

Originally Processed With FOIA(s):

S

FOIA Number:

S

# FOIA MARKER

**This is not a textual record. This is used as an administrative marker by the George Bush Presidential Library Staff.**

---

**Record Group/Collection:** Donated Historical Materials  
**Collection/Office of Origin:** Frieden, Lex, Collection  
**Series:** Related Materials  
**Subseries:** Conferences

---

**OA/ID Number:** 52080  
**Folder ID Number:** 52080-009

---

**Folder Title:**  
"A Health Care Reform Summit" [1994]

---

**Stack:**

**Row:**

**Section:**

**Shelf:**

**Position:**

---



NATIONAL  
HEALTH  
COUNCIL

To: Let F.

1730 M Street, NW • Suite 500  
Washington, DC 20036-4505  
(202) 785-3910 • FAX (202) 785-5923

MEMORANDUM

TO: NHC Members and Friends  
FROM: Joseph C. Isaacs  
DATE: November 16, 1994  
RE: Council Introduces New Publication

---

The National Health Council is pleased to forward to you our new publication entitled, Building Bridges to Find Solutions: A Chronic Illness and Disability Community Response to Health Care Reform. This publication reviews the Council's April 5, 1994, unprecedented summit which brought together leading national and grassroots organizations representing the largely independent chronic illness and disability communities. The conference was designed to "build bridges" between these communities to identify: (1) needed solutions to the health care problems facing their constituents and, (2) common ground for joint advocacy in development of our nation's final reform package.

This report also contains an excellent background paper on the Americans With Disabilities Act (ADA) and its implications for health reform, as well as the joint statement which resulted from the summit which was endorsed by nearly 50 leading health and disability organizations. The statement highlights four major principles for health reform which will improve the lives and employability of people with chronic health conditions and disabilities:

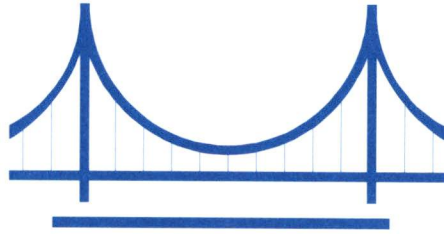
- Reform must provide *universal coverage*.
- Reform must provide a *full range of mental and physical health care services* including preventive, acute, chronic, rehabilitative and long-term care.
- Reform must *promote medical progress* through support of research and development.
- Reform must *involve consumers* at all levels of decision-making.

November 16, 1994  
New Publications  
Page Two

The National Health Council hopes that you find this publication useful. Should you have any questions or comments, or desire additional copies of this publication, please contact our Public Affairs Department at 202/785-3910.

---

# **A Health Care Reform Summit: Building Bridges to Find Solutions**



A Chronic Illness and  
Disability Community  
Response to  
Health Care Reform

---



---

The National Health Council, Inc.

## The National Health Council

The National Health Council (NHC) is a private, nonprofit umbrella association of more than 125 leading national health-related organizations. These include voluntary health agencies (VHAs) such as the American Cancer Society, professional and membership associations such as the American Medical Association, health-related nonprofit organizations such as the American Association of Retired Persons, businesses such as Pfizer Inc. and Aetna, and federal government agencies such as the Public Health Service. The Council fosters communication and collaboration among these diverse members of the health community toward the mutual goal of improving the health of all people.

The Council was founded in 1920 as a clearinghouse and cooperative effort for the nation's voluntary health agencies (VHAs). Today these agencies remain the core of the Council's membership. The NHC's primary mission is to promote and strengthen the movement they embody. VHAs work to improve health by providing patient and family services, community services, public and professional education, medical research support and health-related advocacy.

The many contributions of the Council's VHA members exemplify the virtues of the voluntary health movement. They engage individuals, families and communities across the country to volunteer in the effort to prevent, treat and cure debilitating and life-threatening illnesses, chronic health conditions and other physical and developmental disabilities. With the generous support of these volunteers and the donating public, they fill gaps in service that might not otherwise be met. With a strong sense of human concern, these agencies provide unique and indispensable assistance to those most vulnerable in our society.

---

Copyright 1994 National Health Council, Inc.

All rights reserved. No part of this book may be reproduced or transmitted in any form or by any means, electronic or mechanical, including photocopying, recording, or by any information storage and retrieval system, without permission in writing from the publisher.

# **A Health Care Reform Summit: Building Bridges to Find Solutions**

A Chronic Illness and Disability Community Response  
to Health Care Reform

This conference and publication were made possible with grant support  
from the Robert Wood Johnson Foundation.

The National Health Council, Inc.  
1730 M Street, NW  
Suite 500  
Washington, DC 20036-4505  
(202) 785-3910  
FAX: (202) 785-5923

# Table of Contents

## **Introduction ..... v**

Joseph C. Isaacs, President, National Health Council

## **Session I: The Status Quo — Outlining Problems and Issues**

### **The History of Discrimination ..... 1**

Allan I. Bergman, Director of Federal/State Relations, United Cerebral Palsy Associations, Inc.

### **The Community Response ..... 3**

Robert Silverstein, Staff Director, Senate Subcommittee on Disability Policy

## **Session II: Promoting Systems Change**

### **Universal Coverage: Can it be Attained? ..... 5**

Ronald Pollack, Executive Director, Families USA

### **A Continuum of Care: The Long-Term Care Problem ..... 7**

Joshua M. Wiener, PhD, Senior Fellow, The Brookings Institution

### **A Continuum of Care: The End to the "Acute Care" Bias? ..... 9**

Bob Griss, Director, Center on Disability and Health

## **Luncheon Session**

### **A Call to Action ..... 11**

Tony Coelho, Chairman, President's Committee on Employment of People with Disabilities

## **Session III**

### **Storming the Gates for Health Care Reform: Developing Action Steps ..... 13**

Moderator: Randall Rutta, Vice President of Government Relations, National Easter Seal Society

## **Appendix I**

### **Consensus Statement: Health Care and Discrimination: The Final Hurdle ..... 16**

## **Appendix II**

### **Background Paper: Health Reform and the Americans with Disabilities Act ..... 18**

# Introduction

On April 5, 1994, the National Health Council, with a grant from the Robert Wood Johnson Foundation and support from several leading health organizations, convened a conference that was rich with historic significance and potential.

This meeting brought together, for the first time, representatives from leading national and grassroots organizations addressing the needs of the chronically ill and people with disabilities. Despite the commonality of their interests, the health and disability communities have been largely independent in their advocacy on behalf of needed health reforms. The conference was designed to “build bridges” between these communities to identify: (1) needed solutions to the health care problems facing their constituents and, (2) common ground for joint advocacy in development of our nation’s final reform package.

The gathering was structured as a summit, where everyone had an opportunity to participate and contribute. In addition to major presentations, there were intensive break-out sessions in which participants worked together to iron out principles of agreement and plan concerted action steps.

The outcome was never intended to be an endorsement of any particular piece of legislation. Rather, the meeting was designed to produce a common road map that would enable the disability and chronic illness communities to steer together through the legislative process to reach this ultimate aim: the passage of a health reform package that will responsibly serve the needs of their constituencies and all Americans.

Indeed, the issues that are most important to their constituents — such as the elimination of pre-existing condition exclusions from health coverage, the assurance of coverage portability and the inclusion of a full range of basic benefits, from prevention services to long-term care — are issues that touch all citizens. Every American is vulnerable to the deficiencies of our current health care system, and that vulnerability only intensifies for those already ill or disabled.

The meeting certainly possessed a sense of urgency. Participants generally agreed that the current public policy debate presented our best chance, finally, to significantly improve the country’s health system. Clearly, it was deemed to be the time to put aside any differences between the health and disability communities and focus on those mutual, critical interests that unite them. The stakes are too high for provincialism.

It is my hope that this conference was merely the first in an extended campaign of cooperation among the disability and chronic illness groups. Together, these groups represent the needs of all people and can be an enormously potent voice for those at the center of our reform efforts — health care consumers.

Joseph C. Isaacs  
President  
National Health Council

# The History of Discrimination

Allan I. Bergman, Director of Federal/State Relations,  
United Cerebral Palsy Associations, Inc.

**A**llan Bergman recounted the long struggle of people with disabilities to overcome discrimination in health care. For years, people with disabilities could access health care in only one place, he said: institutions, “places of segregation, isolation, congregation and dependency.”

---

## *Genetic Testing could allow insurers to exclude people on the basis of their genes.*

---

The prevailing attitude was: “Keep them with their own kind. They need to be protected from society, and society needs to be protected from them,” Bergman said. This view was the backdrop for 120 years of American policy on disability.

But attitudes changed in the 1970s with the growth of independent living centers and self-advocacy. Deinstitutionalization brought disabled people back into the community. And in the 1980s, the country turned to individual supports and family supports.

“Now day care centers, recreation centers, schools, employment places and housing are the same places for everybody,” Bergman said. “We tailor individual supports to assist people to be as independent as possible.”

## **Trouble Ahead**

However, changes in attitude haven't pervaded the health insurance system. Indeed, part of the reason insurers exclude people with disabilities from coverage is a legacy of the era of institutionalization, Bergman said. Insurers reason that since disabled people have always been cared for by medical professionals, they must be ill. As a result, insurers often unfairly label people with disabilities as ill, and charge them higher premiums — if they grant coverage at all.

The Human Genome Project, Bergman warned, will greatly complicate the issue of pre-existing conditions, because genetic testing could allow insurers to exclude people on the basis of their genes. “Once this information gets into the system, it isn't going to be used to help you,” Bergman said. “It's going to be used against you, not only in health insurance, but in life insurance and all the other actuarial prediction tables. We're all vulnerable.”

## **Why We Need Health Care Reform**

Bergman enumerated a list of problems in our current health care system, including:

- Little emphasis on preventive care.
- Lack of insurance portability. A February 1994 survey of people being served by independent living centers “found that more than 35 percent had been unable to change jobs because of concerns about being covered for pre-existing conditions,” Bergman said.

- Poor access to health care for children. Nine and a half million children, most of whom are poor, lack insurance, Bergman said. "If your socioeconomic status is low, you have twice as high a probability of low birth weight; three times the probability of delayed immunization; and two to three times the likelihood of severe disability."
- Acute care bias in plan coverage. Insurers still define health as the absence of symptoms or illness. "People with disabilities or chronic illnesses are going to have symptoms," Bergman said. "This acute care bias means limited services, time-limited visits, dollar limits and minimal to no long-term services."
- Lack of parity in coverage for mental health services.

Bergman also criticized Medicare and Medicaid, both of which retain an acute care bias. "The generic notion of disability in the Medicare Act was 'hopeless, helpless, eternally dependent and homebound,'" he said. "Unfortunately, Medicare continues to be the touchstone that the private insurance industry refers to." The program has a limited scope of benefits, no prescription drug coverage and no recognition of independence and function as health outcomes.

As for Medicaid, he said inadequate reimbursement rates result in limited access to care, particularly to specialists, and the mandated services are a long way from comprehensive benefits.

## A Call to Arms

"If we're serious about real rights from an ADA [Americans with Disabilities Act] perspective, we have no choice but to rally, to mobilize and create a different health care environment for the future," Bergman concluded.

"Because without comprehensive health care for all Americans with chronic illnesses and disabilities, we're in trouble, and I would predict a resurgence of the institution and the nursing home as the place for continuity of care by the year 2000." ■

### Insurance Exclusion: A Personal Issue for All of Us

*Allan Bergman related the following personal story about disability and insurance exclusion.*

"I have a daughter 29-years old. When Dina was born, I was a graduate student. Six weeks after her birth, she was in severe congestive heart failure. We rushed her by ambulance to the hospital.

"I had health insurance, but as soon as the company found out Dina had a congenital heart defect, they stopped paying. They paid for the delivery and for the first days of her newborn care in the hospital.

"Eight months later, I was \$124,000 in debt. There was no Medicaid because this was 1964. There was no substantive maternal/child health program. There was only one community organization that was at all responsive, and that was the March of Dimes. They gave us \$1,000. It was like manna from heaven.

"That financial catastrophe took its toll on our family for 10 years. Dina's a wonderful young lady. She's moved to her own apartment. She has a high quality of life. Fortunately, she works for the federal government, and she's in a mass risk pool.

"Let me suggest for those of you who think you are above pre-existing condition exclusions that none of us are. We are all vulnerable."

# The Community Response

Robert Silverstein, Staff Director, Senate Subcommittee on Disability Policy

**O**pening with a theme that was picked up by several other speakers during the course of the day, Robert Silverstein characterized the Americans with Disabilities Act's (ADA's) fundamental precept:

Disability is a natural part of the human experience that in no way diminishes the fundamental right of individuals with disabilities to live independently, enjoy self-determination, make choices, contribute to society, pursue meaningful careers and enjoy full inclusion and integration in all aspects of American society.

President Clinton, Silverstein said, has called for the establishment of a national disability policy based on the three basic creeds of the ADA: "inclusion, not exclusion; independence, not dependence; and empowerment, not paternalism."

Silverstein predicted that without comprehensive health reform, the president's objective and many of the objectives of the ADA — particularly with respect to equal employment opportunity — will not be achieved for millions of Americans with disabilities.

## A Checklist for Reform

Because people with disabilities are a microcosm of America's health care needs, they serve as a good litmus test for measuring the adequacy of health care reform, Silverstein said. "If we can craft health care reform legislation that meets the needs of people with disabilities, we can be certain that we will meet the needs of all Americans."

---

***If health care reform legislation meets the needs of people with disabilities, it will meet the needs of all Americans.***

---

With that in mind, Silverstein laid out the basic components of health care reform from a disability perspective. Some of these, such as portability of coverage and elimination of pre-existing condition exclusions, echoed Bergman's presentation. Among Silverstein's other priorities are:

- Universal coverage. Affordable, quality health care for all Americans that can never be taken away.
- Preserving civil rights by making sure that every entity in the health care system is subject to either Section 504 of the Rehabilitation Act or the ADA.
- Access to specialists and other appropriate providers. Gatekeepers must be qualified and sensitive to the health needs of people with disabilities. This means that in certain circumstances gatekeepers must be specialists or interdisciplinary teams.
- No lifetime caps on coverage. "I checked my thesaurus the other day under the word insurance," Silverstein said. "Protection, security, guarantee, and coverage. That's what insurance is. It's not a policy that says, when you get sick, your lifetime cap for your illness goes down from \$1 million to \$5,000. That's not protection. That's not a guarantee. It's not security. And it sure isn't coverage."

- A guaranteed and specified comprehensive benefit package set out in health reform legislation, not determined after passage. “We need a system for delivery of care that will hold down spiraling health care costs, but we must make sure that it does so in a manner that does not deny medically necessary or appropriate services to people,” Bergman argued. “What good is it if we have a Cadillac basic benefit package and those services do not reach individuals with chronic illnesses or disabilities in a manner to which they’re entitled?”

Silverstein also called for community rating, reasonable limits on out-of-pocket expenses, incentives for insurance plans to keep people with disabilities, health plan accountability mechanisms that focus on the needs of vulnerable populations, and elimination of work disincentives, among other changes.

## Threats of Transition

Finally, Silverstein talked about the need for protective rules to govern the transition from our current health care system to the reformed one that will take shape over the next several years.

“If health plans are figuring out how to position themselves in the interim to get ready for the future, who are they going to throw off the rolls first?” he asked. “I think the answer to that question is obvious: those with disabilities and those with chronic illnesses.” ■

## The Danger of Denying Specialty Care

*To convey the damage that can be done by unqualified health care gatekeepers, Robert Silverstein told the following story.*

**T**his is a story of a man who became spinal chord injured after an accident. He received excellent rehabilitation services and eventually moved into his own apartment and became employed.

“A year later, he noticed a small skin breakdown on his back. He went to his primary care physician — a general practitioner who was the gatekeeper to specialist care and the person designated to keep costs down for his health plan. The doctor treated him with medication, covered the breakdown and sent him on his way.

“However, the dressing was the wrong type. It caused further breakdown. Three days later, this young man had massive infection and had to be rushed to the emergency room.

“The problem now required acute care and a long period of bed rest. Even after months of treatment and recovery, he had trouble.

“The moral: If this young man had been referred to a specialist in spinal chord injury, or had his gatekeeper possessed the proper knowledge, in most cases he would have been treated appropriately. This would not have cost our health care system thousands of dollars.”

# Universal Coverage: Can It Be Attained?

Ronald Pollack, Executive Director, Families USA

**R**onald Pollack underlined the importance of achieving universal coverage by pointing out the scope of the problem. "More than 50 million people, over the course of any year, lose or lack health insurance for at least part of the year," he said. "We're talking about one out of five Americans."

But universal coverage is not only vital in its own right; it is a critical prerequisite to the achievement of other health reform goals, he said. "I don't think there's any question that without universal coverage, long-term care won't be on the table."

However, Pollack added, "I believe that we have a serious shot at getting universal coverage. The reason I think we have such an extraordinary shot — perhaps the best we'll ever have — is the president's and first lady's commitment to getting us there."

## A Fork in the Road

The question is how to achieve that goal. Pollack outlined the two main alternatives: The administration proposes to expand the nation's current, employer-based system so that every employer provides health coverage. In contrast, some members of Congress are championing a plan to achieve universal coverage through individual insurance purchases. Expansion of our employer-based insurance system is far easier than the latter proposal, Pollack said, mainly due to financing considerations.

"If we don't have employers paying for employer-based health care coverage, then the federal government will have to come up with very significant subsidies

to make sure that insurance is affordable," Pollack said. The likelihood of that happening is slim, he predicted.

---

***The odds of achieving universal coverage are better than 50/50, but not a lot better.***

---

However, the president's proposal faces difficulties of its own, particularly from small business advocates who oppose his plan for employer-based insurance. "Small business associations have really been working the hustings and trying to get their members to talk to as many members of Congress as possible," Pollack said. "They're having an extraordinary impact."

The chronic illness and disability communities must fight back. "We have to speak to the small business community about why the proposal that is currently pending before Congress makes a great deal of sense for small business," Pollack said. For example, most small businesses have very little bargaining power with insurance companies and HMOs, he explained. Health care coverage purchasing alliances would allow businesses to band together to negotiate better deals with insurance companies and HMOs than they can individually.

In addition, under a comprehensive approach such as the administration's proposal, small businesses would reap a number of other advantages: They would no longer have to pay for cost shifting.

They would be assured that their premiums would rise no faster than inflation. They would benefit from significantly reduced administrative costs. And some of them would gain subsidies to help pay for insurance, Pollack said.

He labeled opposition from small business the biggest impediment to universal coverage. "We can't ignore it," he said. "Certainly, Congress is not going to ignore that opposition. So when you make presentations in your local communities, make sure that the small business owners in your community understand what's in real health reform for them."

## Overcoming the Opposition

In closing, Pollack predicted that the odds of achieving universal coverage are better than 50/50, but not a lot better. "We are going to get universal coverage if we fight for it, but if this is a spectator sport, we're going to lose," he said. "And we don't even get to first base on long-term care unless we get universal coverage."

"I pray that all of you go meet with your members of Congress," Pollack concluded. "They really need to hear from you. They're saying that they're hearing from a lot of the special interest groups, but they're not hearing significantly from the consumers of health care — those who pay for health care, those who need health care. You can personalize this issue. And unless you do, we're not going to get to yes." ■

## Limiting Individuals' Premium Costs

**A** family or an individual pay no more than 3.9 percent of income for premiums under the Administration's proposal. In contrast, the rate under the managed competition approach offered by Rep. Cooper could reach almost 19 percent or the equivalent of more than 10 weeks worth of pre-tax income for premiums. That doesn't include deductibles, co-pays and costs for uncovered services. That's simply unaffordable.

---

*More than 50 million people, over the course of any year, lose or lack health insurance for at least part of the year.*

---

"Subsidies would correct this inequity, but there's a rub: You have to come up with new revenue — taxes. Members of Congress have been extremely loathe to impose new taxation, other than in some key areas like tobacco.

"Therefore, the practical way to get to universal coverage is through an employer-based effort that builds on our current system. Of course, for those people who don't work, there still needs to be adequate subsidies. But most of the heavy lifting is already done for you without having to increase taxes.

"From a practical standpoint, it makes abundant sense."

# A Continuum of Care: The Long-Term Care Problem

Joshua M. Wiener, PhD, Senior Fellow, The Brookings Institution

**J**oshua Wiener discussed the Administration's plan for achieving long-term care for people with chronic illnesses. With the exception of the politically impalatable single payer option, the President's proposal is the only other option which includes a serious long-term care component.

The first plank creates a home care program available to all severely disabled people, regardless of age and financial status, he said. This program gives states flexibility in putting together a service package tailored to individuals, but expenditures are capped, and there is no legal entitlement to services. When fully implemented in 2002, it is estimated that the program will spend \$38 billion more for home care than would otherwise be spent.

The second part of the program allows Medicaid nursing home patients to keep an extra \$20 a month in income. It includes new regulations for private long-term care insurance and a tax clarification to treat this insurance more like health insurance, Wiener said. It also includes tax credits for long-term service expenditures of the working non-elderly disabled.

## **Bridging the Age Gap**

"Almost all previous debates about long-term care have focused solely on the elderly," Wiener said. "Those days are past. In the current debate, the non-elderly disabled have a seat at the policy table."

The administration would like to make long-term care accessible to persons of all ages, Wiener said, but it

will be a challenge to create a system that meets the different needs of the elderly and non-elderly disabled populations. "Eligibility screens don't work as well for the non-elderly disabled," Wiener said. "The non-elderly disabled need an extraordinarily wide range of services. And advocates strongly prefer a consumer-directed rather than an agency-directed set of services."

Wiener said fiscal realities will require that initiatives be a mixture of public sector and private sector, of means-tested programs and social insurance approaches.

---

***No new long-term care initiatives can be passed without some fail-safe mechanisms to ensure that the financial risk will not exceed a certain level.***

---

## **Legislators' Fiscal Fears**

One of the key issues in providing long-term care will be cost control. "Policy makers are so frightened by the expenditure uncertainties," Wiener said, "that no new long-term care initiatives can be passed without some fail-safe mechanisms to ensure that the financial risk will not exceed a certain level."

However, one criticism of the Clinton plan is that it doesn't coordinate acute and long-term care. Non-elderly patients will get their acute care services through

private insurance. The elderly will continue to get theirs through Medicare. And long-term care services will be administered through the states.

“Acute care is the 800 pound gorilla,” Wiener explained. “Long-term care is a much smaller component of the health care system. If we turn over long-term care money to acute care providers, to acute care health plans, they will just gobble it up.”

## **Tempered Optimism**

In closing, Wiener urged participants to strongly lobby Capitol Hill because there is a real possibility that long-term care will not be included in a health care bill.

“Over the long run,” Wiener said, “I am optimistic that we will get a system that will provide long-term care because, as Winston Churchill liked to say about the American people, you can always count on them to do the right thing, after they’ve tried everything else.” ■

## **Why Reform Should Include Long-Term Care**

**F**irst, the current system is broken and needs to be fixed,” Joshua Wiener said. “We have a strong institutional bias in our financing system, along with welfare dependence and routine catastrophic out-of-pocket costs. The services that chronically ill and disabled people need are often not available.

---

*If we turn over long-term care money to acute care providers they will just gobble it up.*

---

“Second, one of the lessons of the Medicare Catastrophic Coverage Act of 1988 is that the elderly care more about long-term care benefits than they do about expansion of acute care services. In addition, the elderly care a great deal about prescription drug coverage, as was evident in the language of that Act.

“Third, if we exclude long-term care services from the global budget and from other cost-containment mechanisms, we create a strong incentive for acute care providers to push as many services to as many people as possible outside the acute care arena, and call that long-term care. But if there is no major new financing method, the cost burden will be on disabled people, who won’t have a way of gaining the services they need.

“Finally, surveys by the American Association of Retired Persons and the Consumers Union indicate much stronger support for health care reform with long-term care in the package than if it’s outside the package.”

# A Continuum of Care: The End to the "Acute Care" Bias?

Bob Griss, Director, Center on Disability and Health

**O**ur health care system's acute care bias, Bob Griss argued, contributes significantly to America's health care crisis.

---

***The disabled population represents about 14 percent of the non-institutionalized population and yet accounts for about 58 percent of short-stay hospital beds.***

---

"We do not have effective chronic care management. We do not have an emphasis on prevention services. We do not have an emphasis on rehabilitation services," he said. "I suggest to you that the failure to provide comprehensive health care, particularly around prevention and rehabilitation services, is the main contributor to the expansion in acute health care utilization."

The acute care bias particularly affects people with disabilities and chronic illnesses. "Eighty-one million Americans under the age of 65 have chronic health conditions that private insurance companies typically medically underwrite against," Griss said. "That's one-third of the American population."

Even those who have managed to obtain comprehensive benefit packages today could be vulnerable due to a change in health or job status, he pointed out.

Because many people with chronic illnesses and disabilities cannot obtain

coverage for the care they need, they often wind up in the hospital.

"The disabled population represents about 14 percent of the non-institutionalized population and yet accounts for about 58 percent of short-stay hospital beds," Griss said. "It's not that people with disabilities are intrinsically high users of health care. We do not have a health care system that focuses on chronic care management. And until we do, we're not going to get a handle on the acute care crisis."

## Revising the Big Picture

To change the system, Griss said, advocates must reframe the terms of the health care debate.

If we're just talking about adding onto the cost-spiralling acute care system or lumping on a long-term care component, we're never going to convince policy makers that there's enough money. Only by rethinking the logic of the health care delivery system can we begin to open up the debate about what the concept of health means, how health care costs can be distributed in an equitable way and what kind of delivery system allows consumers to play a larger role in choosing their providers.

These are big questions. But Griss raised an even larger one: Revising the nation's concept of health, he argued, means we must consider health care as a civil right. "We must restructure the health care delivery system and the health care financing system so that health is recognized as a right," he said. "It is as important as our legal and

political status in participating in society. Without health, you don't have participation."

Griss explained that the major reform bills introduced in Congress preserve the existing dichotomy between acute care and long-term care. Disability advocates, he said, must not legitimate these distinctions, because doing so is guaranteed to be a losing game. Long-term care must be seen as a component in the continuum of care to which we have access.

## **Prevention: A Prime Example**

Griss closed by emphasizing prevention services as a key area of importance. "A prevention agenda for people with disabilities is really lacking in the current health care debate," Griss said. "There is a clear recognition that immunizations for children, prenatal care for pregnant women, and cancer screenings for older adults make cost-effective sense for the total population. But we don't hear about prevention of secondary disabilities and medical complications for people with chronic illness and disability."

The need for action is clear, Griss said. "We need to expose the preventable conditions that occur as medical complications or secondary disabilities when appropriate health care is not provided. Unless we get this issue on the public agenda, I don't think we're going to be able to effectively combat the acute care bias." ■

## **Who Is the "Average Patient?"**

**Y**ou can't often tell whether somebody has a disability or a chronic health condition," Bob Griss said. "I happen to have an immune deficiency which requires a gamma globulin infusion every month. That costs about \$1,000 on the marketplace. Without it, I would develop a disability that could be life-threatening.

---

*A prevention agenda for people with disabilities is really lacking in the current health care debate.*

---

"Fortunately, I have national health insurance. What I mean is, I'm a patient at the National Institutes of Health, and in exchange for my blood, which they do research on, I get free treatment.

"This experience has raised my expectations about the kind of health care system all Americans deserve. We need more than a health care system that tries to limit the benefits package to core services based on the so-called average patient's health care needs.

"Basic health care must be defined by what is medically necessary to maintain an individual's health, including his or her functional abilities.

"If we allow our definition of health to be limited to what is medically necessary for the so-called 'average' patient, we are doing a tremendous disservice, not only to people with disabilities and chronic illness today, but to the total population. Because at some point, everybody is going to have a chronic condition, a chronic disability or a chronic illness."

# A Call to Action

Tony Coelho, Chairman, President's Committee on Employment of People with Disabilities

**F**ormer Congressman Tony Coelho began his luncheon keynote address by emphasizing the importance of grassroots advocacy in the legislative process.

"The Americans with Disabilities Act (ADA) was adopted by the Congress in record time," he said. "It was a major piece of legislation affecting nearly 50 million Americans, but most members of Congress voted for the ADA not knowing what was really in it. The reason: the grassroots community was out there insisting that ADA be adopted."

Grassroots advocacy will be similarly vital in the health care debate, Coelho said. "It's critically important for those in the chronic illness and disability communities to give this issue the same degree of urgency and support that ADA received."

Viewing health care legislation is part of the ADA's unfinished business, he said. "It doesn't do us any good to have our basic rights and not have the ability to exercise them. Health care provides us with that ability."

## Coelho's Health Care Platform

"We shouldn't have to fear that because we have a certain chronic condition or disability we may not be eligible for health care insurance," Coelho said.

Any health care reform package, he argued, should provide universal coverage that can never be taken away. Insurance must be unconditionally available to all — without exception.

Sickness, injury, medical history, health status or other factors must not be used to deny anyone coverage.

Listing a series of other requirements for reform, Coelho said that health coverage should:

- Be portable. No one should ever have to fear losing coverage if they change jobs or get laid off.
- Provide for long-term care.
- Include coverage for catastrophic illness.
- Include personal assistance services. "This is the highest priority of a large segment of the disability community," Coelho said. "ADA and other guarantees of civil rights don't mean much to someone who can't get out of bed in the morning."
- Provide insured access to specialists, drugs and new medical technologies.
- Establish parity for treatment of mental illnesses. "There should be no discrimination in medical treatment against people with psychiatric or mental illness," Coelho said.

## The Key to Success

Coelho warned against discussing the details of various different health care bills when lobbying Congress. Instead, he said it's important to be emotional. "Talk about personal experiences. Talk about the impact health care has on you, your loved ones or your friends. If you're willing to do that, you'll have an impact."

"It's not easy to talk about the discomforts, the prejudices, the

discriminations that you face,” Coelho acknowledged, “but that’s what has an impact.”

He finished with a call to action: “We can have a tremendous impact on this country and the lives of so many people if you elevate the emotion of this issue, if you’re willing to go out and be committed, if you get your people as aggressively involved as they were on ADA.”

“There will be health care legislation this year,” Coelho said. “What’s in it depends on you.” ■

■

***In summary, there are only six words you have to remember:  
No exceptions. No  
cancellations. No conditions.***

---

## **Personal Experiences Can Influence Policy**

*Tony Coelho illustrated the power of compelling personal stories to have an impact on legislators.*

**W**hen I testified on ADA in the Senate, I talked about when I got kicked out of the seminary because of my epilepsy. The Catholic church did not permit epileptics to be priests because we were considered possessed. And my parents rejected my epilepsy because they believed the church.

“For 29 years, my parents and I did not discuss my epilepsy, even though there was nobody in this country who was more vocal about disabilities than I. Finally, in December of last year, the barrier was broken because of a reporter. My wife and I immediately met with my parents, and we had the best Christmas I’ve had in 29 years.

“At the end of my Senate testimony on the ADA, Senator Hatch was in tears. He said to me, ‘I did not intend to support ADA, but I will because of what you said.’ And he kept his word, even though he was criticized severely by some of his colleagues.

“When you talk about stories that are real, people understand. They react. They feel.

“If you’re willing to talk about what impacts you, your children, your parents or other loved ones, I guarantee your elected officials will respond.”

# Storming the Gates for Health Care Reform: Developing Action Steps

In the afternoon session, attendees broke up into three groups, each of which was asked to answer the following questions.

1. Can we in the chronic health and disability communities agree to jointly advocate on behalf of the following three principles for health care reform?
  - Reforms must provide universal coverage. This means no exclusionary clauses and full coverage portability.
  - Reforms must provide a full continuum of care. This includes appropriate access to specialists, prevention services, rehabilitation services, prescription drugs, durable medical equipment, personal assistive services and long-term care.
  - Reforms must promote continued medical progress. Effective technological advances that may provide improved diagnostics, effective treatments or cures should not be sacrificed in our zeal to contain costs.
2. How can the chronic illness and disability communities best send a unified message to policy makers?
  - Should we coordinate efforts through a single organization/campaign (e.g., the National Health Council, the Consortium for Citizens with Disabilities or the "Real Health Care for All" coalition)?

- Should we utilize the strengths of each of the above groups in a joint effort (e.g., the NHC for public relations, the CCD for lobbying and the "Real" coalition for building grassroots support)?
  - How should we jointly address the underwriting of whatever approach is taken?
3. How do we define our specific action agenda to get the job done?  
Suggestions include:
    - A letter to policy makers signed jointly by chronic illness and disability organizations outlining our three principles.
    - Joint visits to members on Capitol Hill or in their district offices.
    - A series of briefings for congressional members and staff.
    - Well-placed newspaper ads conveying our joint message on health care reform.
    - Letters to the editor or op-ed pieces from health and disability community leaders to major newspapers and journals nationwide.
    - A letter-writing campaign generated from an individual organization's constituencies.

After 90 minutes of small group discussion, the conferees reconvened and the three group leaders read their conclusions.

## Question 1

The break-out groups reached general agreement on this question, but some language was amended and some emphases were added:

- One group defined a “continuum of care” requirement as any health care that an individual needs.
- One group rephrased their universal coverage statement as, “Reforms must provide universal coverage because health problems and disabilities are a natural part of the human experience.” Another group said “...universal coverage, regardless of age, income, current health condition and employment status.”
- Groups stipulated that the benefits package must be defined in the legislation. They were uncomfortable with proposals that would leave such details until later.
- Groups also emphasized the need to provide for mental health services, assistive technology, long-term care services and consumer involvement at all levels of the health care system.

## Question 2

Groups suggested the following ideas to help their organizations work together and more effectively communicate their advocacy messages to policy makers and the public:

- Disability organizations should get involved in statewide health care coalitions which are perhaps not now focusing on disability issues.
- Materials from the recently created “Real Health Care for All” campaign should be made available in camera-ready form to health and disability groups for use in their newsletters.

- Organizations should work together to develop a grassroots mailing list in order to generate local level activities in support of needed reforms.
- Organizations should utilize the state coordinator lists that have already been developed by the “Real Health Care for All” coalition and involve volunteers from their own affiliations.

## Question 3

Suggestions for the action agenda included:

- Immediately sending a letter to policy makers, signed jointly by the chronic illness and disability organizations.
- Using newspaper ads and letters to the editor to convey a joint message. Target local papers, since many members of Congress read their home news, and also target *Roll Call*, since members and staff on Capitol Hill read it religiously.
- Targeting radio talk shows on a local level.
- Identifying employers who would be willing to make Congressional visits to discuss their positive experiences covering productive, hard-working, chronically ill or disabled employees.
- Asking labor unions which are collaborating on television commercials to expand these commercials to include the interests of the chronic illness and disability communities.
- Setting up an 800 number that could tie all of these advocacy efforts together. ■

## Summary Remarks

Randall Rutta, Conference Chair, and Vice President of Government Relations,  
National Easter Seal Society

**R**andall Rutta wrapped up the afternoon session by reiterating many of the day's main themes. "There's clearly a need to get our message across, and that message should be a human message," he said. "We need to address the human experience of health care, the discrimination that takes place and the gaps in financing and coverage."

Rutta spoke of the need for greater consumer empowerment so that people with disabilities and their families are active participants in health care delivery and financing choices. And he said a continuum of care must include an expanded range of benefits that address both mental and physical services.

"There is an interest in building on the work of the *Real Health Care for All* campaign to enact health care reform legislation that addresses the needs of people with disabilities and their families," Rutta said. "You don't have to buy it wholesale, but use the campaign for what it's worth. Use its materials. Take advantage of its network."

Rutta called for newspaper and radio outreach, as well as a joint letter to policy makers. "There were over 100 groups participating in this conference throughout the day," he said. "Let's give them an opportunity to sign on to a letter — soon."

He concluded by urging fast action. "What most clearly comes across is the need to get going," he said. "The National Health Council, the Consortium for Citizens with Disabilities, and others

have had principles in place for a year that meet all of our needs and then some. Let's make sure we have a chance to operationalize those principles in legislation by convincing people that there's a health care crisis and that a response should include universal coverage and access to a continuum of benefits." ■

---

***We need to address the human experience of health care, the discrimination that takes place and the gaps in financing and coverage.***

---

## CONSENSUS STATEMENT

# Health Care and Discrimination: The Final Hurdle

In the past 30 years, our nation has outlawed discrimination based on race, religion, gender, national origin and age. Yet, we continue to sanction discrimination in health care against people with chronic health conditions and disabilities. All Americans are but a serious illness or injury away from becoming part of these populations.

Pre-existing condition exclusions, lack of portability of coverage, inadequate access to specialty care, and exorbitant out-of-pocket costs have regulated millions of people with chronic illnesses and disabilities to second-class citizenry and kept them from their rightful place in American society.

The Americans with Disabilities Act (ADA) helps protect these vulnerable populations from discrimination in many different facets of life. It does not, however, fully protect individuals when it comes to health care — only comprehensive reform of the health care system

can do that. Health reform is needed now or more people will fall through the ever-widening cracks in our current system.

The disability and chronic condition communities agree that the following four principles provide the foundation for real health care reform:

- Reform must provide *universal coverage*.
- Reform must provide a *full range of mental and physical health care services* including preventive, acute, chronic, rehabilitative and long-term care.
- Reform must *promote medical progress* through support of research and development.
- Reform must *involve consumers* at all levels of decision-making.

By endorsing these four basic principles, policymakers would strike a blow for justice and ensure that no one would lack access to care because of factors beyond their control.

More . . .

**This statement is supported by the following organizations:**

AIDS Action Council  
Alzheimer's Association  
American Association of University Affiliated Programs  
Association of Mental Retardation  
American Cancer Society  
American Diabetes Association  
American Kidney Fund  
American Liver Foundation  
American Lung Association  
American Occupational Therapy Association  
American Social Health Association  
American-Speech-Language-Hearing Association  
Amyotrophic Lateral Sclerosis Association  
Arthritis Foundation  
Asthma and Allergy Foundation of America  
Center on Disability and Health  
C.H.A.D.D. (Children and Adults with Attention Deficit Disorders)  
Cystic Fibrosis Foundation of America  
Epilepsy Foundation of America  
Epilepsy Foundation of Greater Knoxville  
Guillain-Barre Syndrome Foundation International  
Huntington's Disease Society of America  
International Association of Psychosocial and Rehabilitation Services  
Interstitial Cystitis Association  
March of Dimes Birth Defects Foundation  
Myasthenia Gravis Foundation  
National Association for Medical Equipment Services  
National Association of State Directors of Developmental Disability Services  
National Down Syndrome Society  
National Easter Seal Society  
National Head Injury Foundation  
National Mental Health Association  
National Multiple Sclerosis Society  
National Neurofibromatosis Foundation  
National Osteoporosis Foundation  
National Parent Network on Disability  
National Psoriasis Foundation  
National Society to Prevent Blindness  
National Tuberos Sclerosis Association  
Paralyzed Veterans of America  
Prevent Blindness America  
RP Foundation Fighting Blindness  
Sjogren's Syndrome Foundation  
Spina Bifida Association of America  
The ARC  
The Joseph P. Kennedy Foundation  
United Cerebral Palsy Association, Inc.  
United Ostomy Association

## BACKGROUND PAPER

# Health Reform and the Americans with Disabilities Act

**M**ore than most, people with chronic health conditions and disabilities experience discrimination in health care.

Discriminatory practices, such as pre-existing condition exclusions, lack of coverage portability, inadequate access to specialty care, and exorbitant out-of-pocket costs, diminish the ability of these populations to lead productive lives.

Pre-existing condition exclusions may be equivalent to lack of health insurance coverage for a person with diabetes. This person likely will then have to pay for his or her insulin and other needed medical devices out-of-pocket — often at an unaffordable price. For the father of a child with cerebral palsy, the lack of portability of health insurance coverage means he must remain in his job to maintain his health benefits even though a better position with a higher salary may be available. For a person with epilepsy, coverage for prescription medications that control seizures means the ability to remain seizure-free or have fewer seizures per day thereby enabling him or her to attend school classes or hold a job. For a young mother with multiple sclerosis, assistive technology may give her the mobility to care for her child and her household.

In reality, every citizen is vulnerable to illness, injury, loss of function, aging, or birth of a child with a chronic condition or disability. Increasingly, people know of someone or have experienced themselves, reduced health care benefits, policy cancellations,

changes to employers' health care package, higher out-of-pocket expenditures, and reduced life-time maximums. These trends are creating a sense of crisis, especially among previously unaffected middle-class families.

Even without catastrophic illness or disability, millions of Americans share the burdens and fears of being uninsured or underinsured, being restricted from access to appropriate and high quality care, and spending substantial portions of their income for medical care.

## Uninsured

According to the United States Bureau of Labor Statistics, 37 million U.S. citizens, representing fifteen percent of the population, have no health insurance coverage. Eighty-seven percent of nonelderly uninsured people are employed (56 percent) or are dependents of workers (31 percent). Most are employed by companies with 25 or fewer workers, part-time workers, or self-employed.

Many small businesses do not provide health care benefits for their workers because the number of employees does not provide a viable basis for spreading risks under current insurance options. Moreover, part-time workers are typically ineligible for their employer's benefits. People with disabilities or chronic conditions who are unemployed are routinely denied insurance coverage and/or are subjected to premium rates so high as to be out-of-reach.

## **Underinsurance**

In recent years, "underinsurance" has become increasingly problematic for people with disabilities or chronic conditions. The term "underinsurance" describes a variety of insurance practices that result in partial health care coverage. Such practices include pre-existing condition exclusions; denial or restrictions on reimbursement for specific treatments or prescription drugs; and exclusion of entire categories of coverage such as mental health services and rehabilitation.

Medical and technological advances have increased life expectancy for people who sustain serious injuries or illnesses. Ironically, these life-saving advances in acute medical care have contributed to the growing need for ongoing and long-term care. Many of these treatments are expensive and services needed to sustain quality of life may continue indefinitely. Researchers believe that these developments have led insurers to attempt to minimize associated costs by adopting practices which exclude and restrict benefits for individuals with such conditions. Often, these have been the very benefits needed to maintain health and independent functioning.

## **Controlling Costs**

Another reason for the growing problem of underinsurance is that employers are struggling to control mounting costs of employee health care benefits. Those who continue to offer them have reduced their coverage and/or increased employee co-payments. Mental health benefits, for example, have been dramatically reduced over the past decade. Such employer reductions cause cost-shifting in which previously available benefits must be borne by employees or not provided at all. When

such benefits are not provided and are expensive, employees unable to afford them may go untreated. This could lead to further complications and greater expenses as the course of treatment often becomes more intensive and the condition more severe.

To measure the impact of underinsurance among people with disabilities and chronic conditions, researchers have examined the percentages of income that individuals pay for medical services. In a 1990 study conducted by the Berkeley Planning Associates and the World Institute on Disability, over 31 percent of privately insured people who describe their health status as "poor," said they expect to spend amounts three times higher than people who described their health as "excellent." An almost identical conclusion came from a survey of 726 privately insured, working-aged people with disabilities in which more than 16 percent had also been denied reimbursement for their health services claims because of a pre-existing condition clause.

## **Managed Care**

A leading concept associated with efficiency and cost-containment is "managed care," familiar to most Americans as the health maintenance organization (HMO) model of health service delivery. Under a managed care approach, health care providers would form cooperatives from which employers and individuals can purchase plans and receive care. The assumption is that by pooling facilities, equipment, and administrative costs, more providers can offer services to more people at lower cost than would be possible under traditional third-party reimbursement plans.

Feedback given to voluntary health and disability organizations by their constituents suggests that people with chronic health conditions and disabilities have experienced problems in the managed care setting. These include misdiagnosis due to lack of access to needed specialists and worsening of conditions due to delays in receiving specialty care.

People with chronic conditions and disabilities must have access to adequate health care to maximize functional outcomes. This is not always the least expensive approach in the short-term, but has been demonstrated to minimize more costly consequences associated with functional loss in the long-term.

## **Personal Choice**

For people with chronic health conditions and disabilities, the health care status quo is unacceptable. The challenge, therefore, is to convince healthy Americans, who are generally satisfied with their health care, that truly comprehensive reform is needed. The vast majority of Americans seek solutions to health care problems that do not interfere with their ability to choose their medical providers or to direct the course of prescribed treatments. Many are concerned that proposed cost-containment strategies will minimize their ability to access the services they want.

While recognizing the importance of cost-containment in health care reform, eliminating discrimination in health care delivery and financing is the primary goal of persons with chronic health conditions and disabilities. Therefore, the challenge for this population is to help all Americans understand that while costs must be contained, it cannot be achieved as long as discriminatory health

care practices are permitted to continue. Health care reform must be an inclusive vehicle, not one that fosters continued inequities.

## **The ADA**

For decades, public policies have made great strides toward improved health and equality of opportunity for all Americans, including those with chronic health conditions and disabilities. Government has invested billions of dollars in medical research, education and employment and other programs that promote opportunities for people with chronic illnesses and disabilities to pursue personal, family, and community goals. America's health care system has evolved over the years, helping millions to survive life-threatening illness and injury. But, barriers persist in denying needed services and supports that enable millions of Americans to lead meaningful lives. For example, coverage for rehabilitation services, such as physical or occupational therapy, enables someone to regain partial function of a limb after cancer surgery. But arbitrary limits withhold the potential for maximizing the function which could enable that individual to return to work or live more independently.

A milestone was reached in 1990 when the Americans with Disabilities Act (ADA) was signed into law. The ADA recognized for the first time that people with disabilities, defined to include those with chronic conditions, are an equal part of society and have the right to participate fully in all aspects of life. The ADA removed many of the barriers to employment, public accommodations, public services, and telecommunications long experienced by people with chronic health conditions and disabilities.

While the ADA provides limited protections for people with disabilities whose employers provide health care benefits, it fails to prohibit discrimination in all aspects of health insurance. The ADA is an incomplete solution to the health care concerns of this population.

## **Title V**

Health care benefits are addressed in the ADA under Title V, but are incorporated by reference into Title I, Employment Provisions. Insurance industry practices in issuing health insurance benefits were singled out by Congress for exemption from the ADA protections. The exemptions allow insurers to continue underwriting, classifying, and/or administering risks as long as their practices are based upon sound "risk classification" principles; are not inconsistent with state underwriting laws; and are not used as a subterfuge to evade the purpose of the ADA. By itself, Title V of the ADA does nothing to change the common practices among insurance providers of excluding pre-existing conditions, limiting coverage for certain procedures, limiting particular treatments, limiting reimbursements for certain drugs or procedures, carving out whole categories of services for benefit packages, dramatically increasing premiums, or dropping coverage altogether.

While these exemptions apply also to Title I, employers, unlike private insurers, have additional obligations under Title I. They must ensure their employees with disabilities receive equal access to all employee benefits, including health care coverage, if provided. Employers are not required to provide health care benefits nor must they provide comprehensive coverage. Further, employers may provide

different benefits or charge higher co-payments to people with disabilities or chronic conditions, if they can prove that providing such benefits would, in effect, create an "undue burden."

The health care insurance exemptions and the employers' broader obligations, both referenced in Title I, have created confusion regarding the ADA's intentions for employers. The "Interim Enforcement Guidance" issued by the Equal Employment Opportunities Commission (EEOC) in June, 1993, clarified that employers are obligated to provide equal access to health care benefits and bear the burden of proof should there be a challenge. The "Guidance" is based upon the principles of equal access, continuation of a private insurance industry, and elimination of discriminatory practices. The "Guidance" appears to strengthen Title I, but the interpretation leaves open some important questions.

## **Self-Insured Plans**

For example, (60 percent) of all workers with employer-provided health care benefits are covered by "self-insured" plans operated by the employer. Those plans are not subject to state laws which govern statewide insurance industry practices. Because the ADA defers to state law in this area, self-insured employers do not have the same obligations as employers who purchase plans from state regulated insurance carriers. Therefore, it is still unclear as to the specific obligations that self-insured employers have to employees with chronic health conditions or disabilities.

Many believe that the ADA could have a wider impact on banning discrimination in health insurance through provisions pertaining to public

services. Title II of the ADA prohibits state and local governments from discriminating on the basis of disability. Some believe that the government agencies proposed in some health reform plans would be subject to ADA guidelines regarding nondiscrimination on the basis of disability. If accurate, this would significantly extend ADA protections into the design and delivery of health care.

The ADA envisions full equality for people with chronic health conditions and disabilities. However, it only begins to eliminate discriminatory practices in health care. Therefore, comprehensive health reform is needed to realize the ultimate promise of this landmark law.

## **The Current Debate**

Health care reform dominates the domestic policy agenda. Clearly, people with chronic health conditions and disabilities have an enormous stake in this debate.

In 1992 the National Health Council developed a list of principles against which proposed health care reform legislation could be evaluated. The Council's Statement of Principles on Health Care Reform addresses priority issues including access and affordability, individual responsibility, public education, breadth of coverage and benefits, cost containment, and medical innovation. (A copy of this statement is appended.)

Several issues of critical importance to people with chronic health conditions and disabilities have emerged.

## **Universal Coverage**

Broad agreement exists among health care consumers that coverage should be affordable and that no person should be

denied or lose his or her health insurance coverage due to illness or injury. However, not all of the health care reform proposals would provide "universal coverage." The chronic health and disability communities strongly support the concept of health care as a right for all, embracing guarantees of nondiscrimination in the provision of services and access to the types of services and settings appropriate to restoring and maintaining maximum function and independence.

## **Continuum of Care**

Comprehensiveness of coverage has been described by the Council and disability groups as a continuum of physical and mental health care which would include preventive, acute, chronic, rehabilitative, and long-term care services and reflect individual needs and choices. Determinations regarding the "appropriateness" of services should be made by the individual in treatment, the family and the health care team, not health plan administrators. This is especially important in ensuring that the desired goal to contain costs does not dictate undesirable treatment decisions.

The quality of health care received by people with disabilities and chronic health conditions is negatively affected by the system's general "acute care" bias. For patients within these populations, cure and restoration is often not time limited or acute. It entails a broad range of services on a continuum of care to be delivered at appropriate intervals across one's entire life span.

The Consortium for Citizens with Disabilities (CCD), in its principles for health care reform, describes long-term care as integral to the comprehensiveness of care for people with disabilities. Such long-term care,

CCD believes, should be available where most appropriate to the individual's needs, whether at home or in the community or at a medical facility. For a person with a disability, the term, "healthy" relates to the ability to maintain or increase functional capacity over the course of a life time.

## **Access to Specialists**

The physical aspects of a chronic condition or disability can influence or be influenced by a course of medical treatment such that many primary care physicians or others not thoroughly familiar with the condition may not have the specific expertise to prescribe safe and effective treatment. The consequences can be severe and life threatening. People with chronic health conditions and disabilities may require frequent consultations with specialists and may even need the specialist to be approved as a primary care physician, allowing physicians trained in the disability to act as "gate keepers" for other specialist referrals.

## **Prevention**

The concept of prevention is associated with health care services which detect or prevent illnesses or injury. For people with disabilities and chronic conditions it can also mean preventing an injury or illness from turning into permanent functional loss, slowing functional degeneration, and preventing the development of secondary health conditions. For many individuals with disabilities and chronic conditions, routine health care can prevent greater loss of function and additional health care expenses associated with acute remedies.

Some disabilities and chronic conditions render people particularly vulnerable to complications which can lead to further functional loss and secondary disabilities. For example, people who use crutches for most of their lives as a result of polio or spina bifida may develop joint problems. In some cases, self-care regimens of diet, exercise, medication and rest will need routine monitoring, such as for people with diabetes who require periodic adjustments to their insulin regimen. Taking responsibility for one's own care, including preventive measures, is one of the Council's guiding principles and is integral to cost-containment.

## **Rehabilitation**

Rehabilitation has often been regarded as strictly related to recovery from trauma or acute conditions such as stroke or work-related injuries. Rehabilitation and habilitation also represent important concepts for prevention of further loss or deterioration of health. Following a stroke, an elderly woman in North Carolina recovered enough mobility to allow her to live alone. When her physical therapy regimen was no longer considered "medically necessary" to her physical restoration, it was discontinued. This led to a subsequent loss of upper body strength resulting in further loss of ability and confidence to move around the building. In addition to her reduced function, she experiences the social side effect of isolation.

For many people, rehabilitation is essential and should be considered part of long-term treatment. Medical rehabilitation representatives make the point that their services are cost effective, increase function, and are person-centered. Services can be delivered in community facilities or in

home-based programs, and allow for maximum flexibility — all qualities of care being sought in health care reform strategies.

## **Continued Medical Progress**

People with diabetes, epilepsy, depression, kidney disease, heart disease, and many other chronic conditions rely on medications to maintain their health. Prescription drugs are not options for these people and often mean the difference between life and death. Prescription drugs are not covered by Medicare, even though Medicare recipients are most likely to rely on them. Furthermore, employers are increasingly dropping prescription drug benefits in an effort to minimize cost.

The explosion of new knowledge and capabilities in biomedical research offers real hope of unraveling the medical mysteries associated with chronic illnesses and disabilities. Effective diagnostic tools, treatment and cures are within reach for such debilitating conditions as cystic fibrosis and forms of muscular dystrophy. Health reforms should actively foster, not inhibit, such research and development.

## **Durable Medical Equipment**

Durable medical equipment includes wheelchairs, hearing aids, speech boards, prosthetic limbs, or other assistive devices that permit an individual to compensate for the loss or limit in function from a disability or chronic health condition. Advances in the technology provide consumers with increased ability to select devices and services that most closely match their needs, maximizing their functioning and

ability to participate fully in community life.

Such equipment is essential, but the costs remain high and coverage is greatly restricted under the current health care purchasing options. The cost of wheelchairs, for example, can range into the thousands of dollars, especially if motorized. When needed services are not covered, people must pay for them out-of-pocket. If unable to afford the equipment, their health and independent functioning may be at risk.

## **Personal Assistance Services**

The costs of personal assistance services are rarely covered by private or public health benefits programs. Yet these services, which include personal attendants, interpreters, readers, and home-health aides, can mean the difference for people with disabilities or chronic conditions between institutionalization and living and caring for oneself independently in the community. Institutional care when required to maintain health, carries high costs for families and providers. Personal assistance services and home-based care can be delivered at a lower cost and with better social outcomes.

## **Acting Together for Meaningful Reform**

The debate over health care reform has touched the life of every American. Not surprisingly, a myriad of groups have emerged to lobby Congress and the administration to achieve their respective agendas. People with chronic health conditions and disabilities are in competition with these varied, often well-financed interests for the attention of health policy decision-makers.

Key members of Congress have indicated that they are not hearing a great deal from the chronic health and disability communities on health care reform. Months of participating in congressional hearings, White House briefings, working groups, and face-to-face meetings with legislators and their staff have not diffused the perception that persons with chronic illnesses and disabilities have yet to weigh-in strongly on health care reform. Policymakers across the political spectrum are encouraging chronic illness and disability representatives to voice collectively their shared concerns and recommendations.

Under the banner of REAL HEALTH CARE FOR ALL, disability advocate Justin Dart conducted a series of teleconferences in March to mobilize a national grassroots campaign for comprehensive health care reform. The campaign is applying the successful approach employed to achieve enactment of the Americans with Disabilities Act. Mr. Dart's call to action challenges every member of the chronic illness and disability communities to join together to convince lawmakers that health care reform cannot move forward without specifically addressing the concerns of these constituencies. The National Health Council summit seeks to communicate that call to the respective communities so that their collaborative strength may be realized.

## Conclusion

Striking similarities exist between people with chronic health conditions and disabilities and the general public concerning the health system's problems and potential solutions. The experiences of people with chronic conditions and disabilities can be viewed as a mirror on many of the weaknesses of the health care system. Meeting the needs of these populations presents a stringent standard against which proposed solutions must be tested. If solutions

fail to meet the health care needs of people with chronic health conditions and disabilities, they ultimately will prove deficient in meeting the health care needs of the public generally.

The unique expertise of this population is integral to ensuring that health care reforms reflect the spirit and intent of the Americans with Disabilities Act. The chronic health and disability communities must do all they can together to make it a reality.

## NATIONAL HEALTH COUNCIL MEMBERSHIP

### VOLUNTARY HEALTH AGENCIES

Alzheimer's Association, Inc.  
American Cancer Society  
American Diabetes Association  
American Kidney Fund  
American Liver Foundation  
American Paralysis Association  
American Red Cross  
American Social Health Association  
Amyotrophic Lateral Sclerosis Association  
Arthritis Foundation  
Asthma & Allergy Foundation of America  
Crohn's & Colitis Foundation of America  
Cystic Fibrosis Foundation  
Epilepsy Foundation of America  
Guillain-Barré Syndrome Foundation International  
Huntington's Disease Society of America  
Interstitial Cystitis Association  
Juvenile Diabetes Foundation International  
Lupus Foundation of America  
March of Dimes Birth Defects Foundation  
Myasthenia Gravis Foundation  
National Alopecia Areata Foundation  
National Down Syndrome Society  
National Easter Seal Society  
National Hemophilia Foundation  
National Mental Health Association  
National Multiple Sclerosis Society  
National Neurofibromatosis Foundation  
National Osteoporosis Foundation  
National Psoriasis Foundation  
National Tuberous Sclerosis Association  
Paget's Disease Foundation  
Planned Parenthood Federation of America  
Prevent Blindness America  
RP Foundation Fighting Blindness  
SIDS Alliance  
Sjögren's Syndrome Foundation  
Spina Bifida Association of America  
Tourette Syndrome Association, Inc.  
United Ostomy Association

### PROFESSIONAL AND MEMBERSHIP ASSOCIATIONS

American Academy of Physician Assistants  
American Association of Colleges of Osteopathic Medicine  
American Association of Diabetes Educators  
American Association of Homes and Services for the Aging  
American College of Cardiology  
American College Health Association  
American Dental Association  
American Dietetic Association  
American Hospital Association  
American Medical Association  
American Optometric Association  
American Podiatric Medical Association  
American Public Health Association  
American Society for Parenteral and Enteral Nutrition  
American Society of Human Genetics  
Association for Health Services Research  
Association of Healthcare Internal Auditors  
Association of Reproductive Health Professionals  
Association of Schools of Allied Health Professions  
Association of Schools of Public Health  
Association of State and Territorial Health Officials  
Association of University Programs in Health Administration  
Biotechnology Industry Organization  
Eye Bank Association of America  
Federated Ambulatory Surgery Association  
Group Health Association of America  
Healthcare Financial Management Association

Health Insurance Association of America  
Healthcare Forum  
National Association for Biomedical Research  
National Association for Healthcare Quality  
National Association of Community Health Centers  
National Association of County Health Officials  
National Association of Health Data Organizations  
National Association of School Nurses  
National Coalition of Hispanic Health  
and Human Services Organizations  
National Foundation for Brain Research  
National Hospice Organization  
National Leadership Coalition on AIDS  
National League for Nursing  
National Organization for Rare Disorders  
Pharmaceutical Manufacturers Association  
Society for Neuroscience

### NONPROFIT ORGANIZATIONS WITH AN INTEREST IN HEALTH

Academy for Educational Development, Inc.  
Alliance for Aging Research  
American Association of Retired Persons  
AmHS Institute  
Combined Health Appeal of America  
Goodwill Industries International  
Grantmakers In Health  
Institute for Alternative Futures  
Medic Alert Foundation International  
Mental Health Policy Resource Center  
National Center for Health Education  
National Head Start Association  
National Rehabilitation Association  
National Voluntary Health Agencies  
Paralyzed Veterans of America  
Save the Children Federation  
Society for the Advancement of Women's Health Research  
United Way of America

### BUSINESS AND INDUSTRY

Abt Associates  
Aetna Life & Casualty  
Allergan, Inc.  
Amgen Inc.  
Burrroughs Wellcome Company  
Chiron Corporation  
CIGNA Companies  
Ernst & Young  
Glaxo Inc.  
Hoffmann-La Roche Inc  
Johnson & Johnson  
Marion Merrell Dow Inc.  
Merck & Company  
Metropolitan Life Insurance Company  
Pfizer Inc  
Sandoz Pharmaceuticals  
Schering-Plough Corp.  
Searle  
SmithKline Beecham Pharmaceuticals  
Sterling Winthrop, Inc.  
The Upjohn Company  
Warner-Lambert Company

### FEDERAL GOVERNMENT

U.S. Department of Defense—Office of Health Affairs  
U.S. Department of Health and Human Services—  
Public Health Service  
Social Security Administration  
U.S. Department of Veterans Affairs—  
Veterans Health Administration  
U.S. General Accounting Office

## Ordering Information

Additional copies of *A Health Care Reform Summit: Building Bridges to Find Solutions* may be obtained at the prices shown below, from:

**National Health Council, Inc.**

1730 M Street, NW  
Suite 500  
Washington, DC 20036

Price List—Prepaid Orders\*

Single Copy

Non-Members .....\$8.95

Council Members .....\$6.95

\*Prepaid Orders. Prices shown are for PREPAID orders only and include the cost of shipping. All orders must be PREPAID unless submitted with official purchase order or on organizational letterhead. A charge of \$3.00 per order, to cover postage and handling, will be added for all orders TO BE BILLED.

Discounts: Quantity discounts are shown below:

4 to 10 copies ..... 15%

10 to 50 copies ..... 30%

50 or more copies ..... 50%

Member agencies prices apply to national organizations (and their affiliates) which are dues-paying members of the National Health Council.

**National Health Council, Inc.**

1730 M Street, NW  
Suite 500  
Washington, DC 20036