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ABSTRACT

This study was designed to identify major issues of access to health insurance and health-related services for persons with disabilities and to develop recommendations that reflect a disability perspective on how these issues can be addressed. Findings and recommendations of the study are based on a review of the literature and testimony from over 75 individuals who participated in 3 public forums. The following findings indicated that: (1) persons with disabilities face major hurdles in obtaining adequate private health insurance; (2) the employment-based private insurance system adversely affects access to private health insurance, particularly for individuals with disabilities who are self-employed or employed by small firms; (3) limitations in the range of services covered under public programs may require that an individual be institutionalized to receive needed services; (4) people with disabilities often forego employment opportunities in order to maintain public health insurance; and (5) the range of services covered by insurance often restricts coverage of services important for persons with disabilities to achieve independence. Recommendations for Congressional action to expand availability and affordability of health insurance are provided. (PB)

Sharing the Risk and Ensuring Independence:
A Disability Perspective on Access to Health Insurance and Health-Related Services

A Report to the
President and the Congress
of the United States

March 4, 1993

National Council on Disability

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An Independent
Federal Agency

Letter of Transmittal

March 4, 1993

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

Dear Mr. President:

On behalf of all members of the National Council on Disability, we submit to you a special report, *Sharing the Risk and Ensuring Independence: A Disability Perspective on Access to Health Insurance and Health-Related Services.*

The Council prepared this report in consultation with an Advisory Committee on Access to Health Insurance and Health-Related Services; numerous persons with disabilities and their families; experts on health insurance and disability policy; advocates; providers; insurers; federal and state government agency representatives; and others interested in this important topic. This report summarizes the findings of a study commissioned by the Council and presents the Council's recommendations for improving access to health insurance and health-related services for persons with disabilities.

The National Council has a long-standing commitment to improving access to health insurance and health-related services. While the landmark Americans with Disabilities Act (ADA) opened many doors for persons with disabilities, it is clear that other major barriers to these opportunities still remain. Access to health insurance and health-related services is a key factor affecting employment decisions and achievement of independence for persons with disabilities. Furthermore, the experience of persons with disabilities in obtaining adequate health insurance reflects the problems facing millions of other Americans. Understanding the perspectives of persons with disabilities can provide important insights into how coverage might be better constructed to promote the health and financial security of all Americans. The Council is confident that the recommendations in this report will provide a foundation for a health insurance system that is better equipped to meet the needs not only of persons with disabilities and their families but of all Americans.

We look forward to working with you as we seek to improve access to health insurance and health-related services for persons with disabilities. In achieving this essential goal we must share the risk and thereby ensure independence for all.

Sincerely,

John A. Gannon

John A. Gannon
Acting Chairperson
February 1993-present

Sandra Swift Parrino

Sandra Swift Parrino
Chairperson
October 1983-January 1993

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

ACKNOWLEDGMENTS

The Council wishes to acknowledge and convey its sincere appreciation to the many individuals who contributed to this report. Members of the Advisory Committee, numerous persons with disabilities and their families, providers, insurers, federal agencies, state agencies, advocates, and other experts from across the country contributed to this effort. We are grateful for their participation in public forums, their attendance at advisory meetings, and their input and assistance to the Council in the process of developing the ideas and recommendations contained in this report. We particularly thank William H. Graves, III, Ed.D., former director of the National Institute on Disability and Rehabilitation Research, who helped to make this project possible.

SHARING THE RISK AND ENSURING INDEPENDENCE: *A DISABILITY PERSPECTIVE ON ACCESS TO HEALTH INSURANCE AND HEALTH-RELATED SERVICES*

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The views contained in this report do not necessarily represent those of the administration, as this document has not been subjected to the A-19 Executive Branch review process.

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- Providing to the Congress, on a continuous basis, advice, recommendations, and any additional information that the National Council or the Congress considers appropriate;

- Providing guidance to the President's Committee on the Employment of People with Disabilities; and

- Issuing an annual report to the President and the Congress on the progress that has been made in implementing the recommendations contained in the National Council's January 30, 1986 report, *Toward Independence*.

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 that affect people with disabilities regardless of age disability type, perceived employment potential, economic need, specific functional ability, status as a veteran, or other individual circumstance. The National Council recognizes its unique opportunity to facilitate independent living, community integration, and employment opportunities for people with disabilities by ensuring an informed and coordinated approach to addressing their concerns and eliminating barriers to their active participation in community and family life.

MISSION OF THE NATIONAL COUNCIL ON DISABILITY

The National Council on Disability is an independent federal agency composed of 15 members appointed by the President of the United States and confirmed by the U.S. Senate. The National Council was established in 1978 as an advisory board within the Department of Education (P.L. 95-602). The Rehabilitation Act Amendments of 1984 (P.L. 98-221) transformed the National Council into an independent agency. The statutory mandate of the National Council at the time of this study assigned the Council the following duties:

- Establishing general policies for reviewing the operation of the National Institute on Disability and Rehabilitation Research (NIDRR);
- Providing advice to the Commissioner of the Rehabilitation Services Administration (RSA) on policies and conduct;
- Providing ongoing advice to the President, the Congress, the RSA Commissioner, the Assistant Secretary of the Office of Special Education and Rehabilitative Services (OSERS), and the Director of NIDRR on programs authorized in the Rehabilitation Act;
- Reviewing and evaluating on a continuous basis the effectiveness of all policies, programs, and activities concerning individuals with disabilities conducted or assisted by federal departments or agencies and all statutes pertaining to federal programs, and assessing the extent to which these provide incentives to community-based services for, promote full integration of, and contribute to the independence and dignity of individuals with disabilities;
- Making recommendations of ways to improve research; the collection, dissemination, and implementation of research findings; service; and administration affecting persons with disabilities;
- Reviewing and approving standards for independent living programs;
- Submitting an annual report with appropriate recommendations to the Congress and the President regarding the status of research affecting persons with disabilities and the activities of RSA and NIDRR;
- Reviewing and approving standards for Projects with Industry programs;

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*Sandra Swift Parrino initiated this study when she was Chairperson of the National Council on Disability. At the time of the study, Ethel Briggs was Executive Director, Harold Snider was Deputy Director, Katherine Seelman was Research Specialist and Kathy Roy Johnson was Program Specialist at the National Council.

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EXECUTIVE SUMMARY

Access to health insurance fundamentally affects the lives of Americans with disabilities, influencing their decisions on occupation, employment, and living arrangements. For persons with disabilities, the current health care crisis is not new; they have faced an ongoing struggle to obtain and retain the health care coverage they need to live independently and productively. Recently, growing numbers of people without disabilities are also facing barriers to affordable health insurance. As problems of access and cost intensify, the political pressure for comprehensive health care reform has increased dramatically.

Persons with disabilities have faced an ongoing struggle to obtain and retain the health care coverage they need to live independently and productively.

People with disabilities have an enormous stake in health care reform. They are the individuals who have been most adversely affected by the current health care system. They have the poorest access to private sector coverage, with its exclusions, limitations, and restrictive underwriting practices. Those who are fortunate enough to have insurance are typically underinsured, with coverage packages that are oriented to acute care and that do not meet their specific chronic and long-term care needs. Efforts by insurers and employers to contain costs have imposed a disproportionate burden on many people with disabilities. Many are deterred from seeking employment or changing their employment status because of concerns over health care coverage.

The National Council on Disability (NCD) is committed to promoting reforms that advance options for independence and productivity for persons with disabilities. In originally proposing the Americans with Disabilities Act (ADA), the Council asserted that access to health insurance and health-related services critically affects the ability of persons with disabilities to pursue employment and achieve independence. While the ADA did not resolve the problem of access to health care coverage for persons with disabilities, it improves access by requiring employers to offer employees with disabilities the same health benefits as those without disabilities and by prohibiting insurers from treating persons with disabilities differently without actuarial justification.

The National Council believes that any proposal for health care reform must be designed from the outset to meet the needs of people with disabilities.

The National Council remains committed to addressing the problem of access to health insurance so that the promise of the ADA may be realized. The Council supports comprehensive health care reform that offers universal access to adequate coverage at an affordable cost for all Americans. It believes that any proposal for reform must be designed from the outset to meet the needs of people with disabilities. A disability perspective will help us address the fundamental problems of our health care system for people with and without disabilities, and will therefore benefit all Americans.

I. SCOPE OF THE STUDY

The National Council on Disability is the federal agency responsible for advising Congress and the President on public policy affecting people with disabilities. As part of its continuing efforts to support independence for persons with disabilities, the Council commissioned Lewin-ICF to conduct the study entitled "Sharing the Risk and Ensuring Independence: A Disability Perspective on Access to Health Insurance and Health-Related Services." The study was designed to identify the major issues of access to health insurance and health-related services for persons with disabilities and to develop recommendations that reflect a disability perspective on how these issues could be addressed.

The findings and recommendations from the study are based on a comprehensive review of the literature and the testimony of over 75 individuals who participated in three public forums. An Advisory Committee of experts and advocates on disability and health policy also provided valuable insights during the two-year study. This final report presents the findings of the study and the National Council's recommendations based on those findings. The full study is available upon request.

II. FINDINGS

About 3 million persons with disabilities have no health insurance and millions more have inadequate coverage.

Throughout the course of its study, the Council was reminded that access to adequate health insurance is a serious problem for persons with disabilities that affects their ability to live independently. An estimated 3 million persons with disabilities--15 percent of the population with disabilities--lack any form of health insurance. Millions more do not have access to **adequate** health insurance. The study identified eight additional findings that illustrate the major obstacles to accessing health insurance and health-related services.

Finding 1:

Persons with disabilities face major hurdles in obtaining adequate private health insurance. While about 60 percent of the population with disabilities has private health insurance, this insurance is unavailable or does not meet the needs of many others. Private insurance often seeks to minimize the risk of serious illness and, as a result, may exclude persons with disabilities from coverage. The following are two of the major reasons private insurance is less accessible to persons with disabilities:

- **Medical underwriting and preexisting-condition exclusions restrict access to private insurance for persons with disabilities and may constitute a discriminatory practice.** These insurance practices limit the availability and adequacy of private insurance for persons with disabilities by allowing insurers to restrict or exclude coverage of individuals with certain health conditions or services associated with treating a specific condition.

- **The employment-based private insurance system adversely affects access to private health insurance, particularly for individuals with disabilities who are self-employed or employed by small firms.** While being employed typically facilitates access to private insurance, it does not guarantee it. Some employers, especially small firms, do not offer coverage. Individuals with disabilities employed in small businesses that do offer insurance may find that they are excluded from their employer's insurance policy based on their health status. An employer often is unable to obtain insurance for other workers if the person with a disability is included in the coverage. Self-employed persons with disabilities face extremely high premiums when obtaining private insurance on an individual basis.

Private insurance often seeks to minimize the risk of serious illness and, as a result, may exclude persons with disabilities from coverage.

Finding 2:

The public health insurance system in the United States fosters dependence rather than independence and isolation rather than integration. When unable to obtain private health coverage, persons with disabilities seek public insurance. Public health insurance programs, however, impose requirements and restrictions that, like private insurance, limit access to needed services, affect decisions about employment, and influence the individual's independence.

- **Limitations in the range of services covered under public programs may require that an individual be institutionalized to receive needed services.** Medicare and Medicaid cover certain services only when they are provided in specified settings or by designated providers. These limitations mean that persons with disabilities have little choice in how their care is provided and may be required to enter an institution to access needed services. Without coverage for certain services, such as personal care, individuals may require institutionalization.

- **People with disabilities often forego employment opportunities in order to maintain public health insurance.** The eligibility requirements of public programs for persons with disabilities are typically related to an inability to work. If individuals become employed and earn more than a designated amount, they may eventually lose their eligibility for public insurance and thus their access to needed services. Despite recent legislation to reduce this work disincentive, the link between income and access induces many persons with disabilities to forego or limit employment in order to retain insurance coverage.

Finding 3:

Persons with disabilities feel that their employment choices are limited by the availability and adequacy of health insurance. The spirit of the Americans with Disabilities Act is diluted by the lack of adequate insurance protection. The employment opportunities and protections promised by ADA offer little for persons with disabilities whose concern about access to adequate health insurance drives their employment decisions, including whether to change jobs or whether to accept employment at all.

The medical model, on which the U.S. health care system is fundamentally based, focuses on curing and improving health status and does not adequately consider the long-term service needs of many people with disabilities.

Finding 4:

The emphasis on acute and episodic care rather than on prevention and wellness runs counter to the needs and objectives of many persons with disabilities. The "medical model," around which the U.S. health care system is structured, focuses on curing and improving health status and fails to consider the long-term service needs associated with many disabilities. Persons with disabilities often require ongoing services simply to maintain the functional ability necessary to pursue independence. In addition, the onset of both initial and secondary disabilities could be deterred or avoided if preventive services were promoted and available on a regular basis. With the emergence of the "new morbidities," such as acquired immunodeficiency syndrome (AIDS), substance abuse, environmental illness, and trauma caused by violence, the availability of ongoing and preventive services will become even more important.

Finding 5:

The range of services covered by insurance is typically limited and often restricts or excludes coverage of many services that are important for persons with disabilities to achieve independence. Health-related services that help maintain or substantially improve an individual's level of functioning, such as assistive devices and personal assistance, are rarely covered by insurance; if these services are covered, the coverage is often restricted in amount, duration, and scope. In addition, the preventive care necessary to avoid the onset of secondary disability is often excluded from coverage.

Finding 6:

International policies toward persons with disabilities are geared toward returning individuals to work through a combination of health insurance and complementary programs of social assistance. Health policies in several countries recognize that medical and health-related service needs differ across populations and that to live independently, persons with disabilities may require services that are not needed by the majority of the population. In order to meet these needs, these countries often explicitly integrate more traditional medical benefits with social assistance programs that offer health-related services to ensure a continuum of care for persons with disabilities and other specific populations. For persons with disabilities in particular, the coordination of systems encourages employment, independence, and community participation.

Health-related services that help maintain or improve an individual's functional capacity, such as assistive devices and personal assistance services, are not adequately covered by most public and private insurance.

Finding 7:

It is difficult to define precisely the nature and extent of the barriers to health insurance faced by persons with disabilities because estimates of the number of persons with disabilities vary and this population is so diverse. The different definitions of disability used by public programs and surveys hinder efforts to develop a comprehensive profile of this population or of the relationship between disability and access to health insurance. Moreover, the lack of a comprehensive survey of persons with disabilities makes it difficult to analyze subsets of the disability population.

Finding 8:

The experience of persons with disabilities provides important lessons about the problems faced by millions of other Americans. Access to health insurance for individuals and their families has become a primary concern for most Americans. The difficulties in obtaining adequate health insurance that persons with disabilities experience provide poignant examples of the problems more Americans will face as health care costs rise and the population ages. Resolving the insurance problems of persons with disabilities will likely alleviate similar difficulties for millions of other Americans.

III. RECOMMENDATIONS

Changes in both the public and private insurance systems are necessary to eliminate the access barriers faced by persons with disabilities. During the course of the study and three public forums, participants suggested numerous ways that access to adequate health insurance for persons with disabilities might be improved. In light of these perspectives, the Council has developed 22 recommendations that focus on strategies to improve both access to and adequacy of health insurance coverage for persons with disabilities. Together, these measures promote the objectives of both the disability community and ADA--helping individuals achieve equal opportunity and independence.

Enact health care reform designed from the outset to meet the needs of people with disabilities, including full portability of coverage and a broad scope of benefits.

Recommendation 1:

Congress and the Administration should ensure that any health care reform plan adequately meets the needs of persons with disabilities, including full portability of coverage and a broad scope of benefits.

Recommendation 2:

Congress should enact legislation mandating community rating for all health insurance plans as a means of spreading the health insurance risk and reducing the cost of coverage for persons with disabilities.

Recommendation 3:

Congress should enact legislation mandating the elimination of preexisting-condition exclusions and waiting periods to increase the availability of private insurance coverage for persons with disabilities.

Recommendation 4:

Congress should halt discriminatory insurance practices by enacting legislation prohibiting medical underwriting that excludes individuals from groups on the basis of their health status.

Recommendation 5:

Congress should enact legislation mandating that insurance be guaranteed for small groups and individuals. Such a law would prohibit insurers from dropping persons from coverage because of deteriorating health and would promote portability of coverage.

Recommendation 6:

Congress should enact legislation that regulates annual insurance premium increases in order to stabilize health insurance costs.

Recommendation 7:

Congress should amend the Internal Revenue Code to permit greater deductions for health care, personal assistance, and assistive technology expenses for persons with disabilities.

The recommendations of the National Council on Disability are designed to offer equal access to health insurance and health-related services for persons with disabilities, and to thereby enhance their ability to live independently and productively in their communities.

Recommendation 8:

Reform public health insurance to expand access to Medicare and Medicaid for persons with disabilities, and to reduce barriers to employment for persons with disabilities.

Congress should amend the Social Security Act to eliminate the 24-month waiting period for Medicare benefits to ensure continuity of coverage for qualified persons with disabilities.

Recommendation 9:

Congress should mandate a Medicaid buy-in for persons with disabilities to reduce employment disincentives.

Recommendation 10:

Congress should expand Section 1619 work incentive provisions of the Social Security Act to Medicare. This would reduce employment disincentives for Medicare beneficiaries.

Recommendation 11:

Improve adequacy of health services coverage, and expand personal assistance options available to people with disabilities.

Congress should revise the Medicare benefit structure to better meet the needs of beneficiaries with disabilities.

Recommendation 12:

Congress should mandate the expansion of home- and community-based service options to reduce the unnecessary institutionalization of persons with disabilities in public insurance programs.

Recommendation 13:

Congress should expand access to personal assistance services and assistive devices either by earmarking an annual appropriation to the Social Services Block Grant (Title XX) or by mandating Medicaid coverage. In addition, states should be permitted to introduce a buy-in component to programs that provide these services so all persons with disabilities may have access to them regardless of ability to pay.

Recommendation 14:

Congress should establish an Office of the Assistant Secretary for Disability at the Department of Health and Human Services to ensure a disability perspective in all future health care policy.

Recommendation 15:

Congress should require state and local agencies that receive federal funds to support services for persons with disabilities to develop coordinated service delivery plans integrating health and social services.

Develop an integrated and coordinated delivery system focused on maintaining health.

Recommendation 16:

The Secretary of the Department of Health and Human Services should encourage schools for health professionals to develop curricula that educate providers about the health concerns of persons with disabilities.

Recommendation 17:

The Agency for Health Care Policy and Research should encourage those who study treatment effectiveness to consider outcomes that are relevant to persons with disabilities.

Recommendation 18:

Congress should direct the Social Security Administration to assess its outreach program for encouraging use of Supplemental Security Income (SSI) work incentives, and to determine why participation is low under Section 1619 and other work incentive provisions.

Recommendation 19:

Congress should authorize and fund a consensus conference on developing an acceptable definition of disability that could be used as a basis for national surveys.

Establish a research and training agenda of disability and health issues to expand the knowledge base on access to health insurance and health-related services for persons with disabilities.

Recommendation 20:

Congress should require the Bureau of the Census to conduct a survey to determine the extent to which persons with disabilities and others lack adequate health insurance.

Develop a common definition of disability for survey purposes and collect data on all aspects of health insurance and health-related services for persons with disabilities.

Recommendation 21:

Congress should direct the Department of Labor, the Social Security Administration, and the Health Care Financing Administration (HCFA), in consultation with the National Council on Disability, to design a study assessing the scope and consequences of underemployment among the population with disabilities that often results from work disincentives in public insurance programs.

Recommendation 22:

Congress should authorize and fund the National Council on Disability to commission a study examining the health consequences and secondary disabilities that persons with disabilities may suffer because of lack of timely, appropriate treatment.

IV. CONCLUSION

The recommendations of the National Council would expand the availability and affordability of health insurance and optimize independence for all persons with disabilities.

The problems persons with disabilities face in accessing health insurance and health-related services are acute. They threaten the health and independence of this group and reflect the growing problems that face the general population in obtaining needed health services. A disability perspective on health insurance and health-related services can inform the national health insurance debate by introducing as the measure of success the ability to maximize individual functional potential and independence. The recommendations of the National Council would expand the availability and affordability of health insurance and optimize independence for all persons with disabilities. Without these proposed changes, the human potential of millions of Americans may be wasted.

A DISABILITY PERSPECTIVE ON HEALTH INSURANCE

> *"... the health insurance system in this nation should be founded on the principle of sharing risk, not on the principle of avoiding risk. We are all at risk: the risk of developing a disability or having children with costly medical conditions. The system we now have punishes the very people it should be designed to serve. It is a system which ... caters to the healthy and least needy and seeks to avoid the most needy."*
>
> *Sandra Swift Parrino, former Chairperson,*
> *the National Council on Disability*

For persons with disabilities, concerns about access to adequate and affordable health insurance drive decisions about many aspects of life. Such concerns influence decisions on occupation, employment, and living arrangements. For a woman with multiple sclerosis, the parents of a deaf child, or a man with cerebral palsy, the need for adequate health insurance may mean choosing unemployment, never marrying, or remaining in an institution.

Concerns over access to health insurance influence decisions on occupation, employment, and living arrangements.

The current health insurance crisis is not new for persons with disabilities; this population has faced an ongoing struggle to obtain and retain the health insurance necessary to achieve functional potential and independence. While the passage in 1990 of the Americans with Disabilities Act (P.L. 101-336) marked an important milestone in the progress toward equal opportunity in employment and services, it did not provide similar opportunity for access to health insurance. As a result, access to adequate and affordable health insurance remains on the policy agenda for the disability community and the National Council on Disability.

A growing number of Americans find themselves facing the same barriers to health insurance as persons with disabilities.

Increasingly, a growing number of Americans without disabilities are finding themselves facing the same barriers to health insurance as those with disabilities. As these problems have affected a larger proportion of the general population, the dissatisfaction with the current health care and insurance system has increased and the urgency to address the problems has intensified.

Access to adequate and affordable health insurance is a major issue on the national policy agenda and is likely to remain a domestic priority throughout the decade. The debate over health care reform has focused on expanding coverage to the uninsured and containing spiraling health care costs. To date, the debate has not incorporated the perspectives of the disability community, even though the experience of this population clearly highlights the experiences of millions of other Americans.

A disability perspective on health care reform can inform this debate by providing insights into how coverage might be better structured to promote the functional well-being, wellness, and independence of all Americans. These issues will gain greater prominence as increasing numbers of Americans live longer with chronic and disabling conditions. The time is right to adopt a disability perspective on health care reform.

BACKGROUND AND INTRODUCTION TO THE REPORT

As the federal agency responsible for advising Congress and the President on public policy affecting people with disabilities, the National Council on Disability commissioned this study on access to health insurance and health-related services for individuals with disabilities to examine the health care issues affecting the disability community and to clearly articulate its perspective on health insurance.

The findings of the study and the recommendations of the National Council are based on the extensive input of experts and advocates who address issues concerning health care and disability, including numerous people with disabilities and members of their families.

This report highlights the findings of the two-year study conducted by Lewin-ICF. These findings were developed through a review of the literature and a series of public forums in which over 75 persons, including consumers, advocates, parents of children with disabilities, health care providers, insurers, employers, policymakers, and others with an interest in disability policy, shared their views with the Council. These findings are the basis for the Council's recommendations on improving access and implementing a disability perspective on health care reform.

The Council intends to engage policymakers, the disability community, and others in an informed debate about the future of the U.S. health insurance system and access to health-related services for persons with disabilities. The remainder of this report is presented in two sections:

- **Findings on Barriers to Health Insurance and Health-Related Services** for persons with disabilities. The review of the literature and other supporting evidence for the findings are found in a supplement to this report.

- **Recommendations** to address the problems identified in the findings. The recommendations represent the National Council on Disability's perspective on access to health insurance and health-related services for people with disabilities.

FINDINGS ON BARRIERS TO HEALTH INSURANCE AND HEALTH-RELATED SERVICES

Access to adequate health insurance is a serious problem for persons with disabilities and affects their ability to live independently. Many persons with disabilities face ongoing health care needs, and living without insurance is not a viable option. Some of these individuals structure their lives around securing health insurance. Maintaining health insurance coverage may mean choosing unemployment, living with parents, never marrying, or remaining in an institution. Despite their efforts, an estimated 3 million persons, or 15 percent of the population with disabilities, lack any form of health insurance.

The major barrier to access to care is the lack of adequate and appropriate coverage.

For most persons with disabilities, simply having insurance is not enough. Many are denied care because they lack adequate and appropriate coverage for needed services such as prescription drugs, rehabilitation, and assistive technology. Coverage for these services is often excluded or restricted, deterring some individuals from receiving needed care and causing them to to risk serious illness and impaired functioning. Examples of the consequences of inadequate coverage are many:

"Although our family was able to secure basic health insurance benefits, we were unsuccessful at obtaining <u>adequate</u> coverage for our son's intensive medical needs."

- A woman with hypertension who has no coverage for her prescription drugs and foregoes several days of medication because she cannot afford it and is later hospitalized with a stroke.
- A child with a speech impairment who cannot obtain speech therapy and falls behind in school.
- A man with postpolio syndrome who cannot obtain personal assistance and who must be institutionalized even though he is able to work and lead an independent life with assistance.

This study found that persons with disabilities who seek adequate health insurance encounter barriers in the private and public insurance system, incentives that encourage dependence rather than independence, and a health care system that is not designed to meet their needs. These observations are reflected in eight findings that support the overall conclusion of the study--that access to adequate health insurance is a serious problem for people with disabilities that affects their ability to live independently.

Supporting research and data are found in a supplement to this report.

Finding 1:

Persons with disabilities face major hurdles in obtaining adequate private health insurance.

Private health insurance is the major source of coverage for persons with disabilities; over 60 percent of persons with a limitation in their major activity have private health insurance. Despite the large number of persons with disabilities who have private health insurance, this coverage remains unobtainable for many in the disability community. Private health insurance is becoming a luxury for the healthy as insurers find ways to exclude persons who show any risk of incurring medical expenses. In addition, insurers are increasingly reluctant to offer policies to small employers and individuals because of concerns about the predictability of expenses among these groups. In particular, two aspects of private health insurance--medical underwriting and preexisting-condition exclusions--have important, and often detrimental, consequences for persons with disabilities.

"An insurer would not write homeowner's insurance on someone whose house is on fire, nor would an insurer want to sell health insurance to someone as he is entering the hospital."

- **Medical underwriting and preexisting-condition exclusions restrict access to private insurance for persons with disabilities and may constitute discriminatory practices.**

Medical underwriting and preexisting-condition exclusions limit the availability and adequacy of private insurance for persons with disabilities by allowing insurers to restrict or exclude coverage for individuals with certain health conditions or for services associated with treating a specific condition. Medical underwriting is the process by which an insurer selects the risks it will (and will not) insure and determines whether a person with a disability is "medically uninsurable." Medical underwriting permits insurance companies to review an individual's medical history to determine whether or not that individual is a good risk in terms of expected use of health insurance. Studies indicate that the list of conditions excluded from coverage or subject to limitations has grown longer.

"Preexisting-condition clauses make it impossible for most of us to obtain insurance for our children."

Exclusions on the basis of preexisting conditions are also prevalent and problematic for persons with disabilities.

Preexisting-condition exclusions are used to reduce an insurer's expected first-year medical claims expense. While health insurance may be offered to an individual with a disability, it may not cover a condition that existed prior to the time the individual sought coverage. For example, a woman with multiple sclerosis may be able to obtain private health insurance, but services related to her multiple sclerosis may be uncovered for a year. Because she cannot remain uncovered for services related to her disability for an entire year, she may choose to stay on public insurance. The most common preexisting-condition limitations are exclusions for certain services and waiting periods. Although these provisions are legal and are considered by insurers to constitute sound business practice, they essentially discriminate against persons with disabilities.

These insurance practices make it unlikely that persons with disabilities will be able to obtain private insurance and suggest that without change some may lose their private coverage. Regardless of past medical claim experience, many persons with disabilities are automatically excluded from private insurance based on their disability. Others must accept coverage that excludes services related to their disability or chronic condition or hope they remain healthy until the waiting period expires. If persons with disabilities are to realize their goals of independence and self-sufficiency, changes in private insurance practices must occur.

While being employed increases the likelihood that a person with a disability will have access to adequate insurance, it does not guarantee it.

- **The employment-based private insurance system adversely affects access to private health insurance, particularly for individuals with disabilities who are self-employed or employed by small firms.**

Many persons with disabilities discover that it is difficult, if not impossible, to obtain private health insurance in the U.S. employment-based insurance system. While being employed facilitates access to employment-based insurance, it does not guarantee it. Some employers, particularly small firms, do not offer insurance. Some persons with disabilities employed by small businesses that do offer insurance may find themselves excluded from coverage based on their health status. Small employers are often unable to obtain insurance for other workers if an employee with a disability is included on the policy.

"If you can find an individual carrier willing to cover an individual with disabilities, the cost is outrageous or the deductible unbelievable."

Self-employed persons with disabilities also face restricted access to private health insurance. Since they are not part of an employer group, self-employed individuals must seek private insurance from the individual insurance market. Over time, the individual market has become restricted as many insurers have discontinued their individual policies in an effort to control rising costs. Some individual insurance plans exclude persons with disabilities altogether. When individual coverage is available, it is extremely expensive and the scope of covered services is typically limited.

Those who are self-employed and do not have access to employer group coverage have few alternatives. While some may be able to obtain and afford individual coverage, and some may be able to access private insurance through a spouse or parent, others will seek public insurance or remain uninsured. Even for those who successfully obtain private insurance, there is no guarantee that this coverage will provide the services required to meet their needs. While the ADA will enhance access to adequate coverage by requiring employers to offer the same benefit packages to people with disabilities as to other employees and by prohibiting insurers from treating people with disabilities differently without sound actuarial justification, it will not eliminate the problem.

Finding 2:

The public health insurance system in the United States fosters dependence rather than independence, and isolation rather than integration.

When unable to obtain private health insurance, many persons with disabilities seek public insurance. Together, the federally supported programs of Medicare and Medicaid finance health services for about 5 million persons with disabilities. These programs are important sources of health care coverage that could potentially restore and maintain the health and self-sufficiency of many persons with disabilities. However, they impose requirements and restrictions that, like private insurance, limit access to needed services, affect decisions about employment, and influence independence.

- **Limitations in the range of services covered under public programs may require that an individual be institutionalized to receive needed services.**

"Medicare stipulates that in order to purchase a wheelchair, the wheelchair be only used indoors. Medicare does not see outdoor use as 'medical justification' for approving an electric wheelchair."

The coverage restrictions of both Medicare and Medicaid present a significant obstacle to independence. Both programs cover certain services only when they are provided in specified settings or by designated providers. Medicare will pay for only certain pieces of durable medical equipment, and may limit the circumstances under which coverage is available (e.g., wheelchairs for use in the home only). Medicaid has an inherent institutional bias whereby certain services are covered only in inpatient hospital or institutional settings. As a result, persons with disabilities are often institutionalized, rather than kept in the community, in order to receive necessary health care services. For example, all states must cover physical therapy in hospital settings under Medicaid, but physical therapy provided on an outpatient basis by an independent practitioner may not be covered. Other services may be provided in noninstitutional settings only if the alternative setting is cost-effective. Therefore, providing individuals with services in a home- or community-based setting is largely at the program's discretion; there is little consideration of an individual's preference or choice.

- **People with disabilities often forego employment in order to maintain health insurance through public programs.**

"Persons with disabilities who enter work while on public benefit programs cannot afford to lose their limited health coverage and must stay in the eligibility limits of the programs, which have fragmented and complicated rules."

Both Medicare and Medicaid have certain eligibility requirements. For persons with disabilities, these requirements are typically related to an inability to work, which is demonstrated, in part, by earnings below a specified level. As a result, if individuals become employed and earn more than the designated amount, they may eventually lose public insurance and, thus, needed services. Despite recent legislation to reduce work disincentives, this link between income and access to health insurance induces many with disabilities to forego or limit employment in order to retain coverage. The ultimate result is limited independence and self-sufficiency.

Finding 3:

Persons with disabilities feel that their employment choices are limited by the availability and adequacy of health insurance, and that the spirit of the Americans with Disabilities Act is diluted by the lack of adequate insurance protections.

As for most Americans, employment is an essential prerequisite to independence and self-sufficiency for persons with disabilities. Employment provides an opportunity to achieve personal and professional satisfaction and financial independence. Most individuals were once able to accept a job or change jobs without worrying about the availability and adequacy of health insurance benefits. Increasingly, all Americans face the possibility of losing insurance when seeking or changing jobs. For no group, however, is the decision about employment more linked to concerns about health insurance than for persons with disabilities.

> *"While the Americans with Disabilities Act is opening doors, current health care coverage options may be blocking access to those same doors."*

Under ADA, persons with disabilities may enjoy guarantees against discrimination not only in employment but also in public services, public accommodations, and telecommunications. ADA extends the equal opportunity and antidiscrimination measures established in Section 504 of the Rehabilitation Act of 1973 beyond agencies or organizations receiving federal funds. However, while ADA prohibits employers from discriminating against persons with disabilities, it does not adequately prevent employers or insurers from using practices that limit access to health plans or services for persons with disabilities. Under ADA, employers and insurers may not treat individuals with disabilities differently from those who do not have disabilities without actuarial justification. Employers and insurers may still engage in restrictive underwriting and coverage if they can justify their practices by sound actuarial data.

> *"[Every] employment decision I have ever made has been determined by the lack of accessible, affordable health insurance. I have not been able to make one independent choice. Any work-related experience I have gotten has taken place <u>in spite</u> of the restrictions of the system."*

While the ability to seek and retain employment is a major factor in achieving independence for many persons with disabilities, it is clear that employment alone is not sufficient. Seeking and retaining employment is often driven by the availability and adequacy of health care coverage. Persons with disabilities who cannot obtain insurance coverage from an employer, or who are offered insurance that excludes needed services or certain conditions for any amount of time, may find employment opportunities empty. The discrimination inherent in the private insurance system requires persons with disabilities to shop around extensively for employment that provides insurance to meet at least some of their health care needs. Parents and spouses of persons with disabilities engage in a similar search to find insurance that will cover their dependents. Insured persons who are diagnosed with a chronic condition, such as diabetes or heart disease, may find themselves locked in their jobs because changing jobs might render them uninsurable.

For persons with disabilities, the alternatives to employment-based insurance are primarily public programs such as Medicare and Medicaid. Persons with disabilities are eligible for these programs only if their condition renders them unable to work, as defined by earnings below a certain amount. Individuals thus face the choice of not working or being underemployed in order to retain public insurance. Highly educated and skilled persons with disabilities who are unemployed or who work well below their abilities in order to retain public health insurance are not uncommon. If these alternatives are unacceptable, persons with disabilities must weigh the risks of working with inadequate coverage or with no coverage at all.

"True realization of the rights now guaranteed by 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, health, personal, and support services."

Without adequate insurance coverage, persons with disabilities are likely to forego employment. For many, the choice is simple. Despite the opportunities fostered by ADA, continuing insurance discrimination is likely to limit the law's impact on employment for persons with disabilities. The unfortunate result of an insurance system that requires individuals to risk their health in order to obtain employment and to sacrifice their independence to preserve their health is the lost potential of millions of Americans.

Finding 4:

The emphasis on acute and episodic care rather than on prevention and wellness runs counter to the needs and objectives of many persons with disabilities.

The American health insurance system has not kept pace with the changing nature of health and illness. Health care is largely viewed from the perspective of the medical model, which focuses on cure and improving health status. Advances in medical technology have prolonged productive life for millions of Americans. However, health services have not met the challenge of the growing population with chronic and disabling conditions who require ongoing services to maintain functioning. The goal of health care continues to be curative. Emphasis on wellness, preventing disabilities, and promoting independence is needed.

As the population ages and more people survive with chronic and disabling conditions, the focus of health care must shift from curative medicine to care that maintains health status and maximizes functional capacity This shift will require an emphasis on preventive services, rehabilitation, and greater integration among health care professionals. The acute care medical model emphasizes curative treatment to restore health following acute illness or injury. Financing mechanisms reflect this focus. They provide coverage for acute episodes of illness, such as those requiring hospitalization, rather than covering health maintenance, long-term care for chronic conditions, or preventive services to avoid the onset of illness or disability.

> *"Essentially, we [persons with disabilities] seek programs of health insurance that liberate while avoiding the oppression of medical management. We wish to be able to access medical expertise and comanage our care without surrendering our independence."*

The private health insurance industry, in general, leans toward providing medical services for acute health needs, and as a result insurers have an incentive to limit access to insurance for individuals who present a risk of long-term or high health expenses. Medicare and Medicaid are principally acute care programs. Medicare, for example, does not cover preventive or wellness care and will often not pay for ongoing maintenance services. However, persons with disabilities who rely on private or public insurance often require long-term services, such as physical therapy, to maintain an advanced level of functioning and live independently in the community.

> *"Unlike the person without a disability who has an acute health need such as the occasional flu or a broken leg, a person with a disability knows that his ongoing health care needs fundamentally will affect his quality of life."*

> *"The orientation of the current health care system for people with disabilities is one which fosters dependency, work disincentives, and oppression."*

The emphasis on curing and improving health status often limits access to services for persons with disabilities because their needs do not meet "medical necessity" provisions. Certain services, such as personal assistance, may be critical to sustaining an individual's level of functioning, but if no improvement in functional capacity results from this service, insurance coverage may be limited. The traditional medical model also represents a narrow view of health care, failing to consider the needs of persons with new morbidities, such as substance abuse, environmental illness, and traumatic injury resulting from violence. With the emergence of these new conditions, the availability of ongoing and preventive services will become even more important.

The underlying paradox is that the success of the medical model has permitted many more individuals to survive beyond the acute stages of illness or injury; persons with disabilities and chronic conditions have the potential to live independently if they can obtain both traditional medical and health-related services consistently over time. In addition, the onset of both initial and secondary disabilities and a range of new morbidities could be deterred or avoided if preventive services were promoted and available on a regular basis. However, without the availability of nonacute, preventive, maintenance, and rehabilitation services, some persons with disabilities may face deteriorating health and functioning that will require repeated episodic reliance on the acute care system.

Finding 5:

The range of services covered by insurance is typically limited and often restricts or excludes coverage of many services that are important for persons with disabilities to achieve independence.

The major difficulties of financing health care for most persons with disabilities arise not from lack of insurance but from lack of coverage for certain medical and health-related services that are required for independent living. For example, sign language interpreters, assistive technology, and certain therapies are likely to be omitted from insurance plans or covered only if certain conditions are met, such as "medical necessity" criteria or service provision by specified providers. The range of covered services and the inclusion of health-related services are key determinants of the adequacy of health insurance for persons with disabilities.

"I have been employed full time most of my adult life and have had access to group health insurance. I do, however, have ongoing health-related costs that are not covered by insurance, such as hearing aid batteries, aspirin to relieve my arthritis, and other costs that are directly related to my disabilities."

Few studies have attempted to document the extent to which health-related services are covered under private health insurance. Some efforts have been made to determine whether certain services are offered under employer benefit plans. The results of these surveys seem to indicate that the majority of employers offer coverage for health-related services, such as medical equipment and supplies, but exclude coverage for many other types of health-related services, such as rehabilitation or assistive devices. However, the limits on these services are not well understood or documented, and as health care costs have continued to escalate, employers are further reducing the scope of services covered under their insurance plans.

A trend in insurance designed to improve the affordability of private coverage is the emergence of "bare bones" benefits, which include coverage for limited services. This trend essentially runs counter to the pressing needs of persons with disabilities because services they are likely to require, such as prescription drugs, mental health care, and physician services, are restricted or eliminated from coverage altogether.

Medicaid and Medicare appear to be more comprehensive in covering health-related services because of their target populations, but many gaps remain. These public programs, like most private plans, were designed to cover acute care services. The services many persons with disabilities require in order to live independently, such as personal assistance and assistive technology, are covered only to a limited extent by Medicaid and to an even lesser extent by Medicare.

Medicaid potentially offers the most comprehensive set of benefits, covering many services outside the traditional acute care model. However, states are under no obligation to offer any of the health-related services considered optional under federal law, except to children under the Early and Periodic Screening, Diagnosis, and Treatment Program (EPSDT). These optional services include physical therapy; occupational therapy; speech, hearing, and language disorder services; personal assistant services; prosthetic devices; rehabilitation; and transportation. Furthermore, states are permitted to determine the scope of services available and to restrict the amount covered. As a result, a person with a disability who requires ongoing physical therapy in order to maintain mobility and health may only receive therapy as long as the provider can document an improvement in health. Ongoing or chronic care services are typically not covered.

The services many persons with disabilities require in order to live independently, such as personal assistance and assistive technology, are covered only to a limited extent by Medicaid and to an even lesser extent by Medicare.

The Medicare program has not kept pace with the changing nature of health care or the needs of its beneficiaries. Persons with disabilities receiving Medicare cannot obtain outpatient prescription drugs and needed assistive technology, such as sensory aids, under the program. Medicare will, however, cover surgical treatment for a cochlear implant even though a hearing aid may have been sufficient. Medicare restricts coverage of wheelchairs for home use and does not cover handrails or grab bars, which severely limits an individual's independence and ability to participate in the community. Medicare's inadequacy and inappropriateness for meeting the needs of persons with disabilities means that many are thwarted in their efforts to achieve self-sufficiency.

Persons with disabilities report that limits on health-related services often prevent them from completing tasks of daily living, participating actively in their community, or maintaining employment, and are thus a major obstacle to independence. When needed services are not covered, many persons with disabilities may pay for them out-of-pocket. Others may simply do without. As a result, the health and functional capacity of these persons may erode.

Finding 6:

International policies toward persons with disabilities are geared toward returning individuals to work through a combination of health insurance and complementary programs of social assistance.

International comparisons show broad coverage for persons with disabilities in several different countries.

International comparisons offer a different perspective on health insurance and disability. An assessment of the health policies in Canada, Germany, and the Netherlands revealed that these countries recognize the different medical and health-related service needs of various populations, and that persons with disabilities may require several services to live independently that are not needed by the majority of the population. In order to meet these needs, each of the three countries has integrated more traditional medical benefits with social assistance programs. The coordination of these systems ensures a continuum of health and social services for persons with disabilities and other specific populations, and also emphasizes the link between health and employment as a means of promoting healthy and productive citizens.

All three of the countries operate federal or federal-state assistance programs distinct from the health insurance system. These programs provide services not covered under the general health care system to individuals with disabilities and other persons with special needs. The rationale for these separate systems is that the health benefits available to the general population needn't be as comprehensive as the benefits for persons with special needs. As the United States develops its own approach to health insurance, it must determine whether to make certain services available at all and whether to include these services as part of the health insurance system or as a distinct but complementary system. This decision must be made within the context of an aging population in which the number of those with chronic and disabling conditions is increasing.

In several countries, health care and other social programs are coordinated to provide services oriented to returning persons to work.

International comparisons illustrate an aggressive program of benefits designed to return persons with disabilities to work. The Vocational Rehabilitation for Disabled Persons Act in Canada, the German 1974 Rehabilitation Act, and the General Disability Benefits Act in the Netherlands all cover a range of services, including rehabilitation and assistive devices for any person with a disability who requires these services in order to work, regardless of income status. Public social and health assistance programs in the United States, in contrast, are based on income standards that limit an individual's ability to work and do not provide services oriented to returning individuals to work.

In the countries studied and in others with universal health insurance, many of the access barriers to health insurance and services are alleviated by guaranteeing that all individuals have access to a basic set of health benefits, regardless of health status and ability to pay. None of the health insurance systems in these countries, however, is adequate to fully meet the needs of persons with disabilities. These needs are met by complementary social assistance programs that appear to fill some of the gaps in coverage and facilitate employment. While these systems inevitably have some shortcomings, especially related to the adequacy of basic coverage and access to long-term care, they are, nevertheless, important models for consideration.

Finding 7:

It is difficult to define precisely the nature and extent of the barriers to health insurance faced by persons with disabilities because estimates of the number of persons with disabilities vary, and this population is so diverse.

The estimates of this population vary greatly because there is no common definition of disability.

Persons with disabilities are a large and diverse population. Children with cerebral palsy, a hearing-impaired woman, a mentally retarded young adult, a person with epilepsy, a blind man, a mentally ill child, and a young woman who uses a wheelchair because of an automobile injury are all persons with disabilities. Estimates of their number range from 23 million to 43 million, with 35 million being the most commonly used figure.

The estimates vary because there is no common definition of disability. Public programs, civil rights legislation, and household surveys all categorize disability differently. The lack of a common definition prevents researchers and policymakers from determining the size and scope of the disability constituency, from identifying their needs, and from assessing the extent to which existing programs meet those needs.

The most recent and sweeping definition of disability is that of the Americans with Disabilities Act, which focuses on substantial limitations in one or more major life activity.

The most recent and sweeping definition of disability is that of the Americans with Disabilities Act. Under ADA, individuals with a disability are defined as (a) having a physical or mental impairment that substantially limits that person in one or more major life activity; (b) having a record of such a physical or mental impairment; or (c) regarded as having such a physical or mental impairment. An estimated 43 million persons are thought to meet this definition and thus are protected by ADA provisions.

Public programs, such as the Social Security Disability Insurance Program (SSDI) and the Supplemental Security Income Program (SSI), employ narrower definitions of disability. These definitions are designed to limit program enrollment and thus program outlays. The federal SSDI and SSI definitions focus on a person's inability to maintain an income. They do not regard impairments that may affect an individual's ability to conduct other major life activities or to function in the community. Many fewer people are identified as having a disability under these definitions than under ADA.

These differences in definition make it difficult to derive a reliable estimate of the population with disabilities that is uninsured or underinsured and the type of barriers to health care they face. For example, are barriers to adequate health insurance and health-related services greater for certain age groups or for certain types of disabilities? What are the employment characteristics of persons with disabilities (e.g., full-time, part-time, firm size, type of industry), and how do these employment characteristics relate to access to adequate private health insurance? Answers to these and other questions would provide much needed information about the relationship between disability and access to adequate health insurance.

Understanding the health care needs of persons with disabilities and the barriers in the current system to meeting those needs will enable policymakers to fashion solutions that overcome those barriers. In addition, knowing how many persons with disabilities remain unemployed or underemployed because of concerns about health insurance could lead to programs that address these problems as well. Without a common definition of disability, however, it is unlikely that public programs can be accurately assessed in terms of the extent to which they provide coverage to those who might benefit and meet the needs of those with disabilities. Thus, making appropriate recommendations for change becomes improbable.

Finding 8:

The experience of persons with disabilities provides important lessons about the problems faced by millions of other Americans.

Access to health insurance for individuals and families has become a primary concern for most Americans. For the population with disabilities and for a growing number of others, the problem with the health insurance system is one of adequacy rather than lack of insurance. Neither the current system nor many of the current proposals for change explicitly address this issue. While efforts targeted at the uninsured may improve access to care for the uninsured with disabilities, these efforts may not

"...the health care crisis in this country grows worse each day. I have never envisioned myself as a person who could 'fall through the cracks of the system'--if you were to see my resumé, you would probably agree--and yet that appears to be happening."

result in adequate coverage for the newly insured or the currently insured population with disabilities. Without efforts to confront insurance discrimination and adequacy, it is unlikely that the current dissatisfaction with the system will abate.

By adequately addressing the problem of access to health insurance for people with disabilities, we are likely to address the problem for all Americans.

As the debate moves forward, persons with disabilities, advocates, and others have called attention to the problems faced by the population with disabilities. These difficulties are faced not only by persons with disabilities, but also by others who may find themselves underinsured because of inadequate health coverage and a lack of available and appropriate services. The perspective, experience, and voice of the population with disabilities largely underscores the experience of the nation as a whole and provides significant lessons for those effecting change.

RECOMMENDATIONS OF THE NATIONAL COUNCIL

The National Council on Disability believes that the current health insurance system does not meet the needs of persons with disabilities. Major reform of both the public and private insurance systems is necessary to eliminate access barriers.

The health insurance debate must be broadened beyond concerns for financing the expansion of coverage to a discussion of how health care should be defined and delivered at a time of emerging new morbidities (e.g., substance abuse, environmental illness, etc.), an aging population, and medical technology that enables many with chronic and disabling conditions to live productive and independent lives. The vision of the Council is to begin defining the health care system in terms of promoting and maintaining the health and optimal functioning of all Americans.

The vision of the National Council is that we begin to define our health care system in terms of promoting and maintaining the health and optimal functioning of all Americans.

The Council hopes that health care reform will adequately and appropriately address the needs of persons with disabilities, and its first recommendation reflects that objective. However, in the event that this does not occur, the Council strongly supports the passage and implementation of a series of incremental measures that will have a timely and significant impact on improving access, as reflected in several subsequent recommendations. These initiatives promote the objectives of the disability community and the Americans with Disabilities Act, helping individuals achieve equal opportunity and independence. Without these proposed changes, the human and economic potential of millions of Americans may be wasted.

The recommendations developed by the Council are designed to respond to the study findings and achieve the following five objectives:

- Expand access to public and private health insurance.
- Reduce barriers to employment.
- Improve adequacy of health services coverage.
- Develop an integrated and coordinated delivery system.
- Establish a research agenda of disability and health issues.

A. Expand Access to Health Insurance

Changes in both the private and public insurance systems are needed to improve access to insurance for persons with disabilities.

Access to health insurance is clearly a problem for the 3 million persons with disabilities who are currently uninsured. Many others with disabilities have been able to obtain health insurance but have had to overcome numerous obstacles in the process. Still others have had to remain on public insurance because private insurance was unavailable. Several changes in both the private and public insurance systems are needed to improve access to health insurance for persons with disabilities.

1. Comprehensive Health Care Reform

The National Council believes that the health care system is in need of fundamental and comprehensive reform. There are many ways in which such reform can be structured and achieved. The Council does not take a position on any specific health care reform plan at this time. However, the Council believes strongly that any plan adopted must be designed from the outset to meet the needs of people with disabilities. It therefore makes the following overarching recommendation:

Recommendation 1:

> **Congress and the Administration should ensure that any health care reform plan adequately meets the needs of persons with disabilities, including full portability of coverage and a broad scope of benefits.**

It is essential that any health care reform proposal be designed from the outset to meet the needs of people with disabilities.

It is essential that any health care reform proposal be designed from the outset to meet the needs of persons with disabilities. In the past, programs such as Medicare and Medicaid considered disability largely as an afterthought. Consequently, these programs have a strong bias toward acute care rather than the chronic care and long-term services, including personal assistance services and assistive technology, needed by many people with disabilities. This bias is difficult to correct if it is initially built into a system. It is, therefore, very important that people with disabilities and their representatives have substantial input in ensuring that health care reform proposals meet their needs and incorporate a disability perspective. The National Council generally endorses the five principles for health care reform, including the broad benefit package and concept of full portability of coverage, adopted by the

Consortium for Citizens with Disabilities and the statement of the National Study Group on Health Care System Reform and Persons with Disabilities (see appendix to this report).

2. Private Insurance Market Reforms

Several market reforms would improve the availability and affordability of private health insurance for persons with disabilities. The goals of these reforms are (1) to ensure that all groups have access to health insurance and that no groups or individuals within these groups can be denied coverage, (2) to prohibit cancellation of coverage based on high claims cost, and (3) to establish greater premium stability in the small-group insurance market. The combination of these reforms would help eliminate the discrimination that now limits insurance options for persons with disabilities. To be effective, the six recommendations related to private insurance should be enacted simultaneously. The Senate Finance Committee, Senate Labor and Human Resources Committee, and House Committee on Ways and Means have jurisdiction in this area. The six recommendations follow:

Recommendation 2:

Congress should enact legislation mandating community rating for all health insurance plans as a means of spreading the health insurance risk and reducing the cost of coverage for persons with disabilities.

By mandating community rating, health insurance can become more affordable to persons with disabilities.

By spreading the health insurance risk across a large pool, community rating can help provide affordable coverage to the large number of employer groups and individuals who are currently uninsured or who face high insurance costs because of their health status. This benefit is accomplished by pooling many groups and setting an average premium rate based on their expected average utilization. The disadvantage of community rating is that it effectively raises the average premium for most people since high-risk persons would now be pooled with those at lower risk. Community rating would make premiums more affordable for persons with disabilities who often face higher-than-average insurance premiums or who are excluded from the private insurance market because insurers expect high health expenses.

To obtain the greatest benefit from community rating, the Employment Retirement Income Security Act of 1974 should be amended to require compliance by self-insured organizations.

As a business practice, community rating is not new; at one time, it was the norm for many health insurers. Community rating has given way to experience rating because the latter permits insurers to better predict risk and set premiums accordingly. The ultimate effect of experience rating has been serious insurance market fragmentation and self-selection, which has essentially excluded potentially high-risk individuals and groups from access to affordable insurance. In light of this situation, there is renewed interest in community rating at both the national and state level, and to date three states have enacted community rating as a statewide health insurance policy for small groups and individuals. The Employee Retirement Income Security Act (ERISA) of 1974 permits self-insured firms to be excluded from state mandates. Thus, efforts to move toward community rating have been limited to the small-group and individual markets. To obtain the greatest benefit from community rating, all firms should be included and ERISA modified. The Council urges Congress to follow suit by mandating community rating and changing ERISA to permit the inclusion of all firms in the community pool.

Recommendation 3:

Congress should enact legislation mandating the elimination of preexisting-condition exclusions and waiting periods to increase the availability of private insurance coverage for persons with disabilities.

The elimination of preexisting-condition exclusions would expand access to private insurance for persons with disabilities.

These insurance practices are major factors in the exclusion of persons with disabilities from private insurance and in the prevalence of insurance plans that many in the disability community find inadequate.

By eliminating these restrictive provisions, employers who offer insurance would have to make the same coverage available to all eligible employees, regardless of their health status. Preexisting-condition exclusions and waiting periods should be prohibited in conjunction with the implementation of community rating so that health insurance costs do not increase to the point of unaffordability. Together, these actions can improve both access to and affordability of private insurance for persons with disabilities.

Recommendation 4:

Congress should halt discriminatory insurance practices by enacting legislation prohibiting medical underwriting that excludes individuals from groups on the basis of their health status.

Like preexisting-condition exclusions and waiting periods, medical underwriting restricts access to health insurance on the basis of health status. Insurers often will not write polices for small groups without medical underwriting in order to better predict and control the health care costs for the group. As a result, individuals with disabilities may find the availability of insurance--and therefore employment opportunities--with small employers limited because insurance is a key factor in their employment decisions. Prohibiting the use of medical underwriting that excludes individuals from a group does not address the adequacy of available insurance. It does, however, help improve insurance availability by further limiting the practice of excluding on the basis of health status.

Prohibiting medical underwriting would discourage discriminatory insurance practices affecting persons with disabilities.

Recommendation 5:

Congress should enact legislation mandating that insurance be guaranteed for small groups and individuals. Such a law would prohibit insurers from dropping persons from coverage because of deteriorating health and would promote portability of coverage.

Insurers should be required to have open enrollment for both small groups (i.e., employers with fewer than 25 employees) and individuals, and to provide coverage to all those who apply regardless of health risk. In addition, neither insurers nor employers should be permitted to exclude individuals from group coverage, even if they present high medical risks. Once insured, neither an individual nor a group should be denied continued coverage because of deteriorating health. These provisions will help ensure that persons with disabilities have continuity of coverage and do not have to fear loss of insurance when considering employment opportunities.

Guaranteed insurance availability and renewability reduce the fear of accepting or changing jobs.

Recommendation 6:

Congress should enact legislation that regulates annual insurance premium increases in order to stabilize health insurance costs.

Regulations on the manner of annual premium increases may enable more small employers to offer health insurance.

It is not unusual for small employers to face three-fold increases in annual insurance premiums. These increases are the result of an insurance practice known as "durational rating" by which insurers raise premiums over time as preexisting-condition exclusions that initially generated savings expire. Premiums can be expected to rise sharply at each subsequent renewal when preexisting-condition exclusions lapse and also as the benefits of medical underwriting erode over time. In order to stabilize health insurance costs, insurers should be required to limit the rate of annual premium increases relative to other groups insured by the same carrier. These limits would typically guarantee that a group pay no more for basic coverage than a percentage of the average cost of similar groups (i.e., similar demographics, geography, benefit design, and industry).

Recommendation 7:

Congress should amend the Internal Revenue Code to permit greater deductions for health care, personal assistance, and assistive technology expenses for persons with disabilities.

a. Congress should amend the Internal Revenue Code to permit self-employed persons with disabilities to deduct the full cost of purchasing health insurance from their income taxes.

Even for persons without disabilities, nongroup health insurance tends to be very expensive and often limited in the scope of covered services. While employed persons who work for a business benefit from spreading the risk across the employer's group, self-employed individuals do not have such an advantage. In addition, both employers who provide health insurance and employees who contribute to the cost of that insurance are permitted to deduct the full cost of their contribution from their gross earnings when determining their taxable income. Self-employed persons are permitted to deduct only 25 percent of the cost of insurance. For persons with disabilities who typically face higher individual health insurance costs, this 25 percent deduction provides little relief. Amending the tax code to permit self-employed persons with disabilities to deduct 100 percent of their health insurance costs would promote more self-employment opportunities for this population. It also may make resources available to pay out-of-pocket for services that insurance does not cover.

b. Congress should amend the Internal Revenue Code to permit persons with disabilities to deduct 100 percent of their health-related expenses from their income tax liability.

Persons with disabilities typically face higher medical expenses because of higher insurance premiums, and a greater need for medical and health-related services that may not be covered under private or public insurance. Currently, only blind persons may deduct the full cost of expenses related to their disability from their income tax liability; others may deduct only the amount of medical expenses that exceeds 7 percent of their adjusted gross income. Amending the tax code to allow all persons with disabilities to deduct the full cost of medically related expenses, including the cost of personal assistance services and assistive technology, would help many of them afford services related to their disabilities because these expenses would be offset by a reduction in taxes. Obtaining these services rather than forgoing or postponing them because of the out-of-pocket expense may help prevent the future onset of secondary disability and help an individual maintain an achieved level of functioning. If this recommendation were enacted, it would not be necessary to increase the tax deduction for self-employed persons with disabilities since they would be encompassed in this proposal.

Amending the tax code to allow all persons with disabilities to deduct the full cost of medically related expenses, including the cost of personal assistance services and assistive technology, would help many of them afford services related to their disabilities.

3. Public Health Insurance Reform

The large numbers of persons with disabilities receiving Medicare and Medicaid suggest that reforms within the public insurance system could have a significant effect on access to needed services and could encourage independence. Jurisdiction for changes in public health insurance lies with the House Committee on Ways and Means, the House Subcommittee on Health and the Environment (Committee on Energy and Commerce), and the Senate Finance Committee.

Recommendation 8:

Congress should amend the Social Security Act to eliminate the 24-month waiting period for Medicare benefits to ensure continuity of coverage for qualified persons with disabilities.

Eliminating the waiting period for Medicare would improve continuity of coverage.

The 24-month waiting period for Medicare following the receipt of SSDI benefits is a particular problem for persons with disabilities who risk deteriorating health during that period in the absence of other coverage. Despite the extension of the Consolidated Omnibus Budget Reconciliation Act's (COBRA) continuation coverage provision for 29 months for employment-based insurance, more than one-quarter of SSDI recipients are uninsured during the last six months of the waiting period. This situation is due in part to the limited impact of the COBRA extension because the premiums for maintaining employment-based coverage as an individual are very high. Eliminating the waiting period for Medicare would allow persons with disabilities who have ongoing health service needs to obtain those services in a timely fashion and would preempt potential secondary conditions that might otherwise occur.

Recommendation 9:

Congress should mandate a Medicaid buy-in for persons with disabilities in order to reduce employment disincentives.

A Medicaid buy-in would reduce employment disincentives for persons with disabilities.

States currently have the option of implementing Medicaid buy-in programs under which persons can obtain Medicaid coverage by paying a premium that may be subsidized by the state. Requiring states to implement the buy-in would improve the availability of this source of insurance for the many persons with disabilities who are uninsured because their incomes are too high to meet Medicaid eligibility, but who cannot afford private insurance. A buy-in program available on a sliding-scale premium regardless of income, such as is offered in Massachusetts, would allow persons with disabilities who are currently uninsured to obtain coverage.

The Medicaid buy-in can have other important implications. Persons with disabilities who are currently receiving Medicaid report that they often turn down employment because the insurance coverage, if available, would be insufficient to meet their needs as well as Medicaid does. Under a Medicaid buy-in, many persons with disabilities would likely seek and obtain employment not otherwise accessible to them because of unavailable or inadequate insurance. The buy-in could also permit employers to pay the premium on behalf of eligible employees. The advantages of such provisions include potential savings to the SSI program as people achieve economic self-sufficiency, in addition to improved self-esteem, mental and physical health, and independence.

The Medicaid buy-in could serve as an important incentive to work for people with disabilities.

B. Reduce Barriers to Employment

While ADA makes substantial headway in expanding employment opportunities to persons with disabilities, additional initiatives are necessary in the health insurance arena to ensure that employment opportunities are indeed viable. The most serious barriers to employment exist in the public health insurance programs as work disincentives that force individuals to choose between access to health services and employment. Recommendation 10 represents an important reform that moves toward alleviating barriers to employment faced by persons with disabilities. Jurisdiction for this recommendation is within the Senate Finance Committee and the House Committee on Ways and Means.

Recommendation 10:

Congress should expand Section 1619 work incentive provisions of the Social Security Act to Medicare. This would reduce employment disincentives for Medicare beneficiaries.

Extending Section 1619 provisions to Medicare would reduce employment disincentives for Medicare beneficiaries.

Like Medicaid, Medicare limits earning levels for its beneficiaries with disabilities. Permitting earnings above the substantial gainful activity level with an offset in SSDI cash benefits while allowing persons with disabilities to maintain Medicare coverage could help reduce SSDI expenditures and encourage economic self-sufficiency.

C. Improve Adequacy of Health Services Coverage

The major health care issue for persons with disabilities is access to adequate health insurance coverage. Improving the availability of health insurance will give some persons with disabilities coverage they would not have otherwise.

Systematic changes in the orientation of health services coverage are necessary to meet the needs of people with disabilities and encourage their independence.

However, the extent of coverage, in terms of benefits and cost sharing, may not be sufficient to meet their needs and does little to foster self-sufficiency. The Council believes that systematic changes in the orientation of health services coverage are necessary to ensure that available benefits meet the needs of persons with disabilities and encourage their independence. Reforms in the scope of health services coverage will influence and support needed changes in the delivery system, particularly the move from an acute care medical model toward ongoing services aimed at keeping citizens healthy and productive. The Senate Finance Committee, the House Committee on Ways and Means, the House Subcommittee on Health and the Environment, and the House and Senate Appropriations Committees have jurisdiction over the recommendations that follow.

Recommendation 11:

Medicare benefits must be reassessed to better meet the needs of persons with disabilities.

Congress should revise the Medicare benefit structure to better meet the needs of beneficiaries with disabilities.

The Medicare program provides health insurance to over 3 million persons with disabilities. The original intent of the program was to finance health care for the elderly, but the 1972 amendments to the Social Security Act revised Medicare's scope to include persons with disabilities. Yet Medicare has not effectively responded to the needs of this broader constituency. Medicare program benefits remain largely oriented to the needs of the elderly. In particular, Medicare does not cover outpatient prescription drugs and has very restricted coverage for durable medical equipment. Wheelchairs, for example, are available only for use in the home. For a working-age person with a disability who needs a wheelchair, this provision impedes independence and participation in the community.

In order to better meet the needs of beneficiaries with disabilities, the Medicare benefit structure should be reassessed from the perspective of those beneficiaries and subsequently amended. The review should examine the extent to which Medicare recipients require services not currently covered under the program, such as communication devices, or covered with restrictions, such as durable medical equipment. Consideration should be given to services that, if provided in a timely and appropriate manner or on an ongoing basis, could limit the need for repeated hospitalizations or institutionalization. If the revisions focus on fostering independence and health, the entire Medicare population will benefit from the change.

Recommendation 12:

Congress should mandate the expansion of home- and community-based service options to reduce the unnecessary institutionalization of persons with disabilities in public insurance programs.

Medicaid has an inherent institutional bias that prevents some persons with disabilities from obtaining coverage unless they are institutionalized and that disallows some services unless they are provided in an institutional setting. Home- and community-based services allow individuals to be served in the community rather than in institutions. Over the past few years, the opportunity for states to provide home- and community-based services under Medicaid has expanded considerably. Most states have taken advantage of Medicaid waiver programs to provide home- and community-based services, and in 1990, these services became optional under Medicaid. However, the current options are largely restricted by enrollment ceilings, funding caps, and the requirement that states demonstrate the cost-effectiveness of providing these services in lieu of institutionalization. As a result, the availability of home- and community-based services is limited even for those individuals who would likely benefit from them. If coverage of home- and community-based services were mandated and some restrictions on reimbursement for these services were relaxed, many more people could benefit from receiving them in a noninstitutional setting.

Home- and community-based services allow individuals to be served in the community rather than in institutions, and should be available in all states.

Recommendation 13:

Congress should expand access to personal assistance services and assistive devices either by earmarking an annual appropriation to the Social Services Block Grant (Title XX) or by mandating Medicaid coverage. In addition, states should be permitted to introduce a buy-in component to programs that provide these services so all persons with disabilities may have access to them regardless of ability to pay.

Broad availability of personal assistance services and assistive technology will lead to greater independence and productivity for persons with disabilities.

Personal assistance services, including personal attendants, interpreters, and readers, are currently subject to many limitations--if covered at all--under public insurance. These services are rarely covered by private plans. Coverage of assistive technology, such as communication devices and motorized or customized wheelchairs, is also typically restricted. Persons with disabilities report that this lack of coverage is a major obstacle to their independence. Without personal assistance and assistive devices, many persons may need institutionalization--often their only alternative to obtaining comparable services necessary for maintaining their health.

Two programs may be used to expand access to personal assistance services and assistive devices: Medicaid and Title XX, the Social Services Block Grant. Covering some personal assistance services is currently optional under Medicaid; about 25 states have adopted this option. But the Medicaid benefit is limited in scope and does not adequately meet the needs of persons requiring personal assistance. States can specify the scope and duration of the benefit; thus, the comprehensiveness of the benefit depends on where a person lives. Also, personal assistance services are subject to medical necessity criteria, which limits the benefit. Moreover, these services are limited to those required inside the home. Medicaid does not pay for personal assistance services outside the home.

If Medicaid is to meet the personal assistance needs of persons with disabilities, the benefit must be broadened. The advantage of using Medicaid is that it currently covers some personal assistance services. However, broadening or mandating Medicaid coverage of personal assistance would be politically difficult because states have opposed additional federal mandates.

A second program option is the Social Services Block Grant, or Title XX. Several of the goals of these grants--to furnish services to promote self-sufficiency and reduce dependency, and to prevent and reduce inappropriate institutional care--could be met more fully if states were allotted a sum of money specifically for personal assistance services and assistive technology. States currently use Title XX dollars to provide a range of special services for persons with disabilities; however, states allocate Title XX dollars to these services at their discretion because the block grant is designed to address a variety of needs. By earmarking monies for personal assistance and technology, states can establish programs to provide these services and be assured of an annual budget. In addition, because states can adopt a buy-in to these programs, persons with disabilities who have inadequate insurance coverage may obtain needed benefits from the Title XX program on an income-based sliding scale. This provision promises the program an additional source of revenue. The Social Services Block Grant offers greater flexibility for personal assistance than Medicaid.

The availability of personal assistance and assistive technology will reduce hospitalization and institutionalization for many persons with disabilities.

Expanding personal assistance services could have far-reaching benefits. The availability of personal assistance and assistive technology will reduce hospitalization and institutionalization for many persons with disabilities. This outcome, in turn, reduces the burden on Medicaid--fewer Medicaid recipients would be institutionalized; others might avoid hospital institutional care that would result in their depleting their resources to become eligible for Medicaid. The burnout experienced by family members who act as personal assistants for loved ones with disabilities could be alleviated because these programs could offer alternative support. Finally, but perhaps most important, many persons with disabilities would be able to seek and maintain employment and live more independent and productive lives because these services would help them attain self-sufficiency.

D. Develop an Integrated and Coordinated Delivery System

Reorganization of the delivery system is needed to promote health status goals.

Persons with disabilities currently must negotiate a maze of bureaucratic, structural, architectural, and attitudinal barriers in order to obtain the array of services they require.

The current medical delivery system has been shaped by a financing structure and financial incentives that value the process of restoring health more than the process of maintaining it. For persons with disabilities, this objective means that their ongoing, long-term needs are neglected, and they may be forced to sacrifice health and independence in order to access the system. Some services may be covered if rendered by specified providers or in particular settings, but it may be difficult to find such a provider who is sensitive to the concerns of persons with disabilities. As a result of this system, persons with disabilities must negotiate a maze of bureaucratic, structural, architectural, and attitudinal barriers in order to obtain the array of services they require. Some reorganization of the delivery system is necessary to ensure that persons with disabilities have access to the services they need.

By reorienting the delivery system to consider the overall health of the community in the long run, the health care needs of persons with disabilities and the community-at-large could be met more appropriately. Providers would be encouraged to coordinate care for patients on an individualized basis, ensuring that a continuum of needed services is available to keep the individual healthy and productive. People would be empowered to participate in decisions about the types of services or providers that best meet their needs and expectations. While this thrust toward promoting health and independence reflects the goals of those with disabilities, it also benefits the general population by creating a healthy community for all. The House Committee on Ways and Means, the Senate Labor and Human Resources Committee, the House Committee on Education and Labor, and the House and Senate Appropriations Committees have jurisdiction in the areas of these recommendations.

Recommendation 14:

> **Congress should establish an Office of the Assistant Secretary for Disability at the Department of Health and Human Services to ensure a disability perspective in all future health care policy.**
>
> Currently, there is no federal official at the assistant secretary level accountable for ensuring that the needs of people with disabilities are addressed in federal health policy. The only assistant secretary with responsibility *solely* for disability issues is at the Department of Education's Office of Special Education and Rehabilitation Services (OSERS), which has no primary jurisdiction over health care issues. While there are several offices and agencies at the Department of Health and Human Services (DHHS) that address disability issues--including the Administration on Developmental Disabilities (ADD), the Social Security Administration (SSA), the Health Care Financing Administration (HCFA), and the National Center for Medical Rehabilitation Research (NCMRR)--there is no subcabinet-level position responsible for coordinating disability issues in health policy. To ensure the incorporation and coordination of a disability perspective in health policy, the National Council strongly recommends the establishment of an Office of the Assistant Secretary for Disability at DHHS.

Recommendation 15:

Congress should require state and local agencies that provide federally funded services for persons with disabilities to develop coordinated service delivery plans integrating health and social services.

Under the current system, social service programs and health service programs tend to operate distinctly and disjointedly. Vocational rehabilitation, mental health and mental retardation, housing, and transportation programs are administered separately from each other and distinct from the health system. The level of separation varies within and among states. The result of this fragmentation is a complex web of programs that are difficult to coordinate to meet the multifaceted needs of persons with disabilities and others. In particular, health system gaps that might be addressed by other programs, such as home care services funded by the Social Services Block Grant, often go unmet because linkages are lacking. For many persons with disabilities, the missing links and lack of knowledge about available support services create one more obstacle to independence.

Greater integration of health and social services will promote health and independence, and this could be achieved through the creation of a new Office of the Assistant Secretary for Disability at DHHS.

Congress should facilitate linkages by requiring state and local agencies that receive federal funds to establish a planning and implementation process for coordinated delivery of social and health services for persons with disabilities. The agencies administering these programs should include vocational rehabilitation; health services; employment and training; housing and transportation; and independent living; among others. Overall system objectives of achieving independence and community commitment should be established. Such integration may reveal a wealth of resources heretofore untapped by or unknown to persons in need and can ensure that a continuum of services is available to fill in gaps in coverage and to promote health and independence.

Programs offering social services such as health care, vocational rehabilitation, employment and training, housing, transportation, and independent living must be better coordinated to meet the needs of people with disabilities.

Recommendation 16:

The Secretary of the Department of Health and Human Services should encourage schools for health professionals to develop curricula that educate providers about the health concerns of persons with disabilities.

Providers should be educated to provide effective health care for persons with severe disabilities, to help them prevent secondary disabilities and to maintain and enhance their health and functional capacity.

In order to better serve the population with disabilities, health-professional training should include training about disabilities. Model curricula should be developed and distributed to help educate future providers about health concerns of people with disabilities and their pursuit of independence. Providers should be encouraged to learn how to examine and provide services to persons with severe disabilities. Sensitization will not only improve providers' skills in serving populations with disabilities, but may also encourage providers to be more accessible to persons with disabilities.

Such a curriculum should be an integral component of a broader educational approach to providers of health services that includes curing, restoring, and maintaining functional capacity. By studying the needs of persons with disabilities and the importance of ongoing services to maintain health, providers may gain insight and perspective on their role in promoting health outcomes in the larger community.

E. Establish a Research Agenda of Disability and Health Issues

The findings from this study reveal that much is unknown about the characteristics of persons with disabilities and their access to health insurance, such as costs by health care category associated with specific chronic conditions and disabilities, figures on access to insurance by chronic condition and disability, and costs of personal assistance and assistive technology associated with different chronic conditions and disabilities. The Council recommends a series of studies be undertaken to help alleviate this information gap. The Senate Subcommittee on Disability Policy, the House Committee on Ways and Means, and the House and Senate Appropriations Committees have jurisdiction in this area.

Recommendation 17:

The Agency for Health Care Policy and Research should encourage those who study treatment effectiveness to consider outcomes that are relevant to the population with disabilities.

Outcomes research and the study of the effectiveness of medical treatments typically do not consider relative effectiveness for those with disabilities. By focusing on particular medical or health outcomes as a measure of effectiveness, a treatment or service may be deemed ineffective for persons with disabilities even though the outcome measure used was inappropriate for them. For example, a study might be designed to explore the effectiveness of physical therapy as measured by returning persons to work and may conclude that physical therapy is not an effective treatment for some persons with disabilities. However, had the measure of effectiveness been improvement in ability to complete activities of daily living, the finding might have been that physical therapy is quite effective for those with disabilities. Incorporating functional outcome and quality of life measures that are meaningful to the population with disabilities will help ensure that findings of effectiveness are relevant to them.

Studies should be conducted incorporating functional outcome and quality of life measures that are meaningful to people with disabilities.

The Agency for Health Care Policy and Research can help promote an understanding of the importance of functional outcomes by encouraging that studies of treatment effectiveness conducted under its auspices integrate functional outcome measures and quality of life indicators.

The Social Security work incentive provisions offer many persons with disabilities the opportunity for employment and a step toward independence, and efforts should be made to expand the use of these provisions.

Recommendation 18:

Congress should direct the Social Security Administration to determine why participation is low under Section 1619 and other work incentive provisions, in order to develop and implement programs that will encourage use of SSI work incentives.

Section 1619 of the Social Security Act became a permanent provision in 1986 under the Employment Opportunities for Disabled Americans Act. Section 1619 is a work incentive program that allows SSI recipients to earn an income above the SSI "substantial gainful activity" level, receive a special SSI payment, and maintain Medicaid coverage. Despite this relaxation of income limits for SSI and Medicaid eligibility, few persons with disabilities take advantage of Section 1619 or other Social Security work incentive provisions. The major reasons for low participation appear to be a lack of information about the provision and a belief that working will disqualify one from coverage.

In order to address these issues, the Social Security Administration has implemented an outreach campaign during the past few years; yet, it is unclear whether this effort has effectively increased participation in Section 1619. The Social Security Administration should assess its current outreach efforts to determine their impact on participation and to identify alternative outreach approaches that might better encourage eligible persons with disabilities to participate. The assessment should consider whether there are particular features of the work incentive program that discourage participation, rather than simply a lack of information and understanding about the program. Section 1619 and the other work incentive programs offer many persons with disabilities the opportunity for employment and a step toward independence. Every effort should be made to improve their accessibility to eligible persons with disabilities.

Recommendation 19:

Congress should authorize and fund a consensus conference on developing an acceptable definition of disability that could be used as a basis for national surveys.

The lack of a common definition of disability has made research and policy decisions related to the population with disabilities confusing and difficult. Congress should authorize a consensus conference to be conducted under the auspices of the National Council on Disability. The conference would provide a forum for researchers, policymakers, disability advocates, and others to develop a strategy for designing a survey that identifies and tracks the population with disabilities. This meeting would be an opportunity to introduce the most current thinking on these issues and to consider what factors, such as level of functioning in a range of activities, constitute the most appropriate indicators of disability. Subsequent development of an annual survey utilizing these measures would provide a better understanding of how the population with disabilities changes over time and would facilitate the development of future surveys targeted specifically at this population.

A consensus conference is needed to develop a strategy and methodology for a longitudinal study on disability, examining a wide array of variables affecting people with disabilities.

Recommendation 20:

Congress should require the Bureau of the Census to conduct a survey to determine the extent to which persons with disabilities and others lack adequate health insurance.

The Bureau of the Census should be required to conduct a national study in conjunction with the National Council on Disability to determine the extent to which people lack adequate health insurance. To date, there have been few attempts to assess how well insurance meets the health care needs of individuals. Determining the level of adequate coverage is critical to developing appropriate priorities and policies that address the gaps in health insurance affecting the health and independence of millions of Americans. The study should attempt to oversample the population with disabilities who might be expected to have inadequate health insurance. Efforts should also be made to capture the service areas that are unlikely to be covered by insurance as well as the level of financial risk (e.g., levels of cost sharing, maximum benefit levels) and out-of-pocket expenses incurred because of insurance shortfalls.

Recommendation 21:

Congress should direct the Department of Labor, the Social Security Administration, and the Health Care Financing Administration, in consultation with the National Council on Disability, to design a study assessing the scope and consequences of underemployment among the population with disabilities that often results from work disincentives in public insurance programs.

These organizations, in consultation with the Council, should construct a study to assess the extent to which persons with disabilities receiving SSDI and Medicare and SSI and Medicaid are employed below their level of ability or skills. These individuals are considered underemployed. There is substantial anecdotal evidence that many persons with disabilities work less than full-time to ensure that their earnings do not exceed the income limits of SSDI and SSI, which would result in the loss of medical benefits. Other individuals may obtain low-skilled or low-paying jobs for which they are overqualified in order to work and still meet income

Better data are needed on all aspects of disability, including health care costs and utilization, access to health insurance, and disincentives to work associated with access to insurance, to enhance the quality of decisionmaking on disability policy.

eligibility requirements. However, no formal study of these issues has been conducted. Such a study should determine how many program participants are underemployed, the extent of their underemployment (i.e., how close they are to working at their full potential), the nature of employment, and the potential cost impact. This study would provide important insight into how these federal programs could be better designed to minimize work disincentives and to promote the productivity and independence of persons with disabilities by supporting their health service needs.

Recommendation 22:

Congress should authorize and fund the National Council on Disability to commission a study examining the health consequences and secondary disabilities that persons with disabilities may suffer because of lack of timely, appropriate treatment.

Americans with disabilities find that the acute care orientation of the health care system fosters deterioration of health until serious medical services are required. Preventive services directed at maintaining health are typically not covered by private or public insurance, even though lack of these services may cause eroding health and secondary disability in some. Many in the disability community believe that ongoing maintenance services, such as physical therapy and personal assistance, can help keep an individual healthy and active, and can prevent the onset of further debilitating conditions. It is also believed that providing services to prevent the onset of secondary disability is cost-effective. These issues need further exploration. A well-designed study should examine the extent to which persons with disabilities experience secondary disability and other health conditions that might have been avoided with timely treatment.

Access to health insurance and health-related services will substantially improve the quality of life of people with disabilities and will enhance their abilities to live independently and productively.

NATIONAL COUNCIL MEMBER AND STAFF BIOGRAPHIES

National Council Members

John A. Gannon, Acting Chairperson

John Gannon of Cleveland, Ohio, and Washington, D.C., founded John A. Gannon and Associates. His firm has offices in Columbus and Cleveland, Ohio; Denver, Colorado; and Washington, D.C. A fire fighter for more than 30 years, Mr. Gannon was an active leader of the International Association of Fire Fighters (IAFF) Local 93. Starting as a member of the local IAFF committee, he eventually became president, a position he held for 10 years before being elected to national office.

In September 1988, Mr. Gannon was elected IAFF President Emeritus. He had served as president of the 170,000-member organization since 1980. Under his leadership, the IAFF expanded its role in occupational safety and health. Concerned about the hazards of his profession, he guided and directed a series of programs to promote greater safety and health protection. One program sponsored research on safer garments and equipment for fire fighters. Mr. Gannon also fostered development of the IAFF Burn Foundation, which raises funds for research on the care of people who have experienced severe burns. In 1985, the Metropolitan General Hospital in Cleveland dedicated a John Gannon Burn and Trauma Center in recognition of his support for the hospital.

Mr. Gannon was elected vice president of the AFL-CIO, with which the IAFF is affiliated. Within the AFL-CIO he is vice president of the Public Employee Department. On the Executive Council, he is a member of several committees. He serves on the board of the National Joint Council of Fire Service Organizations and in 1982 served as its chairman. He is a member of the board of the Muscular Dystrophy Association. Mr. Gannon attended Miami University in Ohio and Glasgow University in Scotland, and studied at Baldwin-Wallace College and Cleveland State University.

Kent Waldrep, Jr., Vice Chairperson

Kent Waldrep has been involved with disability issues on the local, state, and national level since suffering a spinal cord injury in 1974 while playing football for Texas Christian University. Since 1981, Mr. Waldrep has served on the National Council by presidential appointment. He is National Council vice chairperson and chairman of the Research and Prevention

Committee. He was instrumental in formulating the National Council initiative on preventing primary and secondary disabilities.

Mr. Waldrep, one of 15 original drafters of the Americans with Disabilities Act, gave the legislation its name. He has lectured nationwide on subjects ranging from national disability policy to medical research targeted at curing paralysis. He founded the American Paralysis Association and the Kent Waldrep National Paralysis Foundation. He has appeared on *Good Morning America*, the *Today Show*, the *NBC Nightly News*, and CNN, and been featured in *People*, *Look*, *USA Today*, and other magazines.

He was selected by the U.S. Jaycees as one of 1985's ten Outstanding Young Men in America and received a special award from the Texas Sports Hall of Fame and a sports/fitness award from the President's Council on Physical Fitness. Kent Waldrep Days have been celebrated in four Texas cities and Birmingham, Alabama. He serves on many boards, including the Texas Rehabilitation Commission. He is past chairman of the Texas Governor's Committee for Disabled Persons and the Dallas Rehabilitation Institute. He also is chairman of Turbo-Resins, Inc., a family-owned and -operated aviation repair business. He lives in Plano, Texas, with his wife Lynn and two sons, Trey and Charles Cavenaugh.

Linda Wickett Allison

Linda Allison of Dallas, Texas, is a long-time advocate of people with disabilities. She is a board member of the National Paralysis Foundation and a trustee for the International Spinal Research Trust. Mrs. Allison, who grew up in Fort Worth, has three children. Her daughter Marcy was paralyzed from the waist down in a 1979 automobile accident. Marcy graduated from the University of Texas School of Law in 1986 and practices law in Austin. Mrs. Allison's late husband, James N. Allison, Jr., owned the *Midland Reporter Telegram* and other newspapers in Texas and Colorado and was former deputy chair of the Republican National Committee.

Ellis B. Bodron

Ellis Bodron of Vicksburg, Mississippi, has been a practicing attorney since 1947. He served 36 years as a member of the Mississippi legislature, one term in the House of Representatives and eight terms in the Mississippi Senate. He also chaired the Senate Finance Committee from 1961 until 1983.

Mr. Bodron, who is blind, is associated with several civic organizations, including the Vicksburg Lions Club, Vicksburg Chamber of Commerce, and the

University of Mississippi Alumni Association. In addition, he is a member of the Advisory Board of Directors, Deposit Guaranty National Bank.

Mr. Bodron has also been a member of the Agriculture and Industrial Board, which preceded the Board of Economic Development, and the Committee of Budget and Accounting and Board of Trustees of the Mississippi Public Employees Retirement System.

Ellis Bodron graduated with a Bachelor of Arts and a Bachelor of Law Degree from the University of Mississippi. He is married with two children.

Larry Brown, Jr.

Since 1981, Larry Brown of Potomac, Maryland, has been the Xerox business and community relations manager for the Mid-Atlantic Region, Coastal Operations, Custom Systems Division. In 1991 he became Government and Community Relations Manager with Integrated Systems Operations.

Mr. Brown was a running back for the Washington Redskins for eight years. During that time he received many awards, including Most Valuable Player in the National Football League for 1972. He was inducted into the Washington, D.C., Touchdown Hall of Fame in 1991.

After retiring from football in 1977, he worked at E.F. Hutton as a personal financial management adviser. He has been special assistant to the director, Office of Minority Business Enterprise, Department of Commerce. He is involved with youth, people with disabilities, and senior citizens. Mr. Brown has spoken at schools, colleges, and universities on topics such as motivation, discipline, and camaraderie. He works with many organizations, including the Friends of the National Institute on Deafness and Other Communication Disorders, the Deafness Research Foundation, and the Vincent Lombardi Foundation.

Mary Ann Mobley Collins

A former Miss America who lives in Beverly Hills, California, Mary Ann Collins has a career in film and television and on Broadway. She has co-hosted the National March of Dimes telethons with her husband, Emmy-award-winning actor Gary Collins; she is a member of the National Board of the March of Dimes Foundation and is national chair of the Mother's March against Birth Defects. She is a member of SHARE, a Los Angeles-based women's organization that has raised more than $6 million for the Exceptional Children's Foundation r the Mentally Retarded. She serves on the National Board of the Crohns and Colitis Foundation.

Mrs. Collins helped raise funds for the Willowood Foundation in her native Mississippi, which provides homes for young adults with mental and physical learning disabilities. She has received many awards and honors, including the 1990 International Humanitarian Award from the Institute for Human Understanding, Woman of Distinction 1990 from the National Foundation for Ileitis and Colitis, and the HELP Humanitarian Award of 1985 from HELP for Handicapped Children. She has filmed documentaries in Cambodia, Ethiopia, Mozambique, Somalia, Kenya, Sudan, and Bolivia on the plight of starving children and people with disabilities.

Anthony H. Flack

Anthony Flack of Norwalk, Connecticut, is president of Anthony H. Flack & Associates. He has been a member of the board of Families and Children's Aid of Greater Norwalk and has worked with the Child Guidance Center of Greater Bridgeport, the Youth Shelter in Greenwich, Hall Neighborhood House in Bridgeport, and the Urban League of Greater Bridgeport. Mr. Flack is a member of the Allocations and Admissions Committee, United Way of Norwalk, and received the Bell Award for outstanding service in the field of mental health at the Bridgeport Chapter, Connecticut Association of Mental Health.

John Leopold

John Leopold of Pasadena, Maryland, has 18 years' experience in elected state office. He was elected to the Hawaii State House of Representatives in 1968 and was re-elected in 1972. In 1974, Mr. Leopold was elected to the Hawaii State Senate. In 1982, he became the first Republican in Maryland history elected from District 31 in Anne Arundel County to the Maryland House of Delegates, where he served until 1991.

An advocate of people with disabilities, Mr. Leopold is a member of the Learning Disabilities Association of Anne Arundel County, the Anne Arundel County Committee on Employment of People With Disabilities, and the University of Maryland Hospital Infant Study Center Planning Advisory Board. He has served in other appointed and elected positions, including the Hawaii State Board of Education in 1968, the National Advisory Council for the Education of Disadvantaged Children in 1977, and the Maryland State Accountability Task Force for Public Education in 1974.

Mr. Leopold has written and produced cable television commercials in Maryland, written a weekly interview column for a local publication, and hosted and produced a weekly radio public affairs program. He graduated from Hamilton College in Clinton, New York, with a B.A. in English.

Robert S. Muller

Robert Muller of Grandville, Michigan, began his career with Steelcase, Inc., in 1966 and is now an administrator in human resources. He is an adjunct professor in the Department of Psychology at Aquinas College and in the Department of Education at Calvin College in Grand Rapids. He serves on the board of trustees for Hope Network and Foundation in Grand Rapids, which serves 1,700 adults with disabilities. In April 1981, he received an honorary degree in educational psychology from the Free University in Amsterdam, the Netherlands.

Mr. Muller holds a B.S. in business administration from Aquinas College and in 1978 was voted Outstanding Alumnus of the Year. He has lectured at colleges and universities nationally and internationally. He is a board member for several national, state, and local organizations.

In May 1987, Mr. Muller and his wife Carol hosted a first-time event at the White House with the vice president. The Celebration of Disabled Americans at Work was co-sponsored by several major corporations. Mr. Muller now serves as president of the National Roundtable on Corporate Development for Americans with Disabilities. In 1985, he received the Liberty Bell Award from the Grand Rapids Bar Association. In 1988, he was national co-chair of the Disabled Americans for President Bush Campaign and in 1992 was an honorary national member of the Bush/Quayle Disability Coalition Campaign. In November 1992, Mr. Muller was appointed to the Governor's Commission on Handicapped Concerns for Michigan.

George H. Oberle, P.E.D.

Dr. George Oberle of Stillwater, Oklahoma, has more than 40 years' experience in the field of health, physical education, and recreation. He began his career as a high school teacher and coach, and has been a professor and director of the School of Health, Physical Education and Leisure at Oklahoma State University since 1974. Dr. Oberle is a consultant to many organizations in the area of administration and adaptive physical education. In 1988, he worked with the Kennedy Foundation to organize and direct a new program of Unified Sports for the Special Olympics.

Dr. Oberle chaired the College and University Administrators Council (1980-82); was president of the Association for Research, Administration, Professional Councils and Societies (1984-87); and served as a board member of the American Alliance of Health, Physical Education, Recreation and Dance (1985-89). Awards include the 1985 Centennial Award from the American

Association of Health, Physical Education, Recreation and Dance; and Meritorious Service Awards from Indiana and Oklahoma.

He was selected for *Men of Achievement* in 1975 and recognized in *Who's Who of the Southwest* in 1977. Dr. Oberle received his doctorate from Indiana University in administration and adapted physical education. He lectures extensively about wellness promotion, adapted physical activity, sports, and recreation for people with disabilities.

Sandra Swift Parrino

As a member and former chairperson of the National Council, Sandra Swift Parrino has played an active role in key issues affecting the lives of people with disabilities. Nominated by President Reagan in 1982, appointed chair by the President in 1983, and reappointed by President Bush, Sandra Parrino has supported the rights of people with disabilities before Congress, in the media, and before groups nationwide. Under her leadership, the National Council has been a driving force to create public policies that affect the nation's people with disabilities.

During her tenure as chair, the National Council worked for the creation and enactment of legislation for people with disabilities; issued a policy statement, *National Policy for Persons With Disabilities*; convened hearings nationwide to solicit comments and recommendations from people with disabilities about how to eliminate discrimination; issued a major report, *Toward Independence*, that outlines key components of a comprehensive civil rights law protecting people with disabilities; initiated the first national survey of attitudes and experiences of Americans with disabilities, in conjunction with Louis Harris and Associates, Inc.; issued *On the Threshold of Independence*, a report outlining specifics of the Americans with Disabilities Act; created and developed the Americans with Disabilities Act; participated with President Bush at the signing of the Americans with Disabilities Act; conducted the first National Conference on the Prevention of Primary and Secondary Disabilities; issued reports on minorities with disabilities and personal assistance services; and planned reports on health insurance, financing assistive technology, and educating students with disabilities.

Before becoming National Council chair, Sandra Parrino founded and directed the Office for the Disabled, in Ossining and Briarcliff Manor, New York, where she created a regional program for public and private organizations that focused on programs for people with disabilities and compliance with 504. She has more than 25 years' experience on boards, councils, commissions, committees, and task forces at the federal, regional, state, and local levels and as an expert witness, community leader, organizer, and activist.

Mrs. Parrino has represented the U.S. government on disability issues in many countries. She has been invited by the Department of State to represent the United States at the Meetings of Experts in Finland and China, and represented the United States at the United Nations Center for Social Development in Vienna several times. In 1990, 1991, and 1992 she was a delegate at the Third Committee on Social Development of the United Nations. In 1991, she was invited by the People's Republic of China to assist them in their efforts to help people with disabilities. At the request of the government of Czechoslovakia, she and the National Council were invited to conduct the Eastern European Conference on Disabilities for participants from Czechoslovakia, Poland, and Hungary.

Mrs. Parrino graduated from Briarcliff College with a B.A. in history, and completed courses at Bennett College, GuildHall School of Drama in London, and the Yale School of Languages. In 1992, Mrs. Parrino received an Honorary Doctorate of Humane Letters from St. John's University in New York. Her husband Richard is a rheumatologist. They have three children, two of whom have disabilities. Sandra Parrino was born in New Haven, Connecticut, and lives in Briarcliff Manor, New York.

Mary Matthews Raether

Mary Raether of McLean, Virginia, is associated with St. John's Child Development Center, a nonprofit organization providing instruction, employment training, and independent and group home living skills for people with severe mental disabilities, especially autism. Mrs. Raether has been an officer and trustee of St. John's since 1985, has chaired the public relations committee, and participated on the executive, nominating, investment, and development committees.

Mrs. Raether has been active in civic, educational, and religious organizations in the Washington metropolitan area. While community vice president of the Junior League of Washington, she developed emergency grant procedures and fund-raising information services for small and emerging nonprofit organizations. Mrs. Raether has 10 years' experience as legislative assistant to Reps. George Bush and Barber Conable. She specialized in tax, social security, medicare/medicaid, and trade issues. She considers her efforts in clarifying the tax status of lobbying by nonprofit organizations an outstanding career accomplishment. She received a B.A. from the University of Texas at Austin in 1962. She is married and has two children.

Anne Crellin Seggerman

Anne Crellin Seggerman of Fairfield, Connecticut, is the founder of Fourth World Foundation, Inc., a company engaged in the development of interfaith media.

A member of the Bridgeport Urban Gardens and Youth at Risk/Breakthrough Foundation, Mrs. Seggerman founded and serves as the chairman of the board of the Fairfield County Chapter of Huxley Institute for Biosocial Research. She previously was a member of the President's Committee on Mental Retardation.

Mrs. Seggerman is listed in *Who's Who of American Women* and has received numerous honors including an Honorary Doctor of Humane Letters Award from Sacred Heart University, the Association of Knights and Ladies of the Holy Sepulchre, and the American Association of the Order of Malta. She was previously appointed to serve on the Housing of Handicapped Families of the Department of Housing and Urban Development.

Mrs. Seggerman is experienced in providing care, treatment, and rehabilitation to people with schizophrenia and has extensive experience with alcoholics and children with learning disabilities. She is married and has six adult children.

Michael B. Unhjem

Michael Unhjem of Fargo, North Dakota, is president of Blue Cross Blue Shield of North Dakota. He is the youngest person ever elected to the North Dakota House of Representatives, a member of the National Conference of Commissioners on Uniform State Laws, and he served in 1988 as president of the National Mental Health Association.

Mr. Unhjem has been involved in local and national organizations, including the Advisory Mental Health Council of the U.S. Department of Health and Human Services; the Governor's Commission on Mental Health Services; the National Alliance for Research on Schizophrenia and Depression; and the National Mental Health Leadership Forum. Awards include the 1989 Special Presidential Commendation from the American Psychiatric Association, the 1988 Distinguished Leadership Award from the North Dakota Psychological Association, and the National Excellence in Leadership Award from North Dakota.

He has been recognized by *Who's Who in American Politics, Who's Who in North Dakota, Who's Who in the Midwest, Personalities of America,* and *Men of*

Achievement. Mr. Unhjem graduated magna cum laude with a B.A. in history and political science from Jamestown College in North Dakota in 1975. In 1978, he earned a J.D. with distinction from the University of North Dakota School of Law in Grand Forks. He is married and has two children.

Helen Wilshire Walsh

Helen Walsh of Greenwich, Connecticut, is a board member of the Rehabilitation Institute of Chicago, the largest U.S. rehabilitation center. She has been involved in disability advocacy for many years and has been associated with the Institute of Rehabilitation Medicine at the New York Medical Center, where she served as associate trustee. She has served as vice president, president, and chairman of the board of Rehabilitation International USA.

Ms. Walsh has been a member of the President's Committee on the Employment of People With Disabilities, and was appointed by the President to serve as a member of the National Advisory Council of Vocational Rehabilitation. In 1976, Ms. Walsh received the Henry J. Kessler Award for outstanding service in the rehabilitation field. She has received the Rehabilitation International Award for Women and the Anwar Sadat Award for outstanding work in the field of rehabilitation.

National Council Staff

Andrew I. Batavia

Andrew I. Batavia is executive director of the National Council on Disability. He formerly served as research director for Disability and Rehabilitation Policy at Abt Associates. Prior to joining Abt, he was associate director of the White House Domestic Policy Council, where he was responsible for coordinating federal policy on health care, disability, housing, education, and veterans affairs. He received his bachelor's degree in economics and sociology from the University of California, his master's degree in health services research from Stanford Medical School, and his jurisdoctorate degree from Harvard Law School.

After law school, Mr. Batavia served for two years as an attorney for the U.S. Department of Health and Human Services. He left that position in 1986 when he was awarded the Mary E. Switzer Distinguished Research Fellowship in Medical Rehabilitation Finance from the National Institute on Disability and Rehabilitation Research (NIDRR) of the U.S. Department of Education. He then served for four years as associate director for Health Services Research at the National Rehabilitation Hospital Research Center in Washington, D.C. In that capacity, he wrote 2 books and more than 20 other publications on issues of disability and health care policy.

In 1987, Mr. Batavia was made a Fellow of the Washington Academy of Sciences. In 1988, he was awarded the Distinguished Disabled American Award from the President's Commission on Employment of People with Disabilities. In 1989, he received an International Fellowship from the International Disability Exchanges and Studies (IDEAS) Program of NIDRR, and conducted research on how the Dutch Health Care System affects people with disabilities. In 1990, he was appointed a White House Fellow by President Bush and served as special assistant to Attorney General Richard Thornburgh at the U.S. Department of Justice.

Mr. Batavia is the founding associate editor of the *Journal of Disability Policy Studies* and a cofounding board member of Independent Living Assistance, Inc. He is an adjunct assistant professor at the Georgetown University School of Medicine and a member of the Bar of the U.S. Supreme Court, the Bar of the District of Columbia, the State Bar of California, and Georgetown's Kennedy Institute of Ethics.

Billie Jean Hill

Billie Jean Hill joined the staff of the National Council on Disability as program specialist in March 1992. Previously, Ms. Hill was director of communications and editor for the Blinded Veterans Association and earlier served as founding director of a statewide broadcast service for persons with reading disabilities with Mississippi Educational Television in her home state. She was appointed to work on a governor's commission in Mississippi to report on the needs of children and youth in rural Mississippi who are disabled. Ms. Hill studied journalism and education at Mississippi University for Women and at the University of London in England. She serves as chairperson of the Board of Publications for the American Council of the Blind.

Mark S. Quigley

Mark Quigley joined the staff as a public affairs specialist in May 1990. He previously served as a consultant to the U.S. National Commission on Drug-Free Schools. He is a former program coordinator at the U.S. Interagency Council on the Homeless and former director of communications at the White House Conference on Small Business. Mr. Quigley graduated *magna cum laude* in 1979 from Northern Virginia Community College in Annandale, Virginia, with an A.A. in general studies. He received a B.A. in government and politics in 1983, and an M.P.A. in public administration in 1990 from George Mason University in Fairfax, Virginia.

Brenda Bratton

Brenda Bratton, executive secretary for the National Council, was formerly employed as a secretary at the National Transportation Safety Board. Ms. Bratton graduated from Farmville Central High School and the Washington School for Secretaries.

Stacey S. Brown

Stacey Brown is staff assistant to the chairperson and has been employed by the National Council since 1986. Prior experience includes employment as a receptionist and clerk with the Board for International Broadcasting and with the Compliance and Enforcement Unit of the Architectural and Transportation Barriers Compliance Board, where he was a student assistant. Mr. Brown is a graduate of Howard University in Washington, D.C., where he earned a B.A. in political science in 1987.

Janice Mack

Janice Mack, who serves as the administrative officer for the National Council, was formerly employed with the National Oceanic and Atmospheric Administration. Ms. Mack graduated from Calvin Coolidge High School.

Lorraine Williams

Lorraine Williams is office automation clerk for the National Council. She graduated from Valdosta High School in Valdosta, Georgia, and attends Strayer College, where she is majoring in computer information systems science.

APPENDIX

Consortium for Citizens with Disabilities

CONSORTIUM FOR CITIZENS WITH DISABILITIES
HEALTH TASK FORCE

"PRINCIPLES FOR HEALTH CARE REFORM FROM A DISABILITY PERSPECTIVE"

December, 1991
(updated 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
The Arc, Association for Retarded Citizens of the United States
Epilepsy Foundation of America
Immune Deficiency Foundation
International Association of Psychosocial Rehabilitation Services
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 Transplant Support Network
Spina Bifida Association of America
The Association for Persons with Severe Disabilities
United Cerebral Palsy Associations, Inc.
World Institute on Disability

PRINCIPLES FOR HEALTH CARE REFORM FROM A DISABILITY PERSPECTIVE

FROM THE HEALTH TASK FORCE OF THE CONSORTIUM FOR CITIZENS WITH DISABILITIES

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 41 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.

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IMPROVING SERVICE SYSTEMS
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Statement of Principle of the National Study Group on Health Care System Reform and Persons with Disabilities

Excerpted from the Preliminary Report of the Study Group

On December 3-4, 1992, ILRU, with funding provided by the Robert Wood Johnson Foundation, assembled several of the foremost experts in the country on the health care needs of persons with disabilities. The group included members representing the broad range of political thought, including members of the Bush Administration, Clinton campaign, researchers, educators, service providers, and consumers.

Recognizing that the current time represents the greatest opportunity for substantial health care system reform in several decades, the group's mission was to contemplate (1) essential components of health care system reform that address the needs of persons with disabilities, including persons with chronic health conditions, and (2) potential strategies for promoting inclusion of such components in legislative initiatives around health care system reform.

The primary overriding conclusion of the study group was that the needs of persons with disabilities must be a primary consideration at the outset of the design of any health care system reform initiative. Historically, disability issues have been addressed as an afterthought in most health care reform--including passage of Medicare and Medicaid. This historical fact has contributed to situations of forced dependency for many persons with disabilities at great cost to society both in terms of direct care dollars and reduced participation of such individuals in their communities, states, and nation. Any health care system reform initiatives should seek to ameliorate such situations, resulting in savings to society and improved qualities of life for everyone.

The primary focus of existing health care programs has been on acute care services, rather than on preventive and supportive services designed to minimize the need for more costly acute care services. This focus has required incremental modifications and adaptations that have been difficult to incorporate into programs that were not designed to meet the needs of persons with disabilities.

Now more than ever before, with the aging of the population, with our increased capabilities to save and prolong the lives of persons who experience disabling disease and trauma, and with the knowledge that prevention and health maintenance services are much less costly than acute care services, it is essential that the needs of persons with disabilities receive great attention in the design of any health care system reform package.

The study group strongly endorses the five principles of health care system reform for persons with disabilities articulated by the Coalition of Citizens with Disabilities (CCD). The system as a whole must be: (1) <u>non-discriminatory</u>, ensuring that people with disabilities of all ages and their

Improving Service Systems for People with Disabilities is a national program supported by The Robert Wood Johnson Foundation with direction and technical assistance provided by ILRU at The Institute for Rehabilitation and Research (TIRR).

families have the opportunity to participate fully in the system; (2) comprehensive, providing an array of health, rehabilitation, personal, and support services; (3) appropriate, offering services on the basis of each individual's need, personal choice, and situation; (4) equitable, ensuring that no group of individuals bears a disproportionate burden; and (5) efficient, ensuring that system resources are applied effectively in meeting health care needs.

Furthermore, these principles are consistent with a more rational plan for service delivery that should be developed as an integral component of cost containment. It must be recognized that any cost containment measures--including local budgeting, imposition of deductibles and co-payments, and restrictions on services--are likely to have a disproportionately adverse effect on persons with disabilities. Therefore, any health care reform proposal that contains cost containment provisions must be constructed in a manner that does not place an undue burden for such provisions on individuals who are most likely to use services at above average rates.

A major consideration in the design of a health care system reform plan that meets the needs of people with disabilities is the benefit package. Again the study group endorses the broad package principles outlined in the CCD statement. These benefits, which include access to preventive, rehabilitative, and long-term services, are needed by persons with disabilities to maintain productive, independent lifestyles. At the same time, the group recognized that economic realities strongly influence the availability of services for all individuals, not just persons with disabilities.

Therefore, it is imperative that people with disabilities, along with individuals representing other segments of the population, be actively involved in the design of the benefit package and its administration. Top-down decision making, such as occurred with the Oregon Plan, without adequate input from the disability community is likely to result in the devaluation of the needs of people with disabilities, a program that inadequately addresses these needs, and ultimately greater costs to individuals with disabilities and society as a whole.

Now is a time of change for the system of health care as we know it. There is much to be learned from the empowerment principles which guided the efforts of the disability rights movement. One of the most important contributions persons with disabilities can make to the health care system reform debate is to provide input to redefine the concept of health and the way in which persons participate in the management of their health care needs. We all deserve to work together toward a system that better meets the needs of all people. Incorporating key features of the CCD position statement, the Study Group supports a health care system reform initiative that is based on empowerment and education of all persons and that. (1) expands the definition of "health" to include prevention services, rehabilitative therapies, assistive technology, and ongoing health-related maintenance services; (2) distributes all health-related expenses equitably throughout the population; and (3) restructures our health care delivery system to support effective consumer-directed health care management.

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