disabled Americans are also less involved in community life than are non-disabled Americans. Six out of ten non-disabled persons say that they are somewhat or very active in volunteer groups, religious groups, recreation groups, or other community activities. Only 4 out of 10 disabled persons are active in

these kinds of groups.

Disabled Americans express less satisfaction with life than the non-disabled majority does. But a large majority of disabled persons say that they are satisfied with life. Sixty-nine percent of disabled persons say that they are somewhat or very satisfied with life, compared to 90% of non-disabled persons.

The most significant overall measure of the impact of disability is that a 57% majority of disabled Americans feel that their disability has prevented them from reaching their full abilities as a person.

A much higher percentage of very severely disabled persons believe that their disability has impeded their efforts to reach their potential. Seventy-two percent of very severely disabled persons believe that this is so.

The Council regards its legislated mandate to be involved in the development and coordination of disability policy quite seriously. Although our ability is somewhat limited by our size, our enthusiasm is unlimited. Our ability to observe, to shape, and to influence policy is enhanced by our legislated authority and location in government, and our opportunity to improve the status quo for people with disabilities and their families is limited only by our lack of imagination and energy. We hope that by cooperating with all groups and agencies which effect the lives of people with disabilities, we can live up to the expectations which the Congress and the President have of

us, and to those which we have of ourselves.

The Council is aware that millions of people with disabilities living around the world face the same barriers to productivity and independence as Americans with disabilities. We are convinced that a concerted, worldwide effort to eradicate barriers and to develop attitudes, environments, and service programs which are designed to facilitate involvement by disabled people in all aspects of society must be undertaken now. We are prepared to join with all of you in an effort to insure that disabled people have the opportunity to be contributing members of their communities, and that they no longer be regarded as objects of pity, segregated and discriminated against. We believe that change is inevitable and that now is the time for it to occur.