Making Health Care Reform Work for Americans with Disabilities

Summary Information on Five "Town Meetings" on Health Care Reform: A Report to the President and the Congress of the United States

NATIONAL COUNCIL ON DISABILITY

July 26, 1994

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Marca Bristo, Chairperson
John A. Gannon, Vice Chairperson

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National Council on Disability
1331 F Street N.W.
Suite 1050
Washington, D.C. 20004-1107

(202) 272-2004 Voice
(202) 272-2074 TT

(202) 272-2022 Fax

LETTER OF TRANSMITTAL

July 26, 1994

The President
The White House
Washington, D.C. 20500

Dear Mr. President:

Today, as we celebrate the 4th anniversary of the signing of the Americans with Disabilities Act (ADA), I am pleased to submit to you the Council's report entitled ***Making Health Care Reform Work for Americans with Disabilities. Summary Information on Five "Town Meetings" on Health Care Reform: A Report to the President and the Congress of the United States.***

As the original author of the ADA, the National Council on Disability is deeply concerned that ADA's promise of full equality to 49 million Americans with disabilities cannot be kept if we lose the battle for health care reform.

During March and April of this year, the National Council on Disability held five "town meetings" across the United States in order to provide persons with disabilities with an opportunity to express their views on the various proposals for health care reform which are currently being considered by the Congress. This document represents the opinions of over 130 witnesses and the hundreds of people who attended these town meetings. We were able to identify the health care priorities of Americans with disabilities. They can be summarized as follows:

- Universal coverage -- lifetime coverage that can't be taken away, portability and coverage which does not exclude people because of pre-existing conditions.
- Comprehensive defined benefits package -- access to specialists; home and community-based long-term care and personal assistant services; durable medical equipment; prescription drugs; and rehabilitation and mental health services.
- Affordability -- persons with disabilities should not pay a disproportionate share.
- Non-discriminatory -- the health care system cannot discriminate on the basis of a disability.

The 49 million Americans with disabilities applaud your leadership on focussing our nation's attention on this crucial issue. We respectfully hope that this report will provide you and Members of Congress with information that will be useful in constructing a just and productive health care system for all.

Sincerely,

Marca Bristo
Chairperson

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

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INTRODUCTION

During the months of March and April, 1994, the National Council on Disability held five "town meetings" across the United States in order to provide persons with disabilities, family members, and other interested citizens with an opportunity to express their views on the various proposals for health care reform which are currently being considered by the Federal government. The purpose of these town meetings was to identify the concerns of consumers regarding current proposals for reform and to learn of possible ways in which these concerns might be addressed as the various plans go forward. A summary of the process used to conduct the hearings is found in Attachment A.

TOWN MEETINGS SCHEDULE

Town meetings were held on the following dates in these locations:
March 30, 1994, San Diego Hilton, 1775 E. Mission Bay Drive, San Diego, CA
April 5, 1994, Texas Rehabilitation Commission, 4900 North Lamar, Austin, TX
April 6, 1994, Ramada Inn, 420 SE 6th Street, Topeka, KS
April 9, 1994, Holiday Inn Crowne Plaza, 1605 Broadway, New York, New York
April 11, 1994, Holiday Inn City Centre, 1800 Market Street, Philadelphia, PA

Hundreds of people with disabilities and other interested citizens attended these hearings. Over 130 people, the majority of whom were disabled, provided formal testimony to the Council. While our review of the large body of testimony emanating from these hearings is ongoing, several major themes have emerged from our review of the testimony to date. They are as follows:

> ***After five years of crisis-ridden terminal illness, my life was saved in December of 1990 by a liver transplant. My experience represents the best and worst of***

> ***the U.S. health care system. As a result of pioneering medical therapy and the generosity of a donor family, I have been brought back from the brink of death. But I face a protracted and intense struggle to obtain the health care I need every day to stay alive. Since 1985, every decision that my wife and I have made about family life, employment or education has been weighed against my need for access to life-sustaining drugs, tests and treatment.***
>
> **- Robert Fasano**

THEMES

People with Disabilities Are Treated Quite Poorly Under the Current System.

PRIVATE HEALTH INSURANCE COMPANIES

> ***Families sometimes find that soon after their child's diagnosis, their insurance company increases their premiums dramatically, out of reach of their ability to pay. Others report that their policies have been cancelled or that the company refuses to renew them. Families of children whose lives have been saved by sophisticated but expensive medical treatments find that they have reached a "lifetime cap" and that their insurance coverage has vanished.***
>
> **- Kate Maus**

Private health insurance companies frequently deny people with disabilities any coverage at all or provide only limited coverage, often for exorbitantly expensive premium levels. This is frequently due to the exclusion of "pre-existing conditions" in many private health insurance plans. Simply put, people with disabilities cannot receive coverage because of this form of legalized discrimination. While it may be true that certain people with disabilities might require increased medical services, the actuarial information utilized by many private insurance companies to determine whether an individual is eligible for coverage often "lumps" people into very large disability categories (e.g. "cerebral palsy") and provides for exclusion based on these categories, without an individualized determination. And while the Americans with Disabilities Act contains some very weak provisions concerning health care insurance discrimination against people with disabilities, much of this actuarial information used to exclude people with disabilities is quite out-of-date and does not reflect the tremendous progress that has occurred over the past twenty years in treating and ameliorating the effects of disabilities, the explosion of progress in medical and assistive technology devices which substantially improve health status, and the remarkably increased life expectancy for many persons with disabilities. Thus, private health care insurance plans effectively exclude many people with disabilities from coverage.

Even for those individuals with disabilities who do receive coverage, it is often reported that private insurance companies refuse payment for services and items that consumers thought were covered under their health care plans.

> ***I don't have prepared testimony because I was up past midnight working on insurance claims. My nine-year-old son has severe disabilities and I have spent the past nine years negotiating reimbursement for covered services, accumulating documentation, appeals and re-appeals for the payment of covered services. In the past year every one of my son's speech therapy and half of his physical therapy claims have been appealed.***
>
> \- Paula Russell

In addition, co-payment requirements leave many people with disabilities (many of whom are poor, due to the 67% unemployment rate among people with disabilities) unable to pay for required services. This seems particularly true regarding prescription drugs.

> ***I was waiting in line at my pharmacy about a month ago when I overheard the pharmacist talking to the lady in front of me. She was told that she would be given a two-day supply of her prescription, and could get the rest when she came in with the money to pay for it. I wonder if she was able to go back and get the remainder of her prescription. I wonder if she is all right.***
>
> \- Michael Todd

Many witnesses reported that they had to make a choice every month about whether they should buy food or fill their prescriptions. Finally, the existence of "lifetime cap" provisions edge many people with disabilities, particularly children, out of coverage within a short period of time, sometimes as the result of a single illness.

PUBLIC HEALTH INSURANCE PROGRAMS

> ***Some families find that their only effective choice is to stop working completely and go on public assistance so that they will have health insurance for their sick child.***
>
> \- Kate Maus

Public health insurance programs are full of coverage barriers as well. Hundreds of thousands of Americans with disabilities must make a choice as to whether they will work and enjoy even a marginally adequate standard of living or whether they will have health insurance. The poverty-based nature of many publicly funded health care plans makes it impossible for people to work and become more independent.

> *Robert E. Friedman, Chair of the Corporation for Enterprise Development, has pointed out in reference to the welfare system that, "The problem with the current system is not that it rewards indolence, but that it penalizes effort." The same may be said of the Social Security Disability benefits program.*
>
> - Dr. Douglas Martin

Even more insidiously, this forced economic idleness can lead to increased health problems in and of itself. For those who often must choose to forgo an active and contributing life due to the need to have some kind of health care coverage, there are often waiting periods lasting two years until coverage begins.

> *A year ago, I went on SS Disability. I have no medical insurance. I know the awkwardness of not having insurance and having to say, "Take me as a charity case. I am in deep trouble. I need a steroid treatment." It is an extremely demeaning and awkward situation to be in. I don't understand the two-year waiting period for medical coverage under SS Disability. In the real world, I realize, there are economics involved there. But the insecurity of not having medical insurance is very stressful.*
>
> - Paul Kahn

Thus, the cycle of poverty and poor health is exacerbated.

Once individuals become eligible for coverage, they find that many doctors, hospitals, and other health care providers will not accept government insurance due to the excessive paperwork and low reimbursement rates involved. Thus, they must either forgo treatment once again or travel across town to a "Medicaid mill" where persons are "processed" at great speed (and with very little attention to their individual needs) so that the professionals involved may maximize their reimbursement. Even when consumers do access appropriate medical care providers, they often find that publicly-assisted programs will not cover necessary services and equipment. For example, the refusal of Medicaid to cover appropriate wheelchairs for people with physical disabilities borders on legendary.

> *Social Security says it won't pay for a chair my wife can lift, so she'll throw her back out and become disabled. My doctor gave up trying to get me a wheelchair. He said, "Let's steal one." We did. The salesman looked the other way and we took it.*
>
> - Dennis Sharp

At one of our hearings a consumer who uses a wheelchair asked the dozens of other people who used wheelchairs in the room if they had obtained minimally appropriate wheelchairs through the Medicaid program. Not one said they had.

LONG-TERM CARE

> ***I am 67 years old and I have cerebral palsy. I've lived in institutions since I was ten years old.***
>
> ***Health care reform that accommodates the needs of people with disabilities would allow me to live independently in the community for the first time in my life. If I could live in the community with the aid of universal health coverage and guaranteed long-term care services, I could come and go as I please for the first time in my life.***
>
> ***I still have hope that I will be able to leave the nursing home and live on my own. Health care reform that does not meet the needs of people with disabilities like me is not real health reform.***
>
> **- Harry Richardson**

Finally, it must be noted that a significant portion of the billions of dollars spent by government agencies on an annual basis for long-term care coverage is wasted on the unnecessary institutional placement of persons with disabilities (and others) in nursing homes and State and county institutions. Given the tremendous institutional bias of government long-term care options, literally hundreds of thousands of citizens have no other choice but to live in nursing homes and other segregating, dehumanizing institutions. The continued placement of individuals in these inappropriate institutions is not due to their "need" for such placements.

For nearly twenty years, alternatives to these placements have been in place and have been quite successful in providing for the needs of these individuals in home and community based settings, often at lower cost to the government.

> ***Concepts of Independence is a unique approach to home care services in which an individual is given the power to hire, fire and train a home attendant. It has been in existence for fourteen years and currently serves over 350 consumers, so that should be proof enough that it is a doable thing. It is also very cost effective. It would save 50% of the money it would take to maintain a person in an institution. In addition, it allows people to have a more dignified and satisfying way of life by enabling them to maintain themselves in their own homes.***
>
> **- Pat Walls**

Indeed, there are now entire States wherein, for example, nobody with a developmental disability lives in a large congregate care institution. Thus, it is apparent that there is a painful gap between what we know how to do in order to dramatically improve the quality of life experienced by people with disabilities and what the government currently funds. Without a massive redeployment of resources in favor of supporting individuals and their families in home and community-based options, literally millions of people will continue to have their lives wasted for them by the government and waiting lists for community services will continue to expand.

People with Disabilities Live in Fear of the Repercussions of Many of the Current Health Care Reform Proposals.

ACCESS V. COVERAGE

Even given the absolute inadequacy of the current health care insurance situation, many witnesses testified that they were afraid that the situation might become worse if certain proposals for health care reform currently being considered were adopted. First of all, many of these proposals guarantee "access" to health care, not "coverage." As one witness noted,

> ***We all have access to purchasing markets. If we have enough money, they'll be happy to sell it to us. That's what access to health care means: if we're rich, we can buy into it. We already have access. What we need is guaranteed coverage.***

Thus, rhetoric regarding "expanded access" to health care is widely rejected.

HEALTH CARE ALLIANCES

Another fear expressed during the hearings was that the proposed model of "health care alliances" or other similar cooperative ventures would continue (and perhaps expand upon) the current inadequacies of the private insurance industry. Many witnesses saw alliances as perpetuating the current problems they experience in obtaining appropriate coverage. They do not see much chance for change if the same companies which currently provide them with inadequate coverage band together. In fact, many saw the situation as getting worse, even if the goal of "universal coverage" remained in the reform package.

COMMUNITY-BASED COVERAGE V. INSTITUTIONAL COVERAGE

> ***Long-term care which is community based and provided in the home is essential to divert people with severe disabilities from expensive nursing homes which are often paid for by federal dollars. Diverting funds from the nursing home "cartel" to fund community based in-home supports is a cost efficient program that will enable more people with disabilities to work, play and contribute in their communities.***
>
> \- Patricia Yeager

In addition, many witnesses feared that the current institutional bias in publicly-financed long-term care programs would get worse. This was based on the outright exclusion of home and community-based coverage in many proposals and the relatively modest support for home and community-based coverage in even the most sweeping proposals. One fear is that if, indeed, "universal coverage" is mandated for acute and episodic services, and promises are kept wherein the Medicare program remains untouched, current Medicare dollars will, through default, be channelled into long-term institutional settings for older persons. As it is currently the case that many people with disabilities (including thousands of younger people with disabilities) are effectively forced to live in nursing homes and other "chronic care" institutions, an expansion of institutional placements for older Americans will lead to an expansion of the inappropriate institutionalization of people with disabilities, particularly as many institutional facilities are linked to profit-making , multi-State (and sometimes, multinational) corporations, who need to maintain high average daily census counts in order to maximize profits.

CHOICE OF PROVIDERS

Many individuals also expressed fear that their choice of providers would be severely restricted. In some cases their experiences under the current system have caused them to be concerned.

> ***My health care providers are judged by the insurance payors as "preferred" primarily based on the swiftness the provider gets the patient in and out of the system.***
>
> \- Janice Drake

Many adults with disabilities and parents of children with disabilities testified that it had taken them literally years to locate professionals who were familiar with and competent in treating a particular disability. They feared that their choice to continue seeing these professionals would be taken away under most of the current reform proposals.

> ***I tried to get [the managed care insurance company] to understand how my care could be harmed by forcing me to be treated by doctors who know nothing about my history. I have tried to explain that switching providers will force doctors to do expensive and redundant retesting to establish test baselines that describe my condition. Providers who have not monitored my condition over time will not detect changes in my condition that may call for a change of my immunosuppressive regimen or other treatments. And, as observant as I have learned to be over the course of my treatments, there are times when I may not be able to communicate or detect a change in my condition.***
>
> \- Robert Fasano

With a perceived reduction in specialty care, the provision of disability-related treatments and services would not even be considered, as professionals would be unfamiliar with the needs of consumers. Many witnesses stated that they were afraid that these necessary treatments and services would not be available under most of the reform plans, either due to ignorance on the part of providers or limitations on funding.

> ***All plan participants were forced, with one week's notice, to select a gatekeeper from a list of primary care physicians.... When calling primary care physicians***

> ***to ask whether they would act as my "gatekeeper" and coordinate my post-liver transplant immunosuppressive therapy, I was refused by the primary care providers based on my condition. They stated that they would not see me because they are not appropriate providers. They said that my primary care should be coordinated by a physician knowledgeable in post-liver transplant immunosuppressive protocols. .... The problem is that there are no doctors on the managed care plan's list of primary care doctors who are familiar with these protocols. Now I am stuck with a complex medical condition which may be destabilized at any time and a provider who doesn't understand my needs but who can give or withhold care that I need.***
>
> **- Robert Fasano**

RATIONING

Finally, several witnesses stated that they feared that cost control measures (which would inevitably be part of any reform plan adopted by the government) would lead to health care rationing. Such rationing, coupled with the significant discrimination faced by individuals with disabilities, would lead to the denial of necessary -- even life-saving -- treatments and services for persons with disabilities. This is not a theoretical issue. Witnesses cited the 1992 health care reform plan proposed by the State of Oregon which would have excluded people with specific disabling conditions from treatment as evidence of the possible effects of rationing. While this plan was rejected by the Federal government because of possible violations of the Americans with Disabilities Act and was not given approval until this concern was addressed, other pervasive attitudinal barriers (exemplified, for instance, by the current frenzy regarding so-called "physician assisted suicide" targeted mostly at people with disabilities) amply substantiate this fear.

The Goals of Universal Coverage and Comprehensive Benefits for Persons with Disabilities Can Be Achieved.

ELIMINATION OF PRE-EXISTING CONDITION EXCLUSION

> ***It may be clear to some, but not to all, why the allowance of a phrase, such as "pre-existing conditions" is an overwhelming ruse for blatant discrimination. It is pure and simple discrimination because insurance companies have used this phrase repeatedly to exclude our people from covered policies for many years!***
>
> **- Dr. Erik von Schmetterling**

In spite of the many issues cited above, most witnesses were hopeful that the goals of universal coverage and comprehensive benefits could be achieved. First of all, the most basic step toward this goal would be to eliminate the

pre-existing condition exclusions that are embedded in the vast majority of health insurance programs. Simply put, in the views of consumers, it is criminal that people are totally excluded from coverage based on who they are or given coverage for everything <u>other than</u> their major areas of need. The economic impact of these pre-existing condition exclusions -- which effectively *force* people with disabilities into government programs that make it impossible to work -- is staggering.

> ***Princeton sociologist, Paul Starr, points out that three out of ten people say that they or someone in their family have had to give up a better job opportunity because of a pre-existing medical condition.***
>
> \- Dr. Douglas Martin

The resulting loss of independence and basic human dignity is immeasurable. Therefore, the first step toward universal coverage and comprehensive benefits must be the elimination of pre-existing condition exclusions.

ELIMINATION OF LIFETIME CAPS

Second, provisions in current health insurance plans that impose lifetime caps on services should be eliminated. Under the current system, the small number of people who require intensive, expensive services are, in effect, told that their health and even their lives are no longer valuable once they have reached a certain health care expenditure level.

> ***The insurance company at my husband's new employer ... would only cover my lupus to a lifetime limit of $10,000. When you're spending over $300 per month on drugs and hundreds more each year on physician care and laboratory work, that amount wouldn't last very long. One -- even one very brief -- hospital stay would use it all.***
>
> \- Jean Hall

Ironically, this expenditure level is often considerably less than the level that the government spends on one or two health-related grants, grants which are often responsible for the expensive technology used on people until they have reached their lifetime cap. This is not to open a floodgate of expensive medical procedures that will bankrupt the system. With extremely few exceptions, no one would choose to undergo these procedures unless they were absolutely necessary.

UNIVERSAL COVERAGE

Third, there must be a government mandate for universal coverage (*not* universal access). Whether this takes the form of a guaranteed governmentally-supported system, employer mandates, or other mechanisms is open. However, there must be a guarantee of universal coverage.

> ***We must insist upon universal coverage. Everyone in this country must be able to get the health care services they need when they need it. Period.***
>
> - Bill Stothers

This mandate should not encourage the development of a secondary insurance market through its coverage restrictions. For example, it is entirely conceivable that universal coverage could be mandated, yet only cover two respiratory therapy sessions per month. For an infant needing daily respiratory therapy this would obviously not be sufficient. How would the extra sessions be financed? In many situations, family resources would be exhausted quickly. Enter the specter of a secondary insurance market developing in order to cover these "extra" services. Multiply this example across several areas (physical therapy, chemotherapy, testing procedures, etc.) and consumers face the same situation they are in now. The development of this secondary market also makes it easy for the government to not include certain services, dramatically restrict coverage, or eliminate existing coverage provisions due to the very existence of this secondary market.

CONSUMER NEEDS

Fourth, it is important that the mandate covers what consumers actually need, not what is currently available. As mentioned above, health care reform for people with disabilities should eliminate the current disparity between funding for home and community-based services and institutional placements.

> ***I watched a capable individual change when she contracted a very disabling condition who could not do her own shopping. She wanted to live independently. She did not want nursing homes. But the only time she got the right care was in the nursing home because that was the only time she qualified for MediCal. She was unable to pay for the drugs that she needed to live and had to make the choice between the drugs and eating. She turned to another drug that was cheaper and easier to get. It eventually killed her.***
>
> - Linda Thompson

We have known for decades that people with disabilities can and should lead lives of maximum independence, productivity, and inclusion in their local communities, instead of being forced out of their homes and effectively placed under the "ownership" of either the State or medical model corporations. As the supports needed by individuals with disabilities to live in the community are still classified as "health related," health care reform should eliminate the current disparity and significantly redeploy funding into home and community-based options. If this does not occur, tens of thousands of people with disabilities will be effectively denied access to the stated goals of the Americans with Disabilities Act: equality of opportunity, full participation, independent living, and economic self-sufficiency.

> ***I want health care coverage so I can get a job and become a tax paying citizen. Now I can't work because if I do, I can't earn anything above the poverty level or I lose my health coverage. In this state, it is estimated that it costs $72,000 a year to keep a head-injured person in an institution. My family has taken care***

> ***of me, but they are getting on in years. I want to be on my own so I can have some kind of a life.***
>
> **- David Wilson**

EXPANSION OF COMMUNITY MENTAL HEALTH SERVICES

In addition, there should be a significant expansion of community mental health services.

> ***For many people, children and families in particular, [mental health] services just do not exist in their neighborhoods or within a reasonable commute. For others, insurance does not provide coverage for all or any of the services, co-payments may be too high, or sliding scale fee schedules may not be available. Families frequently must relinquish custody in order to access services for their minor children.***
>
> **- Eva Walters**

Current evidence shows that many mental health problems are amenable to a wide variety of medical treatments.

Yet, most of the current proposals for health care reform fail to provide for parity between physical and mental health services. This maybe due to the continuing assumption that mental health problems are really the "fault" of the individual and that they would "go away" if only the individual "behaved." This type of stereotyping and the extreme prejudice faced by people with mental health issues remain as barriers to adaptive public policy regarding equal treatment for physical and mental health services. Furthermore, the denial of mental health coverage results in increased costs for physical health care.

> ***An extremely compelling reason to provide comprehensive mental health coverage is that studies have shown that it results in a decrease in the use of general medical care. Eighty-five percent of all studies on offsets demonstrate that the utilization of medical treatment decreases following mental health treatment - inpatient utilization by about 70 percent and outpatient, by over 20 percent.***
>
> **- Berta Britz**

ASSISTIVE TECHNOLOGY COVERAGE

Next, there should be coverage for assistive technology. While it has been argued that some assistive technology might not be "medically necessary," it is important to note that over the past decade there has been a vast increase in the amount and type of technology available to assist individuals with disabilities. This technology has been instrumental in enabling people with disabilities to become more mobile, more functional, and, in general, much less dependent on the care of others.

> ***I have had polio and use a powered wheelchair. At my work site, I have a computer which recognizes and responds to my voice and I have these braces which are customized for me to get the most potential with my strength. Sometimes I feel like the bionic woman. Without these braces, I wouldn't be able to feed myself; I wouldn't be able to write.***
>
> - Darlene Calvert

Many witnesses testified that the increased mobility and communication skills they enjoy as a result of assistive technology have led to a dramatic reduction in secondary disabling conditions (decubitus ulcers, respiratory infections, etc.) and much greater access to medical assistance through improved communication. When assistive technology is made unavailable, individuals suffer.

> ***I know one individual who has cerebral palsy and puts a lot of stress on his wheelchair because he has a lot of movements. His wheelchair only lasts a couple of years and MediCal won't fund another for five years. His chair fell apart and he didn't have a chair to support his body. I watched him deteriorate because of that.***
>
> - Linda Thompson

It should also be noted that much of this technology has been developed with the support of Federal grants to medical and health-related facilities. Once again, it would seem quite ironic that technology developed under medical auspices should be suddenly considered "non-medical" when consumers seek to access it.

ELIMINATION OF WORK DISINCENTIVES

Finally, any effective effort at health care reform should break the current stranglehold that health insurance currently has on the ability of people with disabilities to work and be productive in society. As noted earlier, current health insurance programs effectively prohibit large numbers of people with disabilities from working. Any health care reform measure that purports to improve upon the current system should eliminate the work disincentives embedded in the current system.

> ***In all of the hoopla about how expensive national health care will be, everyone seems to have lost sight of the fact that so many people will be able to work now that health care is available to them. The disability community is a huge economic engine that is currently stalled because of the high cost of health insurance or its complete unavailability. If people with disabilities can go to work, then we can help pay for this program rather than be forced to live off the public "purse."***
>
> - Patricia Yeager

Strategies Can Be Developed to Make Health Care Reform Responsive to the Needs of Americans with Disabilities.

PRINCIPLES FOR HEALTH CARE REFORM FROM A DISABILITY PERSPECTIVE

Throughout the hearings, people with disabilities and other interested citizens repeated their belief that health care reform efforts should address the principles articulated by the Consortium for Citizens with Disabilities (CCD): non-discrimination, comprehensiveness, appropriateness, equity, and efficiency (please refer to Attachment B for a summary of these principles). In analyzing proposals for health care reform which were pending at the time of the town meetings, witnesses stated that only two of the current approaches being considered would address these principles: the single-payer proposal and the Administration's proposal. It is beyond the scope of this brief summary to provide a detailed analysis of how each of these proposals would need to be modified in order to meet the needs described above or the principles of the CCD. However, it is encouraging to note that consumers did see much promise in both of these approaches and believed that with appropriate amendments, either plan had the potential for meeting the needs of people with disabilities in a substantive, though perhaps not ideal, fashion.

While the single-payer system is seen as one which would meet everybody's needs, consumers did express reservations about several aspects including choice of medical professionals/procedures they would be able to access and the probability of rationing under a single-payer system. And while support was also expressed for the Administration's plan, concerns were also voiced regarding the continuation of gatekeeping responsibilities by the health insurance industry, insufficient attention to durable equipment needs, the continued preference for institutional versus home and community placements, rationing by providers which has a disproportionate impact on people with disabilities, and other issues. Clearly, both proposals would require modification, if either were to better address the needs of people with disabilities.

NEEDS OF PEOPLE WITH DISABILITIES

It is critical to note that while "special interest groups" attempt to sway the health care reform debate to favor their positions or industries, the amendment of current proposals to address the needs of Americans with disabilities does not constitute the extension of favor to a specific interest group. At present, there are 49 million people with disabilities in America. Well over half of the U.S. population has a family member, friend, or colleague with a disability. And, as the population ages, it is inevitable that many people will experience disabilities in themselves or their families and friends during the course of their lifetimes.

Recent Federal legislation has referred to the fact that disability, far from being a rare event, is a natural part of the human experience. Within this context, paying attention to the needs of people with disabilities does not

constitute a "cave in" to a special interest group. Paying attention to the needs of people with disabilities means paying attention to the potential needs of all citizens.

> ***Disability is one of the fastest growing minority groups that anyone can join at any time.***
>
> **- Congressman Jerrold Nadler**

CONCLUSION

This brief report summarizes the many hours of testimony provided to the National Council on Disability during its five town meetings on *Making Health Care Reform Work for Americans with Disabilities*. We are quite grateful to all who took the time and made the effort to attend these meetings, meetings which exemplified one of the best traditions of American democracy. The National Council on Disability looks forward to continuing its work with the community of people with disabilities, the Administration, and the Congress toward the creation of a health care system that meets the needs of all Americans in the near future.

ATTACHMENT A

ATTACHMENT A:

A DESCRIPTION OF THE PROCESS USED TO CONDUCT THE NATIONAL COUNCIL ON DISABILITY'S HEALTH CARE REFORM HEARINGS

Each meeting began with a presentation by John A. Gannon, Acting Chairperson of the National Council, who explained the purpose of the meeting, the role of the National Council in shaping disability policy at the Federal level, and previous work done by the Council in the area of health care for Americans with disabilities.

Next, Justin Dart, former Chairperson of the President's Committee on the Employment of People with Disabilities, described the importance of the issue of health care reform to persons with disabilities, particularly as it related to employment, community living, and the implementation of the Americans with Disabilities Act.

After this, Paul Marchand[*], Kathy McGinley, or Marty Ford of the Arc (formerly the Association for Retarded Citizens of the U.S.), described the features of the major health care reform proposals currently being considered by the Congress.

Next, Gina McDonald, Executive Director of the Kansas Association of Independent Living Centers, described various methods by which consumers could become more involved in the debate on health care reform both at the local and national level.

Finally, Ed Burke, Acting Executive Director of the National Council, described the town meeting process, "groundrules" for testimony, and what would happen as a result of the meetings.

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[*] Note: Mr. Marchand also serves as Chairperson of the Consortium for Citizens with Disabilities, a Washington, DC-based organization of over 100 national associations concerned with the needs of persons with disabilities.

ATTACHMENT B

ATTACHMENT B:

CONSORTIUM FOR CITIZENS WITH DISABILITIES HEALTH TASK FORCE

"PRINCIPLES FOR HEALTH CARE REFORM FROM A DISABILITY PERSPECTIVE"

(February, 1993)

ON BEHALF OF:
AIDS Action Council
Alliance for Genetic Support Groups
American Academy of Physical Medicine and Rehabilitation
American Association for Counseling and Development
American Association of University Affiliated Programs
American Association on Mental Retardation
American Civil Liberties Union
American Congress of Rehabilitation Medicine
American Foundation for the Blind
American Occupational Therapy Association
American Physical Therapy Association
American Psychological Association
American Speech-Language-Hearing Association
Epilepsy Foundation of America
Immune Deficiency Foundation
International Association of Psychosocial Rehabilitation Services
Joseph P. Kennedy, Jr. Foundation
Learning Disabilities Association
National Alliance for the Mentally Ill
National Association for Music Therapy
National Association of Developmental Disabilities Councils
National Association of Medical Equipment Suppliers
National Association of Private Residential Resources
National Association of Protection and Advocacy Systems
National Association of Rehabilitation Facilities
National Association of State Mental Retardation Program Directors
National Council for Independent Living
National Council of Community Mental Health Centers
National Easter Seal Society
National Head Injury Foundation

National Mental Health Association
National Multiple Sclerosis Society
National Organization for Rare Disorders
National Parent Network on Disabilities
National Recreation and Parks Association
National Rehabilitation Association
National Spinal Cord Injury Association
National Transplant Support Network
Spina Bifida Association of America
The Arc
The Association for Persons with Severe Disabilities
United Cerebral Palsy Associations, Inc.
World Institute on Disability

INTRODUCTION

The organizations represented in CCD's Health Task Force appreciate the opportunity to express our priorities for health care reform from a disability perspective. The time is ripe to sharpen the debate for national health care reform. The Consortium for Citizens with Disabilities is a working coalition comprised of over 75 consumer, service provider, and professional organizations which advocate on behalf of persons with disabilities and their families. This statement is presented on behalf of 42 national organizations who comprise the overwhelming majority of CCD Health Task Force members. The more than 43 million Americans with disabilities include individuals with physical and mental impairments, conditions, or disorders, severe acute or chronic illness which limit or impede their ability to function.

Such disabilities may occur as a result of disease, injury, sudden trauma, aging, or congenital anomaly. One of the reasons for the passage last year of the historic Americans with Disabilities Act was to finally recognize not only the existence and importance of these millions of American with disabilities, but also to ensure their individual civil rights.

When one considers the number and range of individuals covered by the definition of disability, it is no wonder that the issue of access to appropriate, adequate, and affordable health care and related support systems is of such critical important to the CCD. In fact, while 43 million is the official number cited for persons with disabilities, the CCD believes that, in actuality, this number is an under-estimation. Therefore, it is also no wonder that any discussion of reform of the nation's health care system must include not only the generic consumer perspective but also the unique perspective of consumers with disabilities. It is the belief of the CCD that addressing the disability perspective in the current health care reform debate will ultimately benefit all Americans.

In considering the issue of health from the disability perspective, it is essential to re-focus our conception of what being "healthy" really is. For so many people with disabilities, health is determined by functional capacity. It is the

ability to maintain or increase this functional capacity that is often the measure of the person with disabilities' opportunity to live an independent life and participate as fully as possible in the life of the community. True realization of the rights now guaranteed by the ADA and other important pieces of civil rights legislation, unfortunately, will continue to be limited as long as people with disabilities do not have access to a seamless array of life-long health, personal, and support services.

The CCD had determined that any effort to reform the nation's health care system must be built on five basic principles: non-discrimination, comprehensiveness, appropriateness, equity, and efficiency. Only in this manner can we ensure that national health care reform efforts take into consideration the needs of Americans with disabilities.

PRINCIPLES

The CCD believes that any ultimate solution to the health care crisis must be based on the principle of non-discrimination ensuring that people with disabilities of all ages and their families have the opportunity to fully participate. The CCD would define a successful health care system as one that offers a comprehensive array of health, rehabilitation, personal, and support services, as well as a system that ensures that these services are appropriate in that they are provided on the basis of each individual's need, personal choice, and situation. In addition, any truly effective solution must be equitable ensuring that no group of individuals bears a disproportionate burden.

Finally, the CCD asserts that an effective and accessible health care system must be efficient ensuring that system resources are utilized to meet health care needs. The CCD strongly supports the right to health care for all persons regardless of income or health status.

Non-Discrimination: People with disabilities of all ages and their families must be able to fully participate in the nation's health care system.

People with disabilities are often discriminated against in the health insurance marketplace because they are presumed to be high health care users. In fact, most people with disabilities are not sick. Nevertheless, private insurers use medical underwriting practices which are designed to ensure that high users of health care are charged higher premiums, subjected to preexisting condition exclusions, or rejected totally as an "unacceptable risk". Discrimination occurs when a sizeable proportion of people with disabilities, who are actually low users of health care, are denied insurance or subjected to preexisting condition exclusions. Discrimination also occurs when high users of health care are denied adequate coverage because they cannot afford the premiums or are subjected to limitations on covered services. From a disability perspective, the very practice of experience-rating, which ensures that premiums are set on the basis of previous utilization, is a form of unfair discrimination against high users.

Access to health care for individuals with disabilities cannot be considered in a vacuum. Historically, discrimination on the basis of disability has limited opportunities in employment, education, housing, travel, and other aspects of daily life. Now, with rights guaranteed in so many of these areas by the passage of the Americans with Disabilities Act and other important civil rights legislation, there is a growing realization in the disability community that access to health care is a major barrier that threatens to interfere with the attainment of these rights. The CCD believes that the present inability of a substantial proportion of people with disabilities to participate in the nation's health

care system at a level which meets their needs is a direct reflection of the continued misperception of both the skills and needs of people with disabilities. Non-discrimination requires that the health care financing system:

- prohibits pre-existing condition exclusions;
- prohibits rating practices that discriminate against higher users of health care;
- ensures that all persons, regardless of income or health status, have access to the all needed health related services;
- provides access without regard to age, race, place of residence, or the characteristics of persons with whom one maintains family relationships;
- ensures continuity and portability of coverage.

Comprehensiveness: People with disabilities and their families must have access to a health care system that ensures a comprehensive array of health, rehabilitation, personal, and support services across all service categories and sites of service delivery.

The CCD asserts that an effective and comprehensive health care system, one that is responsive to the needs of people with disabilities, would provide a seamless array of life-long health related services. Comprehensiveness implies the broadest set of services that assist individuals with disabilities and their families to achieve and sustain optimum physical and mental function. The terms "health, rehabilitation, personal, and support services", used by the CCD, refers to a universe of services delivered by a range of practitioners in a variety of sites and illustrates the necessary breadth of a health care delivery system that is truly accessible to people with disabilities. Over the course of a lifetime, all people commonly require a broad array of health, rehabilitation, personal, and support services. However, access to the entire array of these services must be ensured for people with disabilities. Often it is the availability of these services that can determine their ability to live independent lives and fully participate in the community. Moreover, adequate access can prevent exacerbation of a small health problem into a larger more costly health problem. People with disabilities would most benefit from a health care system that includes access to:

- preventive services, including services to prevent the worsening of a disability
- health promotion/education services
- diagnostic services
- inpatient and outpatient physician services
- hospital inpatient and outpatient care
- long- and short-term home and community-based services
- long-term care in medical facilities
- prescription drugs, biologicals, and medical foods
- mental health, counseling, and substance abuse services
- habilitation services
- rehabilitation services, including audiology, occupational therapy, physical therapy, psycho-social services, respiratory therapy, speech-language pathology services, cognitive, vision, and behavioral therapies, and therapeutic recreation
- personal assistance services and independent living services

durable medical equipment and other assistive devices, equipment, and related services

Appropriateness: People with disabilities and their families must be assured that comprehensive health, rehabilitation, personal, and support services are provided on the basis of individual need, preference, and choice.

Particular attention must be placed on the appropriateness of available services. It is of critical importance to the disability community that full involvement of the "consumer" is assured in all decisions affecting the selection of service, service provider, service timing, and service setting. CCD is concerned that certain forms of managed care create an incentive for under-serving people with disabilities and often utilize gate-keepers who are not knowledgeable about the special health care needs of people with disabilities.

The issue of consumer choice and participation has a particular importance for persons with disabilities. While the present acute-care oriented health care system has a tendency to relegate all "consumers" to a dependent status embodied in the "sick role", this indignity is particularly disempowering to people with disabilities when their chronic health conditions are permanent. That is why the health related services for persons with disabilities must be delivered in a way that minimizes interference with normal activities, and that health care financing policies which govern access to health care for persons with chronic conditions must be sensitive to issues of locus and control.

It is essential that decisions about health care services reflect personal preference and maximum benefit to the individual rather than provider and service setting availability, cost-containment goals, or coverage limits. CCD asserts that meaningful access to health care involves the right of the individual consumer to participate in the decision-making process regarding the provision of needed services and to be educated so appropriate self-care is possible.

In addition, CCD strongly believes that people with disabilities must be involved in policy decisions that will guide the nation's health care system. An appropriate health care system is one which:

includes consumer participation;
ensures consumer choice in relation to services and provider;
ensures a range of service settings through an integrated delivery system;
ensures appropriate amount, scope, and duration of services;
ensure the availability of trained personnel.

Equity: People with disabilities and their families must be ensured equitable participation in the nation's health care system and not burdened with disproportionate costs.

The CCD asserts that equal access to health services will not be readily achievable unless payment for health, rehabilitation, personal, and support services is equitably distributed so that no individual or public or private sector interest is burdened with a disproportionate share of the cost. Because of cost issues, too often people with disabilities and their families have been required to make unfortunate choices between needed health services in appropriate settings and what they can afford. These types of choices obviously do not reflect the principles of non-discrimination, comprehensiveness, and appropriateness of services.

Health care reform must ensure that people have access to services based on health care need and not on their employment status or income level. As a group, people with disabilities have lower income than the general population and many adults with disabilities and families with members with disabilities devote a disproportionate share of their income to health care and disability related services. An equitable health care system would be one which:

- limits out of pocket expenses and cost sharing requirements for participants;
- provides access to services based on health care need and not on income level or employment status;
- ensures adequate reimbursement for service providers;

Efficiency: People with disabilities and their families must have access to a health care system that provides a maximum of appropriate effective quality services with a minimum of administrative waste.

The CCD is concerned that the current fragmentary system has failed to achieve effective cost controls, or a rational allocation of health resources, and contributes to substantial administrative waste. It is estimated that more than 20 percent of health care expenditures are attributed to administrative costs as 1,500 private health insurers require different forms of provider documentation to trace every claim for reimbursement to the utilization by a specific individual with his or her own health insurance plan. In addition, the fragmentary system has contributed to the growth of excess capacity in the health care delivery system, inviting cost shifting, and undermining efforts to achieve effective cost controls. This has reinforced pressures for arbitrary cost containment by limiting coverage in ways that often adversely affect persons with disabilities.

Moreover, health care financing policy has not evolved much beyond acute care, failing to respond to the growing need for preventive care and for chronic health care management which could significantly reduce the growth of preventable diseases.

An efficient health care system is one that:

- reduces administrative complexity and minimizes administrative costs;
- allocates resources in a more balanced way between preventive services, acute care, rehabilitation, and chronic care management;
- ensures the delivery of effective services;
- maintains effective cost controls so that all people can get the health care services which they need.

Based on these "principles" from a disability perspective, CCD is reviewing all the health reform legislation before the Congress and submitting assessments of these bills as they are completed.

CONCLUSION

The disability community needs to be a major player in reexamining health care financing policy. People with disabilities are highly vulnerable to the limitations of both public and private systems as they are squeezed between a private system which is designed to charge accordingly to an assessment of risk and a public system which subsidizes health care according to age, poverty status, family structure, and an inability to work. Private health insurance was developed and has remained a method for spreading risk of incurring excessive costs primarily for hospital and physician services. For individuals with disabilities, access to health care has been severely restricted because of preexisting conditions and the mistaken assumption that most people with disabilities need more hospital and physician care than the population as a whole.

Health care reform needs to eliminate this restriction and assure access to needed hospital and physician services. Equally as important, the tradition of limiting covered services to hospital and physician services must be changed. Rehabilitation services, personal and support services, mental health services, and assistive technology must be recognized as essential components of health care.

Perhaps our greatest contribution will be in clarifying the principles which should guide our health care system. These include: (1) expanding the definition of "health" to include prevention services, rehabilitation therapies, assistive technology, and on-going health-related maintenance services; (2) distributing all health related expenses equitably throughout the population; and (3) restructuring our health care delivery system to more effectively support consumer-directed chronic care management.

ATTACHMENT C

ATTACHMENT C:

NCD PARTICIPANT LIST

San Diego, California
March 29, 1994

Ms. Maurizio Antoninetti
2150 Cam. de la Reina - #201
San Diego, CA 92108
619/294-8889

Ms. Elizabeth Bacon
California Association of
Persons with Handicaps
5667 Fontaine Street
San Diego, CA 92120
619/594-1112

Mr. Jon Barbre
4990 Del Monte Avenue - #3
San Diego, CA 92107
619/226-1810

Ms. Darlene Calvert
Access Center of San Diego
1322 Minden Drive
San Diego, CA 92111
619/293-3500

Michael Conroy, Esq.
3996 Shasta Street - #103
San Diego, CA 92109
619/581-1720

Mr. Joseph Earnest
AARP/VOTE
1468 La Habra Drive
Lake San Marcos, CA 92069
619/471-9159

Dr. Charles Elliot
6161 El Cajon Boulevard - #77
San Diego, CA 92115
619/496-1303

Mr. Tom Evans
1654 Columbia Street - #404
San Diego, CA 92101
619/232-3400

Mr. Roberto Frias
The Access Center
1295 University Avenue - Suite 10
San Diego, CA 92103
619/293-3500

Mr. Roy Gash
Access Center
8838 Mulvaney Drive
San Diego, CA 92119
619/296-8012

Ms. Kim Gibbens
San Diego Center for the Blind
5922 El Cajon Boulevard
San Diego, CA 92115
619/583-1542

Mr. Royce V. Hamrick
California Association of

Persons with Handicaps
7707 Mission Gorge Road - #25
San Diego, CA 92120
619/287-0171

Mr. Wes Johnson
Accessible San Diego
402 West Broadway - Suite 400
San Diego, CA
619/279-0704

Ms. Julie Kingsley
Parent/Exceptional Family Resource Center
663 Woodward Street
San Marcos, CA 92069
619/471-7353

Douglas A. Martin, Ph.D.
1015 Gayley Avenue - #1008
Los Angeles, CA 90024
310/474-0582

Ms. Gretchen Mattson, M.Ed.
California Association of
Persons with Handicaps
2420 44th Street - #C
San Diego, CA 92105-4766
619/262-1683

Ms. Leslie Bryant Morton
Developmental Disabilities Board/Area XIII
4711 Viewridge Avenue - Suite 160
San Diego, CA 92123
619/637-5563

Ms. LaVonne Murphy
National Multiple Sclerosis Society
San Diego Area Chapter
4715 Viewridge Avenue - Suite 150
San Diego, CA 92123
619/974-8640

Mr. Noel Neudeck
Change Agent
6224 Snowbond Street
San Diego, CA 92120-3735
619/382-0576

Ms. Nancy Oro
United Cerebral Palsy Association
4812 Mount Etna Drive
San Diego, CA 92117
619/278-5420

Ms. Michelle Porche
Developmental Disabilities Board/Area XIII
4711 Viewridge Avenue - Suite 160
San Diego, CA 92123
619/454-6889

Mr. Albert G. "Bud" Sayles
Access Center of San Diego
3584 Grim Aveneue
San Diego, CA 92104
619/293-3500

Mr. Dennis Sharp
and Joanne Sharp
Consumer Access Network (CAN)
1230 Umatilla Street
Del Mar, CA 92014
619/755-0555

Mr. Jordan Sher
Southern Caregiver Resource Center
3675 Ruffin Road - Suite 230
San Diego, CA 92123
619/268-4432

Ms. Alisa Shuman
10226 Princess Saint Way
Santee, CA

619/258-6244

Mr. Joe Stern
AARP
6923 Amherst Street - #15
San Diego, CA 92115
619/265-2014

Mr. Marc Stern
National Head Injury Foundation/SELF
P.O. Box 10065
Marina Del Rey, CA 90295-6065
310/450-6077

Mr. Bill Stothers
and Cindi Jones
Mainstream Magazine
2973 Beech Street
San Diego, CA 92102
619/234-3138

Janice M. Thomas, Esq.
Alliance for the Mentally Ill
1832 Garrison Way
El Cajon, CA 92019
619/899-8639

Ms. Linda Thompson
United Cerebral Palsy Association
400N Melrose Drive - #46
Vista, CA 92083
619/743-1050

F. Burns Vick, Jr., Esq.
Vick & Associates
Post Office Box 160695
Sacramento, CA 95816
916/442-7239

Ms. Patricia Yeager
The Access Center
1295 University Avenue - #10
San Diego, CA 92103
619/293-3500

Austin, Texas
April 5, 1994

Mike Bright
The Arc of Texas
1600 E. 38th Street
Suite 200
Austin, TX 78763
512/454-6694

Laura Brown
Coalition of Texans
with Disabilities
316 West 12th Street
Suite 405
Austin, TX 78701
512/478-3366

Ron Cranston
4703 Philco Drive
Austin, TX 78745-1766
512/441-8029

Joyce Dawidczyk
United Cerebral Palsy of Texas
900 Congress - #220
Austin, TX 78701
512/472-8696

Janice Drake
6707 Poncha Pass
Austin, TX 78749

512/891-2522

D. J. Johnson
Texas Department of Human Services
11709 Rydalwater Lane
Austin, TX
512/272-9288

Norman Kieke
United Cerebral Palsy Association
of the Capitol Area
9027 Northgate, #101
Austin, TX 78758-6453
512/834-1827

Constance L. King
600 Barwood Park - #426
Austin, TX 78753
512/867-5131

Margaret Little
4800 North Lamar
Austin, TX 78756
512/459-2580

Mary Jo Magruder
Texas Planning Council for
Developmental Disabilities
4900 N. Lamar
Austin, TX 78751
512/483-4086

Barrett Markland
Advocacy, Inc.
7800 Shoal Creek - #171E
Austin, TX 78757
512/454-4816

Derward McDaniel
5816 Gloucester
Austin, TX 78723

Judith E. Moore
301 A. Algentice
Georgetown, TX 78628
512/930-3652

Carolyn A. Parker, Ph.D.
Texas AIDS Network
P.O. Box 2395
Austin, TX 78768
512/447-8887

Virginia Roberts
Governor's Committee on
People with Disabilities
201 East 14th
Austin, TX 78722
512/463-5742

Ben A. Rosamond
Lone Star Paralyzed Veterans
3412 Gladiolus Lane
Dallas, TX 75233
214/339-7629

Paula Russell
Texas Network for Children
with Special Health Care Needs
2601 Great Oaks Parkway
Austin, TX 78756
512/458-1596

Vincent Sadowski
Directors Association of Texas
Centers for Independent Living
5555 N. Lamar, J-125
Austin, TX 78751
512/467-0744

Jacqueline Shannon
Texas Alliance for the
Mentally Ill
1000 East 7th Street, Suite 208
Austin, TX 78702
512/474-2225

Judith Sokolow

Advocacy, Inc.
7800 Shoal Creek Boulevard
Austin, TX 78757
512/454-4816

Michele Whaling
The Arc of Austin
2818 San Gabriel
Austin, TX 78757
512/476-7044

Becky Zeeck
Capital Area Easter Seal Society
919 West 28 1/2 Street
Austin, TX 78705
512/478-2581

Topeka, Kansas
April 6, 1994

Thomas A. Applebee
State Rehabilitation
2619 Bret
Salina, KS 67401
913/296-4424

Brian Atwell
Link, Inc.
1310 Walnut
Hays, KS 67601
913/625-6942

Michael Byington
Kansas Association for the Blind
and Visually Impaired
909 SW College
Topeka, KS 66606
913/296-4454

Bob Clark
CLASS
P.O. Box 266
Columbus, KS 66725
316/429-1212

A. W. Dirks
AARP
11403 West Douglas
Wichita, KS 67209
316/722-3640

Mike Donnelly
3258 S. Topeka Boulevard
Topeka, KS 66611
913/267-7100

Vicki Doyle
Link, Inc.
1310 Walnut
Hays, KS 67601
913/625-6942

Brenda Eddy
1722 NW Belvoir Court
Topeka, KS 66606
913/296-8172

William Fansler
Kansas Association of the Deaf
1940 Bowman Court
Topeka, KS 66604
913/295-1161

Jean P. Hall
Independence, Inc.
1123 East 2300 Road
Eudora, KS 66025
913/841-0333

Diane Kuhn
P.O. Box 3881
Topeka, KS 66604-0881

913/272-2204

Dawn Merriman
2515 Rockhurst
Salina, KS 67401
913/827-9383

Mike Oxford
Kansas ADAPT
835 800E Road
Lonester, KS 66047
913/267-7100

Garrett Porter
1803 East 26th
Apartment D
Hays, KS 67601
913/628-1901

Joe Porting
Families Together, Inc.
1023 SW Gabe Boulevard
Topeka, KS 66604
913/273-6343

Jeff Simon
Link, Inc.
339 South 7th
Osborne, KS 67473
913/346-5865

Sheryl Tatroe
Kansas Alliance for the Mentally Ill
112 SW 6th, Suite 505
P.O. Box 675
Topeka, KS 66601
913/233-0755

Michael R. Todd
Independence, Inc.
2011 Miller Drive
Lawrence, KS 66046
913/843-2428

Josie Torrez
Families Together, Inc.
1023 SW Gage
Topeka, KS 66604
913/273-6343

David Wilson
3112 Thornton
Parsons, KS 67357
316/421-1305

Marty Wooten
1313 Adams
Fredonia, KS 66736
316/421-5502

Glen Yancey
Rehabilitation Services
Kansas Department of Social
and Rehab Services
300 SW Oakley
1st Floor Biddle Building
Topeka, KS 66606
913/296-3911

New York, NY
April 9, 1994

Ruth Aleskovsky
276 Riverside Drive
New York, NY 10025
212/666-1207

Richard Anderson
951 55th Street
Brooklyn, NY
212/264-4715

Sam Anderson

(no address given)

Kristin-Ann Behrmann
National Easter Seal Society
460-13M Old Town Road
Port Jefferson Station
New York, NY 11776
516/476-3626

James Billy
Harlem Independent Living Center
5-15 125th Street
New York, NY 10027
212/369-2371

Linda W. Blair
Connecticut Union of Disability
Action Groups, Inc.
P.O. Box 461
New Haven, CT 06502
203/777-1921

Gerald Butell
691 FDR Drive
New York, NY 10009

Susan M. Dooha
National Transplant Support Network
443 E. 88th Street - #17
New York, NY 10128
212/852-5025

Tom Duane
New York City Council Member
275 Seventh Avenue - 12th Floor
New York, NY 10001
212/929-5501

Robert Fasano
National Transplant Support Netowrk
443 E. 88th Street
New York, NY 10128
212/876-9380

Joseph Gordon
Self Help for Hard of Hearing
205 West End Avenue
New York, NY
212/724-4856

Sylvia Gould
Concerned Citizens for National
Health Care Single Payer
350 W. 51st Streeet
Apartment 8A
New York, NY 10019

Lois Kaggen
Penthouse G
77 Seventh Avenue
New York, NY 10011-6645
212/691-4406

Corinne Kirchner, Ph.D.
American Foundation for the Blind
15 West 16th Street
New York, NY 10011
212/620-2140

Cheryl Krzewina
New York City Civic
Association of the Deaf
150 East 85th Street - #7B
New York, NY 10028
212/472-6614

Anthony LaGattuta
Metropolitan Chapter of the National
Rehabilitation Association

42-54 196th Street
Flushing, NY 11358-3030
212/264-4017

Enilda Lozada
New York State Head Injury Association
1537 White Plains Road
Apartment 1B
Bronx, NY 10462-4113
518/482-5285

Congressman Jerrold Nadler
U.S. House of Representatives
Washington, DC 20515
202/225-5635

Dina Niedelman
Disabled in Action
17 Vandalia Avenue - #9R
Brooklyn, NY 11239
718/927-4854

JoAnn Piazzi
Westchester Independent
  Living Center
297 Knollwood Road
White Plains, NY 10607
914/682-3926

Joseph Prezioso
332 E. 29th Street
New York, NY 10016

Harvey Rosenthal
New York Coalition for Community
  Mental Health Care Benefits
  in Health Care Reform
23 Elk Street
Albany, NY 12207
518/436-0008

Marilyn Saviola
(no address given)

Richard Seltzer
311 East 23rd Street
New York, NY 10010

Chris Shawn
Vietnam Veterans Agent
  Orange Network
145 East 30th Street
New York, NY 10016
212/686-8782

Ann Souronis
21-06 23rd Avenue, #1A
Astoria, NY 11105
212/852-8000

Arthur Springer
Asthma and Emphysema Support Network
150 West 80th Street - #4A
New York, NY 10024-6313
212/580-9143

Pat Walls
Concepts
332 E. 29th Street
Apartment 4H
New York, NY 10016

Eva Walters
Mental Health Association in
  New York State
75 New Scotland Avenue
Albany, NY 12208
518/434-0489

Harry Wieder
67-11 Yellowstone Boulevard
Forrest Hills, NY 11375
718/544-8906

Frieda Zames
Disabled in Action
60 First Avenue - #2F
New York, NY 10009

212/260-0423

Philadelphia, PA
April 11, 1994

Bonnie Albrecht
790 Bradford Terrace
West Chester, PA 19382
215/431-7295

Berta Britz
Mental Health Association of
Southeastern Pennsylvania
1618 Rose Glen Road
Havertown, PA 19083
215/735-2465, ext. 231

William Byrnes
Office of Vocational Rehabilitation
7324 Shisler Street
Philadelphia, PA 19111
215/560-1951

Eugene W. Cooper
State Office of Mental Retardation
1400 Spring Garden Street
Philadelphia, PA 19130
215/560-2245

Bill Friedman
Center for Literacy
1220 North Broad Street
Apartment 1021
Philadelphia, PA 19121
215/763-9761

John F. Gladstone
Disabled in Action
125 South 9th Street, Suite 700
Philadelphia, PA 19107
215/627-7255 o

Steve Gold
(no address)

Charles Hamilton
401 Longest Lane
Philadelphia, PA

Cassie James
Liberty Resources
4001 Consbolocken Avenue
Philadelphia, PA 19131
215/627-7255

Hillisa Janoff
Liberty Resources, Inc.
One Winding Way - Suite 108
Philadelphia, PA 19131
215/581-0654

Donald Jones
(no address)

Dorothy Keane & Caroline Morgan
United Cerebral Palsy Association
102 East Mermaid Lane
Philadelphia, PA

Paul D. Kahn
National Multiple Sclerosis Society
31 North Maple Avenue
Apartment 413
Marcton, NJ 08013
1-800-445-2453

Michael Lohr
Consumer Connection
1727 West Hunting Park Avenue
Apartment 124

Philadelphia, PA 19140

Joanne M. Marinelli
Matrix Advocacy
6008 Wayne Avenue
Philadelphia, PA 19144
215/438-8200

Kate Maus
Children's Hospital of Philadelphia
34th & Civic Center Boulevard
Philadelphia, PA 19104
215/590-4365

Christie McMahon
2610 Belmont AVenue
Philadelphia, PA 19131
215/877-5224

Stephanie Panavich
(no address)

Marlene L. Perkins
Eastern Paralyzed Veterans Association
5000 Wissahickon Avenue
Philadelphia, PA 19144
215/951-5410

Ann Piccinotti
Liberty Resources, Inc.
14 Berkley Drive
Yardley, PA 19067
215/581-0681

Harry Richardson
Philadelphia Nursing Home
Girard Avenue & Corinthian Street, Room 465
Philadelphia, PA
215/978-2100

Diane Rose
Liberty Resources
1218 N. 64th Street
Philadelphia, PA 19151
215/581-0671

Kimberly Smith-Tann
Epilepsy Foundation of
Southeastern Pennsylvania
3300 Henry Avenue
9th Floor Main Campus
Philadelphia, PA 19129
215/842-7165

Maureen Sweeny
Liberty Resources, Inc.
One Winding Way - Suite 108
Philadelphia, PA 19131
215/581-0654

Erik T. von Schmetterling, M.D.
ADAPT
158 North 23rd Street - #614
Philadelphia, PA 19103-1039
215/627-7555

ATTACHMENT D

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Mission of the National Council on Disability

OVERVIEW AND PURPOSE

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

SPECIFIC DUTIES

The current statutory mandate of the National Council includes the following:

> Reviewing and evaluating, on a continuing basis, policies, programs, practices, and procedures concerning individuals with disabilities conducted or assisted by Federal departments and agencies, including programs established or assisted under the Rehabilitation Act of 1973, as amended, or under the Developmental Disabilities Assistance and Bill of Rights Act; and all statutes and regulations pertaining to Federal programs which assist such individuals with disabilities in order to assess the effectiveness of such policies, programs, practices, procedures, statutes, and regulations in meeting the needs of individuals with disabilities;
>
> Reviewing and evaluating, on a continuing basis, new and emerging disability policy issues affecting individuals with disabilities at the Federal, State, and local levels, and in the private sector, including the need for and coordination of adult services, access to personal assistance services, school reform efforts and the impact of such efforts on individuals with disabilities, access for health care, and policies that operate as disincentives for the individuals to seek and retain employment.
>
> Making recommendations to the President, the Congress, the Secretary of Education, the Director of the National Institute on Disability and Rehabilitation Research, and other officials of Federal agencies, respecting ways to better promote equal opportunity, economic self-sufficiency, independent living, and inclusion and integration into all aspects of society for Americans with disabilities.
>
> Providing the Congress, on a continuing basis, advice, recommendations, legislative proposals, and any additional information which the Council or the Congress deems appropriate;

Gathering information about the implementation, effectiveness, and impact of the Americans with Disabilities Act of 1990 (42 U.S.C. 12101 et seq.);

Advising the President, the Congress, the Commissioner of the Rehabilitation Services Administration, the Assistant Secretary for Special Education and Rehabilitative Services within the Department of Education, and the Director of the National Institute on Disability and Rehabilitation Research on the development of the programs to be carried out under the Rehabilitation Act of 1973, as amended;

Providing advice to the Commissioner with respect to the policies of and conduct of the Rehabilitation Services Administration;

Making recommendations to the Director of the National Institute on Disability and Rehabilitation Research on ways to improve research, service, administration, and the collection, dissemination, and implementation of research findings affecting persons with disabilities;

Providing advice regarding priorities for the activities of the Interagency Disability Coordinating Council and reviewing the recommendations of such Council for legislative and administrative changes to ensure that such recommendations are consistent with the purposes of the Council to promote the full integration, independence, and productivity of individuals with disabilities;

Preparing and submitting to the President and the Congress a report entitled *National Disability Policy: A Progress Report* on an annual basis; and

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

POPULATION SERVED AND CURRENT ACTIVITIES

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

The National Council plays a major role in developing disability policy in America. In fact, it was the Council that originally proposed what eventually became the Americans with Disabilities Act of 1990. Our present list of key issues includes personal assistance services, health care reform, the inclusion of students with disabilities in high quality programs in typical neighborhood schools, equal employment opportunity, community housing, monitoring the implementation of the Americans with Disabilities Act, improving assistive technology, and ensuring that persons with disabilities who are members of minority groups fully participate in society.

STATUTORY HISTORY

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