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OA/ID Number: 52090
Folder ID Number: 52090-009

Folder Title:
HC [Health Care] Reform Speech - Lex Frieden [1994]

Stack: **Row:** **Section:** **Shelf:** **Position:**

Healthcare Reform -- we need it

Status of P.W.D re healthcare

We knew this in 1985 - - Toward Independence
→ ADA

Weicker said no re insurence and ADA
we snuck some in

Clinton provoked change - - propelled it

Wanted data re need - - we did survey
Findings:

overheads
handouts

Evidence of need no surprise

Suprise was experience with managed care

Shocked by ~~abt~~ anecdotes

~~one heads~~

~~This came simultaneously with Clinton Plan~~
~~dependence on managed care - and others~~

Simultaneously with our experience at TIRR -
and others

~~HMO's~~

Managed care in theory is not necessarily bad. -- in practice it sometimes is

How can we assure that health care reform benefits rather than hurts PWD?

How can we assure that managed care ≠ benefits rather than hurts PWD?

Conditions : from Houston meeting
C.C.D.

HCR:

Must include

Considerations

~~Conditions~~

Managed Care:

gate keeper function

& risky

Managed Competition

good concept - got lost

& worked for more $ & fed.

Everyone must lobby together! Use Town Rooms

problem PWD are skeptical of medical professionals

☆ maybe they should be -- who do you regard as your customers?

☆ How many are on your BOD?

everyone risks loosing here

~~use HANGA~~ use Banja example - ref ADA Gerhard Eppering

Leadership

health care providers reaching out
PWD developing understanding and trust

Gerben paper:
Archives of PM Oct '93

ILCs have a role to play -- R.W.J. program

MMO's
new networks
traditional hosp.
MCE

Grissa ideas:

4 Ideas

Universal coverage
elim. pre existing conditions

several possible outcomes
more PWD have primary care coverage
more PWD have rehab coverage
more coverage for PAS and DME and prescription meds.

risk of lowering the standard of care
" " managed care becoming a rationing method
" = losing specialty providers

chance of developing new more effective methods
consumer run self help
rehab programs
rehab without walls

New ideas will be generated ~~by~~ regardless of the outcome of health care reform.

Rationing is my greatest fear

Improved quality at lower ~~costs~~ cost is my greatest hope -- salary corrections may be inevidible

In closing, I want to make 3 comments about standards and I request to you ...

Regarding standards:

① through development, application, and utilization of standards must involve PWD

② They must relate to programs and quality of care rather than facilities and institutional mechanisms

③ They must not be compromised by the market place.

CARF must risk its life to uphold its principals

My request to you:

revaluate your priorities of customers

find ways to involve and support PWD in the community

* ~~my first trips~~ — Boston

Be A Leader --

don't fight over the spoils

don't let competition interfer with rational judgement

~~It~~ is said ~~that~~ Nero fiddled while Rome burned

Let's not be the historical example of the Romans fiddling while Rome burns.

Develop ~~partnerships~~ w/ ~~as~~ people in the community

Thanks you

Create a consensus

Expand your ~~success~~ to do it

Intro/Background Page

- ILRU with support from RWJ conducted an informal, self-respondent survey of persons with disabilities.

- Nearly 750 people with disabilities completed and returned the 12 page 49 item survey to ILRU.

- The overall picture appears to suggest that the current health care system is particularly hard on people with disabilities and chronic health conditions.

How the Current System Affects People with Disabilities

Over two thirds (67%) of the respondents indicated that they were not receiving the kinds of health care services needed to maintain optimal health.

resulte.doc

How the Current System Affects People with Disabilities

Over two thirds (67%) of respondents reported that they were not receiving the kinds of health care services that they needed to maintain optimal health. The range of reasons cited for this included limited insurance coverage, lack of access to health care providers, and exclusions based on pre-existing conditions.

Results

How the Current System Affects People with Disabilities

Other key findings related to health care coverage included:

- 26% had been denied insurance coverage;
- 16% had been dropped or canceled by an insurance company;
- 23% had been denied employment because of a health-related problem;
- 21% had chosen not to work so that they could remain eligible for public health insurance;
- 35% had been unable to change jobs because of concerns about being covered for pre-existing conditions, limitations in health care coverage imposed by a new employer, and/or lack of coverage by a new employer;

Results

How the Current System Affects People with Disabilities

Other key findings -- Continued

- 24% had been denied health care services because of lack of health insurance;
- 46% had been faced with not buying items that they wanted or needed in order to save money to pay for health care services;
- 21% had developed disability-related health problems because health care coverage was lacking or inadequate;
- 16% had experienced additional functional loss because of inadequate health care coverage for needed services; and
- 23% had experienced limitations in work or recreational activities as a result of lacking or inadequate health care.

results.doc

Types of Insurance Coverage Reported by the Respondents

- 34% had Medicare or SSDI;
- 26% had Medicaid;
- 25% had employer-provided insurance;
- 16% had personal health insurance;
- less than 3% had military or veterans health care benefits; and
- a number of other sources of health care coverage were cited, including federal employee disability health care, state high risk programs, and other special public and private programs.
- 7% had no health insurance coverage

resultc.doc

How Satisfied Were the Respondents With the Current Health Care System?

When asked if the health care system in this country had gotten better, worse, or stayed the same over the last five to ten years, 47 percent of the respondents indicated that the system had gotten worse.

How Satisfied Were the Respondents With the Current Health Care System?

When asked to identify the biggest problem with the current health care system, 73% of the respondents said that the high cost of treatment represents the biggest problem that they had encountered with the system.

How Satisfied Were the Respondents With the Current Health Care System?

Other problems identified by respondents included:

- 48% cited inadequate insurance coverage;
- 45% cited lack of understanding of the health care needs and concerns of people with disabilities by physicians and other health care professionals;
- 38% cited inadequate preventive and health maintenance services;
- 34% cited inadequate coverage for assistive technology services;
- 32% cited problems with access to treatment and services;
- 30% cited unresponsive insurance companies and rude and discourteous providers and administrators; and
- 24% cited inadequate personal assistance services to maintain optimal health.

resultd.doc

How the Current System Affects People with Disabilities

The types of services respondents said that they needed in order to maintain optimal health included:

- 79% needed services for disability related health problems and illness;
- 69% needed general health maintenance services;
- 65% needed general preventive/health promotion services;
- 61% needed services for routine health problems and illness;
- 60% needed dental health services;
- 54% needed disability-related health maintenance services;
- 32% needed personal assistance services;
- 29% needed acute care services;
- 24% needed disability-related acute care services;
- 22% needed psychiatric, psychological, or other mental health services;
- 16% needed durable medical equipment or assistive technology.

Services and/or treatments needed but not covered:

- Prescription medicines
- Personal assistance services
- Chiropractic services
- Dental care
- Purchase and/or repairs to durable medical equipment
- Preventative treatments (such as flu shots, mammograms, routine preventive checkups)
- Health maintenance services
- Alternative medical treatments (such as acupuncture, chiropractic services holistic medicines)
- Hearing tests and hearing aids
- Medical supplies
- Mental health services
- Physical therapy
- Vision testing and eye glasses
- Assistive technology

overhead.doc

Medicaid had to authorize payment for a person's transportation to the doctor when the closest doctor was in another town, not once but for each doctor visit.

"I MUST HAVE MEDICAID OK EASTERN TRANSPORTATION TO PROVIDE TRANSPORTATION TO FALMOUTH, MAINE TO BE TREATED BY THE ONLY DOCTOR IN THE STATE WHO TAKES MEDICAID--I NEED HELP."

Because there are so few doctors who accept Medicare/Medicaid, many persons do not get the health care they need until they become so ill that they must go to emergency rooms or are directed by doctors to go to emergency rooms because the doctor will not see them in his/her office.

"THE DOCTOR HAS TOLD ME TO GO TO THE EMERGENCY ROOM WHEN HE IS TOO BUSY TO SEE ME IN HIS OFFICE, THIS COSTS MORE AND MAKES ME FEEL THAT THE DOCTOR IS UNCONCERNED ABOUT ME."

Many persons who are presently in HMOs noted they were not free to go to doctors they had seen for many years because the doctor was not a member of the HMO and the consumer could not afford to pay the out-of-pocket costs for seeing a doctor outside of the plan. When proper referrals are made it can take an inordinate amount of time to see the needed doctor.

"I SOMETIMES WAIT 3-4 MONTHS BEFORE A REFERRAL APPOINTMENT CAN BE MADE--IT TOOK ME 4 MONTHS TO GET A REFERRAL APPOINTMENT FOR THE PAIN CLINIC TO GET A SHOT FOR MY BACK PAIN."

"I OWE SO MUCH MONEY TO HEALTH CARE PROVIDERS THAT IT IS DIFFICULT FOR ME TO ARRANGE TO HAVE A TEST THAT I HAVE BEEN GIVEN A PRESCRIPTION FOR--I FEEL LIKE A SABER IS HANGING OVER MY HEAD AND IT IS GOING TO FALL ANY TIME, THEN I WILL GET NO MORE HEALTH CARE TREATMENT AND/OR HAVE NO MONEY TO LIVE ON AFTER ALL THE BILLS ARE PAID."

Many persons noted problems and issues due to lack of coordination of care among multiple care providers.

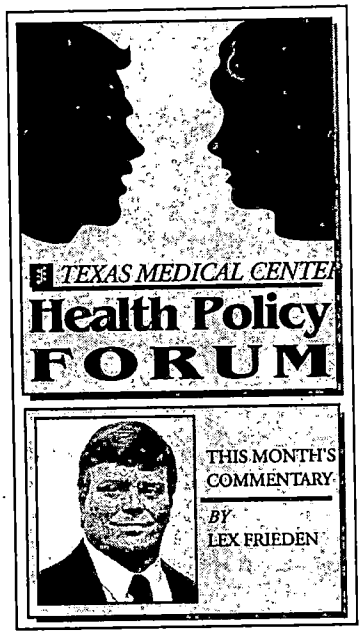
"ONE PHYSICIAN INSTRUCTED ME TO LEAVE AN ARTIFICIAL EYE OUT FOR ONE MONTH DUE TO EYELID INFECTION, WITHOUT CONSULTING A SPECIALIST--AS A RESULT THE EYE SOCKET SHRANK AND I HAD A LOT OF PAIN IN REINSERTING THE PROSTHESIS WHICH ULTIMATELY HAD TO BE RE-MADE SO IT WOULD FIT PROPERLY. ALSO MEDICATION GIVEN TO PREVENT A FURTHER EYE PROBLEM HAS HAD NEGATIVE REACTION WITH OTHER MEDICATIONS I WAS TAKING."

Over and over people wrote that no one was coordinating their care among multiple doctors/specialists, that the doctors never seemed to be communicating with one another, and there was no one health care provider tracking all the medications involved which often resulted in negative health reactions.

Where the Respondents Obtained Their Health Care Services

- 57% from a private physician;
- 19% from hospital emergency rooms;
- 12% from a public health facility;
- 11% from a private clinic;
- 10% from a university hospital or clinic;
- 8% from a rehabilitation hospital;
- 6% from a home health care provider; and the remaining
- 2% from other sources, including nursing homes and school health programs.

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More people today are living with severe disabilities and chronic health conditions than ever before — due in large part to great advances in medical research and technology. The trouble is, after surviving the initial crises associated with their conditions, the vast majority of severely disabled people find that our health care system fails to meet their ongoing health care needs adequately.

The Independent Living Research Utilization Program (ILRU) at The Institute for Rehabilitation and Research recently conducted a survey of persons with disabilities who are served by independent living centers — service and advocacy programs run by and for people with disabilities — across the country. The survey results suggest that the current health care system is particularly dysfunctional for people with disabilities and those with chronic health conditions.

According to the people with disabilities responding to the survey:

- 23 percent had been denied employment because of health-related problems;
- 21 percent had chosen not to work so that they could remain eligible for public health insurance;
- 23 percent had experienced limitations in work or recreational activities as a result of the absence or inadequacy of health care;
- 21 percent had developed preventable health complications related to their disabilities because their health care coverage was inadequate or nonexistent;
- 35 percent had been unable to change jobs because of concerns about being covered for pre-existing conditions, limitations in health care coverage imposed by a new employer, and/or lack of coverage by a new employer;
- 24 percent had been denied health care services because of lack of health insurance;
- 16 percent had experienced additional functional loss because of inadequate health care coverage for needed services;
- 46 percent had been faced with not buying items that they wanted or needed in order to save money to pay for health care services; and
- 26 percent had been denied insurance coverage.

While the survey does not represent the entire spectrum of people living with disabilities, it does provide evidence that the current health care system is not working for a large portion of America's population. As we engage in the debate over national health care reform, it is obvious that there will need to be trade-offs in any plan to control costs and discourage inappropriate use of services. However, a thorough look at the fiscal impact of some of the current policies can provide equally compelling arguments for cost-effective service expansion.

We must recognize that restricting or providing only limited access to preventive and health maintenance services inevitably leads to greater costs associated with acute care services. Not covering needed prescriptions and durable medical equipment significantly increases the risks of developing more serious health problems. Not providing health care coverage for people who are engaged in part-time employment has significant physical and mental health implications and diminishes potential tax revenues. Failure to provide home-based personal assistance services or attendant care will almost certainly restrict people to their homes and beds who otherwise might be able to assume responsibilities outside their homes and even work on a full-time or part-time basis.

Limiting access to rehabilitation specialists and other clinicians who have acquired expertise in treating conditions associated with complications arising from disabilities may result in failure to address health problems in the most timely and most appropriate manner. Arbitrary restrictions on the length of stay and range or depth of services for patients in comprehensive medical rehabilitation programs may limit outcomes to the point where those who might have been able to care for themselves, engage in gainful employment, and play productive roles in family and community life, do not have the opportunity to acquire the skills needed to do so.

These issues must be considered if health care reform is to address the needs of people with disabilities who rely on accessible and high-quality health care in order to maintain physical and economic well-being, as well as long-term quality of life.

For people with disabilities, problems with the health care system are not simply related to difficulties in finding money to cover occasional episodic health problems or making choices between various health care service providers. Indeed, problems with the health care system can prevent them from working and becoming contributing, productive, self-sufficient members of society.

For people with disabilities, problems with the health care system are not simply related to difficulties in finding money to cover occasional episodic health problems or making choices between various health care service providers... The problem can prevent them from working and becoming contributing, productive, self-sufficient members of society.

As we continue to deliberate the issues surrounding health care reform, it is important that we find solutions that will empower people with disabilities and enable them to establish lives of productivity and independence.

Today, there are 43 million Americans who have disabilities. This population, which cuts across lines of gender, race and economic status, is growing. It is our responsibility, and in our national interest, to ensure accessible, appropriate and high quality health care services for all Americans, including those of us with disabilities.

(Lex Frieden is senior vice president of The Institute for Rehabilitation and Research — TIRR, clinical associate professor at Baylor College of Medicine, and program director for the Robert Wood Johnson Foundation's national program, "Improving Service Systems for People with Disabilities.")

The bottom line is this: millions of people with disabilities and other chronic health conditions in this country today need a little help each day with simple tasks like brushing their teeth, washing their hair and getting a bite to eat. Yet, instead of providing relatively inexpensive in-home services to these people, we wait until they get sick from poor hygiene or bad nutrition, and then we pay in a few days what it would have cost to help them be relatively independent for several months or, in some cases, several years.

Talk about voodoo economics -- if the health care policy wizards think they can control health care costs without instituting a national system of personal assistance services and community based supports, then they have been inhaling!

REMARKS BY LEX FRIEDEN

Let me ask you a question? If you break your neck in a car wreck on your way home tonight and become paralyzed, as I did 27 years ago, who will dress you, bathe you, and comb your hair after you leave the hospital? Will it be your parents or your children -- someone from your church -- will it be a volunteer who comes when she can, or can you afford to pay a nurse 10 or 15 dollars an hour for the 4 to 8 hours of help you will need per day?

Do you have the mistaken impression that your present health insurance will cover these costs or that current health care reform proposals address this issue? Do you realize it is almost impossible to arrange volunteer assistance throughout the day and night for an extended period of time -- like the rest of your life!

Let's be frank, the likelihood that you will be permanently disabled on your way home today is about equal to the odds that you'll win the lotto. But, the odds that you or a member of your family will need chronic care sometime during your life are better than even.

From my vantage point, the reality of the situation is both encouraging and depressing. It is encouraging to know that some people, including me, have been able to maintain a comparatively high quality of life and be productive despite severe disability and loss of function. It is also reassuring to know that there are now more than 200 independent living centers across the United States which are run by people with disabilities who know how to organize and manage the needed services. Finally, it is nice to know that we have some good models of personal assistance service systems in States like Maine and Minnesota, and in other countries.

On the other hand, it is terribly depressing to know that the majority of health insurance plans and the current health care reform proposals have no provision for non-medical, in-home personal assistance services, and that most people who can't find volunteers or can't afford to pay for help dressing and undressing, bathing and eating wind up living in nursing homes as public charity cases.

It seems absurd to me that states and the federal government will share the cost of $30,000 or more per year to keep someone in a nursing home who would prefer to be assisted in their own home at less than half the cost to the taxpayer. Furthermore, people living in their own homes seem to be much happier and far more productive.

Health Care Reform That Works For All Americans

by Lex Frieden

Health care is a means for individuals to achieve full health and function, to participate fully in society and to be independent. It is the means for society to reap the varied benefits for a fully functioning, healthy populace. These aims should be considered as we set about reordering health care delivery and financing.

As we engage in health care reform, our decisions should be guided by whether the proposed reforms achieve health for all of our citizens. One group in particular that will be profoundly affected by health care system changes are the more than 43 million Americans who have disabilities. This growing population--which cuts across all lines of gender, race and economic status--is made up of people with varying talents, skills, and resources.

The failure of the current health care system to provide these individuals with access to appropriate health care, such as rehabilitation services, severely limits the contributions that this significant portion of the population can make to our society. As an integral part of the reform debate, it is important that we find health care solutions that will empower people with disabilities, enable them to function as independently and productively as possible, and thereby promote--as a matter of public policy, their full participation in life and work.

Examples of failures within the current system include inadequate coverage for preventive and health maintenance services, which inevitably leads to greater costs for acute care services. A recent study conducted by The Institute for Rehabilitation and Research (TIRR) of Houston, Texas, suggests that more than 20 percent of people who are living with disabilities developed preventable health complications related to their disabilities because their health care coverage was inadequate or nonexistent.

Furthermore, some 16 percent of individuals responding to a national survey reported additional loss in function because of inadequate health care coverage for needed services. Such gaps in coverage are not means to promote full health; rather, they are the undesirable end products of efforts to control access and contain costs. While limited short-term cost savings may be realized from denying certain kinds of services, there is evidence to suggest that significantly higher costs may be the price paid over the long-term for service denials or delays.

A critical dimension of the reform debate relates to ensuring adequate and timely access to specialized providers, such as occupational therapists and other clinicians who have expertise in working with individuals with disabilities and in treating associated complications that can arise. No example is more compelling than in the case of a child with a congenital disability.

In recent hearings before the U.S. Senate Labor and Human Resources Committee, Marilyn Hogan Weisner testified on the importance of outpatient rehabilitation services to the health and well-being of Thaddeus, her nine year old son who has cerebral palsy. Ms. Weisner noted that "...without the physical, occupational and speech therapy he has received, Thad's body would be restricted by contractures; he would suffer hip and shoulder dislocations. He would require repeated painful surgeries to overcome, but never fully correct, these problems. He would have progressing scoliosis which would eventually impinge on his internal organs causing damage... Instead, because of the physical, occupational and speech therapy...he has made tremendous progress in his development."

Because of the services provided her son, Ms. Weisner noted that "I can now anticipate the day when he will become a functioning, productive adult who can contribute to his own support, and hopefully, never live in an institution."

Another important issue raised by many of the major reform proposals is their increased reliance on managed care, through health maintenance organizations (HMOs) and similar health care delivery mechanisms. While managed care has been described by some as rationing, the best current models attempt to coordinate services, to provide better preventive care, and to contain costs.

The preeminent public policy questions which must be considered in the current debate are: Who will make critical service decisions? And, what outcomes will be deemed appropriate for what expenditures? If overall health and optimal functioning are considered the outcomes, the value of services such as rehabilitation increases. If the goal is solely to contain short-term costs, the "ends" of cost containment and access control defeat the "means" to achieve full health and lower long-term costs for health plans and for society.

If managed care is to be the predominant theme in health care reform, several safeguards are required to meet the needs of people with disabilities. To begin with, physicians' judgements about proper care must not be compromised in the drive toward cost containment. Primary care physicians should be able to refer plan participants with disabilities to physician and non-physician specialists without fear of being financially penalized or disciplined for doing so.

Mechanisms should be developed to allow people with special health care needs to secure the services of specialists who can most effectively meet their needs without unnecessary and time consuming visits to primary care providers. In cases where people with disabilities need the services of certain specialists, they should be able to select the provider of choice regardless of whether the provider is a member of a particular network or not.

In cases where specialists provide basic services to individuals with complex conditions, they should be reimbursed at primary care rates. This would prevent costly complications arising when a primary care provider, for instance, engages in unnecessary diagnostic and treatment procedures for an individual with a complicated health care condition when that individual presently only needs treatment for an unrelated minor condition.

Managed care strategies must accept and acknowledge the variety of medical and other conditions patients present while still accommodating the goals of managed care. Attention to these issues can only improve managed care's outcomes in terms of the health of all patients.

The needs of people with disabilities should be considered as a litmus test for the effectiveness of any health care reform proposal. When health care focuses on maximizing the individual's potential by insuring timely and appropriate services, health care reform will then address the issues of all Americans.

###

Lex Frieden is the former Executive Director of the National Council on Disability and he is currently Senior Vice President at The Institute for Rehabilitation and Research (TIRR) and Clinical Associate Professor of Rehabilitation at Baylor College of Medicine in Houston, Texas. He serves as the consumer representative on the Executive Board of the American Occupational Therapy Association.

How We Can Contribute

The disability movement aims to contribute to the debate over health care reform in many ways:

By broadening the concept of health: People with disabilities know that the concept of health must be expanded from the "absence of disease or impairment" to include services that promote function, contribute to chronic-care management and improve quality of life.

THE LEAGUE OF WOMEN VOTERS OF THE UNITED STATES BELIEVES THAT A BASIC LEVEL OF QUALITY HEALTH CARE AT AN AFFORDABLE COST SHOULD BE AVAILABLE TO ALL U.S. RESIDENTS."

LWVUS Health Care Position Statement, April 1993

By battling discrimination: Based on the protective status of disability under federal civil rights laws such as the Americans with Disabilities Act (ADA), people with disabilities can challenge discrimination on the basis of disability and build a bridge to the right to health care for all persons.

By "de-medicalizing" the health care system: Driven by the goals of consumer empowerment and independent living, the disability community can help articulate the need to restructure the health care system by enhancing the role of consumers in managing their own health care needs and by shaping the direction of health care policy and financing.

By building a sense of urgency: Recognizing that without access to health care the ADA will become an empty promise for many, people with disabilities bring a sense of urgency to creating a right to health care for all.

Concerns About Managed Competition

The disability community has a number of concerns about the Clinton administration's health proposal:

1. Competition on the basis of price among health plans may exclude many persons from the plans with the highest quality, thereby perpetuating a two-tiered system based on one's ability to pay.
2. In order to keep premiums low for marginal employers, the core benefit package may omit essential health-related services that are most needed by some persons with disabilities.
3. Ineffective cost containment in the health care system may erode the comprehensiveness of the benefit package and delay universal access.
4. The use of "gatekeepers" in managed care may interfere with choice of health care providers, discourage referrals to appropriate specialists outside of the managed-care plan, or impose arbitrary limits on covered services in order to contain costs.

As a litmus test for health care reform, the disability community can play a strategic role in helping others recognize their common vulnerability in a health care system where health care is treated as a commodity rather than as a right. ■

Bob Griss is senior health policy researcher for the United Cerebral Palsy Associations and cochair of the Health Task Force of the Consortium for Citizens with Disabilities.

Asians and Pacific Islanders

COST-CONTAINMENT FOCUS OVERLOOKS FUNDAMENTAL BARRIERS TO CARE

by Tessie Guillermo



Contrary to the notion of a "healthy minority," the United States' Asian and Pacific Islander (A/PI) population has critical health needs that are not being addressed today.

A/PIs suffer from higher rates of hepatitis B, tuberculosis, suicide, and certain cancers and mental health disorders than do other population groups. And data from the National Center for Health Statistics indicate that, adjusted for health status, Asians and Pacific Islanders have the lowest rate of doctor visits per person, as compared with all other groups.

One explanation for this low rate of health-service use may be problems with insurance—21 percent of the A/PI population is uninsured, compared with 13 percent of the non-Latino white population. Asians' and Pacific Islanders' lack of access to health care, however, has as much, if not more, to do with inequities in the delivery of health care as with financing and insurance problems.

Policy makers, it appears, are currently fixated upon the idea that reforming health care financing will ensure greater access to care. Reforming financing, however, does nothing to bring down the more fundamental barriers of language and culture for individuals who have limited proficiency in English and who are unfa-

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May 9, 1994

Mr. Lex Frieden, Senior V.P.
The Institute for Rehabilitation and Research
1333 Moursund
Houston, Texas 77030-3405

Dear Lex,

I appreciated your remarks at the RWJ Press Briefing on Chronic Care in Washington, D.C. last Tuesday. The acute care bias in our health care system is both an important symptom of and contributor to the health care crisis, but it is not well understood by the general public, health care professionals, or our elected representatives in Washington, D.C. who are very nervous about creating an entitlement to health care.

Although it appears that we are losing the health care debate, I still think that the disability community is in the best position to be the catalyst for grass roots mobilization which is necessary to get comprehensive health care reform through Congress. This is one of my primary goals for creating the Center on Disability and Health.

I would seriously like to explore the possibility of collaborating with you on policy analysis, research, and advocacy related to promoting health care reform from a disability perspective. I do not have any large grants or contracts lined up for next year when the Center will have its 501(c)-3 status, and I am looking for an opportunity to help shape the disability agenda for health care reform which I expect will not be resolved then at the Federal or State levels.

Please read the attached description of the Center and the recent articles on the role of the disability community as litmus test for health care reform which were published in the Coalition Quarterly of the Federation for Children with Special Needs and the League of Women Voters newletter. Then let's talk about projects that we can collaborate on starting January 1995. Hoping to hear from you soon, I remain,

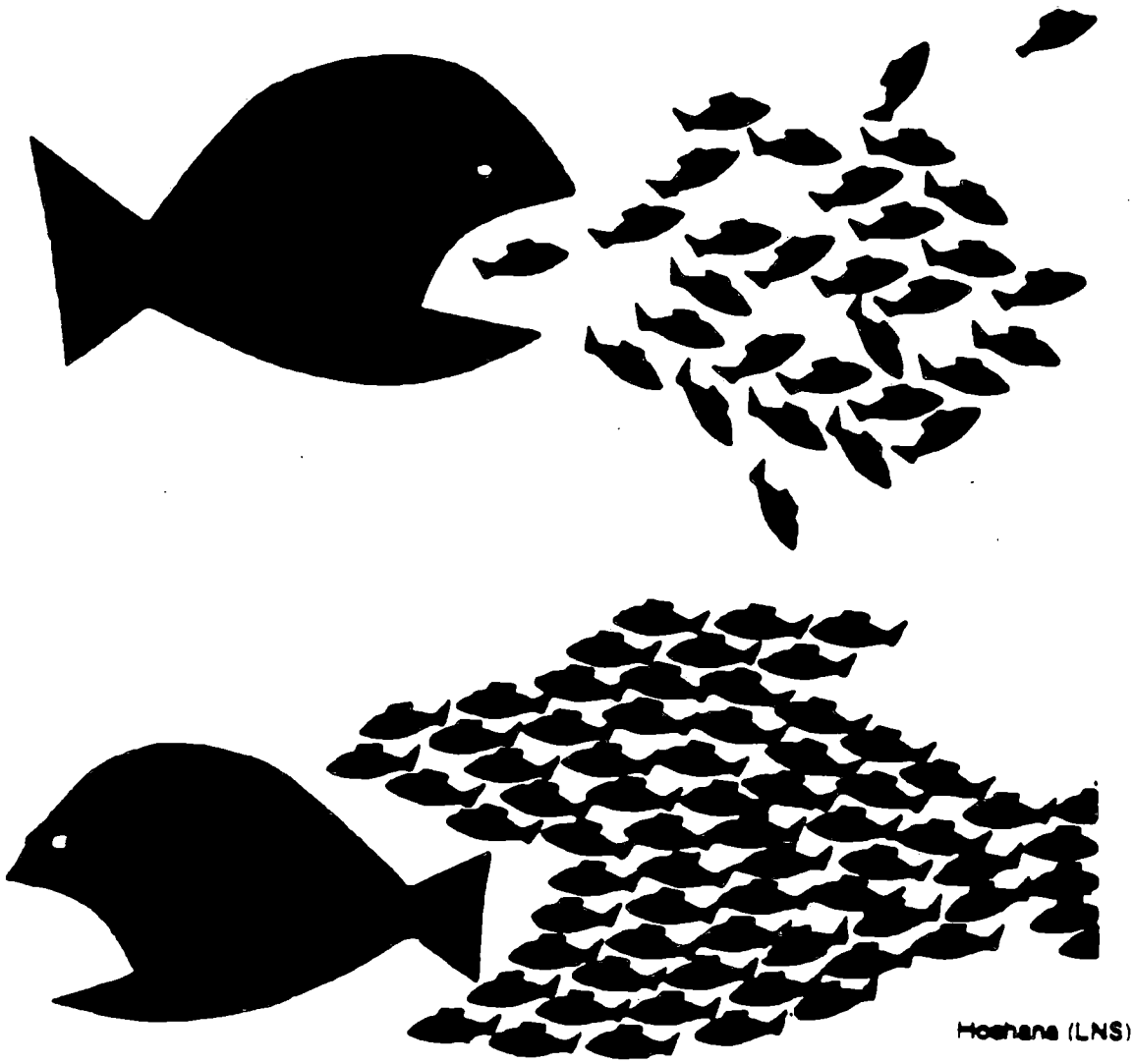
Sincerely,

Bob Griss

Bob Griss

cc: Quentin Smith

OUR MISSION IS TO TRANSFORM SOCIETY THROUGH RECOGNITION OF OUR COMMON NEEDS



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Mission

An independent Center on Disability and Health is being created as a non-profit educational organization with 501-C-3 tax-exempt status to serve as a resource to the disability community by conducting research, providing technical assistance, developing educational materials, and promoting advocacy of health care reform from a disability perspective. The focus of CDH is to increase understanding of the changes needed in the financing and delivery of health care to better meet the needs of persons with disabilities and other chronic health conditions.

Objectives for CDH

(1) conduct policy analysis of critical issues based on the health related needs of persons with disabilities and chronic illness that would be disseminated widely through disability publications, health care journals, and the mass media and presented at conferences;

(2) provide technical assistance to disability groups and government agencies on the adequacy of health care programs and policies for persons with disabilities;

(3) conduct health care research through grants and contracts strategic to health care reform at the federal and state levels;

(4) provide leadership to the Health Task Force of the Consortium for Citizens with Disabilities, and build alliances between national disability and chronic illness groups as the litmus test for health care reform;

(5) promote grass-roots mobilization of the disability community and its linkages to other health care advocates at the national, state, and community levels; develop Action Alerts, information memos, training sessions, and teleconferencing;

(6) develop public awareness of a disability perspective on health care reform as an embodiment of the health care needs of the whole population;

(7) educate Congress and Federal agencies on various aspects of health care reform;

Staffing

The Center staff consists of Bob Griss who serves as Director and Senior Health Policy Researcher and Courtney Morrow who serves as policy associate and administrative assistant. Other staff may be hired as funding and additional projects permit.

Board of Directors: Bob Griss (CDH); Allan Bergman (United Cerebral Palsy Associations); Justin Dart (Real Health Care For All); Peter Thomas (Amputee Coalition of America) ; Irv Zola (Society for Disability Studies); Robert Joondeph (Oregon Advocacy Center); Bob Kafka (ADAPT); and Susan Dooha (National Transplant Support Network).

Funding for CDH

Funding for the Center will be sought from private foundations, government agencies, and disability and health organizations for policy analysis, research, and advocacy, in addition to honoraria for presentations and organizational contributions. Organizational sponsors are encouraged to make a financial contribution to the Center.

EXAMPLES OF BOB GRISS' EFFORTS TO PROMOTE OBJECTIVES OF CDH

Policy analysis

- "Evaluation of the Clinton Health Plan based on CCD Health Task Force Principles" (October 26, 1993)
- "ADA Loopholes Closed by EEOC on Employer Provided Health Insurance" (WW, June/July 1993)
- "Oregon's Medicaid Rationing Plan Wins Conditional Approval",(WW, Mar./Apr./May 1993)
- "Oregon Cleanses Prioritization List to Seek Administration Approval of Medicaid Rationing Plan" (WW, Oct./Nov. 1992)
- "HHS Rejects Oregon Medicaid Rationing Plan: Violates ADA" (WW, Aug./Sept. 1992)
- "President Bush's Tax Credit Approach to Health Care Reform" (WW, Jan./Feb. 1992)
- "The Dangers of Small Group Insurance Reform" (WW, Nov./Dec. 1991)
- "Health Insurance at Risk" (WW, May/Jun/ 1991)

Technical assistance on quality assurance, benefit package, and anti-discrimination for

- State Developmental Disabilities Councils
- National and state level disability coalitions
- Individuals with health insurance problems
- Health policy researchers
- News media

Health care policy research

- Research on the advantages of expanding prevention, rehabilitation, and chronic care management on persons with spinal cord injury, diabetes, and cerebral palsy for the Robert Wood Johnson Foundation (in process)
- Accessibility, Adequacy and Affordability of Health Insurance for Persons with Disabilities or Chronic Illness: Draft Report to Congress with Stuart Hanson, Berkeley Planning Ass., 1990;
- Financing assistive technology by private insurance and Medicare as part of a contract with the National Council on Disability, November 1990-1992;
- Evaluation of Massachusetts' Medicaid Buy-in Plan for Maine
- Report on Health Care Coverage for Working-Age Persons with Physical Disabilities: A Key to Reducing Disincentives to Work, Wisconsin Department of Health & Social Services, 1985;

UCPA and CCD Health Task Force leadership

- Organized opposition to Oregon Medicaid rationing plan based on ADA
- Helped shape CCD Health Task Force Principles for Health Care Reform from a Disability Perspective
- Provided staff leadership to UCPA in developing health care policy initiatives

Grass roots mobilization

- "The Role of the Disability Movement in Health Care Reform" (WW, Jul./Aug./Sep. 1991)
- "UCPA Action Alert to Reverse the Acute Care Bias in the Clinton Health Plan and Ensure Adequate Rehabilitation, Durable Medical Equipment and EPSDT Coverage" (Oct. 1993)
- "The Challenge of Health Care Reform at Disability Independence Day Rally in New York City, July 1993"
- Town Meetings on Health Care Reform: You Can Make A Difference, Jan. 1992

Disability perspective on health care reform

- Presentations to over 100 national and state conferences
- "The Disability Community as Litmus Test: Toward a Unified Strategy for Surmounting the Dilemmas in Health Care Reform", Health/PAC Bulletin, Fall 1993
- "Strategies for Adapting the Private and Public Health Insurance Systems to the Health Related Needs of Persons with Disabilities or Chronic Illness", World Institute on Disability, 1988-1989

Educate Congress and Federal agencies

- Congressional testimony on "Consideration of Benefits for Inclusion in a Standard Benefit Package" (Mar. 1993)
- Congressional testimony on Medical Underwriting (Sep. 1990)
- Technical assistance to Subcommittee on Disability Policy and other Congressional and Federal offices

** WW refers to UCPA's policy bulletin Word from Washington.*

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Biographical Profile

Bob Griss is Director of the Center on Disability and Health in Washington, D.C. which he has recently formed as a resource to the disability community for conducting research, providing technical assistance, developing educational materials, and promoting advocacy of health care reform from a disability perspective. For the past three years, Bob was the Senior Health Policy Researcher for the United Cerebral Palsy Associations and a Co-chair of the Health Task Force of the Consortium for Citizens with Disabilities.

Mr. Griss authored two policy bulletins on Access to Health Care through the World Institute on Disability; drafted a Report to Congress on health insurance for persons with disabilities and chronic illness; served as a consultant to state and federal agencies on Medicaid buy-in programs, problems with high risk pools, and health care reform; and is currently working on a Robert Wood Johnson contract to estimate the savings that would occur if persons with disabilities and chronic illness had better access to preventive services, rehabilitation therapies, and chronic care management services.

Among Mr. Griss's many priorities is using the Americans with Disabilities Act as a "bridge" to creating a right to health care for all Americans. He has been a major critic of the Oregon Medicaid rationing plan on both ADA and public policy grounds, and a tireless opponent of discrimination in access to health care through private or public health insurance. Mr. Griss is considered one of the leading policy analysts in the U.S. on health insurance issues for persons with disabilities and chronic illness.

A Litmus Test for Health Care Reform

A Unique Role for the Disability Community

By Bob Griss, Director
Center on Disability and Health, Washington, D.C.

Bob Griss is founder and director of the newly established Center on Disability and Health in Washington, D.C. The following article elaborates on a speech Mr. Griss gave at the annual conference of the National Associationof Developmental Disability Councils held in Washington, D.C., in October 1993. At that time, Mr. Griss was senior health policy researcher for United Cerebral Palsy Associations, Inc., and co-chair of the Health Task Force of the Consortium for Citizens with Disabilities.

People with disabilities are experts on the barriers to access, adequacy and affordability in the acute-care-oriented U.S. health care system. Although portrayed as a minority of 43 million persons, people with disabilities embody the health care needs of the whole population. This includes persons who are "temporarily able-bodied" — our fellow citizens who do not know now what health care services they will need when they or their loved ones develop a chronic condition. There are actually more than 81 million persons under age 65 with chronic health conditions that private insurance companies typically would medically underwrite against, if they apply for health insurance individually or in small groups. In fact, we all have between six and eight genes that predispose us to chronic health conditions including such common diseases as cancer, hypertension and diabetes, even if we show no symptoms today.

Nevertheless, many people with disabilities are denied health care coverage because of preexisting conditions or are subject to preexisting-condition exclusions that deny coverage for the health-related services they are most likely to need. In addition, the disability community generally faces restrictive definitions of "medical necessity" and arbitrary limits on covered services. And often, we are required to pay higher premiums, deductibles and copayments.

Besides acute care, people with disabilities often have a range of special health care needs. To live and work independently, for example, many people with disabilities need durable medical equipment and other forms of assistive technology. We may also find ourselves in need of rehabilitation therapies, personal assistance services, prescription drugs, mental health services, care coordination and other services. The health care system should promote the wellness of persons with disabilities and prevent secondary complications resulting from a disability —just as it should provide prenatal care for pregnant women, immunizations for young children and cancer screening for older adults.

How We Can Contribute

The disability movement can contribute to the debate over health care reform in many ways:

By broadening the concept of health: People with disabilities know better than anyone else that the concept of health must be expanded from the "absence of disease or impairment" to include services that promote function, contribute to chronic-care management and improve quality of life.

By exposing the financial vulnerability of people with disabilities or chronic illness and their families: People with disabilities can reveal in unmistakable terms the financial burdens associated with chronic health conditions and show that these costs must be distributed equitably if everyone is to have an equal opportunity to participate meaningfully in society.

By battling discrimination: Based on the protected status of disability under federal civil rights laws such as the Americans with Disabilities Act (ADA), people with disabilities can challenge discrimination on the basis of disability and build a bridge to the right to health care for all persons.

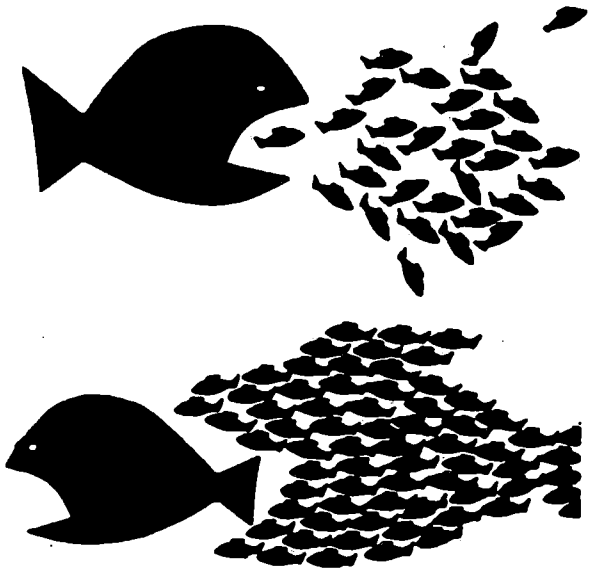
By "de-medicalizing" the health care system: Driven by the goals of consumer empowerment and independent living, the disability community can help articulate the need to restructure the health care system in a way that enhances the role of consumers in managing their own health care needs and by shaping the direction of health care policy and financing.

By creating a sense of urgency: Recognizing that without access to health care the ADA will become an empty promise for many, people with disabilities bring a sense of urgency to creating a right to health care for all.

Challenge of Health Care Reform

As a litmus test for health care reform, the disability

community can play a strategic role in helping others recognize their common vulnerability in a health care system that treats health care as a commodity rather than as a right.



The Clinton plan has important strengths. First and foremost: Everyone would be entitled to a federally guaranteed benefits package, regardless of income, employment status, health status, age, or family composition — all factors that currently influence a person's ability to access health care. The benefits package would include: acute care without limits, some preventive services, prescription drugs, some mental health and substance abuse services and post-acute outpatient rehabilitation services and durable medical equipment.

In addition, there would be a separate long-term care program expanding home- and community-based services, including personal assistance services. The Clinton plan would also eliminate preexisting-condition exclusions, waiting periods, and pricing practices that charge higher premiums for people who use more health care. Low-income persons would receive premium subsidies; there would be no lifetime caps, which exist now in many private insurance plans; and there would be a stop loss [upper limit set on out-of-poctket expenses, after which the insurance company pays 100 percent of covered benefits] on cost-sharing for deductibles and copayments. Cost-containment would be promoted by: cost limits on premiums; banning of self-referral by physicians to laboratories they own for services that may or may not be necessary; creation of a regional fee-for-service price schedule; prohibition against balance billing, and would allow states to develop a single payer state option. These are just a few of the positive things about this plan.

Concerns About Managed Competition

At the same time the President's plan raises some troubling concerns, including:

(1) Managed competition creates intensified pressure for cost containment among for-profit insurers that may lead to reduced quality of services for people with extensive health care needs: the accountable health plans are really accountable to the shareholders who benefit from the profits they make. Under the pressures of cost containment, insurance plans may not cut the right costs — administrative waste, unnecessary procedures, or red tape. Instead, they may choose to cut necessary health care or to interfere with the clinical judgments of the health professionals.

(2) Choice of provider is a second major issue. It is very important for all people — with and without disabilities — to be able to choose their own providers. Although you can choose your plan with the managed competition approach, your choice of plan may determine the degree of choice you have over your providers. Those who want a fee-for-service plan will have to pay a higher premium as well as a higher deductible and copayment. A cap on the fee-for-service premium would help ensure that low- and moderate-income people have the same freedom to choose providers as others would have.

(3) A third weakness in the Clinton proposal is its acute-care bias. If for-profit insurers get to decide what services are "medically necessary," there is a danger that assistive technology such as augmentative communication devices and environmental control switches may be excluded. Also, outpatient rehabilitation is an important health-related service but, as currently proposed, it would only be provided in cases of illness or injury. In deciding whether or not to continue therapy after 60 days, the Clinton plan stipulates that the insurance plan evaluate whether sufficient progress is being made. Currently, this plan does not recognize that preventing deterioration of function is itself an important outcome of outpatient rehab. We need to build that recognition into the basic benefits package. The proposal for long-term care reform continues to have an institutional bias: it caps the new home- and community-based services for persons with severe disabilities but places no caps on ICF/MRs or nursing homes.

(4) Fourth, competition among health plans through the regional alliances is the method proposed for controlling costs. However, when three, four, or five large insurance companies compete in a geographical area, some call it competition — others call it oligopoly. Some people think competition

would result in cost savings; others think the result may be price fixing. But if we do not achieve cost savings, how are we going to preserve and extend the comprehensive benefits package that we depend on for our life and health?

The Advocacy Dilemma

Criticizing the Clinton plan without undermining the momentum for comprehensive health care reform is not an easy challenge. Supporting the plan without raising our concerns increases the likelihood that these threats to people with disabilities will be incorporated into future health care reforms at the federal or state levels. But opposing the Clinton plan, without recognizing the greater dangers of many alternative plans, would merely add to the opposition from those who want to preserve the status quo.

Many of the changes needed in the Clinton plan can be made within the structure of managed competition: the comprehensiveness of the benefits package can be expanded; the financial burden of cost sharing can be removed or modified; empowerment of consumers in the governance of regional alliances can be increased as it is proposed for the long-term care program.[1] Some changes, however, may not be possible within the structure of managed competition and may require a publicly accountable single-payer system. This option, as well as others, needs to be discussed not only in Washington, DC, but in your state governments and local communities so that we can begin to treat health care as a public utility rather than as a profit-driven industry. But grassroots mobilization is absolutely necessary for any *meaningful* health care reform to succeed.

Strategies for Grassroots Mobilization

To illustrate the very real vulnerability of people with disabilities, we must share our experiences with our neighbors, friends and elected representatives at the federal, state and local levels of government.

- Personal stories must underscore the potential vulnerability of everyone and show the preventable costs to the individual, the family, the community, and society if needed health-related services are not covered. We need to visit, write to, and telephone our elected representatives and tell our stories loud and clear at public forums, town meetings, and through the media, including television and radio talk shows and press conferences.
- We need to hold demonstrations and demand our rights as citizens. Health is a civil rights issue, and the disability community can make access to health care the civil rights issue of the 1990s.
- We need to promote alliances with other constituencies, including women's groups, children's advocates, minority groups, unions, employer groups, religious and civic groups, and health professional groups because we are not the only ones who depend on health care.
- Finally, we need to share our experiences with our counterparts in other countries so that we can raise people's expectations about what is possible and learn how to avoid replicating here problems that occur elsewhere. After all, a right to health care was created in Sweden in 1865, in Germany in 1883, in England in 1911, and in Canada in 1971.

Although special interests, which depend on health care as a source of profits, may be better organized and financed than the people who depend on health care as a right, this is a struggle that as a democratic society we cannot afford to lose.



Don't Ever Give Up!

[1]The long-term care component of the Health Security Act (Title II, Subtitle B) calls for consumer participation in the governance of the program in the following ways: A **Federal Advisory Group**, composed of a majority of members with disabilities and their representatives, is to advise the HHS Secretary and the states on all aspects of the program. **State Advisory Groups**, composed of a majority of people with disabilities and their representatives, are given the following charges: advise states on guiding principles, policy directions, and specific components of the state plans *before* they are developed; work with states in developing, reviewing and commenting on the plans; participate in the public hearings; document differences between the groups' recommendations and the plans; document the degree to which the plans are consumer directed; and meet regularly with state officials to provide advice on all aspects of implemenation and evaluation of the plans (Pages 411-412).

This kind of consumer empowerment needs to be built into the regional alliances and health plans in the acute care component of the Health Security Act.

Different Communities, Different Needs

Universal access. It's more than just another selling point for comprehensive reform of the nation's health care system. The requirement that all Americans have access to a basic package of quality health care services is now widely accepted as a guiding principle for reform.

It is not only for altruistic reasons that universal access has been so enthusiastically embraced by the nation's health care reformers. As the League of Women Voters has long recognized, any reform plan that fails to provide access for all Americans to affordable, quality care will only perpetuate what's wrong with the system as it now stands—too much emphasis on expensive emergency and acute care instead of prevention, those with insurance coverage paying for those without it, high rates of infant mortality, etc.

With the aim of investigating precisely what it will require for health care reform to deliver on the promise of universal access, *The National Voter* invited several guest writers to comment on the health needs and concerns of specific communities of Americans. In the articles that follow, individuals representing persons with disabilities, Asians and Pacific Islanders, Hispanics, Native Americans and African Americans spell out how the nation's health care system could better serve their communities, plus what they are looking for in reform.

While the articles go a long way to illustrating the multitude and breadth of demands on the nation's health system, they also uncover widespread agreement on the issue of access. The nation's health care system will only be truly reformed, our contributors assert, when it serves all Americans equally and without prejudice.



Americans with Disabilities:

A LITMUS TEST FOR WHETHER REFORM SERVES ALL

by Bob Griss



People with disabilities are experts on the barriers to access, adequacy and affordability in the acute-care-oriented U.S. health care system.

Although portrayed as a minority of 43 million persons, people with disabilities embody the health care needs of the whole population. This includes persons who are "temporarily able-bodied," meaning they do not know now what health care services they will need when they develop a chronic condition. There are actually more than 81 million persons under age 65 with chronic health conditions that private insurance companies typically underwrite against, thereby denying or limiting coverage. Moreover, we all have between six and eight genes that predispose us to chronic health conditions even if we show no symptoms today.

Nevertheless, many people with disabilities are denied health care coverage because of pre-existing conditions or are subject to pre-existing-condition exclusions that deny coverage for the health-related services they are most likely to need. In addition, the disability community faces restrictive definitions of "medical necessity" and arbitrary limits on covered services. And often, we are required to pay higher premiums, deductibles and copayments.

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THE JOHN STANLEY COULTER LECTURE

Health Care Reform and Disability: Affirming Our Commitment to Community

Gerben DeJong, PhD

As we embark on the task of health care reform, it is important to reflect on the values we bring to the process and on the larger political and social context in which medical rehabilitation finds itself today. Health care reform is not just about the adequacy of health insurance coverage, the quality of medical care, or about runaway costs. It is also a test of our ability and willingness to come to terms with some of the unresolved structural deficits that challenge our economic and political life as a nation.

In this lecture, I want to reflect on medical rehabilitation's role in the health care reform debate vis-à-vis its relationship with the disability community it seeks to serve. Health care reform is mainly a pretext for my remarks since what I say here also applies to medical rehabilitation's participation in the health policy-making process generally and in the overall civic life of our nation.

Before reflecting on medical rehabilitation's particular role in health care reform, I want to take note of our nation's seeming inability to achieve consensus on some of the most important issues of our time and to identify some of the reasons for policy gridlock. In helping to chart a way for medical rehabilitation, I will introduce a framework that may help us achieve consensus and also help resolve some of the underlying antagonisms between medical rehabilitation providers and consumers. Finally, I want to introduce the concept of "social capital" and identify some of the concrete steps that medical rehabilitation can take as the nation moves forward in the health care reform debate.

INABILITY TO ACHIEVE CONSENSUS

Over the last 25 years or so, I have been struck by our nation's inability to achieve consensus on major health and social policy issues. As a civic-minded student of public policy, I find this state of affairs most discouraging especially given our enormous individual and institutional capacities for creativity, ingenuity, and problem-solving.

In looking back over these years, I find that public policy issues fall into one of six categories, four of which are high-risk or grave-yard categories as outlined in table 1. These days only Category 6 issues appear to muster the consensus needed for legislative enactment. The crude typology of public policy issues outlined in table 1 may not be exhaustive but I do hope it illustrates the enormous difficulty our nation has in moving forward on key policy issues.

This six-part typology does not bode well for the future of health care reform since health care reform falls into at least three of the four high-risk categories. It could also become a Category 1 issue if coverage of abortion becomes a focal issue in the debate. Health care reform's success will depend, in part, on the extent to which it can also be made a Category 6 issue without evoking too much opposition from special interests such as the small business community. The "play-or-pay" approach to health care reform touted in the 102nd Congress (1991-92) was clearly an attempt to make health care reform a Category 6 issue.

The future of health care reform will also depend on our ability to sort out our conflicting values about the role of the competitive market versus the role of government supervision and regulation. However, my thesis is that our inability to achieve consensus stems less from our conflicting views about the role of the public versus the private sector but from a major deficit in American civic culture which Etzioni[1] defines as the gap between (1) our strong sense of entitlement to the community's protection of rights and the provision of services and (2) our weak sense of obligation to the local and national community of which we are a part. I believe that this deficit underlies all the categories enumerated in table 1 except perhaps for the first.

OUR CIVIC (AND FISCAL) DEFICIT

Our civic deficit, as defined above, is the result of an enormous imbalance between our sense of rights and entitlements on the one hand, and our sense of responsibility and commitment on the other. We demand more from our communities and governments than we are willing to pay in taxes, premiums, or personal involvement. For instance, if accused, we expect to be tried by a jury of our peers but we often go to great lengths to avoid jury duty by claiming, rightfully at times, that we have compelling obligations at work or at home. There are some in our communities who claim that they have a right to ride a motorcycle without a helmet or to drive an automobile without seat belts but, if injured, assert that they have unassailable claims to the best medical and rehabilitative care possible.

This civic deficit is especially great in health care. We have enormous expectations of, and make endless demands of, the health care system but many of us are unwilling to make the adjustments in lifestyle that would lower these demands. We want more from biomedical research but are unwilling to support new obligations that result from our successes. For example, we invest heavily in neonatal technologies but do not provide adequately for the care of chil-

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Table 1: Six Public Policy Categories

No.	Category	Examples
1	We are able to achieve consensus on neither the nature of the problem nor the character of the solution because points of view are highly polarized	Abortion; gay and lesbian rights
2	We are able to achieve consensus that there is a problem but cannot agree on the solution	*Health care reform*
3	We know what has to be done but special interests get in the way	Gun control (NRA); *health care reform*
4	We know what has to be done but are unwilling to pay for it	Deficit reduction; *health care reform*
5	We know what has to be done and have no choice but to pay for it without courting complete and immediate disaster	The savings-and-loan bailout; war
6	We know what has to be done and it costs the public treasury little or nothing	ADA; Family and Medical Leave Act; federal mandates to states and employers

dren with disabilities beyond the acute stages of their medical care.

The notion that we could expect and demand more from our communities by offering little or nothing in return was strongly reinforced in the 1980s. We were led to believe, for example, that lowering taxes would stimulate economic activity and that tax revenue would increase accordingly. We believed that cutting taxes would increase tax revenue. In other words, it was possible to get more from the larger community by paying less for it. In short, I believe that the national fiscal deficit is not so much a product of an imbalance between spending and revenues as it is an imbalance between our sense of entitlement and our unwillingness to own up to our responsibilities to the larger community, ie, our civic deficit.

The larger this civic and fiscal deficit becomes, the more difficult it will be to achieve consensus on major health and social policy issues. In other words, Category 4 policy issues will become more prevalent and less amenable to resolution. To lower the deficit we have to reduce our sense of entitlement or increase our commitment to the common order or both. Fortunately, I sense a new national willingness to bring our demands and contributions into somewhat better balance but few of us are willing to give up some of our individual or group advantages for a common good from which new future benefits are often indirect and ill-defined. Few of us can be convinced that it is in our individual interests to experience short-term pain in hopes of some long-term ill-defined gain.

INTEREST GROUPS

Medical Rehabilitation as an Interest Group

What does the notion of a civic deficit have to do with medical rehabilitation and health care reform? To answer this question, I would like to begin by evaluating medical rehabilitation's role as an interest group in the health policy-making process.

Interest groups are one of the more important vehicles by which our individual or professional wants are expressed in the political process. In political terms, medical rehabilitation is an interest group that is represented by a myriad of professional and trade organizations, some of which are more active in the political process than others. These groups employ legal counsel and lobbyists who represent the interests of the field well.

Over the last decade or more, medical rehabilitation has prospered. It has grown significantly both in size and in professional stature. During this time, medical rehabilitation capacity in this nation has about doubled and is now an estimated $17 billion per year industry. Medical rehabilitation's academic capacities have helped to legitimize the field among its academic peers. More medical school graduates are selecting medical rehabilitation for their residencies than ever before. Recently, the field has gained an important foothold in the National Institutes of Health with the establishment of the National Medical Rehabilitation Research Center. Membership in the Association for Academic Physiatry (AAP) is growing rapidly. Concurrent with this new-found academic legitimacy has been the rapid growth of physician and allied health salaries in medical rehabilitation.

As the health care reform debate moves forward, medical rehabilitation is naturally anxious to retain its recently acquired advantages. The question I would like to pose is this: Does medical rehabilitation see itself as just another "special interest" competing to retain its share of health care resources or does it see itself as part of a larger community to which it has important contributions to make? My concern is that the more anxious the field becomes about its relative standing in the health care system, the more it will be prone to act merely as a special interest but will, in the long-term, do so at its own peril. Moreover, special interest behavior, while a needed corrective in many instances, is also prone to contribute to the gridlock that has come to characterize health and social policy in our nation.

Consumer Interest Groups

Much of the initiative in health care reform is designed to strengthen the consumer or demand side of the market which has been weak relative to the provider or supply side of the market. Consumers of health services are often less well-organized and less well-financed than their provider counterparts. Health care providers of all types are, in some circles, viewed increasingly with suspicion especially as they mount their well-heeled marketing and public relations campaigns. Their less-than-well-documented claims to cost-effectiveness are often viewed as simply self-serving. This may help to account for the arms-length relationship that the Clinton Administration's Health Care Reform Task Force attempted to maintain with organized provider and payer groups.

Consumer groups are no less prone to becoming just another set of special interest groups. The political theory of democratic pluralism asserts that eventually strong interest on one side of an issue eventually begets strong countervailing forces from the other side of an issue and thus brings the public policy process into an equilibrium which defines the "public interest." The political theory of democratic

pluralism is the analog to the economic theory competitive market where equilibrium is established when supply and demand are brought into balance.

Competition and conflict are important to the political process. Through conflict, we are forced to examine our basic assumptions, the accuracy of our data, and the merits of our case. However, I have always believed that the public interest can be something greater than the mere balance of countervailing forces in the political process. There is something inherently suboptimal when we have to settle for an outcome that merely seeks to split the differences between opposing parties, delays a future confrontation, and leaves many of the underlying antagonisms in place.

One of my concerns is that the underlying antagonisms between health care providers and persons in the disability rights movement are not abating but may be intensifying. These antagonisms have their roots in the conflict between (1) the assumptions of the medical model and sick role and (2) the values of the independent living (IL) and disability right (DR) movements.[2] During the 1980s the IL paradigm of research and service delivery challenged the thinking of health and human service providers bound to a more traditional rehabilitation paradigm in which disablement was thought to be mainly a function of the disabled individual's limitations. As a result, there has been a marked change in medical rehabilitation which has gradually assimilated many of the values of the IL movement. Medical rehabilitation, unfortunately, often fails to receive the credit it deserves for many of the changes it has made in making its programs more responsive to the values of the IL and DR movements. Some medical rehabilitation facilities, for example, have forged important relationships with local IL centers and have helped to underwrite some of the costs associated with the initial development of local IL centers and programs. At the same time, unfortunately, some medical rehabilitation facilities still lapse into communicating messages and images that are out of sync with how people with disabilities wish to be viewed today.

Regardless of the extent to which medical rehabilitation has adopted or supported IL/DR goals, there remains, in the disability community, a strong suspicion of medical rehabilitation providers and health care providers generally. Nationally, this probably comes to its clearest expression in ADAPT's crusade against nursing homes and their quest to reallocate funding from nursing homes to consumer-directed attendant service programs. ADAPT supporters refer to nursing homes as prisons that limit the autonomy of people with disabilities. By characterizing the nursing home industry as a villain of sorts, ADAPT has helped bring a level of drama and theatre to the unresolved national debate about personal assistance services. ADAPT's characterization of the nursing home industry flourishes, in part, because of a strong undercurrent of opinion—often well-justified—in the disability network that health care providers generally are not responsive to needs of people with disabilities.

HEALTH CARE REFORM AND MANAGED COMPETITION

It is this underlying current of opinion that those in the vanguard of the DR/IL movement take into the health care reform debate and where it poses a major challenge for health care providers in general and medical rehabilitation providers in particular.

For many years, the DR/IL network distanced itself from health policy issues because it wanted to keep an arms-length relationship with any program or policy remotely connected with the medical model. The current health care reform debate has changed that. People with disabilities have awakened to the fact that, as disproportionate users of health care services, they have a disproportionate stake in the outcome of the debate.[3-7]

If managed competition becomes the framework for health care reform, consumers with disabilities are also likely to have a more significant role in our future health care system because of the enhanced role consumers will have in the purchase of health plans and in the governance of new health-related institutions. Managed competition is predicated in large part on the observation that in today's health care market, consumers are not on an equal footing with the providers of health care services. Managed competition seeks to redress this imbalance by establishing new ground rules for competition through the use of community ratings instead of experience ratings and through the use of a uniform basic package of health care services that will enable consumers to compare prices on the basis of a homogenous bundle of services. Managed competition also introduces a new set of consumer-dominated policy-making institutions such as the proposed National Health Board and regionally-based Health Insurance Purchasing Cooperatives (HIPCs) or health alliances as they are sometimes known. According to Enthoven,[9] one of the architects of the managed competition approach, HIPCs are designed to "empower the demand side" in health care.

Managed competition also reflects a distrust of the political process to achieve consensus on some of the most vexing issues in health care. It shifts the debate from the political arena where providers and payers are better organized to a newly organized market place where consumers will have a more equal voice in the organization and selection of health care services.

These changes, if they materialize, will also mean that medical rehabilitation's principal constituencies will no longer be mainly its payers, physicians, and various professional trade groups, but will in the future include yet-to-be disabled people purchasing health plans and persons with disabilities who will be represented on various policy-making boards in the new health system.

If consumers are to become a more prominent force in health care, it behooves medical rehabilitation to determine how rehabilitation is viewed by leaders in the consumer community and whether consumers with disabilities are prepared to advocate for an adequate rehabilitation capacity in this country. On this score, I have somewhat disappointing news for medical rehabilitation providers. In my contacts with those in the disability rights community most concerned about, or involved in, health care reform, I have not detected a keen interest in medical rehabilitation services. I believe this poses a major challenge for medical rehabilitation in the present health care reform debate and in future health policy development.

TOWARD A NEW FRAMEWORK

To overcome some of the overt or latent polarization between consumers and medical rehabilitation providers, we need a new frame of reference in which we can resolve differences, achieve consensus, and avert the gridlock that has characterized so much of public policy in recent years. I believe that such a framework can also lead to policy outcomes that are superior to the mere balancing of competing interests and demands.

The frame of reference that dominates our thinking in rehabilitation practice, disability policy, and even in the disability rights movement, is what I will call the *individual-in-society* (I/S) view. This view stems from the classical liberal tradition of Thomas Hobbes, John Locke, and David Hume, which later came to expression in the utilitarianism of Jeremy Bentham, James Mill, and John Stuart Mill.[10] At the core of this tradition is the concept of the autonomous individual and utility maximizer who is best able to determine his or her own interests and who should be left free to pursue those interests through the competitive market and through a free and open political process.[11] This view of the individual has come to dominate our thinking in all spheres of American life—our politics, economics, religion, philosophy, bioethics, and even in the social sciences and biomedical research. As in the 17th and 18th centuries when it emerged, this intellectual tradition has served as an important corrective to all forms of oppression and social control whether in the form of autocratic monarchy or in the form of paternalistic medicine.

The classical liberal tradition and its derivative political theories, such as democratic pluralism, have a strong view of the individual but a weak notion of society. As a result, the public interest cannot be defined in normative terms but and is instead, as suggested earlier, simply the point where conflicting individual preferences and interest groups achieve a measure of mutual accommodation and equilibrium.

The I/S view is pervasive in the value systems we find in medical rehabilitation, independent living, and disability rights. Individual autonomy is highly valued. Independence, or independent living, is a cherished goal in medical rehabilitation and is also the prime label used in terms such as "independent living movement" and "independent living centers." In medical rehabilitation, considerable deference is given to patient-centered goals. In both medical rehabilitation and independent living circles, we talk about people's ability to have choices, to manage their own personal attendant, to participate as individuals in the competitive market, and to become economically *self*-sufficient. Our choice of words also conveys what some[11,12] refer to as *expressive individualism,* which is chiefly concerned with *self*-direction, *self*-actualization, and *self*-realization, terms common to various *self*-help movements including the IL movement.

The language of individualism comes naturally to Americans and to those associated with disability issues. It is what Bellah and associates,[12] in *Habits of the Heart,* refer to as our "first language." It is a language that ". . . speaks in terms of the self's interests rather than the needs of others or of the common good. It reflects a lack of understanding of the essentially social or communal nature of the self."[11] Bellah (1985)[12] calls for a "second language," the language of community that values shared responsibilities, mutual help, interdependence, reciprocity, social contract, and common aspirations or what I would like to call the *person-in-community* (P∩C) view (table 2). This view draws on the Judeo-Christian concept of a covenant community and the Greek and Roman notions of virtue and citizenship. This view does not seek to diminish the individual or his or her capacity for individual expression. Rather it seeks to strengthen the individual by transcending narrow self-interest and by linking the individual with the larger community. The P∩C view argues that the ability of individual to thrive depends on the health of the community of which the person is a part. In terms of the political process, it sees the public interest as something greater than the sum of all individual and group preferences at equilibrium.

The relationship between person and community is seen as interdependent and reciprocal (hence the ∩ sign) in contrast to the I/S view in which the relationship between individual and society is often considered antagonistic (hence the / sign). In the I/S view, individual rights must be protected against society's encroachments and society's interests must be protected against private greed, malfeasance, and the unrelenting demands of special interests.

In the P∩C view, a person not only has rights but also has responsibilities. In fact, people have a moral responsibility, if not a prior responsibility, to help themselves as well as their community to the extent they can.

The I/S and P∩C views are not always mutually exclusive and people often hold and cherish views from both. For example, some of us may at times value competition as a means of achieving greater economic efficiency but at other times see the need for reciprocity if we are to experience a modicum of harmony and cooperation in our respective communities. It is perhaps more accurate to say that in the P∩C view of the world, reciprocity does not preclude competition. The P∩C view merely asserts that competition without reciprocity, like rights without responsibilities, is an inadequate basis for achieving the good society.

The P∩C view transcends ideology and political labels. The I/S and P∩C views are not part of a left-right continuum on which social democrats own one end of the spectrum while political conservatives own the other. The P∩C

Table 2: I/S and P∩C Models Contrasted

Individual in Society (I/S)	Person in Community (P∩C)
Voter/spectator	Citizen/participant
Interest group member	Community member
Impartial, disinterested	Concerned, involved
Value neutral	Community norms
Independence	Interdependence
Rights/entitlements	Rights & responsibilities
Competition	Reciprocity
Special interest	Social contract/covenant
Individual gain	Social capital
Public interest = Σ Individual preferences	Public interest ≥ Σ Individual preferences
Gesellschaft	*Gemeinschaft*

view, especially, has been claimed by both liberals and conservatives who embrace family and community values.[10] Even Ronald Reagan spoke frequently about "family, work, and neighborhood" albeit more as "objects of conservative nostalgia."[15] The concept of community cannot be understood as part of a left-right debate about the merits of government versus the market as the main mechanisms of social organization.[15]

In fact, both government and markets "depend on the values that community institutions transmit."[15] Modern political and economic institutions, if they are to work effectively, need what James Fallows has called "Frank Capra values:" ". . . loyalty, responsibility, a willingness to contain private appetites and private interests in the name of the community, a desire to do right by others simply because that is the right thing to do."[15] In short, Dionne is calling for a public interest that is more than the sum of our private appetites.

I believe that the P∩C view offers a more workable framework in which some of our most vexing health and social policy issues can be resolved. This view can also become the framework that guides medical rehabilitation's involvement with the larger disability community, particularly people with disabilities and those in the vanguard of the IL/DR movement as the nation seeks to address issues of health care reform and health policy generally. To the extent that medical rehabilitation views organized consumer groups merely as competitors in the health care reform debate, the more likely will it be disadvantaged in the current debate. To the extent that consumers and medical rehabilitation providers see themselves as part of a larger interdependent community based on reciprocity and goodwill, the more likely will the outcome of the current debate reflect the needs of both consumers and providers as well as the interest of the larger community of which we are all a part.

In the years ahead, as consumers acquire a greater voice in health care policy development, medical rehabilitation will fare poorly in the policy making process if it merely sees consumer groups as incipient competitors in health policy development and merely seeks to maximize its own narrow interests. Consumers and providers in medical rehabilitation must forge a new relationship and a new compact for the era that lies ahead.

In doing so, it would be well to take stock of the P∩C values already present in both medical rehabilitation and in the IL/DR movement.

MEDICAL REHABILITATION'S LATENT P∩C VALUES

While the I/S view is clearly dominant, medical rehabilitation is not devoid of community values. Take, for example, the concept of the "comprehensive interdisciplinary rehabilitation team," one of medical rehabilitation's most cherished beliefs. In its ideal form, this concept denotes a sense of community and a sense of shared responsibility for the well-being of others—for the patient, for the family, and for fellow professional team members. This core value is under financial attack in medical rehabilitation mainly because it is expensive and may not survive the challenge of health care cost containment. The question for medical rehabilitation is whether it can retain the community values inherent in the team approach in the face of a more fiscally demanding health care economy.

More importantly, medical rehabilitation is not a reductionistic discipline that reduces the problem to a single pathology or organ system. It is a holistic discipline that looks at the whole person, ideally in the context from which the person came or to which the person will go.[16]

Moreover, the role of the physical and social environment has become an increasingly important component in the epidemiology of disability and medical rehabilitation's understanding of disability as reflected in various models of disablement that seek to characterize the progression from pathology → impairment → disability → social disadvantage.[17-21] Clearly, medical rehabilitation and disability researchers owe a great debt to the IL movement for highlighting this important component.[2,22]

However, the environmental component in our various models of disablement still does not adequately capture the importance of community. For medical rehabilitation, community is still that mythical destination at the end of the rehabilitation process, somewhere beyond the walls of the rehabilitation center. Nor is the concept of community an integral part of our different approaches to the study of medical rehabilitation outcomes.

Medical rehabilitation's rather weak notion of the post-rehabilitation community life is reflected in the goals established for medical rehabilitation "patients." Medical rehabilitation patients are expected to become as independent as possible in their activities of daily living and have a responsibility to help themselves as best they can. In the quest to minimize the person's dependence on others, medical rehabilitation fails, often inadvertently, to communicate that people with disabilities, like everyone else, also have a responsibility to contribute to the well-being of others. The ability to contribute is as important, if not more so, to life satisfaction and quality of life than is the ability not to have to depend on others for toileting or dressing. Thus, interdependence, not raw independence, should be the goal of rehabilitation.

THE IL/DR MOVEMENT'S LATENT P∩VALUES

Despite its name, the IL/DR movement also has a strong communal component. The movement has shunned the politics of victimology and continues to emphasize what people with disabilities can contribute to their communities and to society at large. Noticeably absent in the movement's political agenda to date is a quest for higher levels of public income assistance although the movement does rightfully, I believe, take umbrage with the underlying policy assumptions of various income assistance programs. Instead it has sought, not compensation, but reasonable accommodation.

The notion of self-help, usually associated with expressive individualism, has a strong communal component in the IL movement. Self-help is not merely an individual goal but also a group phenomenon. IL centers emphasize community change as well as individual need. IL movement participants generally exhibit a high level of mutual solidarity with respect to the need for community and societal change. Moreover, the IL movement, as it has come to ex-

pression in the larger DR movement, has emphasized cross-age, cross-disability inclusivity, as it did in the passage of the Americans With Disabilities Act.

INVESTING IN "SOCIAL CAPITAL"

In sum, medical rehabilitation and the IL/DR movement find themselves in a tension between the dominant I/S values of the larger society and the P∩C values that have emerged, in part, from within their own respective cultures. The extent to which medical rehabilitation and the IL/DR movement see themselves in I/S terms, the more likely are they to view themselves and each other as special interests, if not competing special interests, in the immediate health care reform debate and in the health policy development process more generally. Each will be prone to maximize their own respective interests as the logic of the I/S model would suggest. Conversely, the extent that medical rehabilitation and the IL/DR movement see themselves in P∩C terms, the more they are likely to view each other as collaborators with mutual interests in future health policy development. They are more likely to view each other's needs in the political process as interdependent.

In furthering this potential collaboration and mutual accommodation, I would urge that the medical rehabilitation community take the first step by asking: Whom does it see as its primary constituency? For years, medical rehabilitation has marketed its efforts to referring physicians and payers. More recently, because of the growing head injury part of the trade, it has also marketed its services to family members who are searching for an appropriate medical rehabilitation program. For the most part, people with disabilities, once having completed the rehabilitation process, have not been seen as an important medical rehabilitation constituency. (To those who would dispute this observation, I would simply ask: How many medical rehabilitation facilities have boards of directors with significant consumer participation?) I believe this view is outdated especially given the fact that, under health care reform, consumers will have, as mentioned earlier, a more important voice in how health services are delivered at the national, state, and regional levels.

What initiatives can medical rehabilitation take? I believe that medical rehabilitation needs to view itself and people with disabilities as part of a community in which it needs to invest at all levels beginning with the local community. Medical rehabilitation already has several exemplary models of community behavior. Consider the manner in which the Rehabilitation Institute of Chicago invested in its local community when it supported the development of Access Chicago, a nationally recognized IL center. The director of that center is the new chair of the National Council on Disability and brings with her an understanding of medical rehabilitation issues. Consider, for example, the working relationship between the University of Michigan's Department of PM&R and the Ann Arbor Center for Independent Living. Consider, for example, the investment that the Rehabilitation Institute of Michigan in Detroit is making in the development of a primary health care program to meet the ongoing health care needs of people with disabilities. Consider, for example, the Rehabilitation Consumers and Providers Coalition (RECAP) in New England which recently collaborated on the development of a position paper on assistive technology. Finally, consider the investment that The Institute for Rehabilitation and Research (TIRR) in Houston has made in the development of its Independent Living Research Utilization (ILRU) program. This program has also been a springboard for national consumer-based leadership on both IL/DR and medical rehabilitation research issues.

These are examples of what Putman[23] refers to as investments in *social capital,* a concept that is analogous to the economic concepts of physical capital and human capital, ie, the facilities, the equipment, and the training that enhance productivity. Social capital refers to those investments that foster trust, build networks, and "facilitate coordination and cooperation for mutual benefit."[23] Social capital encourages reciprocity. According to Putman,[23] "[a] society that relies on generalized reciprocity is more efficient than a distrustful society, for the same reason that money is more efficient than barter." Trust, that comes with reciprocity, is the currency of social and political life. "Investments in physical capital, financial capital, human capital, and social capital are complementary, not competing alternatives."

The concept of social capital provides an important alternative to the destructive competition that characterizes the participation of special interests in the policy making process that often results in either suboptimal policy outcomes at best or policy gridlock at worst. It also helps to remove the perception that, when certain groups advocate in the public arena, they are motivated solely by their own interest and not the interest of the larger community. In the words of Putman,[23] "[s]*ocial capital is not a substitute for effective public policy but rather a prerequisite for it . . .*" [italics his].

At the local level, there is much that medical rehabilitation facilities can do to invest in social capital and build trust with the consumer communities. These do not necessarily require enormous sums of monies. For example, medical rehabilitation facilities have significant resources in financial management, personnel management, and marketing skills that can help a new IL center get off the ground or help a growing center improve its capacities in these areas. A medical rehabilitation facility's legal counsel might file an amicus brief in the case of a group of disabled persons who have filed suit pursuant to the Americans with Disabilities Act. Equally important, medical rehabilitation facilities need to look to the expertise that the consumer community can give to improve a facility's own programs and services. For example, a local IL center might work with a medical rehabilitation facility in helping to organize personal assistance services as part of a person's discharge plan. Or, for example, a medical rehabilitation facility might look to having consumer experience and expertise represented on the hospital's ethics committee.

Finally, medical rehabilitation can do much more at the local level to invest in its own alumni who can offer a facility many dividends in goodwill, community contacts, and financial support. Many colleges and universities have alumni representation on their boards of trustees. Medical

rehabilitation centers could do the same or reach out to other consumers who can bring important perspectives. Historically, hospital boards have reached out to various community elites in order to secure its ties with community decision makers, local industry, local government, and the banking community. It is time to also view people with disabilities as an important elite in the matrix of community decision makers.

At the state and national level, medical rehabilitation might advocate on issues of mutual interest as it did to a limited degree in matters such as the passage of the Americans with Disabilities Act (ADA). If there is any one opportunity for social capital investment and trust-building in the immediate future, it is in the area of personal assistance services (PAS). Consumer-directed PAS is the number one post-ADA item on the IL/DR legislative agenda. (I am utterly appalled that after all these years we have not achieved consensus on this policy issue. I believe that the need for such services is finite and affordable and that service delivery issues are reasonably straight forward.) By all accounts, this should be a solvable public policy issue. Medical rehabilitation brings considerable creditability to consumer-directed PAS. It certainly has no vested professional interest in such services other than the fact they would help meet the discharge needs of its own patients. Vigorous medical rehabilitation support for this service alone would be one of the most important trust-building steps that could be undertaken.

TOWARD A NEW COMPACT

I am urging that medical rehabilitation work toward a new compact and a new alliance with people with disabilities to help forge a new sense of community at all levels in our society—local, regional, state, and national. The interests of consumers and providers are not always the same but to focus merely on one's own narrow base of interests is to miss out on opportunities for solutions that can better us all, including the larger community of which we are a part. For starters, in the current health care reform debate, I would urge that the medical rehabilitation community and its component professional and trade associations carefully examine the position that the Consortium of Citizens with Disabilities has staked out in the health care reform debate and be prepared to use the Consortium's framework[8] for its own advocacy in the current health care reform debate. ACRM's Legislation Committee, with the aid of its legal counsel, has already taken steps in this direction.

However, we must do more than simply demand that more resources flow from the public treasury to the various communities of interest of which we may be a part. We should also be prepared to explain how these services should be paid for; what steps we are prepared to take to make sure that public funds are used equitably and efficiently; what consumers and providers are prepared to give in return; and what risks we are willing to assume and share. For example, medical rehabilitation as an industry, in collaboration with its consumer constituency, should determine what is an appropriate medical rehabilitation capacity for the nation. In other words, it should start by determining what kind of capacity would best serve the public interest and advocate accordingly. This would help to eliminate the destructive competition and excess capacity that exist in some markets today. Likewise, in determining an appropriate payment policy for medical rehabilitation, the field needs to move beyond who will win or loose under alternative payment scenarios by first asking what kind of payment policy would best serve the public interest and then try to accommodate the legitimate needs of existing providers.

Medical rehabilitation cannot single handedly break the political gridlock and policy stalemate in this country. But it can be a leader. Medical rehabilitation already has within it a value system and a professional orientation that is perhaps more P∩C-friendly than the practices found in most other medical disciplines. Moreover, the IL/DR movement also brings several important P∩C-friendly values to the political process. Although medical rehabilitation and the IL/DR movement are both part of an I/S-dominated political culture, both have much to contribute to the resolution of key issues in health care reform and in long-term services such as personal assistance.

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PENN TOWER HOTEL

On the University of Pennsylvania Campus

Experiences with medicine
Results of expertese by ~~osmosis~~.
Osmosis

P.W.D. in rehabilitation become experts

They first expect ~~position~~ pyshians and allied health personel to be the experts but soon discover they can not answer the hardest questions

As I think of things I will add
Draft - but would also like some feedback
as this should help me think of other things

What has been learned about the RWJ program as a whole as well as the individual RWJ project sites:

1) A significant number of the project sites have expressed to varying degrees that the one year planning grant was not that useful, and it might have been more useful to have had the first three to six months as the planning period and the remainder of time for project implementation--many have stated that the project as a whole should have been four or five years.

2) In several cases it appears that some sites did not get the information and/or technical assistance which was needed to undertake a totally new business venture--for example, Missoula followed advice given by program office advisory committee members who discouraged their initial proposal to establish a durable medical supply business and were advised instead to do only medical supplies however, at this point the information shows that they might have done better going for the durable medical supply business. They have also followed all the advice they received from a local consultant in establishing this venture but at this point are very much in a crisis mode and are just now accessing TA on small business ventures with a consultant referred by RWJ. It may also be that this particular site took on too many ventures without the support and advise they needed to succeed. Dealing with this site has also surfaced some information which it would have been good to know from the beginning--Missoula could not get a small business loan because Able Medical was wholly owned by Summit ILC and the SBA will not fund businesses who are owned by a non-profit however, if Able Medical was owned by individuals or a for-profit entity they would have not been allowed to spend RWJ monies on Able Medical.

3) In several cases it would have been useful for RWJF staff to refer this office as well as project sites to marketing and financial consultants very early in the program which could have possibly allowed the individual sites to access the information when they needed it most and provided the TA needed to develop more realistic business plans, marketing plans, etc. so that staff got a better sense of the probability of success in each of their ventures.

4) Several of the sites made some significant changes in their projects from their original proposal and for the most part these changes have been good ones.

5) The passage of the ADA and its implementation has had a fairly significant impact of the program as a whole as well as the individual project sites. This occurrence added a whole new dimension to the project sites as they began to see the opportunity to begin ADA related consulting services. In some cases the ADA related activities became the core of their project and for other Centers it assisted in the promotion of the delivery of independent living related fee-for-services by ILC's.

6) The program as a whole promoted an entrepreneurial component for the sites and for many it began the debate regarding charging a fee for independent living services while maintaining the advocacy and overall mission of the Center. Some of the sites have made a very successful transition to the "for-profit" mindset while other sites have had a difficult time with this

transition. As we know Alpha One was already in this mind set when the program began and to some degree they assisted some of the other sites struggling with this issue.

7) For a few of the project sites their board composition was radically changed over the grant period as many of the board members who had been involved in developing the Center's original proposal moved on and new board members were appointed. For some this has caused difficulty in fully implementing the proposed project as many of the new board members were reluctant to buy into the original plan and had their own views regarding the activities they believed the Center should be involved in and how RWJ monies should be spent. Helena has been most affected by this issue and they continue to have some difficulty. Some of the sites have expressed on feedback forms used in the marketing training that they need assistance in selling the "for-profit" mode to their board members.

8) Several of the project sites experienced key staff changes over the course of the project. For most this was a fairly smooth transition but for others it caused some delays. The two sites effected most by staff turnovers were Tulsa and Helena however, Amherst is now without its original project director (Robin Shaikun) and this has begun to cause some communication issues between the site and the NPO but hopefully this will be resolved. At this point Tulsa seems to have resolved the difficulties they dealt with related to staff turnover.

9) At this point it is difficult to determine what the overall impact each of the project sites will have on specific service delivery systems in their individual communities--this appears to be something which will be difficult to measure. Also it does not really appear that many of the sites will depend less on federal dollars, but rather because of their RWJ project they will be in a better position to apply for funding from other federal sources (i.e., Center for Public Health, HUD, other??). However, there are sites who because of this experience will have a much better chance accessing other foundation and private sector funding.

10) It is my impression that eventhough the individual project sites have said over and over that they wanted to have better and more frequent access to the other RWJ sites to get a better sense of what the other sites were doing as well as to share and exchange information the reality has been that the project site staff for the most part have taken little initiative in contacting staff from other sites but instead have relied on the NPO to provide them with updates on the other sites and to facilitate communication through conference calls and time set aside at the annual meeting.

11) The national health care reform issue provided both the NPO and the individual project sites with the opportunity to more clearly define the link between disability and health care. This opportunity has allowed ILRU to gather and distribute information related to health care reform and disability. Most importantly it has allowed ILRU to develop and present health care reform materials for the general population, state and federal policy makers, disability related organizations, health care providers, and consumers. In addition, through our efforts with the sites and NCIL we have assisted the IL field to educate policy makers at a national level regarding the issues pertaining to health care and disability.

12) The health care reform component of our current program may become the catalyst for continuing our current program or in developing a new program with RWJ as the Foundation sees the outcome of our efforts. I hear over and over that many doctors want the same things as consumers but there needs to be a more clearly identified link between the medical community and the disability community so that together we can present the key issues along with recommendations regarding their implementation.

especially providers

hospitals

physicians

to be left out of

health care reform

Time to write representatives on health-care reform



Molly Ivins

AUSTIN — OK, team, this is it — rally time. Now or never on health-care reform, and only about four weeks left for you to have any say in how it comes out. The bills are in committee, it's deal-cuttin' time.

Remember, you don't have to understand the details of any of the proposals — what your member of Congress needs to hear from you is just what your experience with the current health-care system has been: What happened when you lost your job or when your brother-in-law was in a car wreck, how about your neighbor whose wife got cured of cancer but now he can't leave for a better job because she has "a pre-existing condition"? Just tell them your stories.

"Rep. Joe Doaks, The Capitol, Washington, D.C." and a 29-cent stamp can save you a world of money, worry and pain. Because Texas has a higher rate of uninsured residents than any other state, we stand to benefit disproportionately from health-care reform. Let's hear from the Lone Star on this one.

As y'all already know, what Congress does most easily is nothing. Congress has a majority in favor of health-care reform but, as yet, no majority in favor of any single plan.

They can vote themselves into a pluperfect knot; each one of them can declare that he or she voted for some kind of health-care reform while their refusal to compromise dooms any chance of reform. That's why they need to hear from you: The only thing that will get them off the dime and their duffs is voter pressure. Believe me, it works.

The funny thing is that as they get down to comparing and contrasting this portion of one plan with the same portion of another, the better single-payer looks. That's the one with 92 co-sponsors in the House, and if they'd just pass it as the working model from which to compromise down, we'd be a lot better off. The key points in health-care reform are universal coverage, the freedom to choose your own doctor and effective cost control. Cost control is probably what they'll have the most trouble with because anything short of single-payer offers only iffy cost control.

As part of health-care reform, we should insist on ways to get more general practitioners and nurse practitioners and fewer specialists because the specialists are the ones who really drive up costs. Primary care — getting a child to a doctor before the kid gets so sick that he needs a zillion dollars' worth of treatment — has to be one of the goals here.

In terms of financing health-care reform, here's the real reason to regret that Rep. Dan Rostenkowski is allegedly a petty crook. Rostenkowski was the only guy around with clout who would talk about taxes to finance this thing.

Before you start moaning at the mention of the T-word, keep in mind that taxes to finance health-care reform would be in lieu of, not in addition to, what you are currently paying for health care. The best answer is a broad-based combination of sales and income taxes, but you know how politicians get the fantods when taxes are mentioned. The Republicans would immediately cast themselves in the role of your heroic defenders, up there to save you from those tax-loving Democrats (thus, of course, costing you a bundle in the long run, and even the short run).

But with Rostenkowski gone, the best bet is employer mandates, which actually aren't a very good idea in terms of the total economy. They're like a tax on employment, which we don't need with people out of work, and they hit small business harder. And, of course, they do nothing for the unemployed.

However, employer mandates are not the deal-killer that some of the obstructionists keep insisting they are. There are various ways to protect small businesses. For one thing, they could form their own giant health-insurance co-op, and for another thing, when Hawaii instituted employer mandates almost two decades ago, the roof did not fall in on small business in Hawaii. I suggest that you regard the screams of terror now emanating from small business with some skepticism.

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Why we'd better not blow it on health-care reform



Molly Ivins

WHILE THE political world braced for Oliver North (Hey, how many other Senate candidates can you name who have been declared persona non grata by a close ally like Costa Rica for having run drugs?), the real news was, as usual, buried.

A joint report by the U.S. departments of Labor and Commerce, a pair not often found in conjunction, confirms what less formal studies have been finding for some time: We are increasingly being divided into a nation of haves and have-nots.

The report details the development of an underclass of low-paid and unskilled workers. Labor Secretary Robert Reich said the growth of this underclass is taking place in the context of an increasingly adversarial climate between management and labor while America is slipping behind other industrialized nations in wages and benefits.

A society divided between the haves and have-nots or the well-educated and poorly educated cannot be a stable society over time. The report concludes that a healthy society cannot long continue along the path the United States is moving.

Among the troubling phenomena that the report documents are:

- Falling real earnings for less-educated and less-skilled workers.
- Stagnant earnings for more skilled employees.
- High levels of occupational injuries.
- Lack of health insurance and other fringe benefits for many workers.
- An increased proportion of young male workers in prison.
- High rates of joblessness for the unskilled.
- A large, growing population for whom illegal activity is more attractive than legitimate work.

OK, there are the real problems, and is our political debate relevant to them? Well, let's see — family values, prayer in the schools, Bill Clinton's sex life before he became president, banning cigarettes in public buildings, the failure of Madison Guaranty Savings and Loan, Hillary Clinton's 1978 cattle futures trades, etc., etc. And Tonya Harding and Nancy Kerrigan.

They say Nero fiddled while Rome burned, but we may be the first case of Romans fiddling while Rome burns.

All our endlessly backward thinking — all our wringing of hands about the decline of the family, the rise in illegitimate births, teen-age crime and gangs (all of which the right wing now says can be cured by abolishing welfare) — stems from the fact that more and more Americans have neither jobs nor hope nor opportunity.

Hard work will not get them ahead; it will leave them further behind. No wonder many of them are choosing crime; it's obviously more remunerative, and they're not stupid. The anger of those who are treated unfairly by society will ultimately destroy it.

This is what we need to talk about, concentrate on, find solutions for. Universal health care is a big piece of starting to resolve these problems, and it is apparently mired in the congressional thickets.

If it turns out that Congress actually fails to reform health care in a significant way because the insurance industry spent $10 million on the Harry-and-Louise campaign to scare people into thinking that health-care reform is a bad deal, I'm going to find it pretty hard to feel sorry for us. A people that dumb doesn't deserve much sympathy.

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PEOPLE WITH DISABILITIES SPEAK OUT ABOUT THEIR HEALTH CARE CONCERNS

The Independent Living Research Utilization (ILRU) Program at The Institute for Rehabilitation and Research (TIRR) in Houston has just completed a survey to gather data on the health care needs of people with disabilities. Specifically, ILRU was interested in the health care concerns of people who were being served by independent living centers around the country. Independent living centers are organizations that provide a range of services to people with disabilities that allow them to live in community settings rather than in long-term care institutions.

With support provided by The Robert Wood Johnson Foundation through its national program on Improving Service Systems for People with Disabilities, ILRU sent survey forms to all of the independent living centers in the country. Staff of each center were asked to provide copies of the 12-page 49-item survey to people they served, other staff members with disabilities, board members with disabilities, and other people with disabilities involved with the center. The costs for returning the completed forms to ILRU were assumed by people completing them.

It is a sign of the compelling nature of health care issues that nearly 750 people with disabilities took the time to complete the lengthy survey forms and pay the postage to return them to ILRU. The information provided by respondents to the survey suggests that the current health care system is particularly hard on people with disabilities and chronic health conditions. Some of the more important issues highlighted by survey respondents are summarized below.

How the current system affects people with disabilities

Over two thirds (67%) of respondents reported that they were not receiving the kinds of health care services that they needed to maintain optimal health. The range of reasons cited for this included limited insurance coverage, lack of access to health care providers, and exclusions based on pre-existing conditions. Other key findings related to health care coverage included:

- 26% had been denied insurance coverage;
- 16% had been dropped or canceled by an insurance company;
- 23% had been denied employment because of a health-related problem;
- 21% had chosen not to work so that they could remain eligible for public health insurance;
- 35% had been unable to change jobs because of concerns about being covered for pre-existing conditions, limitations in health care coverage imposed by a new employer, and/or lack of coverage by a new employer;
- 24% had been denied health care services because of lack of health insurance;
- 46% had been faced with not buying items that they wanted or needed in order to save money to pay for health care services;

- -21% had developed disability-related health problems because health care coverage was lacking or inadequate;
- 16% had experienced additional functional loss because of inadequate health care coverage for needed services; and
- 23% had experienced limitations in work or recreational activities as a result of lacking or inadequate health care.

Where the respondents obtained their health care services

- 57% from a private physician;
- 19% from hospital emergency rooms;
- 12% from a public health facility;
- 11% from a private clinic;
- 10% from a university hospital or clinic;
- 8% from a rehabilitation hospital;
- 6% from a home health care provider; and the remaining
- 2% from other sources, including nursing homes and school health programs.

Types of insurance coverage reported by the respondents

- 27% had Medicare;
- 26% had Medicaid;
- 25% had employer-provided insurance;
- 16% had personal health insurance;
- 7% had Social Security Disability Insurance;
- less than 3% had military or veterans health care benefits; and
- a number of other sources of health care coverage were cited, including federal employee disability health care, state high risk programs, and other special public and private programs.
- 7% had no health insurance coverage

Pre-existing conditions

Nearly one quarter of the respondents indicated that pre-existing conditions were excluded in their insurance coverage. Of the three quarters who did not indicate exclusions, waiting periods during which pre-existing conditions were not covered varied from three to twelve months. One person reported a waiting period of over two years before pre-existing conditions were covered; and one person reported a permanent exclusion of pre-existing conditions.

How satisfied were the respondents with the current health care system?

When asked if the health care system in this country had gotten better, worse, or stayed the same over the last five to ten years, 47 percent of the respondents indicated that the system had gotten worse.

When asked to identify the biggest problem with the current health care system, 73% of the respondents said that the high cost of treatment represents the biggest problem that they had encountered with the system. Other problems identified by respondents included:

- 48% cited inadequate insurance coverage;
- 45% cited lack of understanding of the health care needs and concerns of people with disabilities by physicians and other health care professionals;
- 38% cited inadequate preventive and health maintenance services;
- 34% cited inadequate coverage for assistive technology services;
- 32% cited problems with access to treatment and services;
- 30% cited unresponsive insurance companies and rude and discourteous providers and administrators; and
- 24% cited inadequate personal assistance services to maintain optimal health.

Over two thirds (67%) of the respondents indicated that they were not receiving the kinds of health care services needed to maintain optimal health. The types of services respondents said that they needed in order to maintain optimal health included:

- 79% needed services for disability related health problems and illness;
- 69% needed general health maintenance services;
- 65% needed general preventive/health promotion services;
- 61% needed services for routine health problems and illness;
- 60% needed dental health services;
- 54% needed disability-related health maintenance services;
- 32% needed personal assistance services;
- 29% needed acute care services;
- 24% needed disability-related acute care services;
- 22% needed psychiatric, psychological, or other mental health services;
- 16% needed durable medical equipment or assistive technology.

Conclusions

This survey process was not conducted with a scientifically selected sample, and as such, no inference about the representativeness of the outcomes of the survey with regard to the larger population of persons with disabilities, or even about the population of persons with disabilities served by independent living centers is intended. What the results of the survey do is provide further evidence that the present health care system is not meeting the needs of a large portion of the population.

For many people without disabilities, problems with the health care system may mean reduced options in choice of health care providers, longer waits to obtain services from a public health provider, or higher out-of-pocket costs to obtain health care services. For people with disabilities and chronic health conditions, these same problems with the system can force choices between working and not working, staying in a dead-end job or taking advantage of personal and professional advancement opportunities, and in some cases, additional loss of functional capabilities that are essential in maintaining a reasonable quality of life.

Additional research on the social and economic impact of inadequate health care services for people with different types of health-related problems is needed if health care reform is to address the needs of people who rely on accessible high quality health services to maintain narrow margins of health. The survey conducted by ILRU indicates that the impact of problems with the current health care system on people with disabilities is significant. A more rigorous examination of health care issues and their impact on people with disabilities is needed to guide efforts toward reform.

Copies of the complete survey report are available free of charge by writing to: ILRU, 2323 Shepherd Drive, Suite 1000, Houston Texas 77019

ILRU (Independent Living Research Utilization) was established in 1977 to serve as a national center for information, training, research, and technical assistance for independent living. It is a program of The Institute for Rehabilitation and Research (TIRR), a nationally recognized, free-standing comprehensive rehabilitation facility. TIRR is a part of TIRR Systems, which is a not-for-profit corporation dedicated to providing a continuum of services to individuals with disabilities.

Lex - FYI - I got these in a mailing from RWJ along w/a booklet "Readings for the 1993 advocacy Video Conference" from the Benton Foun. - Did you get these? do you want future copies?

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Following Page

HARVARD SCHOOL OF PUBLIC HEALTH

Department of Health Policy and Management
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PUBLIC OPINION UPDATE ON HEALTH CARE REFORM #5

Prepared for the Health Subcommittee
U.S. House Committee on Ways and Means

by the Harvard Program on Public Opinion and Health Care

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In this, the fifth in a series of updates on key trends in public opinion about health care reform, we look at the American public's current attitudes about President Clinton's health reform plan, benefits and taxes, and ways of extending health insurance coverage and controlling costs. We also examine public knowledge and attitudes concerning major reform proposals.

1. SUPPORT FOR PRESIDENT CLINTON'S PLAN TO REFORM HEALTH CARE

Since the first of the year, public support for President Clinton's plan has declined. Most polls now show more Americans disapproving than approving of the plan.

	1993				1994		
	9/26	10/30	11/4	11/21	1/17	2/28	3/30
Approve	59%	45%	52%	52%	56%	46%	44%
Disapprove	33	45	40	41	38	48	47
No opinion	8	10	8	7	6	6	9

(Gallup/CNN/USA Today)

	1993			1994			
	9/22	10/10	11/14	1/23	2/8	2/27	3/27
Approve	56%	51%	46%	48%	51%	44%	42%
Disapprove	24	39	43	39	41	48	48
No opinion	20	10	11	13	8	8	10

(ABC News/Washington Post)

	1993		1994			
	9/23	10/28	1/18	2/10	3/3	3/10
Favor	57%	43%	50%	43%	41%	43%
Oppose	31	42	33	42	45	43
Not sure	12	15	17	15	14	14

(Yankelovich Partners/Time/CNN)

	1993			1994
	9/22	10/26	12/14	3/8
Favor	51%	47%	47%	37%
Oppose	18	37	32	45
Need to know more (v)	17	12	15	12
Not sure	14	4	5	6

(NBC News/Wall Street Journal)

2. WHAT SHOULD CONGRESS DO WITH THE CLINTON PLAN?

Americans are now about evenly split over what Congress should do about the Clinton plan. About half would pass it with minor or no changes; the other half would either reject it or pass it only with major changes. If respondents are not given the option of passing the plan with minor changes, more than two-thirds say they want it rejected or passed only with major changes.

	1993			1994		
	9/22	10/10	11/14	1/23	2/27	3/27
Pass without changes	9%	5%	6%	6%	4%	5%
Pass with minor changes	48	47	42	41	41	44
Pass with major changes	23	26	29	26	32	28
Don't pass	10	18	17	19	19	20
Don't know	10	5	6	9	4	3

(ABC News/Washington Post)

	1993		1994		
	9/26*	11/4	1/30	2/28	3/30
Pass as is	23%	24%	24%	20%	19%
Pass with major changes	54	50	55	47	47
Reject plan	15	20	16	28	26
Don't know	8	6	5	5	8

(Gallup/CNN/USA Today; * = Gallup only)

3. WILLINGNESS TO PAY TO INCLUDE VARIOUS BENEFITS IN A NATIONAL HEALTH PLAN

When the public was asked which of 24 benefits they wanted included in a standard national plan, majorities wanted all but five benefits. But when asked if they wanted the benefits included even if they would have to pay additional taxes or premiums, Americans gave only two items majority support. If more money were needed to pay for the Clinton plan, Americans would rather scale back the plan than raise taxes or the deficit, or cut existing programs.

	% who think the benefit should be included even if additional taxes or premiums would be required
Well-child care and immunizations	54%
Hospitalization for illness, accident, child birth	53
Pre-natal care	48
Inpatient and outpatient surgery	46
Office/clinic visits to doctor for diagnosis/treatment	45
Routine tests (PAP smears, mammograms, colorectal)	43
Prescription drugs	42
Dental health care for children other than braces	42
Hospice care	42
Organ transplants	42
Long term care in nursing home	40
Long term care at home	38
Dental health care for adults other than braces	35
Complete physical exams every two years	34
Psychological/psychiatric counseling	34
Vision care including glasses and contacts	32
Family planning services other than abortion	32
Drug and alcohol counseling and treatment	26
Chiropractic services	21
Treatment with experimental drugs	16
Abortions	14
Infertility treatment	12
Elective cosmetic surgery	4

(University of Cincinnati, 1/28/94)

If more money is needed to pay for the Clinton health care plan...

	Favor	Oppose	Not sure
Cut back the plan to reduce its cost	53%	41%	6%
Raise additional money from taxes	34	65	1
Make cuts in Medicaid and Medicare	24	74	2
Increase the deficit	12	85	3

(Gallup/CNN/USA Today, 9/26/93)

4. PUBLIC SUPPORT FOR VARIOUS TAXES TO PAY FOR UNIVERSAL COVERAGE

In terms of raising the resources to pay for universal coverage, the most popular approach would be to increase the major "sin" taxes. Increasing the federal income tax and enacting a new national sales tax are the least popular.

	% who support each tax
Raising federal taxes on liquor[1]	79%
Raising federal taxes on beer and wine[1]	76
Raising federal taxes on tobacco products other than cigarettes[1]	75
Raising federal taxes on a pack of cigarettes 75¢[1]	73
An increase in the federal tax on alcohol[2]	71
An increase in the tax on cigarettes[2]	69
Taxing the purchase of guns and ammunition[1]	68
A new tax on guns and ammunition[2]	65
Requiring people who smoke or who drink heavily to pay more for their health insurance[1]	65
Raising the monthly fees paid by middle and upper income Medicare recipients[1]	57
Taxing the Medicare benefits of high-income elderly[3]	56
Requiring all employers to pay at least 80% of the cost of their employees' health insurance premiums including part-time employees[1]	55
Payroll tax similar to Social Security payroll tax[4]	53
Cutting government payments to doctors and hospitals that treat patients on Medicare and Medicaid[1]	42
Taxing employers for any health insurance benefits they provide that are better than a basic health insurance package approved by the federal government[1]	32
Adding new taxes on hospitals and clinics[1]	31
Taxing employees for any health insurance benefits they receive at work that are better than a basic health insurance package approved by the federal government[1]	31
Raising the monthly fees paid by all Medicare recipients[1]	26
A new national sales tax[2]	23
An increase in the federal income tax[2]	22

(1 = University of Cincinnati, 1/28/94; 2 = Time/CNN/Yankelovich Partners, 3/3/94; 3 = CBS News/New York Times, 9/19/93; 4 = Gallup/EBRI, 7/93)

5. PUBLIC OPINION ON EXTENDING INSURANCE COVERAGE

Two of the most popular goals for health care reform are eliminating pre-existing condition clauses and making sure that everyone is covered. When it comes to an employer mandate, requiring employers to provide insurance for full-time employees has the greatest support; a smaller majority favors requiring that employers pay for all employees.

	Favor	Oppose	Not sure
Requiring that insurance be available for those with pre-existing conditions[1]	88%	9%	3%
Making sure that all Americans are covered by a health plan[1]	81	17	2
Requiring all employers to provide health insurance to their full-time employees[2]	73	26	2
Requiring all employers, regardless of size, to provide health insurance for their employees[3]	57	37	6
Requiring all employers to pay at least 80% of the cost of their employees' health insurance premiums including part-time employees[4]	55	42	3
Requiring all employers to pay most costs of health care coverage[1]	53	43	4

(1 = Time/CNN/Yankelovich Partners, 3/3/94; 2 = ABC News/Washington Post, 2/27/94; 3 = NBC News/Wall Street Journal, 3/8/94; 4 = University of Cincinnati, 1/28/94)

6. PUBLIC OPINION ON WAYS TO CONTROL COSTS

Among proposals aimed at controlling health care costs, the public provides its strongest support for various forms of price controls on the health care industry. The least popular proposal is to tax employees for their health insurance benefits.

	Favor	Oppose	Not sure
Federal price controls on medical expenses such as doctors' fees, hospital charges and drug prices[1]	70%	27%	4%
Having government regulate the costs of prescription drugs[2]	66	31	3
Program in which people pay more money to choose their own doctor, and less money if they went to an assigned doctor[1]	61	37	3
*Having government set controls on what doctors, hospitals, and other health providers can charge[3]	58	34	8
Imposing overall limits on how much the U.S. spends on health care[2]	52	39	9

6. PUBLIC OPINION ON WAYS TO CONTROL COSTS (Cont.)

	Favor	Oppose	Not sure
An insurance program that would not pay for some treatments, such as those that are not medically necessary or have little chance of success)[1]	46%	51%	4%
Limiting tax deductions to only basic health insurance[4]	44	36	20
Taxing employers for any health insurance benefits they provide that are better than a basic health insurance package approved by the federal government[5]	32	64	4
Taxing employees for any health insurance benefits they receive at work that are better than a basic health insurance package approved by the federal government[5]	31	67	2

(1 = ABC News/Washington Post, 2/27/94; 2 = Time/CNN/Yankelovich Partners, 3/3/94; 3 = NBC News/Wall Street Journal, 3/8/94; 4 = Princeton Survey Research/Newsweek, 2/4/94; 5 = University of Cincinnati, 1/28/94)

* Historical Note: The current level of public support for price controls is similar to that found in a survey conducted for President Nixon in 1971, when 64% said the government should control prices for health care services. (Nixon Surveys, conducted by the Opinion Research Corp. and archived at the Roper Center for Public Opinion Research, Storrs, CT)

7. PUBLIC KNOWLEDGE OF THE CONCEPTS BEHIND THE MAJOR REFORM PROPOSALS

Even though most Americans have a view of whether they favor or oppose the Clinton reform plan, they admit they know relatively little about it. Fewer still have heard about the major alternatives.

	% saying they have heard of such an idea
Employer mandate	63%
Single payer	43
Individual mandate	30
Other voluntary enrollment plans	24
Medical savings account	18

(Kaiser/Harvard/PSRA, 2/24/94)

Note: Respondents were read a paragraph describing each approach, then asked whether or not they had heard of the idea before.

Understanding of Clinton plan		Heard of a better plan than Clinton's	
Have a good understanding	34%	Yes	10%
Hasn't been enough information or explanation	64	No	86
Don't know	2	Don't know	4

(New York Times, 3/11/94)

8. THE PUBLIC'S RATING OF HEALTH CARE PROPOSALS

When the major health care reform options are compared to each other, the employer mandate approach achieves the most public support.

	Said this plan had great deal or some appeal	Preference among the plans
Employer mandate	76%	32%
Individual mandate	48	9
Medical savings account	42	14
Other voluntary enrollment plans	34	11
Single payer	31	9
Wouldn't vote for any of these	NA	26
Don't know	NA	11
	(NBC News/Wall Street Journal, 3/8/94)	(Kaiser/Harvard/ PSRA, 2/24/94)

HARVARD SCHOOL OF PUBLIC HEALTH

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PUBLIC OPINION UPDATE ON HEALTH CARE REFORM #3

Prepared for the Health Subcommittee
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by the Harvard Program on Public Opinion and Health Care

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In this, the third in a series of updates on key trends in public opinion about health care reform, we address three important issues: 1) how the public feels about the Clinton health reform proposal; 2) how the public sees health reform as a problem and priority for action; and 3) attitudes about the inclusion of an abortion benefit in a health plan.

HOW THE PUBLIC FEELS ABOUT THE CLINTON HEALTH REFORM PROPOSAL

1. Support for President Clinton's health reform plan has gone up slightly in the post-holiday season.

Support for President Clinton's plan to reform health care

	9/26/93	10/30/93	11/4/93	11/21/93	1/17/94
Approve	59%	45%	52%	52%	56%
Disapprove	33	45	40	41	38
No opinion	8	10	8	7	6

(Gallup/CNN/USA Today)

2. However, the strength of public support for the Clinton plan may be overstated because many polling organizations do not allow individuals an easy opportunity to say they don't know enough or they are not sure of their position on this issue. One in five Americans, if given a chance, say they don't know enough or have no opinion about President Clinton's health reform proposal.

Support for President Clinton's health care program

Favor	47%
Oppose	32
Need to know more (vol.)	15
Not sure	6

(NBC News/Wall Street Journal, 12/14/93)

3. Recently there appears to be a gap between public support for the Clinton health plan and approval of how the Administration goes about its work in the health policy area.

Approval of the President's handling of health care policy

	9/12/93	9/26/93	10/30/93	11/4/93	1/17/94
Approve	43%	55%	51%	53%	46%
Disapprove	38	33	43	40	44
No opinion	19	12	6	7	10

(Gallup/CNN/USA Today)

Approval of the President's handling of health care reform

	8/3/93	10/19/93	11/14/93	1/17/94
Approve	41%	43%	49%	41%
Disapprove	43	40	37	43
Don't know	16	17	14	16

(CBS News/New York Times)

4. Of a number of major components of the Clinton plan, universality of coverage has the greatest public appeal, while having the government cover the health costs for early retirees is the least popular. Support for setting an overall limit on U.S. health care spending remains at about 50%.

Support for key elements of the Clinton plan

	Favor	Oppose	Not sure
Universality			
Federal govt guarantee health care for all Americans (Yankelovich/Time/CNN, 9/23/93)	72%	24	4
Guaranteeing coverage for all Americans regardless of health or employment status (NBC News/Wall St Journal, 12/14/93)	78%	17	5
Employer mandate			
Requiring all employers incl. small businesses to provide health insurance to every employee (Yankelovich/Time/CNN, 9/23/93)	60%	35	5
Requiring all businesses to pay at least 80% of medical coverage for their employees and give small firms govt subsidy (NBC News/ Wall St Journal, 12/14/93)	65%	29	6
Providing exactly the same comprehensive benefits package for everyone (NBC News/Wall St Journal, 12/14/93)	65%	29	6
Charging all Americans the same for health care, regardless of factors like their age and where they live (NBC News/Wall St Journal, 12/14/93)	52%	42	6
Spending cap			
Global budgeting, established to control expenditures, but could limit money govt would have available (Gallup/EBRI, 7/93)	50%	46	5
Imposing overall limits on how much the U.S. spends on health care (NBC News/Wall St. Journal, 12/14/93)	51%	37	12
Having the government cover retirees under age 65, instead of their previous employer as is now the case (NBC News/Wall St. Journal, 12/14/93)	43%	47	10

HEALTH CARE AS A PROBLEM AND PRIORITY

A. Is Health Care a Problem?

There are four ways of looking at how important health care is as an issue: 1) where the public ranks it among the most important problems facing the country; 2) how important health care is as a personal concern; 3) where the public ranks it as a priority for government to deal with; and 4) whether or not Americans believe there is a health care crisis.

1. Recent surveys indicate that concern about crime has risen, thus affecting the ranking of health care as an issue. But health care remains among the top three problems facing the country.

Most important problem facing the country today (open-ended, single response)

12/14/93			1/5/94			1/17/94		
1(t).	Econ/jobs	(22%)	1.	Econ/jobs	(23%)	1.	Economy/jobs	(26%)
1(t).	Crime/violence	(22%)	2.	Crime/violence	(22%)	2.	Crime/violence	(19%)
3.	Health care	(13%)	3.	Health care	(16%)	3.	Health care	(15%)
			10(t).	Welfare	(1%)	8(t).	Welfare	(2%)

(CBS News/New York Times)

Most important problem facing the country today (open-ended, multiple responses)

9/12/93			1/17/94		
1.	Economy/jobs	(47%)	1.	Crime	(37%)
2.	Health care	(28%)	2.	Economy/jobs	(33%)
3.	Crime	(16%)	3.	Health care	(20%)

(Gallup/CNN/USA Today)

2. Looked at from a personal point of view, health care ranks as a solid second or third among problems facing "you and your family." A particularly interesting finding is that a majority of Americans believe that worries about a family member not having needed health insurance are something the federal government can do something about.

Biggest problem facing you and your family these days (open-ended, multiple responses)

1.	Finan/econ problems	(49%)
2.	Health care/insur cost	(15%)
3(t).	Taxes, Crime	(6% each)

(Princeton Survey Res/Times Mirror, 12/5/93)

Personally worry about most for you/your family (reg. voters) (open-ended, single response)

1.	Crime/violence	(17%)
2.	Econ/jobs	(16%)
3.	Health care (cost/lack)	(10%)

(Lake/Goeas/US News, 12/10/93)

You/family member...	How much you worry about (percent saying "A great deal" or "A lot")	How much federal govt can do about
Won't have enough money when you/they retire	45%	45%
Won't have health insurance when needed	41	58
May be victim of serious crime	39	35
May lose job	31	34

(Harris/Business Week, 1/10/94)

3. On a list of issues President Clinton should address, health care reform and crime now tie for second, close behind the economy/jobs; welfare reform ranks sixth. But when offered a choice between only health reform and welfare reform, Americans either say they want to do both or they slightly prefer welfare reform. These findings suggest that those who name welfare reform in a two-way choice will switch to other national issues if given a wider range of choices, while those who choose health care reform are less likely to switch.

Problems facing the country that Clinton should work hardest to solve this year

	1st Choice	2nd Choice	Combined
Strengthening economy/Creating jobs	26%	22%	48%
Reforming health care system	22	20	42
Dealing with violent crime	23	19	42
Dealing with illegal drug problem	9	12	21
Reducing the federal budget deficit	9	10	19
Reforming the welfare system	6	9	15
Handling foreign affairs	3	4	7
Bringing needed change to govt	2	3	5

(Washington Post, 1/18/94)

Which issue should be the higher priority?	
Reforming the welfare system	16%
Reforming the health care system	20
Both	62
Neither (vol.)	1
No opinion	1

(Gallup/CNN/USA Today, 1/17/94)

More important issue for the federal government to concentrate on first	
Reforming the welfare system	49%
Reforming the health care system	43
Both (vol.)	7
Don't know	1

(CBS News/New York Times, 1/17/94)

4. Eight in ten Americans think there is a crisis in the nation's health care system.

In your opinion, is there a crisis in health care in this country today, or not?

	1991	5/12/93	1/17/94
Yes	91%	90%	84%
No	8	9	15

(Gallup/CNN/USA Today)

B. What is the Nature of the Health Care Problem, From the Public's Perspective?

1. When Americans talk about the health care problem, two main concerns predominate: They see their costs as too high, and they feel insecure about their coverage.

Where Americans say their health care coverage is not very good or poor

Providing benefit security	45%
Being affordable	37
Allowing selection of doctors, hospitals, and medical services	27
Promptness, i.e., making sure you don't have to wait for treatments or payments	24
Providing access to the best health care	22
Convenience, i.e., providing treatment and services at a reasonable distance from home	17

(Los Angeles Times, 9/28/93)

The public's greatest concerns about their health insurance
(open-ended, with multiple choices allowed)

Costs are too high		50%
Policy too expensive to afford	48	
Prescription drug costs too high	2	
Lack of security about coverage		42%
Benefits are not adequate to protect health	21	
Fear losing coverage	11	
Benefits cut back	6	
Can't get coverage because of pre-existing condition or other reason	4	
Other concerns		18%
Lack of quality care	4	
Lack of choice	3	
Health plan too complicated	2	
Convenience or access problems	2	
Other	7	
No concerns		11%

(Los Angeles Times, 9/28/93)

2. For those who are uninsured, the bulk of people say their main obstacle is that they cannot afford to buy a policy. Fewer than one in ten say they do not want to buy a policy.

Can't afford it	59%
Can't obtain it for job reasons	22
Don't want it	7
Can't obtain it for health reasons	3

(Kaiser/Commonwealth/Harris, 8/30/93)

PUBLIC ATTITUDES ABOUT INCLUDING ABORTION BENEFITS IN A HEALTH PLAN

1. Many Americans are torn by two conflicting values on the subject of abortion. About half of the public believes that abortion is morally wrong, yet a large majority supports the legal availability of abortion, at least in certain circumstances.

Do you personally believe abortion is wrong?		Do you think abortion should be illegal, or not?	
Yes, wrong	46%	Yes, should be illegal	28%
No	47	No	65
Not sure	7	Not sure	7

(NBC News/Wall Street Journal, 5/19/92)

2. Many of those who think abortion is morally wrong but should be legally available are reluctant to have the government pay for abortions. Although only one in three think abortion should be illegal, a majority opposes having the government help pay for abortions for poor women.

Do you think abortion should be illegal, or not? (If it should not be illegal) Do you believe the federal government should or should not help pay for abortions for lower-income women who cannot afford them?

Illegal	35% \		
Not illegal, but govt should not help pay for	21 /	Govt. should not help pay	56%
Not illegal, not sure if govt should help pay for	5		
Not illegal, govt should help pay for	32		
Not sure if it should illegal	7		

(NBC News/Wall Street Journal, 4/20/93)

3. Americans are resistant to including abortion benefits as part of a basic national health care plan, although there is greater support in certain circumstances, especially if the abortion is medically necessary.

Should abortion for women who want it be covered as part of a basic health care plan, or should it be paid for directly by the women who want it?

Covered	25%
Paid by women who want it	66
Don't know	9

(CBS News/New York Times, 6/3/93)

Do you think the national health care program should include coverage for abortions or not?

Should include coverage	32%
Should not	52
In some cases (vol.)	11
Not sure	5

(NBC News, 9/22/93)

Do you favor or oppose including covering abortions that are medically necessary or appropriate in the national health care basic benefit package for everyone?

Favor 64%
(Mellman, Lazarus, Lake/National Women's Law Center, 5/14/93)

For further information about American attitudes toward abortion, see Robert J. Blendon, John M. Benson, and Karen Donelan, "The Public and the Controversy Over Abortion," *JAMA, The Journal of the American Medical Association,* 270:2871-2875; December 15, 1993.

HARVARD SCHOOL OF PUBLIC HEALTH

Department of Health Policy and Management
Robert J. Blendon, Sc.D.
Roger I. Lee Professor and Chairman

PUBLIC OPINION UPDATE ON HEALTH CARE REFORM #4

Prepared for the Health Subcommittee
U.S. House Committee on Ways and Means

by the Harvard Program on Public Opinion and Health Care

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In this, the fourth in a series of updates on key trends in public opinion about health care reform, we look at the American public's current attitudes in the reform debate and provide a special examination of the public's response to some alternatives that have been proposed.

1. RANKING HEALTH CARE AS AN ISSUE

The answer to how important the public thinks health care is as an issue depends on how the question is phrased. As a problem for government to address, health care ranks #1; but as a problem facing the country, it ranks #3. The difference in responses to these two wordings relates to the question of whether or not the public thinks the government can do something about an issue at a given time. Currently Americans believe government is better able to do something about health care than about crime, violence, or drugs.

	Most important problems for govt to address	Most important problems facing the country	Difference
Health care	45%	21%	+24
Crime/violence	36	56	- 20
Econ/jobs	26	25	+ 1
Deficit/budget	8	5	+ 3
Drugs	6	20	- 14

(Harris, 2/6/94)

2. IS THERE A CRISIS IN THE HEALTH CARE SYSTEM?

The issue of whether or not the public perceives the existence of a health care crisis has received considerable attention. Once again, the answer depends on how the question is asked. Given a choice between "crisis" and "no crisis," 8 of 10 Americans see the health care system as being in crisis. But given an intermediate choice, that there's a problem but not a crisis, the public splits about evenly between "crisis" and "problem."

Do you think there is or is not a health care crisis in this country today?

Is	79%
Is not	17
Don't know	4

(Princeton Survey Res/Newsweek, 2/4/94)

Do agree or disagree that there is a health care crisis in this country?

Agree	84%
Disagree	15
Not sure	1

(Harris, 2/6/94)

Questions in which alternatives are offered

There is a health care crisis	57%
System has problems, but is not in crisis	42
Don't know	1

(Gallup/CNN/USA Today, 1/30/94)

There is a crisis in our health care system	43%
There is a problem, but not a crisis	51
There is not a health care problem	5
Don't know	1

(Yankelovich/Time/CNN, 2/10/94)

3. HOW WELL IS PRESIDENT CLINTON HANDLING HEALTH CARE REFORM?

The public remains divided on the Administration's handling of its health reform efforts. As the results in section 4 indicate, the public is more positive about the President's reform plan than about his handling of the issue.

	8/3/93	10/19/93	11/14/93	1/17/94	2/17/94
Approve	41%	43%	49%	41%	39%
Disapprove	43	40	37	43	46
Don't know	16	17	14	16	15

(CBS News/New York Times)

4. SUPPORT FOR THE CLINTON PLAN

Most Americans have not yet made up their minds about the Clinton plan. Almost all surveys show that support for the Clinton health plan has declined since the President's speech in September 1993.

Public understanding of the Clinton plan

Have a good understanding of what the Clinton plan will mean	27%
Too early to tell	70
Don't know	3

(CBS News, 2/17/94)

Support for President Clinton's plan to reform health care

	9/23/93	1/18/94	2/10/94
Favor	57%	50%	43%
Oppose	31	33	42
Not sure	12	17	15

(Yankelovich Partners/Time/CNN)

	9/22/93	10/10/93	11/14/93	1/23/94	2/8/94
Approve	56%	51%	46%	48%	51%
Disapprove	24	39	43	39	41
No opinion	20	10	11	13	8

(ABC News/Washington Post)

	10/6/93	11/15/93	2/6/94
Favor	64%	58%	59%
Oppose	30	34	34
Not sure	6	7	7

(Harris)

5. WHAT SHOULD CONGRESS DO WITH THE CLINTON PLAN?

Surveys show the majority of Americans do not favor passing the Clinton reform plan as is. However, responses differ depending on how the questions are phrased. If people are given a four-way choice, approximately half would have Congress pass it with minor or no changes, the other half would prefer to see it pass only with major changes or not at all. But a question that does not offer the opportunity to say "Pass

with minor changes" gives the impression that the overwhelming majority would prefer to see Congress pass the Clinton plan only with major changes or reject it.

Pass without changes	6%	Pass as is	24%
Pass with minor changes	41	Pass with major changes	55
Pass with major changes	26	Reject plan	16
Don't pass	19	Don't know	5
Don't know	8	(Gallup/CNN/USA Today, 1/30/94)	
(ABC News/Washington Post, 1/23/94)			

6. HOW PEOPLE THINK ABOUT THE CLINTON PLAN

The public sees health care costs as a bigger problem than universal coverage, but universal coverage is the most popular aspect of current health reform plans. This suggests that although the public is very concerned about costs, they are less enthusiastic about the specific cost control proposals in the Clinton and other health reform plans.

Which is the bigger problem...?

Health costs are too high	67%
Coverage is not available to all	27
No opinion	6

(Yankelovich Partners/Time/CNN, 2/10/94)

Universal coverage

	Agree/ Approve	Disagree/ Disapprove	DK
Insurance must be available for those with pre-existing conditions[1]	86%	10	4
We need health reform that will guarantee universal health insurance for all Americans[2]	86%	12	1
Guaranteeing coverage for all Americans regardless of health or employment status[3]	78%	17	5
Universal health insurance for all Americans[1]	73	20	7

Cost control

We should not have a health reform that will substantially increase government spending[2]	60	35	5
Government regulation on costs of care and drugs[1]	57	36	7
Charging all Americans the same for health care, regardless of factors like age and where they live[3]	52	42	6
Imposing overall limits on how much the U.S. spends on health care[3]	51	37	12
Limiting tax deductions to only basic health insurance[1]	44	36	20

Note: 1=Princeton Survey Research/Newsweek, 2/4/94. 2=Harris, 2/6/94. 3=NBC News/Wall Street Journal, 12/14/93

7. WHY PEOPLE APPROVE OR DISAPPROVE OF THE CLINTON PLAN

This pattern of support for universal coverage but worries about costs and cost controls can be seen in why people approve or disapprove of the Clinton plan.

Why people approve of Clinton plan		Why people disapprove of Clinton plan	
Universal coverage/security	48%	Will cost too much	38%
System needs change	24	Too much government	18
Current costs too high	14	Less choice/quality of care	16

(Princeton Survey Research/Times Mirror, 12/5/93)

8. EMPLOYER MANDATES

Currently about half of the public approves of an employer mandate. But support goes up if the question mentions subsidies for small businesses or restricting the mandate to full-time employees.

Small businesses should not be forced to pay for health insurance for all their employees		Requiring all employers to pay most costs of coverage	
Agree	50%	Approve	51%
Disagree	46	Disapprove	41
Not sure	4	Don't know	8
(Harris, 2/6/94)		(Princeton Survey Res/Newsweek, 2/4/94)	

The government should...

Require employers to provide insurance to all workers, even part-timers and temporaries	53%
Let companies decide whether or not to provide workers' health insurance	40
Don't know	7

(CBS News, 2/17/94)

Requiring all businesses to pay at least 80% of medical coverage for their employees and giving small firms some government funds to subsidize their coverage

Approve	65%
Disapprove	29%
DK	6%

(NBC News/Wall Street Journal, 12/14/93)

Employer mandates for...	Full-time employees	Part-time employees
Should be required	60%	31%
Should not be	37	63
Don't know	3	6

(Yankelovich Partners/Time/CNN, 2/10/94)

9. HEALTH ALLIANCES

Surveys show that fewer than 1 in 4 Americans say they know what a health alliance is. As a result, the public's responses depend heavily on how positively or negatively the alliances are described. Support is very strong when the description mentions discounts and does not mention bureaucracy or compulsory membership. Support is very weak when the emphasis is on the creation of multiple government agencies.

Knowledge of health alliances, or consumer purchasing cooperative

Heard of, say they know meaning of	22%
Heard of, but don't know meaning of	32
Never heard of	45
Don't know	1

(Princeton Survey Research/Harvard/Kaiser, 10/5/93)

Health cooperatives to bargain for the best price on care and drugs

Approve	73%
Disapprove	16
Don't know	11

(Princeton Survey Res/Newsweek, 2/4/94)

Favor/oppose Clinton plan if it would create 79 new govt agencies/commissions

Favor	29%
Oppose	63
Don't know	8

(National Review, 10/28/93)

Some experts have suggested that the federal government create consumer purchasing cooperatives which would negotiate and buy health insurance plans at a discount. Each employer would continue to contribute to the cost of each employee's insurance plan, but the plan would be administered through the consumer cooperative. Supporters say the plan will likely produce health plans offered at a discount. Opponents say the plan will require that consumers deal with a new, untested agency.

Support creating consumer cooperatives	44%
Oppose	21
Don't know/refused	35

(Boston Globe/Harvard/KRC, 9/8/93)

10. WILLINGNESS TO PAY TAXES

A majority of Americans would be unwilling to pay a tax increase to see President Clinton's plan enacted, but they are more willing to pay taxes to support the principle of universal coverage.

	9/19/93	9/22/93	10/10/93	11/14/94	1/23/94
Favor	39%	45%	40%	39%	41%
Oppose	58	50	57	57	54
Don't know	3	5	3	4	5

(ABC News/Washington Post)

Would you support a health plan that guarantees private health insurance coverage that can never be taken away if it raised your taxes?

Support	57%
Oppose	36
Don't know	7

(Gallup/CNN/USA Today, 1/30/94)

11. CONFIDENCE IN KEY PLAYERS IN THE HEALTH REFORM DEBATE

The public does not have a great deal of confidence in any of the key players in the health reform debate. The Clinton Administration has the highest rating, while health insurance companies rate the lowest.

Confidence to improve the health care system

	A lot	Some	Hardly any	DK
Clinton Administration	25%	41%	31%	3%
Doctors	19	49	29	3
Hospitals	17	49	32	2
Democratic party	17	47	31	5
Businesses	16	56	24	4
Republican party	14	44	38	4
Congress	11	50	34	5
Health insurance companies	11	38	48	3

(Yankelovich Partners/Time/CNN, 2/10/94)

SPECIAL ISSUE

PUBLIC ATTITUDES ABOUT ALTERNATIVES TO THE CLINTON HEALTH REFORM PLAN

Survey organizations are just beginning to poll on alternatives to the Clinton health reform plan. What follows is an analysis of the early results.

1. AMERICANS' KNOWLEDGE OF ALTERNATIVES TO THE CLINTON PLAN

Most Americans have not heard or read about two major alternative ideas to pay for universal coverage: single-payer and individual mandates.

	% who said they had heard/read about each approach aside from the description read in the survey
Employer mandate	54%
Single-payer	43
Individual mandate	33

(Harvard/Princeton Survey Research/Robert Wood Johnson Foundation, 1/16/94)

Because they are unfamiliar with specific alternatives to the Clinton reform plan, most Americans say they have not heard of a plan better than the President's.

Have heard of a plan better than Clinton's	12%
Have not	83
Don't know	5

(CBS News, 2/17/94)

2. PUBLIC PREFERENCES ON WAYS OF PAYING FOR UNIVERSAL COVERAGE

Given a choice among three major plans to pay for universal coverage and an option to say they don't favor any of them, no plan currently has majority support. However, an employer mandate approach has by far the most support of any of the three plans. The responses to this question also show that one in four Americans have not come to a judgment about which of these major plans they would prefer.

"Employer mandate" plan. Under this plan, you pay for health insurance indirectly through your employer. All employers are required to offer health insurance to their workers. Your employer pays a fixed amount of your health insurance costs, while you pay the rest. You are given a choice of private health insurance plans. Small businesses and low-income individuals are offered a subsidy to help them pay their health insurance bills.	40%
"Single payer" plan. Under this plan, you pay a direct tax to the government and receive a health insurance card. As with Social Security, both individuals and businesses pay taxes to fund the program. Like Medicare for those over age 65, the government--not private insurance companies--runs the system.	19
"Individual mandate" plan. Under this plan, you pay for your own private health insurance through your job or buy it yourself from an insurance broker. Everyone	

is required to buy health insurance, just as many states require all drivers to buy auto insurance. Your employer might pay some of your health insurance costs, but is not required to--if not, you must pay the full costs yourself. Low and moderate income Americans receive a subsidy or tax credit to help them pay for health insurance.	17
Wouldn't vote for any of these three plans	16
Don't know	8

(Harvard/Princeton Survey Research/Robert Wood Johnson Foundation, 1/16/94)

3. EMPLOYER MANDATE VS. INDIVIDUAL MANDATE

When offered a choice between only two plans, an employer mandate or an individual mandate, Americans favor an employer mandate nearly two to one.

Employer mandate is better	53%
Individual mandate is better	27
No difference (vol.)/Don't know	20

(CBS News, 2/17/94)

4. HOW AMERICANS WOULD LIKE TO RECEIVE THEIR HEALTH INSURANCE

These policy preferences are also reflected in the public's practical choice of where they would like to get their health insurance. Offered the chance to get insurance through an insurance broker or from a non-profit community or regional organization, a majority of Americans still prefer to get insurance from their employer or the government.

Directly from your employer	34%
Directly from the government, like Social Security and Medicare	23
Through an insurance broker, like auto insurance	19
Through a non-profit organization serving an entire community or region	17
Other/No preference (vol.)/Don't know	7

(Harvard/Princeton Survey Research/Robert Wood Johnson Foundation, 1/16/94)

The preference for employer-provided coverage is again illustrated if people are asked whether they would prefer to have their employer contribute directly to the cost of their health insurance or to receive the cash value of the employer's contribution and buy their own insurance policy.

Have your employer contribute directly to the cost of your health insurance policy at work	62%
Have your employer give you the cash value of their contribution and buy your own health insurance policy	31
No preference (vol.)	3
Don't know	4

(Harvard/Princeton Survey Research/Robert Wood Johnson Foundation, 1/16/94)

5. PUBLIC WILLINGNESS PAY MORE TO COVER ALL AMERICANS

When offered a choice between, on the one hand, universal coverage with higher taxes and, on the other, a plan that covers some but not all of the uninsured and would not raise taxes, the public is split. But when an explicit figure is mentioned for the number of Americans who might remain uninsured under a less costly plan, Americans strongly prefer a more costly plan.

Prefer a health plan that raises taxes in order to provide health insurance for all Americans	46%
Prefer a plan that does not provide health insurance to all Americans but keeps taxes at current levels	42
Don't know	12

(Yankelovich Partners/Time/CNN, 2/10/94)

A congressional plan that is less expensive than the Clinton plan because it relies on competitive buying of insurance, but which might leave more than ten million Americans without coverage.	20%
President Clinton's health care plan, which may cost more than the congressional plan, which provides more benefits and cost controls, and guarantees coverage for every American.	69
Neither (vol.)	6
Not sure	5

(NBC News/Wall Street Journal, 12/14/93)

Health-Care Report Cards Are Getting Low Grades From Some Focus Groups

By Ron Winslow
Staff Reporter of The Wall Street Journal

Consumers consult buyers' guides for everything from toasters to Toyotas. So it stands to reason that many are clamoring for data ranking the performance of health providers.

But many aren't, including Alan Smith, a 49-year-old telecommunications specialist. After spending several minutes poring over a prototype report card that rated a hospital on 28 different criteria, he said: "I'd probably rely on a doctor's recommendation more than this in making a decision whether to go there."

Mr. Smith participated in a recent focus group in Westchester, Ill., arranged by the Joint Commission on Accreditation of Healthcare Organizations. His comment amounts to a reality check for the burgeoning movement to provide consumers with report cards on the quality of care delivered by doctors, hospitals and health plans. Employers and health-reform advocates are counting on report cards to play an important role in health-care reform in the belief that consumers armed with such data will make sure providers don't sacrifice quality to hold down costs.

According to focus groups and other data, a gap exists between the kind of information employers and policy makers consider important and what consumers want. Moreover, as more consumers get care from providers recommended by their health plans, they may find limited usefulness in data ranking individual doctors and especially hospitals.

"Every health-reform proposal [in Washington] has a consumer report-card component," says David B. Nash, director of health policy and clinical outcomes at Thomas Jefferson University Hospital, Philadelphia. "But one of the major problems . . . is, what kind of report cards are we talking about?"

The National Committee for Quality Assurance, or the NCQA, a Washington, D.C., group that accredits health plans, has launched a report-card project to rate health-maintenance organizations based in part on such standardized quality measures as immunization and mammography rates and hospitalization rates for children with asthma or adults with congestive heart failure. Some employers view such criteria as important indicators of quality and are using them in deciding among health plans for their employees.

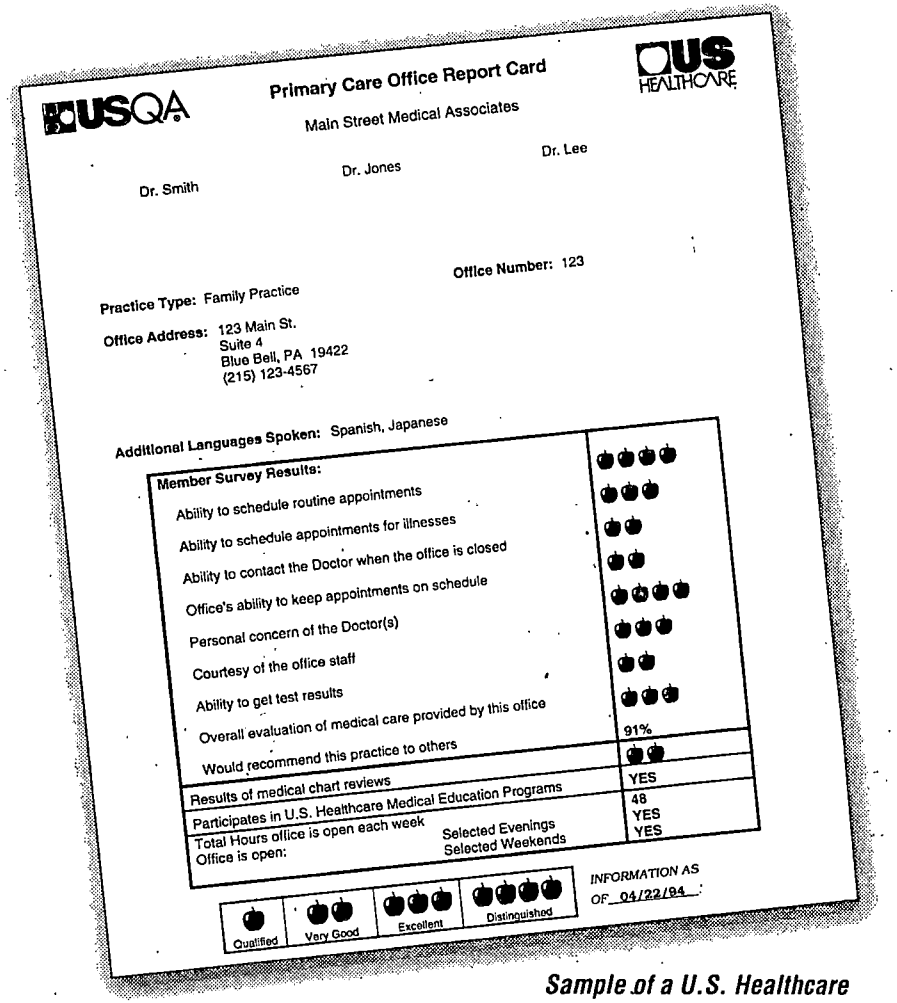
But a recent national survey by Harvard Community Health Plan, the big Boston HMO, found that among five categories of information, consumers themselves placed the lowest value on these quality measurements in choosing a health plan. They preferred information on which doctors belong to the plan, what care is covered and how satisfied other members are with their care. And 55% of the 750 respondents indicated they considered a health plan's reputation among friends, neighbors and co-workers more important than satisfaction surveys and standardized quality ratings.

"We've got a lot of work to do to let individuals know how those kinds of quality measures might be important to them," says John Ludden, medical director at Harvard Community Health Plan and a participant in the NCQA project.

The NCQA acknowledges that consumers evaluating prototype quality ratings have found them difficult to understand. "Part of the problem is that we're at such a primitive stage" in developing report cards, says Margaret E. O'Kane, president of the NCQA.

Of course, consumers are often initially skeptical of new products or procedures. But once they become more widely available, consumers often find them useful — even indispensable. Ms. O'Kane expects consumers who now consult neighbors for information on a prospective doctor's bedside manner will eventually use

Please Turn to Page B6, Column 4



USQA

Primary Care Office Report Card

USHEALTHCARE

Main Street Medical Associates

Dr. Smith, Dr. Jones, Dr. Lee

Practice Type: Family Practice

Office Number: 123

Office Address: 123 Main St.
Suite 4
Blue Bell, PA 19422
(215) 123-4567

Additional Languages Spoken: Spanish, Japanese

Member Survey Results:	
Ability to schedule routine appointments	●●●●
Ability to schedule appointments for illnesses	●●●
Ability to contact the Doctor when the office is closed	●●
Office's ability to keep appointments on schedule	●●
Personal concern of the Doctor(s)	●●●●
Courtesy of the office staff	●●●
Ability to get test results	●●
Overall evaluation of medical care provided by this office	●●●
Would recommend this practice to others	91%
Results of medical chart reviews	●●
Participates in U.S. Healthcare Medical Education Programs	YES
Total Hours office is open each week	48
Office is open: Selected Evenings	YES
Selected Weekends	YES

Qualified ● Very Good ●● Excellent ●●● Distinguished ●●●●

INFORMATION AS OF 04/22/94

Sample of a U.S. Healthcare report card, in this case rating a family practice

Health-Care Report Cards Receive Bad Marks From Some Consumers

Continued From Page B1

report-card data as well.

The report card being developed by the joint commission is derived from data it gathers as the chief accrediting body for more than 5,300 hospitals in the U.S. but has never made public. "This is a sea change for us," says Dennis O'Leary, the commission's president. "The public is saying, we're going to have information [on health providers]. For us to say, 'We've got the good information, but you can't have it,' is foolish."

But translating such data into terms meaningful to consumers isn't easy. The commission's proposed format gives a hospital an overall performance score and an indicator of how it stands against other facilities; it does the same thing for 28 individual categories.

For instance, an evaluation of a fictitious "General Hospital," distributed to members of the focus group in Westchester, said the facility scored 80 overall, which was better than 68% of all other hospitals evaluated within a three-month period. Then it rated the facility on such topics as "assessment of patients" (81, better than 67% of other hospitals) or "medication use" (78, better than 62%). The report card also rated services such as emergency care.

Many of the 10 focus-group members, most with recent or pending hospital stays, welcomed the prospect of such rankings, but some considered the technical content more suitable for doctors or health-plan administrators. Others wanted to know if the hospital helped with billing problems, an issue of no concern to the commission.

John B. Laing, vice president for marketing and external relations at the commission, says participants in other focus groups were more enthusiastic but acknowledges that consumer interest in the data is difficult to predict. The commission expects to publish its first reports on about 500 hospitals by the end of this year.

Meantime, officials at **U.S. Healthcare** Inc., the HMO based in Blue Bell, Pa., have taken a different tack. As part of a program to evaluate its member physicians, the HMO sends out one million consumer-satisfaction surveys a year to its members. Now, based in part on the findings, it can prepare a report card for each of its primary-care doctors on such criteria as ease of scheduling appointments, office-staff courtesy and ability to get test results. This month, it is testing the report card during an open-enrollment period when New York City employees are choosing health plans.

"We very much believe in sophisticated measures of performance," says Steven Zatz, president of U.S. Healthcare's U.S. Quality Algorithms unit. "We also believe the consumer wants a lot of information about what their experience is going to be like."

P&G Sues Ranir/DCP, Mi-Lor Over Design Of Toothbrush Handle

By a WALL STREET JOURNAL *Staff Reporter*

CINCINNATI – **Procter & Gamble Co.** said it filed lawsuits against **Ranir/DCP Corp.** and **Mi-Lor Corp.**, alleging violation of the design patent and product-configuration rights of P&G's toothbrush handles on its Crest Complete line.

In addition to unspecified monetary damages, the consumer-products concern said its suit seeks to stop Mi-Lor and Ranir/DCP from making and selling the toothrushes in question.

P&G also is asking that all toothbrush inventory in violation of its rights be destroyed. The Crest Complete toothbrush includes a ribbed insert on the handle and distinctive shape, P&G said.

Ranir/DCP, based in Grand Rapids, Mich., makes the Oral Pure brand. Ranir/DCP President Barry Silverman said: "According to what we are manufacturing, we feel there is significant difference in the two products." He added that Ranir/DCP looked into the similarities of the handles before developing its product, which he said the company had been marketing for six to seven months and "never heard a word about it before."

The toothbrushes under dispute made by Leominster, Mass.-based Mi-Lor are sold under the Kare, Pro and Thrifty names, P&G said. Mi-Lor's president declined to comment.

P&G wouldn't name a federal district court where the suits were filed.

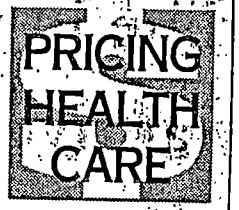
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Don't Punish Smaller Businesses That Self-Insure

By Eric Olson

Imagine that Congress suddenly found a way to provide quality, prevention-oriented health care for millions of Americans at a cost significantly lower than that of traditional health insurance. Given health care reform's widely touted goals of universal coverage and cost containment, it's obvious that this discovery would be hailed as a breakthrough and promptly written into the health care reform package, right? Wrong.

In fact, the opposite is true. The major health care proposals under serious consideration in Washington would outlaw this special kind of coverage by firms with fewer than 1,000 employees—coverage that is already being provided by smaller businesses to about 10 million workers and their families, about 22 million Americans in all.



An Anchorage, Alaska, creamery; a Clarksville, Md., auto dealer; a Kingfisher, Okla., telephone cooperative; a Cleveland producer of educational materials; a Fresno school district; and, yes, even a Little Rock savings and loan association—these are just a few of the nation's thousands of small and medium-size companies that self-insure, providing their employees with customized coverage at affordable prices.

That 22 million Americans would be deprived of this option is one of the best-kept secrets of the health care debate. Indeed, forbidding self-insurance for companies with fewer than 1,000 employees would cut off the option for 98% of U.S. businesses.

Only big business would be allowed to self-insure under three prominent plans: President Clinton's plan, the alternative being circulated by Rep. John Dingell (powerful chairman of the House Energy and Commerce Committee), and the only package to pass any type of legislative test (through Rep. Pete Stark's Ways and Means health subcommittee). Under these options, smaller businesses would be forced to buy expensive insurance policies covering all their health care costs, a boon for big insurance companies.

Not only that, but smaller self-insured companies would be pushed into the "community rating pool" with the uninsured. While big business escapes, and big insurance laps up the premiums, these companies already doing the right thing would be forced to bear an unfair share of the health costs of the unemployed and the previously uninsurable.

This is not health care reform—it's health care regression.

Self-insurance works for 405,000 smaller businesses with fewer than 1,000 employees for the same reason it works for big business—through cost controls and quality plans. In all, about 85 million Americans now receive health care through self-insurance—millions more than just a few years ago.

Under self-insurance, companies with as few as a dozen workers set aside a preset amount for routine health claims and purchase special insurance for catastrophic or unusual losses. The copayments and deductibles compare favorably with those of traditional health insurance plans. Typically, employees can choose from several options, including HMO, fee-for-service and preferred-provider plans.

Because better health means lower costs, employers using self-insurance offer employees more programs aimed at encouraging healthy lifestyles and preventing illness. These programs emphasize wellness, prenatal care and nutrition, and thus help brake inflation by eliminating or greatly reducing the possibility of future costly and debilitating illnesses. When the Department of Health and Human Services surveyed health promotion activities at various companies, it found that self-insured companies were more likely to offer these to workers in all 20 categories studied—ranging from blood pressure screening to smoking education.

As a result of prevention programs, and the direct stake self-insured companies have in controlling costs, these plans cost less than traditional plans and consume only 6% of coverage costs for administrative expenses. Since traditional insurance plans cost two to six times more to administer, self-insurance already is saving millions of dollars nationally. And it has the potential to save much more.

The only argument being used against self-insurance for smaller companies—that these companies hire only the "young and healthy"—is bogus. Actuarial reviews show that employees with these health plans have the same risk profiles as those in other groups. There's nothing special about the work forces of companies with self-funded health insurance.

Despite all the health care stories that have been saturating the media in the past several months, a wall of silence has surrounded the move to eliminate the self-insurance option for smaller companies. This point was illustrated beautifully several weeks ago when Hillary Rodham Clinton visited a chain supermarket in Washington to tout her health care plan. The 10-minute photo-op received massive and favorable coverage in the press. All but ignored the same day was a warning by Thomas Haggai, chairman and CEO of the 2,500-store Independent Grocers Alliance, that IGA's 40-year-old self-insurance plan for 37,000 supermarket employees and their families would be eliminated under the Clinton proposal.

The driving force behind health care reform is supposed to be a desire to help the little guy. Yet banning self-funded health care insurance for smaller businesses does just the opposite. Destroying the option would be a major mistake. Somebody should tell Congress.

Mr. Olson is president of VASA Brougher Inc. of Indianapolis, a large provider of catastrophic insurance to self-funding small and medium-size businesses.

Mental-Health Care Could be Expanded In Clinton Plan at Same Cost, Study Says

By Michael W. Miller
Staff Reporter of The Wall Street Journal

A major new study of state and private medical bills argues that President Clinton's proposed national health plan could offer much wider mental-health benefits for no extra cost.

State mental-health agencies and the managed-care industry will unveil the study today, heating up the fight over the most controversial benefit in health-care reform. The study contends that Congress could remove the Clinton proposal's strict limits on therapy visits, mental-hospital stays and substance-abuse treatment.

The Clinton plan budgeted an annual cost of about $250 per person for mental health. But fearing that an unrestricted benefit could bankrupt the health plan, it imposed special limits for all patients.

The new study argues that the Clinton proposal didn't take into account the widespread use of "managed-care" techniques to control costs case by case. Managed-care could hold the annual cost of mental health to about $220 a person – without any across-the-board limits, the authors estimate.

The study comes amid rising support in Congress for stripping the Clinton plan's limits on mental-health care. Just this week a House Education and Labor subcommittee approved expanding the White House plan's mental-health benefits. Yesterday the powerful Senate Labor and Human Resources Committee headed by Sen. Edward Kennedy (D., Mass.) began weighing a proposal that also includes significantly broader mental-health care.

"There's a growing consensus in Congress that the president's plan is deficient with response to mental-health and substance-abuse benefits and that these benefits should be treated on par with other illnesses," said Daniel Weiss, chief of staff for Rep. George Miller, a California Democrat who pushed the House subcommittee's new mental-health provisions.

The new study offered harder data than many health-cost estimates whirring through Washington. It surveyed all 50 state mental-health agencies about the actual cost of treating uninsured patients. It also surveyed 14 companies that specialize in mental-health managed care, covering a total of 35 million insured patients.

The authors offered a strong argument against setting limits that apply to all patients. "Rationing via arbitrary limits backfires," said Michael Hogan, director of the Ohio department of mental health. "If somebody has a 30-day in-patient benefit, they'll get their 30 days," no matter how trivial or serious their condition, he said.

Lex

How to Watch the Legislative Health Care Bazaar



Politics & People

By Albert R. Hunt

Anyone trying to sort out the vagaries of what, if any, health care legislation might be enacted this year should recall the oft-cited admonition of Otto von Bismarck: The two things you should never watch being made are sausage and laws.

The situation is a mess. The Clinton health care initiative has lost support, except when compared to all the others. Voters basically are content with their own health care but want the system significantly changed. The political dividends for passing a major health care bill may be minimal, but a Mellman-Lazarus-Lake survey plainly shows that incumbents will be hurt if they don't.

This is enough to buffet any politician faced with millions of dollars of special interests and campaign contributions and lobbying; with one-seventh of the gross domestic product on the line, the stakes are huge. Thus consensus is more elusive than ever. Insiders—members of Congress, White House officials, lobbyists—vacillate daily on what might happen.

Here's what to watch for in the crucial next six weeks:

• Will Dan Rostenkowski be indicted before late June? Sadly, this is critical. Although the Ways and Means Committee lacks a majority for any measure today, Chairman Rostenkowski invariably steps up to such difficult tasks. This is the pivotal committee in the House; the Commerce Committee is deadlocked, and the liberal bill clearing the Labor panel would be dead on the House floor.

If Mr. Rostenkowski avoids legal trouble over the next month, he'll probably send a modified version of the Clinton proposal to the full House by late June. But if indicted, he automatically has to relinquish his chairmanship and all bets are off.

• Southern Democrats hold the key. The most visible is Tennessee Rep. Jim Cooper, author of a more conservative rival plan. Rep. Cooper is refusing to play ball so far. But he's probably maximized his advantages, in terms of publicity and reams of campaign contributions from health industry interests. The aloof representative faces a tough Senate contest against a populist-sounding Republican; politically he's better off being part of a solution rather than an obstacle.

But Rep. Cooper lacks clout with other members and would bring few with him to any compromise. More influential will be some other uncommitted Southern or border-state Democrats, such as South Carolina's John Spratt, Virginian Lewis F. Payne (a Ways and Means member), Oklahoma's Dave McCurdy and Buddy Darden of Georgia.

• In the Senate, look to the Finance Committee. Ted Kennedy's Labor Committee markup, which started yesterday, is only a pressure group exercise. The divided Finance Committee deliberations are complicated by the coolness between the chairman, Daniel Patrick Moynihan, and Senate Majority Leader George Mitchell, who also sits on the influential tax-writing panel.

The crucial votes are in the middle, with moderate Republicans John Chafee, David Durenberger and John Danforth, and conservative Democrats David Boren and John Breaux. An agreement is an uphill battle, but these legislators genuinely want to enact health care reform.

• The Republican role in the Senate is essential, but the significance of Bob Dole is exaggerated. Sen. Moynihan persists in thinking the Senate GOP leader must be part of any final deal. GOP political advisers say that's a pipedream. Nationally, Bob Dole believes he has to neutralize right-wing opposition, and that means fighting any substantive health care legislation. Today Sen. Dole thinks he's going to run for president in 1996, which is more important than the fact that the odds are no more than 50-50 that he actually will.

But if any reasonable compromise is crafted, more than a few GOP members could fall in line. In 1965 Republicans railed against Medicare, including a second-tier actor and aspiring politician who warned that if it passed we would spend "our sunset years telling our children and our children's children what it once was like in America when men were free." That was Ronald Reagan. In the end, however, almost half the Republicans in the House and Senate voted for Medicare; there were similar dire warnings in 1935 before more than three-quarters of the tiny band of congressional Republicans voted for the Social Security Act.

Republican Lineup On Major Social Legislation

SOCIAL SECURITY (1935)	
House:	77 for; 18 against
Senate:	15 for; five against
MEDICARE (1965)	
House:	65 for; 73 against
Senate:	13 for; 14 against

• There are a lot of tough issues, but the big enchilada is mandates. Without mandates, or a big tax hike, it's impossible to get close to the universal coverage that the president and many Democrats feel is necessary. The oft-repeated fears of fence-sitting House members is that if they vote for any mandate they will be "BTUed." This refers to when the House approved a controversial BTU tax last year, only to have the Senate and administration cave in later.

That's why some congressional Democrats and the White House were delighted Tuesday when Sen. John Breaux, an opponent of mandates, suggested totally exempting only employers with 10 or fewer employees. That's the stuff of a compromise, such as a mix of employer and employee mandates or a phase-in; administration officials note, however, that 13.5% of the work force is employed by companies with 10 or fewer employees and there probably would have to be a fairly big subsidy to remedy that inequity.

• Watch whether the White House lowers the bar of universal coverage, which it wants to do, but only slightly. The apparent fault line for the president is somewhere between total universal coverage and the Cooper-Breaux measure, which would provide about 90% coverage.

Officials insist a watered-down version that focuses on insurance reforms and falls well short of universal coverage is unacceptable. A strong-willed president—a Truman or a Reagan—would salivate over vetoing such a measure and taking the case to the country. But most lawmakers believe this president lacks guts and will sign anything Congress passes.

• Watch Hilary Stout, The Wall Street Journal's health care reporter, and David Rogers, who covers Congress; they have been ahead on this story all along. A decade ago, after the Republicans initiated the Gramm-Rudman spending restrictions, House Democrats laboriously worked to modify the measure so it tilted more to Democratic programs. Yet, as it was about to pass, House Speaker Tip O'Neill, no master of legislative detail, was asked about Gramm-Rudman and replied: "The only two people in the country who know what's in it are Phil Gramm and David Rogers." On health care legislation, Mr. Rogers may be alone.

Letters to the Editor

The New War on Drugs

As a former police officer who walked the beat and ran three major police departments, I have witnessed firsthand the pain, despair and lawlessness surrounding the drug trade. It is in sadness rather than in anger that I elaborate on the recent criticism in editorials and editorial-page articles.

You have observed that drugs are the source of many of our nation's crime, health and welfare problems, and that the degree to which drugs fuel these social ills is a matter of moral import. As the nation's drug director, I couldn't agree more. That is why the 1994 National Drug Control Strategy builds its foundation on four elements: 1) we must reduce demand, especially chronic, hardcore drug use; 2) we must reduce drug-related violence; 3) we must support community-based programs; and 4) we must provide international leadership. In the past, our efforts failed to address adequately chronic, hardcore drug use—the major source of the crime, health and welfare problems. Unfortunately, while the "Just Say No" and "Zero Tolerance" campaigns affected casual drug use, they did nothing about hard-core drug use.

The president's 1994 National Drug Control Strategy incorporates the largest budget commitment to drug policy in the history of this office—$12.2 billion, at a time of austere budgets with many agencies experiencing cuts. In fact, the drug budget requests $1 billion more in fiscal 1995, mostly for demand reduction programs. Consider the facts. For the first time:

- The drug office is accorded cabinet-level status and as such plays a more active, and substantive role in formulating drug policy and coordinating antidrug efforts than in previous administrations.
- The drug office is not staffed with scores of political appointees, being so honored for political services rendered.
- The drug control budget is in line with real drug control program needs, with resources devoted to demand reduction exceeding 40% of the total federal drug control budget.
- The problems of hard-core drug use are recognized and a major treatment effort is proposed to address the needs of an additional 140,000 chronic, hard-core drug users.
- Drug policy is viewed as an integral part of domestic policy, linked to health care, welfare reform and economic reform.
- Efforts to secure permanent success against casual use are under way through a coordinated, nationwide prevention effort.
- Action supplants rhetoric in how we work with communities in the drug-control efforts—community policing, the Empowerment Program and National Service are just a few of the major efforts underway to enable and empower neighborhoods to deal with the multifaceted nature of the drug problem.
- The strategy promotes programs that work and rejects those that don't—consider for example the controlled shift of supply reduction program emphasis from the random patrols in the transit zone to source countries.

Clearly, the effectiveness of drug policy is enhanced by greater expenditures. More important, it is enhanced by linking it to other domestic policies. For years, national leaders have characterized drug use as a serious problem that requires long-term, dedicated efforts to overcome. The Clinton administration is the first to address it in this manner. Effective, continuing control of substance abuse will be possible only if homelessness, joblessness and other sources of social distress are addressed.

Your continuing criticism of administration policies is not unexpected. What was unexpected was the gratuitous and erroneous partisan statement (Review & Outlook, May 3) regarding drug use by our young people. You told your readers that drug use by 8th, 10th, and 12th graders had been in a steady, 10-year decline until 1993, and then risen. The obvious inference is that the previous administrations had effectively reduced drug use and that this administration was failing to do so from the beginning. The truth, of course, is that use of some drugs by this group was rising in the 1991-92 school year and continued to do so in the 1992-93 school year. This was well before when we took office.

As someone who has dedicated his life to public safety, I have never sought political gain from the crime and drug issue. This administration has taken the same tact, and the reason is simple: our children are using drugs. This is not a partisan matter. But it is one that calls for bipartisan action.

LEE P. BROWN
Director
Office of National Drug Control Policy
Washington

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Managed Competition: The Model For Health Care Reform

The Shifting Competition Paradigm

While the details of the national health care reform package will definitely change as it is evaluated and massaged by Congress, the market impact of state initiatives and evolution of managed care is clear. Competition is taking on a significantly different definition. No longer will health care providers be competing for market share as it has been traditionally defined.

Discharges as a measure of market leadership will be replaced by enrollment measures such as covered lives or numbers of contracts. Success will take on an entirely different meaning as capitation becomes a more frequent form of reimbursement. No longer will high occupancy, growth in admissions, and increases in surgical cases define a successful provider. Successful providers will be those who are able to keep their enrolled populations healthy and out of the hospital. When services are required, organizations must provide them in the most efficient and cost-effective manner. Meeting the changing demands of payers will become more important.

Changing Payer Demands

Whether the party responsible for reimbursement of health care is the government, private industry, Health Insurance Purchasing Cooperatives (HIPCs), or even individuals, these payers will continue to have demands. Successful providers will seek out stronger relationships with payers in order to monitor payer needs and build collaborative solutions.

Value

Demands for value in health care purchases will continue. *Value* for health care is not unlike value in any other industry: the expectation for product quality commensurate with cost. Purchasers will expect providers to demonstrate the efficiency that leads to lower costs as well as the outcomes related to clinical effectiveness. Patient satisfaction will also be a measure of value.

Geographic Access

Whether payers are large industries, HIPCs, or the government, they will be looking for provider systems that can provide geographic access for what is expected to be a diverse group of health care consumers. Consumers'

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Herman Smith Associates, a Division of Coopers & Lybrand, offers consulting services in Strategic Planning and Marketing, Facilities and Equipment Planning, Management and Organizational Development, and Operations Improvement.

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demands for convenience in health care will continue to mirror their demand for convenience in all other service industries. They will expect to be able to receive care close to both home and work.

Access to Continuum of Care

Closely related to the demands for geographic access are demands for access to the full continuum of services that an enrollee may require to meet their health needs. This continuum will range from primary care and screening/prevention services to sophisticated diagnostic and treatment to post-acute or long-term care. Payers will be developing relationships with integrated delivery networks that can provide a single point of contact for reimbursement and communication, while meeting consumer needs.

The challenge to providers is to examine the demands of delivery reform as an opportunity.

Acceptance of Risk

While capitation as payment for care engenders the concept of risk, it remains to be seen what form of reimbursement will be embraced. Despite this or perhaps in preparation for it, purchasers are seeking arrangements with providers who are able to take on financial risk for the delivery of cost efficient care. A first step in this direction is the development of global pricing or package pricing for certain services — one payment made to cover both the hospital's and physicians' fees. It is the purview of the individual institutions to develop satisfactory methods for dividing this reimbursement.

Strategic Responses of Providers

The viability of health care providers depends on their success in responding to these changing payer demands. The challenge is to examine these demands as opportunities for improvement rather than nuisances or punishments. Successful responses have both strategic and operational components.

Education and Redirection

The first step toward success is to educate the entire provider organization about the changing environment, the demands it creates, and the necessity for change. The leadership of the organization must present these challenges as opportunities to revitalize and redirect the culture of the organization toward a new vision of the future. Flexibility and creativity must be key components of this vision.

Demonstrating Value

This is the most important response to payer demands. Health care organizations must focus on evaluating and improving their cost and quality position. A variety of methods, including Business Process Reengineering and activity-based cost accounting, will aid in this process. The success of these processes depends on the availability of information with which to make decisions to improve efficiency or clinical effectiveness. Reliable and accurate information systems will be the only way to demonstrate value to purchasers of health care.

Building Strategic Alliances

Purchasers' demands for geographic access and access to the full continuum of care are high expectations for a single institution to fulfill. The creation of Accountable Health Plans in the reform initiative reinforces the need to develop strategic alliances. These relationships should be an "exchange" to meet the needs of each partner. Community hospitals must develop alliances with referral or academic medical centers for the tertiary and quaternary services they cannot provide. General acute care providers must build relationships with post-acute providers of skilled, subacute, and rehabilitation care to provide lower cost appropriate alternatives to acute care settings. In-

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Developing A Hospital and Physician Network

Many health care systems are facing increasing competitive pressure from other systems and hospitals trying to capture market share and from payers (especially, large employers and managed care entities) trying to reduce their outlays on health care services. Five to 10 years ago, a hospital's strategy would have focused primarily on facilities, equipment, and services. Today, an increasingly important source of a hospital's strategic advantage is the clinical skill, organizational loyalty, and sensitivity to resource management of its medical staff. Payers are especially attracted to those hospital/physician combinations that provide a continuum of high quality services at a reasonable cost.

Integration Model

Long-term objectives for providing high quality at a low cost cannot be met without extensive physician collaboration. Only by working closely with physicians can a hospital manage costs while not harming quality. Consumers view quality of service along a continuum — from physician offices to a hospital setting. Therefore, quality and service must be managed across all delivery sites, and hospitals clearly cannot do this alone. Hospitals often find that productivity improvements alone do not lead to the level of cost savings that are required in a managed care environment. This is primarily because operational efficiencies are not sufficient to meet the demands of managed care; what is needed is a fundamental shift in the way care is delivered for a given population. This requires the support and active participation of physicians.

Linking the hospital to its attending staff is, in our opinion, key to the future success of nearly every health care organization. However, we also believe that the long-term stability and success of the specific physician linkage arrangements developed today depend less on how close they come to a currently popular *general model* and more on how well such arrangements are tailored to address and meet the *specific needs* of participating physicians and the way health care is delivered locally and regionally. In other words, the "best" model that will stand the test of time is likely to be built by selecting those specific components that satisfy both the unique needs of the physicians as well as the constraints and unique characteristics of the local marketplace. That model is determined by answering two business questions:

- What economic and operational arrangements do the physicians require to commit to forming an integrated structure?
- What services are demanded by the local and regional markets, and what resources are needed to deliver those services?

With regard to the first issue, there is wide latitude in the type of organizational arrangements that could be adopted by the physician community. The extent of this range is reflected in the great variety of organizational, ownership, and governance structures that can be adopted. We believe that what the medical staff chooses must reflect their respective values and shared vision as much or more than what is considered to be "today's model."

Concerning the second issue, there is less freedom of choice because external forces and constraints of the marketplace and competitors determine what services and terms are in demand. These decisions will be influenced not so much by the values and vision of the medical staff as they will by the characteristics that convey a competitive advantage in the local, regional and national markets in which the hospital and medical staff currently or expect to service. Each medical community has its own objectives, culture,

(Continued on page 4)

"Hospital Network" cont. from p. 3

formal and informal organization, needs, sensitivities, and competitive pressures. These need to be reflected in the specific decisions regarding the options for organization, ownership, compensation, governance, operations, and risk sharing for the linkage program to be successful and sustainable over time.

Potential Integration Levels

Approaches for physician-hospital linkage are best understood from a market context, in which two dimensions define potential levels of integration.

Selecting alternative physician-hospital relationships requires an understanding of the environment and economics.

One dimension concerns the degree of **physician-physician integration.** The continuum ranges from independent to completely interdependent. At the independent end are solo practitioners who have no linkages with other practices. Somewhere in the middle are "group practices without walls." At the interdependent end are multispecialty group practices in which practitioners have joined together in a legal corporate entity and are economically tied to the group.

The second dimension relates to the degree of **integration between physicians and hospitals.** At one end, the relationship exists at "arm's length" with no joint decision making or shared risk. At the opposite end, the physicians and hospital belong to an integrated corporate entity. Between these two extremes are joint ventures, or "co-op" type arrangements, service bureaus, physician management contracts, forms of integrated decision making, and managed care contracting vehicles.

As hospitals move to develop linkages with physicians, it will be critically important to analyze the physician community in a way that suggests which linkage model or combination of models is most feasible, as well as to understand the market's needs and interests. Understanding will be enhanced by knowledge about practice economics and how the environment is affecting these economics, physicians' views of the hospital as a potential partner, and the value physicians place on independence. Since the independent physician community is typically conservative, a model that includes high levels of shared risk or requires fundamental change in the corporate structure of the practice may be rejected. Therefore, a management services organization or group without walls model may be appropriate for certain segments of the physician community.

- *Management Services Organization.* One of the alternatives for independent physicians would be to provide practice management or support services. Services to be offered could include billing/receivables management, nursing and/or support staff management, practice marketing, patient correspondence management, and management of the interface with utilization review entities and practice consulting services.

  This strategy often enables a limited initial entry into a relationship with independent physicians and serves as a recruiting tool. This approach does not provide a vehicle for developing managed care contracts and may be attractive as a near-term step to be augmented with a managed care contracting vehicle later.

- *Group Without Walls.* Typically, physicians would merge their professional corporations into a single private corporation and would begin consolidating administrative support services. Physicians could remain in existing offices initially. This approach could provide an attractive vehicle for linking outlying primary care physicians and establishing managed care con-

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"Hospital Network" cont. from p. 4

tracts for them. The hospital could provide management services to the new entity to help ensure the organization's success and give appropriate direction for the group.

- *Physician-Hospital Organization.* This model would enable the independent physicians to retain their private practices while acting collectively to negotiate managed care contracts. This model also would provide a formal structure for contracting directly with employers.

The PHO development process requires that a variety of practice effectiveness issues be addressed since the providers are likely to be at risk for some part of medical costs. For example, physician fee schedules must be established, and treatment protocols for common or expensive diagnoses are often developed. This model has been used successfully by numerous providers.

The two major risks in developing a PHO are that there is not a large enough market willing to contract through the PHO, and that the PHO is being developed with a goal of perpetuating traditional practice rather than developing a more efficient delivery model.

Lessons To Be Learned

A number of other organizations, similarly motivated to improve competitive position, have developed various forms of physician-hospital linkage. These groups range from fully integrated models to joint venture relationships for medical technologies, to physician practice arrangements for independent physicians. It is helpful to tap into the experience base of others who can describe successes and failures with physician-hospital linkage programs that are of interest.

How To Maintain Relationships

The linkage program that will be developed should be responsive to the needs of key independent physicians. However, not all physicians will be asked to participate because either the linkage program will be inappropriate for their needs or because the program implemented early on will not be suited to their situations until a later stage, when the program has evolved into a more sophisticated model. Each hospital must take steps to maintain good relationships with physicians who are not asked or who choose not to participate. Toward this end, a communications plan should be developed to keep information flowing to and from the medical staff. Personal discussions with high admitters or others whose relationships are especially important to the hospital should be held.

How Will The Integration Program Be Structured and Operated?

In any effort that involves bringing two parties together, there are a number of decisions that are best made by consensus. Key issues that should be addressed include:

Organization Design

— What are the objectives for the new entity?

— For what decisions will governance be shared or will physicians have the primary voice (e.g., quality assurance, cost control, utilization review, physician fees, new services)? What governance approach will support these new decision-making roles?

— What are the management requirements for leading the new organization (e.g., marketing, advertising, systems, legal, financial)? What will be the management approach?

Financial Arrangements

— On what basis will economic interdependence be created?

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Observation Medicine — Transitional Care In A System Being Transformed

The drive to provide an appropriate level of care for "unclassified" patients and to optimize use of resources is leading many health care executives to develop observation units. Referred to as "hospitals without walls," 24- to 72-hour beds, 23-hour 59-minute recovery units, these approaches to patient care are growing.

Implementation of any one of these concepts provides care to patients who would otherwise be discharged to home care or another provider or admitted to the acute hospital. While the hospital will not be reimbursed at full inpatient rates for such patients, recently clarified policies encourage hospitals to use 24-hours as only a "benchmark" for "observation" patients. In essence, the time during which a patient can remain on observation has become more elastic, and patients don't have to be discharged or categorized an "inpatient" and assigned a DRG at the end of 24 hours.

Observation beds are not reimbursed at Medicare inpatient rates. They are reimbursed based partially on costs and partially on a prospective payment basis. Providers with decreasing inpatient populations would do well to investigate this intermediate reimbursement/care concept. We recommend a three-phased approach:

- Define the patient population which could benefit from this level of care
- Evaluate estimated reimbursement on both a DRG basis and an observation basis for the same length of stay
- Model the resources required to ensure financial effectiveness of the observation beds/units.

Definition of Patient Population

A first step in defining the potential patient population is to document the number and type of patients who could benefit from observation status. (In some instances, discharge planners and nursing staff can assist in this estimate.) A similiar estimate based on clinical programs and therapeutic and diagnostic services will help define the appropriate logistics and resources necessary for patients' care. Patients who require cardiac monitoring, respiratory therapy and oncological therapy, or emergency and post-surgical patients who need extended multi-level observation may fall into these categories.

After ascertaining whether there is a patient population who will benefit from this level of care, the hospital must also research what resources will be required and where these units will be located.

Estimating Reimbursement

Estimates of reimbursement can be based on a comparison of potential patients' inpatient DRG reimbursement and Medicare's observation category of reimbursement for the same procedure or stay. This exercise will determine the financial viability of an observation medicine service.

Estimating reimbursement is an important step to determine the number of observation beds or the optimal size of the proposed observation units. In some instances, hospitals have gone so far as to convert all their inpatient beds to observation beds, giving them the capability to provide inpatient resources to observation patients while reimbursement is essentially based on an outpatient care formula.

Model of Resource Requirements

Lastly, the formal patient definition process provides a basis for estimating staffing needs, equipment requirements, acuity of patients, number of observation beds, and appropriate location of beds.

Hospitals are using two different approaches to establishing observation beds. Some hospitals establish dedicated units for observation status

(Continued on page 7)

"Hospital Network" cont. from p. 5

— What are the capital requirements, if any, for the integration program?
— What financial commitments are expected from the system, the hospital, and the physicians?
— How will returns or benefits be allocated? How will risks be shared?

Legal Structure
— What are the legal implications of the linkage program for the hospital and the physicians?
— Are the business objectives of the system, the hospital, and physicians achievable within a legal structure that will obtain a "clean legal opinion"?
— Is a "clean" legal opinion acceptable to the physician?

Physician Participation
— How large should the organization be in terms of number of physicians?
— On what basis will physicians be invited to participate? How will those invited but not yet interested be accommodated? What relationships, if any, will be retained with physicians who are not invited?
— How will the role of primary and specialty physicians vary?
— How will physicians be compensated?

"Observation Medicine" cont. from p. 6

patients. While these units benefit from having dedicated observation nursing staff, they may suffer from a lack of appropriate monitoring and therapeutic equipment for each patient's specific needs and limited specialty-specific care givers. Other hospitals scatter their observation beds throughout the hospital's acute care units based on the patients' clinical diagnosis (e.g., cardiac, oncology, surgery). These patients benefit from units already equipped and staffed for their specific diagnoses.

There is no right or wrong answer in selecting an approach. Many hospitals employ both options, maintaining separate units for less resource-intensive candidates and scattering certain observation patients in specialized wings.

Making it Work

Education of multi-disciplinary task forces of physicians and nurses on the use of observation beds and the appropriate documentation required to assure proper reimbursement provides pivotal information for the success of observation units. In particular, physicians play a critical role because physician documentation at the time of admission determines whether a case qualifies for reimbursement by the fiscal intermediaries.

Conclusion

Inpatient bed need/1,000 population has decreased from 4.0 to 2.5 or less; excess hospital capacity will become the norm rather than the exception. Exploring reimbursable care alternatives that also optimizes use of existing hospital resources is extremely important.

Observation bed status provides the flexibility to convert bed use from inpatient to outpatient while the hospital continues to receive some level of reimbursement. While outpatient reimbursement is lower than that for inpatients, observation patients will generate revenues that might otherwise be directed to other providers. Observation bed status may provide a vehicle to arrest the decline in reimbursement, while ensuring a continuum of quality care for the patient.

REMARKS BY LEX FRIEDEN

Let me ask you a question? If you break your neck in a car wreck on your way home tonight and become paralyzed, as I did 27 years ago, who will dress you, bathe you, and comb your hair after you leave the hospital? Will it be your parents or your children -- someone from your church -- will it be a volunteer who comes when she can, or can you afford to pay a nurse 10 or 15 dollars an hour for the 4 to 8 hours of help you will need per day?

Do you have the mistaken impression that your present health insurance will cover these costs or that current health care reform proposals address this effectively issue? Do you realize it is almost impossible to arrange volunteer assistance throughout the day and night for an extended period of time -- like the rest of your life!

Let's be frank, the likelihood that you will be permanently disabled on your way home today is about equal to the odds that you'll win the lotto. But, the odds that you or a member of your family will need chronic care sometime during your life are better than even.

From my vantage point, the reality of the situation is both encouraging and depressing. It is encouraging to know that some people, including me, have been able to maintain a comparatively high quality of life and be productive despite severe disability and loss of function. It is also reassuring to know that there are now more than 200 independent living centers across the United States which are run by people with disabilities who know how to organize and manage the needed services.* Finally, it is nice to know that we have some good models of personal assistance service systems in States like Maine and Minnesota, and in other countries.

On the other hand, it is terribly depressing to know that the majority of health insurance plans and the current health care reform proposals have no adequate provision for non-medical, in-home personal assistance services, and that most people who can't find volunteers or can't afford to pay for help dressing and undressing, bathing and eating wind up living in nursing homes as public charity cases.

It seems absurd to me that states and the federal government will share the cost of $30,000 or more per year to keep someone in a nursing home who would prefer to be assisted in their own home at less than half the cost to the taxpayer. Furthermore, people living in their own homes seem to be much happier and far more productive. In fact, 2/3 of PWD who are receiving benefits say that they would prefer to work rather than . . .

* Independent Living Centers provide peer counseling, advocacy and personal assistant services to People with many types of disabilities.

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Page 2: Remarks

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Talk about voodoo economics -- if the health care policy wizards think they can control health care costs without instituting a national system of personal assistance services and community based supports, then they ~~have been inhaling!~~ must have missed a turn on the freeway.

~~Then somebody needs to check the water.~~

~~Then somebody needs a reality check.~~

~~Then they need a reality check.~~

~~Then they missed a turn on the freeway,~~

~~Then they must be hallucinating.~~

Page 2: Remarks

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Mid week

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EXECUTIVE SUMMARY

The American Rehabilitation Association is the principal national membership organization representing providers of medical, vocational and residential rehabilitation services. This paper reviews the Health Security Act proposed by President Clinton as it potentially affects the delivery of rehabilitation services to people with functional limitations as a result of disease, stroke, injury and/or congenital defects.

The Association applauds President and Mrs. Clinton for addressing a difficult and challenging problem and supports the six principles the President has set forth as the basis for his plan. These are security, simplicity, choice, quality, savings and responsibility. The Association will support these principles as health care reform legislation is considered by the Congress. The recommendations discussed below are designed to clarify the plan and help to fulfill its objectives.

Everyone will probably need at least one rehabilitation service. As we debate the future of health care in America, no one can contemplate having a stroke, breaking a hip and injuring our spinal cord, or falling off a bicycle and hitting our head, being shot or stabbed, or having a child born with a disability. For many Americans unwittingly, unexpectedly, and unfortunately these things happen. These types of illnesses or injuries require rehabilitation services to help return people to home, to work, to school, and ideally to the active life they enjoyed. Additionally, for someone that is born with a congenital or genetic disorder, rehabilitation services can increase the ability to walk, move, write, eat, and therefore attend school, participate in social events and enjoy life.

Rehabilitation services are designed to restore the abilities of people to function. Rehabilitation produces independence and reduces the likelihood or extent of need for health care services.

[1]All bill references are to S. 1757.

POLICY RECOMMENDATIONS

I. COVERAGE MANDATE AND DEFINITION OF AN EMPLOYEE (Sections 1001, 1901)[1]

Recommendations:

- **The Association supports** universal coverage, access to care without regard to health status and elimination of preexisting conditions clauses.
- The Plan should not include in the definition of "employee" persons who are receiving Supplemental Security Income or Social Security Disability Income.
- The two-year waiting period for Medicare eligibility by virtue of disability should be eliminated. Persons found to be disabled under Social Security should receive immediate Medicare coverage, retroactive to the date of disability.
- Fringe benefit allowances in wage rate on Javits-Wagner-O'Day contracts should be increased as necessary to include the cost of health insurance as mandated by the Health Security Act.
- Rehabilitation facilities and their employees should be eligible for all subsidies in the Plan for payment of health insurance premiums.

II. COMPREHENSIVE BENEFIT PACKAGE (Section 1101 *et. seq.*)

A. Inpatient and Outpatient Hospital Services (Section 1111)

Recommendation: The final bill should include the recognition of rehabilitation hospitals and units and the hospital level rehabilitation services they provide and should do so without any day limit, as the bill provides.

Final conference language should include an explicit reference to coverage of rehabilitation hospitals and units services under this benefit and make explicit there is no day limitation on this level of services.

B. Extended Care Services (Section 1119)

Recommendation: For purposes of the extended care benefit, "rehabilitation facility" should be defined so that a continuum of care is available for rehabilitation patients, where possible through a single facility. The intensity of nursing and therapy services under the extended care benefit would be less intense than those needed by patients in a rehabilitation hospital or unit level program. To this end, the Plan should be clarified to establish that a rehabilitation hospital or a rehabilitation unit in a general hospital can provide these extended care services as a "rehabilitation facility" which will be at a less intense level than is the case for hospital services.

C. Nonhospital-based Outpatient Services (Section 1123)

Recommendations:

- The list of services comprising the Outpatient Rehabilitation Services benefit should include psychology, social services and rehabilitation nursing services when provided by Comprehensive Outpatient Rehabilitation Facilities as defined under Section 1861(cc) of the Social Security Act. The CORF benefit was added to the Medicare Act in 1980 in recognition that rehabilitation is the collective and coordinated application of therapies and other services, rather than a series of individual services.
- Cognitive therapy, audiology and hearing tests should also be added.
- Congenital disabilities should be added to illness and injury as qualifying conditions for services.
- The 60-day evaluation period should be used only as an evaluation period as is the current practice under Medicare with which the field is familiar, and not be interpreted as a limit.

D. Definition of the Benefits Package

Recommendation: Coverage should be determined by statute.

III. MEDICAL NECESSITY (Sections 1141 and 1154)

Recommendation: The Medicare coverage guidelines for inpatient rehabilitation hospital care should be adopted for determinations of the need for inpatient rehabilitation by alliances and plans. In any event, the determination of medical necessity should be made by the attending physician.

IV. ADMINISTRATIVE STRUCTURE (Title I, Subtitles C, D, E and F, Part 1)

The Association recommends that a mechanism must be in place to assure the referral for, and the delivery of, covered rehabilitation services.

A. National Health Board

Recommendations:

- The Board should set standards to be met by the states before health plans are approved, prior to the Board approving any state plan and prior to any state plan certifying any accountable health plans or designating an alliance. These standards should be consistent from state to state and alliance to alliance. Recommendations for such standards are in Attachment B.
- The membership of the Board should be expanded and include a provider of rehabilitation services, a consumer of rehabilitation services, and a person with a disability.

B. State Responsibilities (Section 1200 *et. seq.*)

Recommendations:

- States should assure that the alliances and plans adhere to the standards in Attachment B.
- Rehabilitation providers should be eligible to become specialty providers and centers of excellence in Section 1203(e)(2).
- Rehabilitation providers should participate with states on all advisory and planning committees.

C. Health Alliances (Section 1300 *et. seq.*)

Recommendations:

- To put rehabilitation providers in the strongest position to negotiate on fee schedules and to live under prospective budgets, the patient classification system based on the function related groups (FRGs) system needs to be finalized.
- Plans should also comply with the standards recommended in Attachment B.
- The Provider Advisory Board should include rehabilitation providers, not just professionals.
- **The Association supports** the annual open enrollment period to allow individuals to switch plans if they find their current plan unsuitable. People needing rehabilitation services and persons with disabilities need this flexibility, especially if their plan is not responsive to their needs.
- Rehabilitation providers should have an opportunity to work with each alliance in developing the outcomes information to be requested. The Association is developing a patient classification system (FRGs) that can predict length of stay based on the patient's functional status at admission. It is being refined to examine functional change from admission to discharge. A copy of the tool used, the Functional Independence Measure, is attached as Attachment D.
- **The Association supports** the role of the ombudsman, but recommends that it be strengthened to assure prompt resolution of enrollees' concerns. Again, our previous experience with managed care companies and their focus on saving funds has been

at the expense of enrollees.

D. Health Plans (Section 1400 *et. seq.*)
Recommendations:

- To assure referral and delivery of necessary rehabilitation services, plans should meet certain standards. Several of these are recommended in Attachment B.
- There should be an adequate number and variety of rehabilitation providers allowed to contract with each plan to assure that a full continuum of care is available to plan enrollees.
- **The Associaiton supports** the nondiscrimination provisions which prohibit preexisting conditions clauses and practices that have the effect of attracting or limiting enrollees on the basis of personal characteristics, including health status and the anticipated need for health care, among others.

V. RISK ADJUSTMENT (Section 1541)

Recommendations:

- Add functional ability to the list of factors used for risk adjustment in order to avoid an impediment to enrollment of persons with disabilities by health plans. Disincentives to enrollment should be removed. An appropriate risk adjustment formula is one factor in removing such disincentives.
- Rehabilitation providers and persons with disabilities should be represented on the Advisory Committee for the Risk Adjustment System.

VI. GRIEVANCE MECHANISMS (Title V, Subtitle C)

Recommendation: **The Association supports** the grievance mechanism in concept and urges that additional safeguards be added for persons with disabilities who do not receive a referral for needed services or are denied such services, to assure they have prompt access to such mechanisms.

VII. PLAN PAYMENTS AND BUDGETS (Section 6201 *et. seq.*)

Recommendation: The Plan should be modified to include a requirement that payments to providers for services covered under the Plan conform to the standard now governing state plans under the Medicaid program (the Boren Amendment). This requires that such rates "are reasonable and adequate to meet the costs which must be incurred by efficiently and economically operated facilities in order to provide care and services in conformity with State and Federal laws, regulations and quality and safety standards."

VIII. MEDICARE COST SAVINGS (Sections 4101 and 4103)

Recommendation: The Association had proposed a rebasing of TEFRA limits for rehabilitation hospitals and units for a two-year period and adoption of a Medicare prospective payment system for rehabilitation. Furthermore, the types of patients coming to rehabilitation hospitals and units has changed over the last 13 years. To recognize these changes, the current criteria used to define a rehabilitation hospital of unit for exclusion from the PPS should be expanded to add pain and rehabilitation of patients within the categories of oncology, cardiology and pulmonary.

IX. MEDICARE INTEGRATION (Section 4001)

Recommendation: The Association is concerned that allowing, or essentially forcing, Medicare beneficiaries into alliances or managed care plans will jeopardize their ability to receive rehabilitation services. As noted above, the Association has heard from members that the current HMO Medicare contractors are not referring beneficiaries for rehabilitation services.

X. QUALITY MANAGEMENT PROGRAM (Section 5001)

Recommendations:

- Rehabilitation's focus is on improved motor and cognitive function which are measurable outcomes. The outcomes information requested should include information on improvement in physical and cognitive functions as well as including vocational and living status (See Attachment D).
- Rehabilitation providers should be members of and work with the National Quality Management Council and National Quality Consortium, each state, alliance and plan in developing the outcomes.
- Persons with disabilities should be represented on the national council and any other committees charged with developing the quality management program.
- Rehabilitation providers should be included in the development of practice guidelines and utilization review protocols at the national, alliance and plan levels.
- Rehabilitation providers should be included in the design and conduct of outcomes research which should focus on the resulting quality of life of patients as well as more narrow indicators of functional ability.

XI. SUPPLEMENTAL INSURANCE (Section 1421 *et. seq.*)

Recommendation: Any supplemental insurance should be examined carefully to assure that it does not undermine the continuum of rehabilitation services in the compre-

hensive benefit package and have an adverse effect on persons needing services. If there is a supplemental insurance program, it should supplement the limits of the comprehensive program and interface with the comprehensive benefits package to assure that care for those who can afford to purchase it is seamless.

XII. LONG TERM CARE (Title II, Subtitle B)

Recommendations: **The Association supports** this new commitment to long term services with an emphasis on home and community based services. **The Association also supports** the use of multiple eligibility criteria provision of personal assistance services, emphasis on consumer involvement, and the basic philosophy that long term services must be part of a health care reform program.

The Association also recommends:

- Eligibility should be expanded to cover three of five ADLs *or* four of seven IADLs (mobility, communication, managing money, taking medications, shopping, etc.).
- The Association supports recognition of cognition as an eligibility factor.
- The personal assistance services included under the program look more like personal care services. While a good first step, **The Associaiton recommends** that states be required to offer a full range of personal assistance services.
- The Association is concerned that there be no incentives between the alliance based health plan and the LTC plan to limit the rehabilitation services people are receiving under the alliance plan, and move them prematurely to a LTC plan. **The Association recommends** that, before services are terminated under the alliance plan, there be a separate evaluation to determine if continued functional improvement is possible and that the plan is not terminating them prematurely or for its financial advantage.
- Consumers must continue to have a role in the initial development of plans and services that are delivered at the national, state and individual plan level.
- There should be a cap placed on out-of-pocket coinsurance payments.
- Psychiatric services required over time which are beyond those covered by the basic benefits package should be addressed.
- Issues regarding state medical practice and nurse practice acts in relation to health-related tasks performed by personal assistance providers such as medication administration and catheterization should be resolved.

XIII. TAX INCENTIVES FOR PERSONS WITH DISABILITIES WHO WORK (Section 2501, 7901)

Recommendation: The Association supports this proposal.

XIV. WORKERS COMPENSATION AND AUTOMOBILE INSURANCE (Title X)

Recommendations:

- The bill should acknowledge the diversity of state laws to assure that those states that cover vocational as well as medical rehabilitation services, which may be beyond the Plan's coverage, are recognized and covered.
- The definition of a "specialized workers compensation provider" should be amended to include medical and vocational rehabilitation providers as well as occupational health and occupational therapy.
- Long term care services provided under workers compensation programs should include the support services needed due to a work related disability.
- Rehabilitation must be included in the mission of the Commission on Integration of Health Benefits and Integration.
- Rehabilitation providers should be included in the Commission on Health Benefits and Integration and as consultants to the Departments of HHS and Labor to develop protocols for the appropriate treatment of work related conditions.
- The same recommendations are made for automobile insurance.

XV. OTHER

A. ESSENTIAL COMMUNITY PROVIDERS (Section 1431-1432)

Recommendation: Rehabilitation providers should be allowed to be essential community providers.

B. ADMINISTRATIVE SIMPLIFICATION (Section 5130, 4031 *et. seq.)*

Recommendation: The Association supports administrative simplification with the caveat that any additional costs must be paid to providers. Furthermore, for smaller rehabilitation providers, adequate time and funds should be available to allow them to change to electronic billing.

C. A NEW HEALTH WORKFORCE (Title III, Subtitle A)

Recommendations:

- **The Association supports** all efforts to expand programs, faculty and financial support for those who wish to become rehabilitation professionals.
- **The Association supports** the role of rehabilitation physicians as the primary care physician for persons with disabilities.

D. PREVENTION AND HEALTH RESEARCH INITIATIVES (Sections 3201, 3202)

Recommendations: The Association supports:

- Continued efforts to reduce disabilities from accidents and environmental conditions, particularly seat belt

and helmet laws, smoking cessation and all efforts to contain violence;

- Health research to develop quality and outcomes measures, especially in rehabilitation;
- Programs promoting wellness, including wellness and injury prevention in the work site and in the home; and
- Continued research into long term care.

E. DEMONSTRATION OF ACUTE AND LONG TERM CARE INTEGRATION (Section 2601)

Recommendation: This program would apply only to people with disabilities and chronic illnesses. The Association believes that if it is to be conducted, it should assure that the same rehabilitation benefits proposed under the comprehensive benefit package and the long term care proposal are included.

F. COST SHARING (Section 1131 *et. seq.*)

Recommendation: Annual and lifetime out-of-pocket expenses must be limited for persons who experience cancer, spinal cord injury, traumatic brain injury or other illness or injury because of the high costs of complications and acute care. Subsidies must be available to persons with disabilities who have low incomes.

G. LONG TERM CARE INSURANCE (Title II, Subtitle B, Part 3)

Recommendations:

- The Association supports development of long term care insurance and that the proposed benefits include rehabilitation and preventive services.
- Nonambulance transportation should be added as a covered service.
- Such coverage must be supplemental to services under the Plan and not in lieu thereof.

Wyatt

HEALTH CARE REFORM

A Summary of the Proposals

April 1994

Wyatt

Actuarial Services
Administrative Systems Consulting
Benefits Administration
Communications Consulting
Compensation Consulting
Compensation and Benefits Surveys
Employee Communication and Education
Executive Compensation Consulting
Expatriate Compensation and Benefits
Financial and Retirement Planning
Group and Health Care Benefits
Human Resource Strategies
International Consulting
Investment Consulting
Managed Care Consulting
Organization Effectiveness Consulting
Outsourcing
Public Policy Evaluation
Recordkeeping
Research and Information Services
Retirement Program Consulting
Risk Management Consulting
Software Services

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Consumer Campaign to Reward Small Employers Who Provide Health Insurance and Support an Employer Mandate: Key to Health Care Reform at the Community Level

by Bob Griss

A consumer campaign is needed immediately at the community level to reward employers who provide health insurance and support an employer mandate. While surveys indicate that a majority of small employers provide health insurance, Health Care Reform is being undercut in Congress right now by very effective lobbying by a minority of employers who oppose an employer mandate that would require all employers to contribute to the health insurance premiums of their employees and dependents.

Employer mandate essential for creating a right to health care

Opposition to an employer mandate is undermining a fundamental commitment to create a right to health care for everyone. Even though there are many more consumers who favor a right to health care, Members of Congress are reluctant to support a truly comprehensive benefits package, and are willing to delay the phase-in of universal coverage without an effective way to finance health care. Despite an outpouring of consumer support for universal coverage and comprehensive health benefits, Members of Congress claim that they are hearing more from organized business interests opposed to an employer mandate.

Need for target at the community level

The health care debate will not be won in Washington, D.C. unless there is a grass roots movement for comprehensive health care reform. What has been missing from an effective strategy for grass roots mobilization is a target at the community level. If a consumer campaign can be organized at the community level to favor employers who provide health insurance to their employees and dependents over those who do not, community pressure can create a strong economic incentive for employers to support an employer mandate. Since employers who provide health insurance are bearing an additional cost over their competitors in the absence of an employer mandate, it is appropriate for consumers who support a right to health care for everyone to reward them with our patronage.

Purposes of a consumer campaign

There are two immediate purposes for a consumer campaign to reward employers who provide health insurance. One is to raise awareness among consumers that when they go to the store, or a fast food restaurant, or a gas station, they are not only buying a product but also casting a vote on health care reform. By opposing an

employer mandate, some employers are not only denying responsibility for the health care needs of their employees and their dependents, but also showing disdain for the health care needs of their customers!

The second purpose is to create an incentive for many employers to dissociate themselves from the minority of employers who oppose an employer mandate. Members of Congress need to hear now that most employers are willing to contribute their fair share of health care costs.

Employer protections in the Clinton Health Security Act

President Clinton has proposed many ways to protect employers from rising health care costs. Among these protections are: (1) a premium cap of 7.9% of payroll, when most employers are already paying more; (2) a premium subsidy for small employers with low wage employees that could lower an employer's share to 3.5% of payroll; and (3) greater leverage, especially for small employers over private insurers through an administrative structure that spreads administrative costs among all payers, and ensures consumer choice among health plans for a guaranteed comprehensive benefits package. With more effective approaches to cost containment through the creation for the first time of a total health care budget, employers will be better protected from the spiraling health care costs which they continue to face in the health insurance marketplace. Most employers, especially small employers, have not been able to successfully protect themselves from these out-of-control costs through managed care which limits consumer choice of provider, reducing benefits, or shifting costs to their employees through higher employee premiums, deductibles, or copayments. An employer mandate would also benefit employers that already are paying their share-- plus an extra amount to cover the care provided to people whose employers don't provide them with insurance coverage.

Interestingly, when the Vermont Retailers Association decided to support the goals of a guaranteed right to health care, they challenged the conventional wisdom and endorsed a single payer approach as the least expensive way to achieve the goals of universal coverage and a guaranteed benefit package. Both President Clinton's Health Security Act and the single payer bill utilize an employer mandate to help finance comprehensive health benefits for everyone.

Employers depend on community goodwill

Employers are fond of displaying in their windows signs of their support for the community whether through contributions to the United Way or local charities. They do this because they depend on the goodwill of the community to survive. Since opposition to an employer mandate is threatening to interfere with creating a right to health care for everyone, it is appropriate for consumers to support employers who already provide health insurance to their

employees and dependents and support an employer mandate. This strategy not only offers a local target that exists in every community, but it also focuses on the meaning of community responsibility since community is the group with whom one shares risk.

Forms of a consumer campaign

The success of a consumer campaign will ultimately depend on the organizational capacity of consumers at the community level. Given the need to get Congress' attention immediately on health care reform, there is an advantage to a coordinated national campaign that targets one or more national franchises or dealerships which are strongly supportive of an employer mandate, while many of their competitors refuse to provide health insurance. A consumer campaign is likely to have more leverage where consumers make frequent purchases and where there is a choice among employers who provide health insurance and those that do not. Some employers deliberately hire part-time employers in order to avoid paying for health insurance.

A consumer campaign can have maximum leverage in the short run if it is targeted at employers in the Congressional districts of Members of Congress who are on committees with direct jurisdiction over health care reform. As the consumer campaign begins to generate pressure in these communities, it will naturally spread to other communities and to other types of employers. The value of this strategy is to mobilize people at the community level who have not otherwise been involved in the health care debate. Depending on the targets that are chosen, a consumer campaign can enlist the support of many types of consumers, including youth who though they may not vote have a unique stake in health care reform, as well as the religious community, seniors, the disability community, labor unions, professional groups, and civic organizations.

How employers indicate support for an employer mandate:

There are different ways that employers could indicate their support for an employer mandate. One way would be to take a **pledge** for supporting certain principles which are essential for a right to health care. These include: (1) Universal coverage by a date certain. (2) All employers must contribute their fair share. (3) Comprehensive benefits. (4) Affordable for all. (5) Real cost controls. (6) Quality of care. and (7) Single payer option for states. A list of these principles on a sign could be displayed in their window. A second way would be to ask employers to sign a **petition** addressed to their elected representatives in Congress endorsing an employer mandate. A third way would be to ask employers to contribute to an **advertisement in the community newspaper** listing all of the employers who agreed to support the seven principles for a right to health care for everyone. This strategy would not only generate widespread employer support for comprehensive health care reform, but it would also reinforce an appreciation of our interdependence at the community level.

Conclusion

Consumers must shift the health care debate from whether small employers can afford a comprehensive benefits package to what kind of health care Americans should be satisfied with in a country that spends at least 40% more than any other country on health care per person. Instead of trying to define a bare-bones minimum benefit package for the next guy in order to contain costs, Americans should be trying to ensure that everyone has the quality health care that they need, while health care reforms eliminate the excess capacity, administrative waste, and excess profits that drive health care costs out-of-control. The health care debate has been about the fictional "choices" of Harry and Louise rather than about the real obstacles to medically necessary services for all people based on their income, employment characteristics, and their health status. While opponents argue that health care reform will cost jobs, interfere with federal deficit reduction, and lead to rationing, only universal coverage and comprehensive health benefits, financed in part through an employer mandate, will provide the health security that all Americans deserve, and generate the pressure to control total health care costs in an efficient publicly accountable way. A consumer campaign to reward employers who provide health insurance and support an employer mandate is an effective way to mobilize grass roots support and focus community attention on our common interests in creating a right to health care for everyone.

Bob Griss is Director of the Center on Disability and Health in Washington, D.C.

CONSUMER CAMPAIGN TACTICS

Employer roles:

1. employers to display pledge card or sticker in window expressing support for a fair employer contribution

2. employers to make financial contributions for advertisement in community newspaper listing employers who support employer contribution and advertising consumer campaign for health care

3. employers to sign petition to Member of Congress supporting employer mandate

Organizer roles:

1. advertise consumer campaign to consumers

2. identify employer targets and district targets

3. educate employers about savings to them under Clinton plan and single payer using an insurance savings worksheet

4. develop and distribute employer pledge cards or stickers

5. collect money from employers for advertisement

6. circulate petitions to employers

ADVERTISEMENT MESSAGE

If employers do not contribute to the health insurance of their employees and dependents, this shifts costs to employers who provide insurance, and deprives their **customers** as well as their employees and dependents of a right to health care.

Approximately 44 percent of employers with under 10 employees offer health insurance to their employees (HIAA Employer Survey, 1993) and 20% of all employees in firms with fewer than 10 employees receive coverage directly from their employer (Current Population Survey, March 1993). Some employers use part-time or temporary employees to avoid contributing to health insurance benefits.

In the absence of a broad-based tax that distributes health care costs equitably throughout the population, all employers should be expected to pay their fair share. Approximately three-quarters of the uninsured are currently employees or dependents of employees.

Recognizing the costs associated with health insurance, consumers should reward employers who provide health insurance to their employees and dependents and support an employer mandate. When you purchase a product, you are helping to determine when the U.S. will create a right to health care for everyone.

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SINGLE PAYER: YARD-STICK OR MOST VIABLE OPTION FOR HEALTH CARE REFORM?

by Bob Griss

People with disabilities or chronic health conditions are the **litmus test** for health care reform. We are experts in the barriers to access, adequacy, and affordability in the health insurance marketplace. Unless we share our experience, people who are "***temporarily able-bodied***" will not know how ***vulnerable*** they may be if and when they develop a chronic illness or disability. Without comprehensive health care reform, they may not have access to rehabilitation therapies, durable medical equipment, prescription drugs, mental health services, or personal assistance services, even though the U.S. spends at least 40% more on health care per person than any other country.

The politics of consensus among Members of Congress is rapidly eroding the goals of universal coverage and comprehensive benefits for all persons (regardless of income, employment status, or health status) in the absence of a politically acceptable financing mechanism. Concessions are being made to delay universal coverage, restrict the comprehensiveness of health benefits, and transfer more health care costs from employers to individual consumers in order to pass ***any*** form of health care reform, before the November election.

President Clinton has proposed a complex structure of managed competition to achieve the ***principles*** of single payer, but appears unable to get a sufficient number of members of his own party to support his plan. The President thought that his plan was more politically expedient than single payer because: (1) it relies on an **employer mandate** (rather than a broad-based tax); (2) it provides for **choice of plans** based on ability to pay (though not ensuring everyone the right to choose their own health care providers without the financial obstacles of premiums, deductibles, and copayments); and (3) it encourages **private insurance companies to compete in the marketplace to control costs through managed care** (rather than utilizing global budgeting at the federal and state levels, negotiated fee schedules with health care providers, and publicly accountable planning mechanisms to ensure that everyone has equal access to medically necessary services).

Nevertheless, analyses by the Congressional Budget Office and the U.S. General Accounting Office continue to provide growing evidence that single payer is both the **least expensive** way to control health care costs and the **most efficient** way to ensure that everyone has equal access to health care. ***How much extra do our elected representatives think the American public is willing to pay to preserve the inequities and inefficiencies in our existing health care system, over what a single payer system would cost to ensure that everyone has equal access to all medically necessary services?***



The public can no longer treat health care reform as a spectator sport. ***The right to health care is the civil rights issue of the 1990s!*** New political strategies must be undertaken immediately to mobilize the grass roots in every community to ensure that Congress enacts single payer legislation now or at least closes the loopholes in the Clinton plan to more effectively achieve the principles of single payer. To do any less, will drastically increase the inequality in our health care system and society, and squander the resources that the disability community knows only too well are necessary to pay for comprehensive health benefits that **all** Americans deserve.



Don't Ever Give Up!

OVERVIEW OF MAJOR HEALTH CARE REFORM LEGISLATION IN RELATION TO PRINCIPLES OF CONSORTIUM FOR CITIZENS WITH DISABILITIES HEALTH CARE TASK FORCE

CCD PRINCIPLES	McDermott/Wellstone (H.R. 1200/S. 491) American Health Security Act of 1993 [Single-payer bill] House=92 / Senate=5	President Clinton, Gephardt/Mitchell (H.R. 3600/S. 1757) Health Security Act [White House bill] House=100 /Senate=31	Thomas/Chafee (H.R. 3704/S. 1770) Health Equity and Access Reform Today [Senate Republican Leadership Task Force] House=5/ Senate=20	Cooper/Breaux (H.R. 3222/S. 1579) Managed Competition Act of 1993 [Conservative Democratic Forum] House=59 / Senate= 4 Bipartisan: D=33;R=26 in the House	Michel/Lott (H.R. 3080/S. 1533) Affordable Health Care Now Act of 1993 [House Republican Leadership] House=139 / Senate=10	Stearns/Nickles (H.R. 3698/S. 1743) Consumer Choice Health Security Act House=18 / Senate= 25	Gramm/Santorum (H.R. 3918/S. 1807) Comprehensive Family Health Access and Savings Act House=2 / Senate=10	Stark (Chairman's Mark) Subcommittee on Health, House Ways and Means Committee For:6 Democrats Against:5 Republicans
NON-DISCRIMINATION	• every citizen or national of the U.S. and legal resident aliens in same system by 1995 regardless of income, employment status, health status, disability, or age • no pre-existing condition exclusions or waiting periods for pre-existing conditions • no annual or lifetime caps on medically necessary covered services	• employer and individual mandate supplemented by Federal subsidies to guarantee universal coverage for all legal residents by 1998 • no pre-existing condition exclusions • no caps on medically necessary covered services (except for mental health services and orthodontia) • health plans must accept all applicants and renew policies; no cancellations • actions by the National Health Board, state, alliances, health plans, and health care providers are subject to the federal anti-discrimination protections of the Americans with Disabilities Act or Section 504 of the Rehabilitation Act • supplemental coverage is subject to a waiting period for pre-existing conditions	• individual mandate by 2005; requires all employers to offer but need not pay for health insurance • limits preexisting condition exclusions up to 6 months • insurers may not reject individuals or small group employers on the basis of health status • health plans must renew policies; no cancellations • children with special needs eligible for SSI are not required to enroll in managed care • disallows limits or cost-sharing requirements for services for severe mental illness which do not apply to other services	• all U.S. residents are eligible to enroll in health plans if they can afford it • small employers (under 100 employees) and individuals have to purchase through voluntary purchasing cooperative • employer must offer but need not contribute to health insurance; • no individual mandate to guarantee coverage • limits pre-existing condition exclusions to 6 months • insurers may not reject individual or small group employers on the basis of health status • health plans must renew policies; no cancellations • disenrollment patterns not reflective of demographic distribution of enrollees may result in revocation of health plan	• no employer mandate or individual mandate to guarantee universal coverage • limits preexisting condition exclusions to 6 months in small group market (2-50 employees) • requires continuity and renewability of coverage for all group plans	• individual mandate with tax penalty for failure to purchase catastrophic insurance by 1997 • limits preexisting condition exclusions for up to 1 year for persons not continuously insured • guarantees renewability and portability of coverage	• higher rates can be charged to persons with pre-existing conditions; lower rates can be charged to those who adopt "healthy lifestyles" • insurers are required to renew policies • provides subsidies to help people with pre-existing conditions purchase coverage if premiums for catastrophic insurance cost more than 150% of average premiums for similarly situated healthy people or exceed 7.5% of family income	• each eligible individual entitled to guaranteed national benefit package either through private health plan or through a new Federal plan called Medicare part C by 1997 • health plans could not deny coverage or increase premium based on preexisting conditions, claims experience, medical history • year round open enrollment without waiting period • guaranteed renewability • Federal standards for guaranteed national benefit package and for standardized supplemental benefit packages to be enforced by States

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COMPREHENSIVE-NESS OF BENEFITS	• guarantees comprehensive services that are "medically necessary and appropriate for the maintenance of health, diagnosis, treatment or rehabilitation of a health condition", including: hospital, health professionals, primary and some preventive services, prescription drugs, mental health and substance abuse, home health, outpatient rehabilitation, durable medical equipment, dental for those under 18, home and community based care, hospice, and nursing homes • combines acute care and Long Term Care in the same benefit package increasing awareness of interdependence of these health related needs	• guarantees medically necessary and appropriate acute care, selected prevention, and some limits on mental health and rehabilitation in nationally guarantee benefit package • separate long term care program for persons with severe disabilities providing home and community based services including personal assistance services through a consumer-directed or agency-directed model • tax credit for up to $7,500 for working persons with disabilities to pay 50% of personal care expenses up to maximum of $15,000 • Medicaid supplement for low income population • continuation of Medicaid Long Term Care services for the time being • Guaranteed benefit package does not include: custodial care, hearing aids, eyeglasses for adults, private duty nursing	• National Commission creates a standard benefit package including medically necessary hospital, physicians, prescription drugs, home health and rehabilitation related to acute episodes, durable medical equipment, limited mental health for some illnesses, substance abuse services, and hospice. • Not specifically covered: laboratory and diagnostic tests, reproductive services, extended care, vision, hearing, dental, and Long Term Care • Commission may delete, but may not add, benefits. If funding is not available, the Commission must reduce benefits and/or increase cost-sharing. •tax-exempt Medical Savings Account may be used to purchase Long Term Care (LTC) services; tax incentives to purchase private LTC insurance	• An independent Health Care Standards Commission establishes a "uniform set of effective benefits" which can be disapproved by Congress under expedited procedures. • standard benefits may be limited based on treatable diagnosis • effective benefits might not include prescription drugs, eyeglasses, and hearing aids • Long Term Care becomes State responsibility with no Federal financial participation; Medicaid LTC to be phased-out over four years	• no standard benefit package of essential and medically necessary medical, surgical, hospital, and preventive services • National Ass. of Insurance Commissioners sets target actuarial values for standard and catastrophic plans. Insurers in the small group market (companies with 2-50 employees) "have the flexibility to develop the benefit provisions as long as they meet the target actuarial values." • no mention of preventive care, mental health, substance abuse, and long term care • government cannot require that particular benefits be covered	• federally qualified plan must cover "medically necessary acute medical care" including: physician services, inpatient, outpatient and emergency services, and prescription drugs. • benefit package need not include preventive services; mental health and substance abuse; or Long Term Care • tax incentives to purchase private Long Term Care insurance	• catastrophic policy would cover expenses "such as physician services, hospital care, and diagnostic tests" • low income workers would also be eligible for a preventive package	• guaranteed national package defined in statute includes inpatient and outpatient hospital services, physician services, diagnostic testing, prescription drugs, home health, durable medical equipment, orthotics and prosthetics, mental health and substance abuse, rehabilitation services (Medicare Part A and B) **plus** prescription drugs, prevention services for children, and prenatal care • low income individuals entitled to supplemental benefits as a wrap-around to Medicare part C or employer-sponsored health plan • Medicaid acute care replaced by Medicare part C but Medicaid would continue for long-term care and supplemental services for low income persons • non-refundable tax credit for personal assistance services for working person with disabilities

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APPROPRIATENESS	• free choice of health care provider independent of income • consumer choice is not subject to gatekeeper in capitated managed care plan unless chosen by consumer • governance/planning process at the District, State, and Federal levels to ensure consumer priorities, includes representatives of consumers with special health care needs on Advisory Committees	• consumer choice of competing health plans through mandatory regional alliance • health plan controls providers through managed care • out-of-network option costs more • regional alliance provides report card on quality of health plans • quality assurance protections including grievance procedures and ombudsman at alliance level •50% of regional alliance is composed of consumers	• consumer choice of health plans through voluntary alliance • choice of health plan depends on ability to pay • each health plan required to provide data on outcomes and effectiveness • appeals must go through alternative dispute resolution	• consumer choice of health plans through voluntary alliance for individuals and small employers (under 100 employees) • choice of plan depends on ability to pay • health plans required to meet minimum quality standards by purchasing cooperative which would also conduct enrollee satisfaction survey and monitor disenrollment patterns • alternative dispute resolution to appeal denial of claims • purchasing cooperative operatives ombudsman for dispute resolution	• employee chooses from three plans employer must offer • choice of health plan depends on ability to pay	• consumer must purchase at least a catastrophic policy • choice of plan depends on ability to pay	• employees choose from three options offered by employer - continuation of current policy - managed care - medical savings account/catastrophic policy • choice of plan depends on ability to pay	• benefits offered on fee for service, managed care, or out-of-network (point-of-service basis) • health plan performance report card

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CCD PRINCIPLES	McDermott/Wellstone (H.R. 1200/S. 491) American Health Security Act of 1993 [Single-payer bill] House=92 / Senate=5	President Clinton, Gephardt/Mitchell (H.R. 3600/S. 1757) Health Security Act [White House bill] House=100 /Senate=31	Thomas/Chafee (H.R. 3704/S. 1770) Health Equity and Access Reform Today [Senate Republican Leadership Task Force] House=5/ Senate=20	Cooper/Breaux (H.R. 3222/S. 1579) Managed Competition Act of 1993 [Conservative Democratic Forum] House=59 / Senate= 4 Bipartisan: D=33;R=26 in the House	Michel/Lott (H.R. 3080/S. 1533) Affordable Health Care Now Act of 1993 [House Republican Leadership] House=139 / Senate=10	Stearns/Nickles (H.R. 3698/S. 1743) Consumer Choice Health Security Act House=18 / Senate= 25	Gramm/Santorum (H.R. 3918/S. 1807) Comprehensive Family Health Access and Savings Act House=2 / Senate=10	Stark (Chairman's Mark) Subcommittee on Health, House Ways and Means Committee For:6 Democrats Against:5 Republicans
EQUITY	• tax-financed through corporate and income taxes with persons with higher incomes paying more to ensure that everyone has access to medically necessary health care (employee payroll contribution is 2.1% of income; employer contribution is 8.4% of wages or 4% for small employers; self-employed individuals taxed at 9.5%) • no premiums, deductibles, or copayments for acute or preventive care • premiums and copayments for Long Term Care • free choice of health care provider • balance billing prohibited	• premium-financed with employers required to pay 80% of the **average** premium in the regional alliance; consumers pay balance • public subsidies for premiums for low income persons and small employers with low wage employees; (consumer's contribution limited to 3.9%; employer's contribution ranges from 3.5%-7.9% of payroll) • community-rated premium regardless of health status for plan selected through mandatory regional alliance • reliance on cost-sharing (deductibles and copayments) for users of service • choice of health plan above average cost plan and choice of health care provider depends on ability to pay •balance billing prohibited • risk adjusted premiums or reinsurance to protect insurers from adverse selection • tax deduction for qualified Long Term Care services	• community-rated premium for specific plan selected through voluntary regional alliance regardless of health status • choice of health plan depends on ability to pay • full subsidies for Medicaid recipients • premium subsidies phased in for persons under 240% of poverty by 2005 if Medicaid and Medicare savings in federal health expenditures permit • reliance on cost-sharing • risk adjusted premiums or reinsurance to protect insurers from adverse selection •balance billing allowed • tax exempt Medical Savings Account may be used to purchase LTC services; tax incentives to purchase private LTC insurance • individuals who do not purchase health insurance by the year 2005 will be assessed a penalty equal to 120% of the cost of premium	• community-rated premium for specific plan selected through voluntary purchasing cooperative for individuals and small employers (under 100 employees) regardless of health status, but premium differentials permitted based on age • no limits on cost of premiums • reliance on cost-sharing • choice of health plan and choice of health care provider depends on ability to pay • federal premium subsidies for persons under 200% of state poverty level capped with no assurance of adequate funding • consumer is taxed on value of benefits over **lowest** priced plan in geographical area but eligible for a tax deduction on out-of-pocket premium costs •employer subject to 34% excise tax for premium contributions which exceed cost of lowest priced plan • balance billing prohibited spending	• no purchasing cooperatives to spread risks • rating bands on premiums in small group market; premium rates can vary by health status by as much as 35% • low income premium subsidies available up to the level that State would have spent on Medicaid acute care • does not establish community rating • no limits on copayments or deductibles; $1,800 deductible for individual; $3,600 deductible for family • choice of health plan depends on ability to pay • balance billing allowed • deductibility of premiums increased for self-employed and those without employer-sponsored coverage • Federal costs financed through Medicare reductions	• personal income tax credits to offset health insurance premiums and medical care expenses as a proportion of a person's income; replaces current tax exclusions for employer-sponsored health insurance • out-of-pocket limit of $5,000 • Federal grant to States for public subsidies for cost of health insurance, acute medical care and prevention services for persons under 150% of poverty • employers must maintain coverage provided before 1997 or pay the difference to employees in wages • Federal costs financed through Medical and Medicare spending reductions, elimination of tax deductibility for employer-sponsored health insurance and elimination of welfare benefits for non-citizens • individuals failing to purchase at least catastrophic plan by 1997 would pay financial penalty • balance billing allowed	• persons above 100% poverty level not eligible for premium assistance. If individual incurs medical expenses,must exhaust all assets before becoming eligible; unrecovered expenses garnished from wages over 7 years • no limits on premiums • balance billing allowed	• employer required to contribute 80% of the actuarial cost of guaranteed national benefit package under Medicare part C for full time employee but not required to contribute to family coverage •health plans required to phase-in community-rated premiums for guaranteed benefit package • public subsidies for premiums for low income individuals (up to 200% of poverty) • supplemental benefits provided under Medicare part C to individuals under 100% of poverty or to children under 18, pregnant women, or AFDC or SSI cash recipients under 200% of poverty • 20% coinsurance for outpatient services plus deductibles; inpatient services without co-insurance, deductibles, or spell-of-illness restrictions • risk adjusted premiums or reinsurance to protect insurers from adverse selection

Developed by the Center on Disability and Health, 1522 K St. N.W., Suite 800, Washington, D.C. 20005-1202; telephone (202) 842-4408

OVERVIEW OF MAJOR HEALTH CARE REFORM LEGISLATION IN RELATION TO PRINCIPLES OF CONSORTIUM FOR CITIZENS WITH DISABILITIES HEALTH CARE TASK FORCE

CCD PRINCIPLES	McDermott/Wellstone (H.R. 1200/S. 491) American Health Security Act of 1993 [Single-payer bill] House=92 / Senate=5	President Clinton, Gephardt/Mitchell (H.R. 3600/S. 1757) Health Security Act [White House bill] House=100 /Senate=31	Thomas/Chafee (H.R. 3704/S. 1770) Health Equity and Access Reform Today [Senate Republican Leadership Task Force] House=5/ Senate=20	Cooper/Breaux (H.R. 3222/S. 1579) Managed Competition Act of 1993 [Conservative Democratic Forum] House=59 / Senate= 4 Bipartisan: D=33;R=26 in the House	Michel/Lott (H.R. 3080/S. 1533) Affordable Health Care Now Act of 1993 [House Republican Leadership] House=139 / Senate=10	Stearns/Nickles (H.R. 3698/S. 1743) Consumer Choice Health Security Act House=18 / Senate= 25	Gramm/Santorum (H.R. 3918/S. 1807) Comprehensive Family Health Access and Savings Act House=2 / Senate=10	Stark (Chairman's Mark) Subcommittee on Health, House Ways and Means Committee For:6 Democrats Against:5 Republicans
EFFICIENCY	• national health budget established at Federal level and distributed to the States • maximum leverage over health care providers through global budgeting and negotiated fees at the State level • replacement of private health insurers for the nationally guaranteed benefit package • Medicaid and Medicare integrated into single payer system • National Board approves allowable drugs and negotiates payment rates for drugs, medical devices and equipment • State approval required for capital expenditures • State uses selective utilization review (UR) to replace route UR for all services	• leverage through mandatory alliance in negotiating with health plans to provide nationally guaranteed benefit package; large employers (over 5,000 employees) can create their own corporate alliance • cost containment through financial incentives of managed care • competition among health plans through mandatory alliance on the basis of costs and quality • premium targets administered through regional alliance to control growth of all health care expenditures • integration of Medicaid through regional alliance for acute care with continuation of Medicaid for supplemental services and Long Term Care; Medicare remains separate • drug price review mechanism • single payer state option	• limit tax deductibility to reduce premiums • cap on federal Medicaid payments to States for acute care • States could shift Medicaid recipients to qualified health plans and impose mandatory Medicaid managed care • tax incentives to purchase private Long Term Care insurance • accelerated death benefits excluded from taxable income for terminally ill persons • no single payer state option	• limit employer tax deductibility to the value of the lowest priced health plan to constrain premiums • limit participation in purchasing cooperative to employers with under 100 employees; do not allow states to put more than half of employees in a purchasing cooperative • competition among health plans through voluntary purchasing cooperative on the basis of costs and quality • encourage growth of managed care without quality assurance or consumer protections • replace Medicaid acute care with low income premium subsidies • no single payer state option	• allows small employers to form voluntary purchasing cooperative; individual consumers can act on their own; existing employer and group plans can continue outside of purchasing cooperative • cap on Federal Medicaid payments to States • allow states to purchase private insurance for Medicaid recipients; Medicaid recipients could be subject to managed care • no single payer state option	• individual consumer will act as their own purchasing agent • termination of employer insurance expense deduction • limitation on deductibility of individual tax expenditures • Medicaid acute care capped • no single payer state option	• reduce Medicaid spending by capping Federal payment, transferring Medicaid recipients to private coverage, and allowing States to enroll beneficiaries in medical savings accounts or HMOs • limits employer tax deductibility for premiums • no single payer state option	• all individuals required to enroll in private health plan, self-insured plan, or in Medicare part C • guarantee of coverage could be through a State single payer or public plan, an employer mandate, or a combination of public and private coverage • Federal Medicare-type payment rates or State all-payer provider reimbursement established under Medicare and under private plans • States encouraged to establish their own health reform systems • States required to enforce national health spending limits or be subject to Federal control • voluntary alliances permitted for individuals and employers with fewer than 1000 employees • employers would pay Medicare part C premiums to the IRS as payroll taxes are paid and individuals would pay their Medicare part C premium as part of their annual payment

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631-2331

Please find attached draft policies and procedures pertaining to research and grant funded endeavors at TIRR. Please consider

Speak Note

Hattie Carr

Independence

culturally determined characteristic

People in our culture value independence
self dependence
self direction

Asking for help is not natural in our culture
interdependence
interpersonal relationships
socialization

Resocialization (after disability or other major life change - child moveing, divorce)
even more difficult

Long Term Care Policy in the U.S.

one size fits all mentality

institutions
nursing homes
day centers
24 hour home care

A.D.A. -- 3 lessons

① Don't burn your bridges
Don't necessarily distrust a politician

If you want a job done right, then do it yourself.
Just do it

② Don't discount / write off any one
Don't assume they won't support you

③ focus, focus, focus
define the objective
narrow the objective to make it managable
make the objective tangible, measurable

④ if somebody says it can't be done, it either means they don't know how to do it or they don't want to do it

Be the best you can be
Maximize your abilities
do the most you can with what you have
no more than anyone else knows about something
try to learn more than anyone else knows
about something

Problem solving (the process) is the most important skill to have

adapting, coping, adjusting, reacting all are problem solving behaviors

decide where you want to go
If you can't get there from here, get help

What can one person do?

Two concepts -- briefly

Independence -- from a personal perspective.

What does it mean?

Concept questions after disability

Concept began to develope at TU.

Do it by yourself
Do not depend on anybody else
Move away from home
Be self sufficient
Be autonomous
Be uncommited — don't go with the flow
Be nonpartisan
Don't join a fraternity / Sorority / Club
Unaffiliated
Non-aligned — solve problems for yourself
Free — make your own decisions
Be Grown-up — don't use crutches
Be Self Reliant
Thinks for Yourself

Dress yourself
tie your shoelaces
Bath yourself
Use the toilet like a grown up

~~In~~dependence -- not necessorily doing it ~~yourself~~ yourself, but engineering it, seeing that it gets done,

~~In~~dependence -- self determination

making decesions which affect your own life

self reliance without ~~the~~ physical ~~characteristics~~ requirements

Definition / concept can be adjusted, adapted, customized

Sometimes adaption of concepts is necessary in order to maintain consitancy of ~~the~~ theoretical or ~~conceptual~~ conceptual framework

Interdependence

a more powerful concept than independence

To be independent:

mow the yard
wash the clothes
carry out the trash
drive the limo

fix the roof
fix the leak
fix the radiator
fix the lights

raise the cattle
raise the wheat
raise the vegetables
raise ~~the~~ the fruit

sew
~~sew~~ the clothes

pushing the concept to
absurd limits -- extremes

Socialization

Synergy -- the ~~the~~ whole is greater ~~than~~ the sum of its parts

Independent Living

interdependence

Synergy

empowerment

symbiosis

inclusion

ADA history
ADA implementation
ADA implications
employment, public accommodations

Health Care Reform
managed care
long term care
day care
independent living
personal assistance services

making choices

choosing from a range of acceptable options

there are many many things each of us can do

there are many many opportunities for us to do things now and there will always be many more

as human beings, we have a limited amount of energy and time to do things

our ~~to~~ greatest challenge is to choose the opportunities which most nearly match our abilities and which

1 STEP AHEAD

SPECIAL REPORT

Guide to Health Care Reform *for People With Disabilities, Their Families, and Their Friends*

***One Step Ahead* Special Report**
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SPECIAL REPORT

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Introduction

People with disabilities must be active participants in the health care reform debate. Congress is beginning to overhaul the nation's current health care system by considering several proposals in 1994. How the new health care system created by Congress will affect people with disabilities largely depends on how actively people with disabilities participate in the development of these proposals.

The purpose of this Guide is to provide enough background information to people with disabilities so that they may play an active role in this debate and influence the lawmakers' views on the issues of vital importance. The Guide also provides readers with information on how to share effectively their views with Congress. Disabled persons, their families and friends must participate in the process so that their concerns are heard by lawmakers.

At present, there are numerous health care proposals before Congress. Many of these proposals will fall by the wayside. Others will survive. Keeping track of the survivors will be difficult because all of

the current proposals will change form many times as individuals and interest groups express their views on the bills. A month from now, no bill will look the way it does today. As the debate heats up, these changes will come even more quickly.

No guide will be able to provide an absolutely up-to-date account of the contents of each proposal. In this Special Report, ***One Step Ahead*** will show you the spectrum of proposals by describing four of the major health care bills before Congress. We will also provide updates on the development of major proposals throughout the year. In this way, ***One Step Ahead*** hopes that you will actively join the health care debate.

Section 1 of this guide explains why health care reform is taking place. Section 2 describes the basic health care principles that should be part of any health care reform proposal. Section 3 contains information on how to communicate effectively with Congress. Finally, Section 4 discusses the reality of the legislative process. In the Appendix, we discuss President Clinton's plan and three other major health care bills that Congress will consider.

Section 1: Why Reform is Needed

Many problems exist with our health care system today. This is the only statement about health care on which all sides agree. Some of the reasons change is needed include...

- **Cost**
  The cost of health care is out of control. The health care system now accounts for over 14 percent of our nation's Gross Domestic Product (GDP). Meanwhile, our international counterparts pay an average of less than 8 percent of their GDP on health care.[1] Quite simply, our health care system is using too much of our money.

- **Gaps in Coverage**
  Even though our nation spends so much on health care, many American households do not have access to affordable health insurance, leaving them with inadequate health care. Medical problems for uninsured and underinsured families can mean financial disaster.

- **Productivity and Portability**
  For those whose employers provide health benefits, many cannot afford to change jobs for fear of losing all or part of their health insurance coverage. Health insurance isn't portable, which means you can't take your health coverage from employer to employer. Often, this forces employees, especially people with disabilities, to stay in jobs they do not like or to refuse an offer of a higher paying job in order to keep their health insurance. This

decreases worker productivity and prevents workers from reaching their full potential.

In other instances, the lack of health insurance coverage is a disincentive to employment. Often, people with disabilities who are receiving health benefits like Medicare or Medicaid do not seek employment out of fear of losing this coverage.

- **Insurance Discrimination**
  Insurance companies unfairly base premium rates on certain risk factors. As a result, they discriminate against certain groups of consumers, including people with disabilities. Far too often, insurance companies will not cover preexisting conditions. Insurance companies also can reduce coverage, cut off plans, or deny coverage altogether. Consequently, people's health care is at the mercy of insurance companies and is not necessarily dictated by medical need.

- **Lack of Preventive Care**
  The current health care system is geared toward acute care. The system waits until you are sick before it starts to work. Primary care and preventive care, which can help people avoid more serious illnesses, are limited in today's health care system.

Exactly how Congress will correct the flaws in our current system remains to be seen. How well the new health care system covers disabled individuals may depend on your involvement in the debate.

Section 2: Principles of Health Care Reform

One Step Ahead will closely follow the health care reform debate and provide regular updates. As final legislation is shaped, we will analyze how these changes will affect your life. We will look at the debate from the point of view of people with disabilities, using these four principles: Universal Access, Comprehensive Health Services, Consumer Control and Choice, and Efficiency With Equity.

These principles outline the range of services and health care that people with disabilities need. An ideal health care reform bill would meet all these principles. The principles have been adapted from materials developed by the Consortium for Citizens With Disabilities and other sources.

Remember, these principles are ideals. The perfect health care reform bill would provide the full range of services and care for the individual needs of all people with disabilities. Since we do not live in an ideal world, though, the final legislation will likely meet only some of the needs. At *One Step Ahead*, however, we need to look at the health care reform legislation from the idealistic point of view so that we can compare the developing legislation and effectively inform you where it does or does not meet our needs.

1. Universal Access for People With Disabilities

Universal access means health care coverage that would...

- prohibit preexisting exclusions regardless of your disability
- prohibit use of insurance rating practices that discriminate against people with disabilities
- provide for continuous health care services regardless of

employment status or income
- provide for continuity and for portable coverage to enable movement in jobs and residences

2. Comprehensive Health Services Available for People With Disabilities

A comprehensive array of health services would include...

- acute care hospital, physician and diagnostic services
- preventive health care services, including services that will prevent the worsening of a disability
- long- and short-term home- and community-based services
- prescription drugs and related medical supplies, biologicals and medicinal foods
- durable medical equipment, assistive devices and related services
- personal assistance services and independent living services
- rehabilitation services; audiology; occupational and physical therapy; respiratory, cognitive, vision and behavioral therapy; speech-language and psycho-social services; therapeutic recreation
- mental health counseling and services
- substance abuse services

3. Consumer Control and Choice

Our health care system must...

- ensure consumer choice of services and providers
- guarantee a range of services available to consumers to meet individual needs, to ensure meaningful choice and to promote independence
- provide an adequate amount, scope and duration of services

4. Efficiency With Equity

The financing mechanism in our health care system must...

- ensure that people with disabilities are equal participants

in the health care system and not an afterthought
- allocate resources so that people with disabilities do not suffer undue harm in the face of budgetary limits
- impose realistic costs for health care insurance, including limits on out-of-pocket expenses
- allocate resources in a more balanced way among preventive services, acute care, rehabilitation and chronic care management

What Is Your Point of View?

The four principles are described in greater detail below. As you read further, keep in mind how they apply to your personal health care needs. Tell us and others about your concerns, and make your views and ideas known so that you can be involved in the debate. Your ideas are important, and you need to share them with your friends, family and the Congress.

PRINCIPLE #1:
Universal Access for People With Disabilities

A minimum level of insurance for all citizens should be part of any reform of our health care system. Every American deserves the security of knowing that serious illness will not result in heavy financial losses. People must be allowed to receive all needed health services regardless of their income or health condition.

Similarly, a person's age, race, or place of residence should not prevent him or her from getting health care. The largest and most basic problem with today's health care system is that many people do not have insurance to cover their medical expenses. For this reason, guaranteed coverage for all Americans must be at the heart of health care reform.

Nondiscrimination

Health care reform must also include measures which end the discrimination taking place in today's system. People with disabilities and their families must be able to fully participate in our nation's health care system. Currently, many people with disabilities cannot buy health

insurance because many plans deny coverage for consumers who have certain "preexisting conditions." Other consumers with certain medical conditions are rejected by insurance companies because these consumers are considered high-risk individuals.

Many disabled people are actually infrequent users of health care; yet, they are unfairly denied insurance solely because of their disabilities. Such discrimination is legal at present. For those who are able to get insurance, the premiums, co-payments and deductibles they pay are usually high — higher than the costs paid by nondisabled people.

Thus, changes in this system must make preexisting condition exclusions illegal. Also, the price of plans should no longer be based on the level of an individual's past use of medical services. Only then will people with disabilities have equal access to needed health care.

Insurance Must Follow the Consumer

Our country can no longer afford to rely on a system in which most health insurance coverage is based on a person's place of work. Our health care system forces employees to stay in jobs which offer valuable health benefits for the employees and their families. These workers fear that switching jobs or moving to a different area of the country would mean losing their insurance. For many, such a job change would equate to financial disaster. The result is unhappy workers locked in jobs which they don't like or which do not provide professional growth. This "joblock" leads to poor worker productivity and the inability of the nation's workforce to work to its potential. This hurts our national economy and our ability to compete with other countries.

To correct this problem, health care reform must ensure that health care coverage follows the consumer rather than staying with the job.

PRINCIPLE #2: Comprehensive Health Services for People With Disabilities

For people with disabilities, health care reform must create a system which offers a wide variety of lifelong medical assistance, including health, rehabilitation, personal and support services. This assistance should include the following:

- preventive services
- health education services
- diagnostic services
- inpatient and outpatient services
- hospital care
- short- and long-term home- and community-based services
- long-term care in medical facilities
- prescription drugs, biologicals and medicinal foods
- mental health services
- habilitation services
- rehabilitation services, including audiology and occupational therapy; physical and respiratory therapy; speech-language pathology services; cognitive, vision and behavioral therapy; and therapeutic recreation
- personal assistance services and independent living services
- durable medical equipment and other assistive devices, equipment and related services

It is important to have access to such a broad range of services which often allow people with disabilities to lead independent lives and contribute to the community. Use of these health services can prevent a small, simple health problem from becoming a larger, more serious problem.

PRINCIPLE #3:
Consumer Control and Choice

Certain forms of "managed care" proposals attempt to control costs by limiting access to certain health care services which are considered unnecessary. Some proposals call for a "gatekeeper" — a doctor, nurse or case manager who would decide if you need medical attention. However, "gatekeepers" may not always understand the health care needs of people with disabilities. In addition, there could be a conflict of interest between a disabled individual's needs and the "gatekeeper's" responsibility to keep costs low. As a result, under these "managed care" proposals, persons with disabilities could often be denied medical procedures which may really be needed.

People with disabilities have the right to participate fully in the delivery of their own health care. The care must be based on need, preference and choice. People with disabilities should be able to choose their own doctors and the services these doctors provide. We must also be able to choose when and where health care takes place. Only by keeping the ability to choose will people with disabilities have true control over the health care they receive. The result will be more efficient and appropriate medical services.

Prevention, Not Specialization

Health care reform must emphasize a greater use of primary and preventive care. The old saying, "an ounce of prevention is worth a pound of cure," still holds true today. Instead of using expensive health care services when a person becomes seriously ill, our system should encourage the use of simpler, less costly services which prevent serious illness from ever developing. We can do this by providing people with disabilities the health care designed to prevent secondary conditions that might eventually develop as a result of an individual's disability.

Prevention includes social, educational, nutritional and medical services. Preventive services should focus on treatment for specific primary disabilities so that they do not worsen over time. The result would be fewer seriously ill people and fewer expensive health care bills.

PRINCIPLE #4: Efficiency With Equity

In today's health care system, certain groups of people pay larger health care costs than other groups of people. If a person is able to get a job with a major corporation or with the federal government, health care expenses are small because the employer usually offers and pays a large share of the health insurance costs as part of a compensation package. Large companies and state and federal governments can negotiate coverage rates with insurance companies because they have so many employees. The result is very low health insurance premium payments for these workers.

For the unemployed and for those people whose employers do not or cannot offer health insurance, buying even limited health care cover-

age is very expensive. Often, people with disabilities are forced to use a large portion of their paycheck for limited health insurance coverage and for health care services. Too many times, needed health care is dependent on what a family can afford.

Reforms must address this inequity. The costs of health care should be more equitably spread among individuals, employers, and the government. One way to solve this problem is called community rating. Using this method, insurance companies would establish premium rates on the past insurance claims of communities as a whole. Rather than basing prices on someone's employment status or on an individual's medical history, prices would reflect the costs of health care for the entire community. Thus, premiums would be the same for everyone in a community. The community rating system would lower the cost of coverage for people with certain disabilities.

Keeping These Costs Down

Regardless of the reforms that take place, there are sure to be measures aimed at reducing the cost of health care. The measures instituted to control costs may be called "global budgets," "cost controls" or "cost caps." However, these measures must not, in any way, penalize consumers for needing adequate care. Arbitrary cost controls will likely result in the rationing of health care, services and equipment that are available to people with disabilities.

REMEMBER...

It is important that you keep these four principles in mind when you evaluate the various health care reform proposals. You may have other important principles based on your individual needs or beliefs. Whatever principles are important to you, remember this: The key to evaluating any proposal is to ask yourself the question, "Does this plan meet my health care needs?"

Section 3: Let Congress Know Your Views

Unless you make your views known, you may be ignored as the health care debate heats up in 1994 and proposals are introduced and changed by Congress. **Do not underestimate your power and influence with Congress.** Let your representatives in Washington know how you feel. Tell your friends and your family to make their needs known to Congress. Telling Congress how you feel does make a difference.

Identifying Your Representatives

Each person living in any of the 50 states is represented by two senators and one member of the House of Representatives. If you cannot easily find names of your congressional representatives in the phone book, you can call the U.S. Capitol at (202) 224-3121. The Capitol operators need only your zip code to give you the names of your senators and representative.

Writing Letters

Letters are the most effective way to communicate with your elected officials. Each representative or senator receives hundreds if not thousands of letters a day, and the congressional staff keep records of who writes to their bosses and on what issues. When you write your elected officials, be sure to include your name and address in your letter. Letters lacking this information are thrown away. Also, letters usually receive more attention than postcards.

In your letter, you should explain your particular situation and tell what elements and principles of health care are important to you. If you wish, specifically mention a bill you are interested in and ask for your

legislator's views on the proposal.

To write to your senators, address your letters like this:

The Honorable (senator's name)
United States Senate
Washington, D.C. 20510

To write to your representative, address your letters like this:

The Honorable (representative's name)
U.S. House of Representatives
Washington, D.C. 20515

Usually, you will receive a written response to your letters within two to four weeks. Don't hesitate to write again about your concerns. Periodically ask your legislators for updates on the development of the health care proposals and how they affect your situation. If you are not happy with the response, write and express your views again or ask for more information.

Telephone Calls

Telephone calls generally are less effective than letters. Most congressional offices receive hundreds of calls each day. A tally may or may not be kept of your phone calls. If you do call, ask to speak with the person on staff who handles health care reform. Before you end your conversation with that person, ask him or her to take your name and address and to mail any updates to you.

Meetings

If you are planning a trip to Washington, try to arrange a meeting with your representative, senators or their staff to discuss health care reform. You can also attempt to arrange a meeting with your legislators when they return to your district or state. If such a meeting is not possible, you can attend periodic town meetings conducted by your representatives. Such meetings are designed to give voters access to elected officials when the officials are working back in their home districts or states. Town meetings are held in various towns and cities and may be advertised in local papers or through special mailings. You can also call your legislators' local offices to find out when they will be holding town meetings.

Section 4: Conclusion—Reality and Expectations

Most Americans, according to the numerous surveys and polls, feel that something must be done to change our current health care system. Our lawmakers in Washington understand this. As a result, legislators from both the House and the Senate and in both parties have introduced many different proposals to solve our health care problems. The problem is that the President, the members of the House and Senate, and the American people do not agree on what the final health care bill should include and how we should pay for it.

Two major goals are driving the health care reform effort: the need to provide quality care and adequate coverage for the estimated 36 to 38 million uninsured people in the United States; and the drive to reduce the overall cost of health care and the effect on the federal deficit. These goals are to some degree contradictory. Providing quality care and universal coverage to all Americans will likely increase the overall cost of health care in America, unless there are real savings that result from the reform. Whether or not these savings will occur is the subject of much debate.

What we do know is that the final health care reform bill will be a compromise and that none of the existing legislation presently in Congress will survive intact. As the debate goes on there will be much give and take, with the special interest groups fighting to protect their constituents' interests and their own economic interests. How will people with disabilities, and the four principles discussed in Section 2, fare in this battle?

Ideals and Reality

The four principles we discussed in Section 2 are ideals. If the final health care package meets those principles and includes the full range of services and health care, people with disabilities will be able to get the health care they need to meet their individual needs. But that is not likely to occur. And you must not expect to see the President and Congress develop a final bill that meets all of our needs.

As the bill moves through the committees, the congressional debate and legislative process, there will be many deals made and many trades and compromises negotiated. The final legislation will meet the needs of some people, and it will not meet the needs of other people. WILL YOUR NEEDS BE MET?

As stated earlier, there are numerous health care bills being discussed in Congress, making it extremely difficult to follow the development of each proposal. In the Appendix, we have provided summary overviews of four of the major plans under consideration. After reading about these leading approaches to health care reform, you probably agree with certain elements of each plan and disagree with others. Think again about your health care needs and the four principles. Then, contact your elected officials and express your views. Keep in touch with your senators and your representative. If you don't participate in this debate, your health care needs may be left out of our country's new health care system.

[1]White House Health Care Task Force, "Health Care Update: The Need for Health Care Reform" (August 1993): 7.

Appendix: Four Proposals for Health Care Reform

By providing a look at President Clinton's plan, as well as three other popular health plans which will be considered by Congress over the next year, ***One Step Ahead*** hopes to give people with disabilities a better understanding of the health care reform debate. This way, disabled persons will be able to participate in the decision-making process and let their concerns be heard.

Proposal 1: The Health Security Act of 1993

President Clinton's proposal is called the "Health Security Act of 1993" (H.R. 3600) and has 99 sponsors in the House of Representatives. The President's plan attempts to create competitive markets within the health insurance industry while simultaneously imposing significant government regulation on securing health care coverage. We are providing a more detailed look at the President's proposal because Congress is using this plan as a frame of reference in this debate.

The central principle of the Clinton plan is that every American is entitled to **comprehensive lifetime health insurance**. Thus, no health plan would be allowed to deny coverage or charge some people more than others based on health status, age, place of residence, employment status or income level.

What Will Be Covered?

Under this proposal, consumers would receive a health security card, giving them access to a standard set of benefits through three different types of health plans. Most Americans would receive their insurance through health maintenance organizations (HMOs), managed care entities which offer a certain combination of doctors and hospitals in return for a flat annual fee. People also would be able to join a fee-for-service plan which is more like today's system, allowing consumers to choose their own doctors. The final option would be some sort of combination of these two types of health plans. Regardless of which of these three a person chooses, each plan would have to offer the following set of benefits:

- hospital services
- emergency services

- services of physicians and other health professionals
- clinical preventive services
- mental health and substance abuse services
- family planning services
- pregnancy-related services
- hospice
- home health care
- extended-care services
- ambulance services
- outpatient laboratory and diagnostic services
- outpatient prescription drugs and biologicals
- outpatient rehabilitation services
- durable medical equipment, prosthetic and orthotic devices
- vision and hearing care
- preventive dental services for children
- health education classes

Definitions of Certain Disability-Related Benefits

- Durable Medical Equipment
  Items must improve functional abilities or prevent further deterioration in function. Does not include custom devices.
- Outpatient Rehabilitation Services
  Coverage is only for therapies used to restore functional capacity or minimize limitations on physical and cognitive functions as a result of an injury or illness. The need for continued treatment is reevaluated after each 60 days of treatment.
- Home Health Care
  Used only as an alternative to institutionalization after an injury or illness. The need for continued care is reevaluated at end of each 60 days of treatment.
- Extended Care Services
  Covers inpatient services in a skilled nursing or rehabilitation facility. Used only after an acute illness or injury as an alternative to hospitalization. Allows a maximum of 100 days per year.

Home- and Community-Based Services

The Clinton plan would increase federal authority and federal funding to expand home- and community-based services to people with severe disabilities without regard to income or age. This would be accomplished through federal-state partnerships. Benefits would include personal assistance services and standby assistance to perform the activities of daily living: eating, bathing, toileting, and transferring into and out of bed. In general, individual states would be given a certain amount of flexibility to define and design home- and community-based services.

Other Issues Concerning People With Disabilities

The proposal includes tax incentives for disabled individuals who work. Employed persons who require assistance with activities of daily living and who purchase personal assistance services may obtain a tax credit of 50 percent of their costs up to $15,000 per year.

This plan outlaws excluding people with preexisting conditions or overcharging more frequent users of health care. Instead, it establishes community rating — charging everyone in the community the same rate based on its overall past use of health care. Also included in the plan is the guarantee that a consumer will never lose his or her health insurance coverage, even if he or she changes jobs or moves to a different area.

How Would Consumers Buy Their Insurance?

Health insurance policies would be purchased through Health Alliances which would be set up in each community. These government bodies would analyze the market of health plans available to the public and provide information regarding the price and quality of each plan. Consumers would then use this information to find a policy which is right for them. By pooling groups of buyers together, the alliances would be able to bargain with health plans over price. The structure of these health plans would differ greatly, although all would be required to offer at least the standard package of benefits. Large corporations with over 5,000 employees would have the option of bypassing these alliances by offering a choice of plans directly to their employees.

Who Will Pay for My Insurance?

Employers would play a significant role in contributing to the cost of each employee's health insurance. President Clinton's plan would require employers to pay roughly 80 percent of the cost of the policy, leaving the rest for the employee to pay. Low-wage earners, as well as small businesses, would receive government assistance to help them pay their share.

Financing the President's Plan: Taxes and Savings

President Clinton has proposed paying for this plan through a 75-cent tax on each pack of cigarettes as well as through a one percent payroll tax on large companies that stay out of the health alliances. These measures would raise roughly $105 billion. Another $238 billion would be saved as a result of reductions in the growth of Medicare and Medicaid from 1995 to 2000. Also, the plan places limits on tax deductions for premiums over a certain amount.

Decreasing Health Care Costs

In addition to the hoped-for lowered prices resulting from the competition among providers of health insurance, the Clinton Administration is counting on heavy administrative savings from the use of standardized application forms and the grouping together of purchasers through the health alliances. A new national health board would be created to set a limit on what our nation spends on health care. This board would determine the annual increases in the prices of individual health plans. The allowable yearly increase in the price of each plan would be tied to the growth of our nation's Gross National Product.

Proposal 2: The Managed Competition Act of 1993

Congressman Jim Cooper, a Democrat from the state of Tennessee, has introduced The Managed Competition Act, which has become the major competition to President Clinton's bill. The act has the broadest support from both Republicans and Democrats and has 58 sponsors in the House of Representatives.

Insurance Market Reform

The plan guarantees access to health care for all Americans by using the tax laws to encourage health care providers and insurance companies to join together and form Accountable Health Plans (AHPs). The AHPs will compete with each other, theoretically driving down the cost of health insurance. Through these organizations, both insurance and health care will be sold as a single product. As a result, the AHPs will have a financial incentive to keep their enrolls healthy.

The AHPs will not be allowed to exclude people based on preexisting conditions, and they will not be able to charge higher rates to individuals who have a history of medical expenses. AHPs will have to provide a uniform set of benefits as defined by federal regulations. AHPs will have to comply with quality and cost requirements.

Access to Insurance

Individuals and small businesses will be able to join regional Health Plan Purchasing Cooperatives that will offer lower group rates. Individuals will be able to choose from a menu of all qualified plans in the area. These menus will provide information on price, quality of care, and enrollee satisfaction.

Low-income individuals will have their health care premiums paid

by the federal government either in full or on a sliding scale depending upon income level. In rural and underserved urban areas, the act provides for the establishment of new programs, development of provider networks, and the integration and coordination of clinics and public health services.

What Will Be Covered?

The act calls for the creation of an independent Health Care Standards Commission to oversee the health care market and to establish and update the standard package of health care benefits. The standard package of health care benefits must provide for the "full range of medically appropriate treatments and preventive services." Each year the commission will review and update the benefits and send them to Congress for a yes or no vote.

Individuals will be able to purchase health care plans and supplemental plans that provide for a greater range of benefits than the standard plans established by the commission. But all plans must offer the standard benefits as a minimum package.

Plan Financing and Decreasing Health Care Costs

The tax laws will be changed to limit the deductions employers can take for health care premiums to the basic benefit costs. This move is expected to raise $79 billion. Cuts in Medicare are expected to raise $40 billion. And all Medicaid funds will be used to subsidize health insurance for low-income persons.

Increased competition among the insurance companies, malpractice reform, and simplified administrative forms and procedures will save money.

Proposal 3: The American Health Security Act of 1993

Americans receive health insurance from many sources, all of which have different requirements, regulations and procedures that complicate the system and drive up costs. These administrative expenses could be avoided, some say, in a single-payer system similar to the one used in Canada. There, the government controls and pays for the health care of all persons. Since insurance is provided by one source, the system is very simple. As a result, payments are easily controlled, and wasteful administrative expenses are avoided.

Congressman Jim McDermott, a Democrat from the state of Washington, has introduced a health plan (H.R. 1200) which has become the leading single-payer proposal in Congress. Ninety-one members in the House of Representatives are cosponsoring the bill. His bill, the American Health Security Act of 1993, would create a health insurance program that would replace all public and private insurance. This program would offer health insurance to every American by January 1, 1995, and provide health security cards to all citizens at birth. The cards would be used by people to make insurance claims.

The Role of States

The American Health Security Program would be run by each individual state. States would receive a certain amount of federal funds to pay for their programs. The amount of money given to a state would be based on its population and economic condition. The federal government would end up paying for roughly 85 percent of a state's insurance expenses, leaving the rest for the states to pay.

Each state would create a health program based on specific federal rules outlined in the plan. Separate health boards would be required to

oversee the health delivery system in each state. The performance data, collected on a hospital-by-hospital basis, would have to meet certain federal standards. This single-payer health care system would replace Medicare, Medicaid, the Federal Health Benefits Program, and CHAMPUS.

What Will Be Covered?

This single-payer plan would provide health insurance for a large number of medical services. For people with disabilities, home- and community-based long-term care services would be covered for persons who are "unable to perform at least two of five activities of daily living without assistance." The bill defines those five activities as bathing, eating, dressing, toileting, and getting into and out of a bed or chair. The plan will pay for these services as long as the total expense is not more than 65 percent of the average cost of putting that person into a nursing home.

Other, more general services which every American will receive free of charge include...

- inpatient and outpatient hospital services
- durable medical equipment
- preventive services, including those that maintain health status
- nursing facility services
- hospice care
- prescription drugs and biologicals
- pediatric dental services
- mental health services
- chemical dependency treatment
- diagnostic tests
- home dialysis
- emergency ambulance services

In addition, individual states and employers could choose, at their own expense, to offer insurance for any other medical services.

People would always have these basic insurance benefits regardless of their job or where they live. The bill also calls for the creation of a national electronic database of customers so that patient records would be available to any doctor in any state. This database would cut down

on the large cost of today's complicated administrative system which uses multiple insurance forms and is expensive and inefficient.

Financing the Single-Payer Plan

To pay for this plan, many different broad-based taxes will be placed on individuals and employers. The goal of any single-payer plan is to spread the costs of national health care evenly throughout the country. The American Health Security Act would raise individual income tax rates. Income tax rates are usually considered a good way to apply equally a broad-based tax on the entire population because these taxes are based on income and, in turn, the ability to pay. This act would also increase payroll taxes — taxes that are based on a flat percentage of wage income and are limited by a ceiling amount. Some people oppose this type of tax because it hurts lower-income individuals more than higher-income individuals.

The bill also raises corporate income taxes for large companies and places a surtax on individuals with incomes over $1 million. Additional funds would be received from current sources of revenue: Medicare, Medicaid, and other federal health programs. Various other tax changes would help to pay for this Canadian-style health care system. Quite simply, everyone — individuals, governments, and employers — would be required to share the responsibility of providing our entire country with health care.

Decreasing Health Care Costs

Each year, a national budget would place limits on how much America can spend on health care. A new government body called the American Health Security Standards Board would increase this annual budget based on the past year's cost of health care plus the growth of America's Gross Domestic Product. This way, the costs of health insurance would be watched closely and controlled by the federal government to prevent the unnecessary growth of health care expenses.

The single-payer bill also recognizes the need to cut down on the amount of paperwork, which currently wastes so much money in our health care system. According to the White House Health Care Task Force, "25 cents out of every dollar on a hospital bill goes to administrative costs and does not buy any patient care." [1] To solve this problem,

each state would not be allowed to spend more than 3 percent of its budget on administrative costs.

Expanding Primary Care

The bill stresses the need for more primary care in our health care system by setting a national goal that at least 50 percent of medical residencies be in family practice, general internal medicine or general pediatrics. This goal must be accomplished within five years after the bill is passed. To do this, the bill calls for a wide variety of increases in the transfer of money to programs supporting education for health care professionals. It sets up a group of experts to advise the Health Security Standards Board on different ways to expand primary care in America.

Proposal 4: Health Equity and Access Reform Today

The Senate Republican Health Care Task Force, led by Senator John Chafee (RI), introduced its proposal for reform to Congress in November. The bill, titled "Health Equity and Access Reform Today," or HEART Act of 1993, is a comprehensive piece of legislation which calls for less drastic changes than Congressman Jim McDermott's single-payer plan or the President's plan. It is an effort to work within today's system while drawing upon the proven strengths of health care in America. Based on the premise that 85 percent of Americans already have access to quality health care, this plan strives to avoid unnecessary reforms which might disrupt what is currently good about this country's health care system.

Insurance Market Reform

The HEART Act of 1993 would establish a series of standards which all health plans would have to meet to be considered qualified options for people seeking insurance coverage. Such standards would include the requirement that every health plan have an internal quality assurance program. Plans would have certain rules for reporting information so that consumers would be able to easily choose the most appropriate plan. Only after health plans establish these standards would the plans be certified by their state.

All plans would have to guarantee eligibility for all applicants and could not, in any way, discriminate on the basis of health status. All plans would include a standard benefit package which would have to meet specific quality standards. Every American would be required to have insurance for this set of benefits, and employers would be required to offer it.

The purpose of these insurance market reforms is to eliminate competition among insurers based solely on covering those people who are low-risk consumers. Rather, the proposal aims to create a market in which competition is based on quality, price, and service.

What Will Be Covered?

This plan would establish a Benefits Commission whose job would be to set health insurance coverage guidelines and annually submit to Congress recommended changes in the standard benefits to be included in all health plans. The preliminary set of benefits includes the following:

- medical and surgical services and equipment
- prescription drugs and biologicals
- preventive health services
- rehabilitation and home health services related to an acute-care episode
- services for severe mental health problems (narrowly defined)
- substance abuse services

While meeting basic health care needs, this required set of benefits would attempt to discourage insurers from using plans which attract only low-risk individuals. This format would also allow consumers to easily make comparisons among the various competing plans.

In addition, consumers would be able to choose a catastrophic benefit plan as an alternative to the standard benefit plan.

Small Business and Individual Purchasing Cooperatives

The Republican plan would force states to set up a series of purchasing cooperatives in which businesses with fewer than 100 workers and people who are not part of an employer-based health plan would get together and buy their health plans as a group. Larger corporations which provide insurance coverage to their employees would continue to operate as they do in today's system. The cooperatives would provide their members with information concerning the quality, extent and prices of the competing health plans in their geographic area. Because people would buy their plans as a group, the Chafee bill hopes to provide small businesses and individuals with the significant market advantages which only large companies enjoy today. This, along with increased

competition among the various plans, would decrease the price of coverage.

Decreasing Health Care Costs

In addition to relying heavily on competitive forces to keep the cost of health care low, this plan would establish a panel to create data standards involving the exchange of electronic health care information. In an attempt to combat the wasteful administrative bureaucracy of today's system, these standards would streamline operations by reducing the amount of paperwork used in the health care industry. The system would be simplified by creating one claim form. The panel would also set measurable standards concerning the quality of health plans, giving consumers another method of comparing their various options.

Other methods of controlling health care costs within this proposal include medical liability reform, significant changes to antitrust laws and a new national antifraud program.

Long-Term Care

For the purpose of protecting those people with long-term care expenses, the plan clears up the confusion surrounding tax treatment for this group of consumers. The bill states that all institutional, home- and community-based care would be tax deductible. Thus, payments made under long-term care health plans will not be taxable when they are received. As for insurance companies, they would be able to deduct the lumps of money which they set aside to pay for the benefits of their long-term care clients. All of the health plans would be required to meet certain consumer protection standards to qualify for the tax breaks. The tax code reforms would help to keep costs low for people with disabilities who receive long-term care.

Primary Care

Another element of this bill which is important to people with disabilities involves efforts to shift away from specialty care and toward primary and preventive care. To help increase the number of primary care providers, funding would be expanded for the National Health Service Corps and the Public Health Service for primary care provider education. In addition, some money from the Medicare graduate med-

ical education fund would be redirected toward preventive health care training programs.

Financing This Plan

To finance the reforms outlined in this proposal, the plan would reduce spending by Medicare and Medicaid. Over the next six years, the annual rate of growth in these federal assistance programs would decrease from 12 percent to 7 percent, saving an estimated $213 billion. Much of this money would go toward the plan's long-term goal of making insurance coverage available to everyone. Thus, these savings would be used to fund a phase-in of federal assistance to all individuals who are unable to afford health care coverage.

Furthermore, the Congressional Budget Office (CBO) would be required every year to analyze how much the plan's structural reforms are actually saving. The scheduled phase-in of extending coverage to the poor would be adjusted depending on the CBO's findings.

[1] White House Health Care Task Force, "Health Care Update: The Need for Health Care Reform" (August 1993): 2.

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America's Health *in* Transition

Protecting and Improving *Quality*

A Statement of the Council of the Institute of Medicine

INSTITUTE OF MEDICINE
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The serpent has been a symbol of long life, healing, and knowledge among almost all cultures and religions since the beginning of recorded history. The image adopted as a logotype by the Institute of Medicine is based on a relief carving from ancient Greece, now held at the Staatlichemuseen in Berlin.

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high priority as health reform moves forward, and they must be diverse enough to reach groups with particular social, economic, and health needs. These are significant challenges and responsibilities for public agencies and private health plans that engage in reform efforts at the state and local levels, as well as for the federal government.

THE IOM SPECIAL INITIATIVE

The challenges and questions raised in this White Paper call for considerable investments of time, money, and effort from many different constituencies. **To respond to this need the IOM is pursuing its existing quality-of-care agenda and applying it aggressively to the points raised in this White Paper through a special initiative, designated "America's Health in Transition: Protecting and Improving the Quality of Health and Health Care."** This IOM-wide, 3-year effort will be a coordinated, focused examination of quality-of-care issues. The IOM has more than 20 years of experience in drawing attention to problems of inadequate systems of care and deficiencies in health services, as well as in devising approaches to measuring and assuring quality (see the Bibliography). This past work will be a solid starting point. In addition, the IOM will undertake further activities as the direction of health reform evolves, with special attention to the health of the public and to that of specific vulnerable populations. This program will involve both analytic studies and convening activities such as forums and workshops. Through this initiative, the IOM will remind policymakers and the public of the need for continuing efforts to monitor and improve the health and well-being of Americans and the quality of care that they receive during this period of potentially rapid and unpredictable change.

STEERING COMMITTEE ON AMERICA'S HEALTH IN TRANSITION: PROTECTING AND IMPROVING QUALITY OF HEALTH AND HEALTH CARE

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that various people or groups find useful today may not be what they will need tomorrow. We must avoid the simplistic assumption that a single set of measures will meet the needs of all interested parties.

Regardless of the direction that reform takes, the problems associated with obtaining and using comparative data for conducting health policy, making health care decisions, and improving quality of care must be surmounted. **These challenges will require significant health services research efforts as well as a national commitment to improving a wide variety of data sources such as consumer surveys, computer-based patient records, and administrative data files.**

Who Needs to Be Well-Informed About Quality of Care?

The answer is "Everyone." The audiences for information about quality of care are numerous: patients and their families; consumer agents and advocates; health professionals; administrators of health plans and facilities; payers for and purchasers of health care services; and policymakers at the national, state, and local levels. A considerable amount of public outreach, education, and communication will be required for the nation to track quality-of-care issues over the long term and for the American people to know whether the health care systems that emerge are working or breaking down.

The twin messages that quality can be measured and improved are the most important ideas to reinforce. Doing this means: (a) making sure that quality-of-care issues stay on the reform agenda; (b) stating clearly what risks and opportunities reform poses; (c) indicating how health plans and providers can be accountable to patients and society and, conversely, how individuals can take responsibility, where appropriate, for their own health; and (d) fostering multiway communications among all these groups. Such educational and communication endeavors, involving all interested parties to a degree not yet seen in the quality-of-care field, must be a

Numerous barriers keep us from realizing the goals of adequate data acquisition and information dissemination. Contemporary databases cannot reliably provide information that is dependable, accurate, complete, and appropriate for the quality-of-care and "comparative" report card tasks at hand. In addition, databases that may yield good information for policymakers at a state or national level may not provide useful information for health care professionals or consumers at a local level—and the reverse is also true. Furthermore, the collection of data, especially in clinical settings, should not be allowed to impede the delivery of optimal care.

Strategies for carrying out quality assurance and improvement are evolving rapidly, but all rely on having more and better data and data systems. Many people advocate using report cards to give consumers comparative information about individual health plans, hospitals, physicians, and other providers. We must learn more about the appropriate content of such report cards, and we must also gain more experience with making information consistent and comparable across regions and states and across health plans and providers.

How consumers could use such information to make safe and appropriate choices and find high-quality care at reasonable prices is not well understood, and there has been little systematic examination of the effects of information disclosure to the public. Thus, we need to know whether public disclosure of quality-related information on health plans, providers, or practitioners will materially influence individuals' decisions about health care or demonstrably improve the processes and outcomes of their health care. We also need to determine what influence public disclosure of such information may have on the quality of data in various databases, and whether it will improve or contaminate certain kinds of information (e.g., on malpractice actions).

Furthermore, different audiences will need different types of information for different purposes. What administrators or public officials may want to know may be quite distinct from what patients or their families may want to know, and the information

Preface

At its best, health care in America is superb. But the very best care—including prevention, early diagnosis of illness, and advanced therapeutic services—is not available to millions of Americans. Many Americans with insurance, including Medicare and Medicaid, do not have access to even adequate care. Some Americans receive too much care in the form of inappropriate or unnecessary procedures.

Aggregate health care expenditures in America are too high and threaten to undermine our ability to meet other socially important needs in education, housing, transportation, social services, and economic development. We must control total health care expenditures if we are to have the resources to meet these other needs.

In the context of this nation's history of employer-based health insurance, we are currently trying to resolve the issues of access and costs by expanding systems of managed care. Not only are these approaches spreading rapidly for the privately insured, but they are also being extended to Medicaid populations in many states.

By its charter, the Institute of Medicine is committed to efforts that will improve health and health care for all Americans. The members of the Institute, like Americans in general, have many individual views on how to accomplish this. But all of its members subscribe to the commitment to achieving the highest quality of health promotion,

disease prevention, and health care for individuals and communities in every part of our nation.

During the next few years, as change continues, we cannot lose sight of the urgent need to monitor and improve the quality of health and the effectiveness of health care within our society. This White Paper reiterates the Institute of Medicine's belief that maintaining and indeed enhancing the quality of care is a central element in reform of our health care system—quality *can* and *must* be measured, monitored, and improved. Policymakers, whether in the public or the private sector at local, state, or federal levels, must insist that the tools for measuring and improving quality be applied. These approaches require constant modification and reassessment—that is, the continual development of new strategies and the refinement of old ones. Furthermore, credible, objective, and nonpolitical surveillance and reporting of quality in health and health care must be explicitly articulated and vigorously applied as change takes place.

The Institute of Medicine, with a membership that includes leaders in public health, nursing, medicine, dentistry, biomedical science, ethics, law, administration, economics, health services research, and numerous other fields, stands ready to participate in this process. As the Institute embarks on its Special Initiative—**America's Health in Transition: Protecting and Improving the Quality of Health and Health Care**—this White Paper represents the first of many calls for high standards of quality that it will make in the service of good health and health care for all the American people.

Kenneth I. Shine, M.D.
President, Institute of Medicine

to have easy-to-use knowledge and tools, and these are increasingly available. We also need to relate retrospective measures of performance (e.g., "report cards") to actions that should be taken to guide the delivery of high-quality care.

***External* monitoring of quality of care will be necessary, however, to ensure the integrity of the quality management procedures used by plans and providers and the quality-of-care information they report and to make assessments from a broader population perspective.** It is imperative that the impact of reform on the quality of health care and the health status of the entire population be tracked. The absolute necessity of having a dual approach—internal *and* external quality monitoring and improvement—as a way of understanding the effects of reform on quality of care is not well understood by the health care community, policymakers, or consumers; thus, these issues must be explained more carefully and fully to all these audiences.

Can We Gather and Disseminate the Data We Need?

The answer is "We can in principle but current data are inadequate." Improving the performance of this society's health system and the health status and well-being of all its members—the touchstone of reform efforts—will require the collection of better, more consistent, and more comprehensive health data from a variety of sources. The uses for more and better data were recently catalogued in *Health Data in the Information Age: Use, Disclosure, and Privacy.* These are to:

> assess the health of the public and patterns of illness and injury; identify unmet regional health needs; document patterns of health care expenditures on inappropriate, wasteful, or potentially harmful services; identify cost-effective care providers; and provide information to improve the quality of care in hospitals, practitioners' offices, clinics, and other health care settings.

None of today's approaches to quality assurance and management can serve *all* the aims of reform simultaneously. Reform goals include changing provider behaviors and improving the processes of care at the health plan and practitioner levels; informing consumers about local health matters of interest so they can make better choices; providing useful, comparable data by region or across the nation as a whole; ensuring that all who need care receive it; *and* promoting good health outcomes for all Americans. The challenge is to learn more about the strengths and limitations of current quality improvement approaches in relation to the goals of health reform. This will not be easy or without cost.

Health care providers have special responsibilities for ensuring quality of care—now and as health care reform proceeds. These responsibilities involve continuing education and training, expanded health services research, and active involvement in quality improvement programs. No current reform proposals tackle these issues head on, and no single organization or institution in the private sector has fully addressed them either. Formal linkages between quality review and improvement organizations and the nation's academic health institutions may prove instrumental in fostering greater leadership and participation by all the nation's health professionals in quality-of-care activities.

***Internal* quality improvement and management efforts to develop and design care and to monitor quality of care are essential—both health plans and provider groups must act on their own to measure and improve their performance and their patients' outcomes.** Reform efforts must reinforce the steps that physicians and other health care professionals can take now toward improving the performance of local health care institutions and health plans, so that intrusive programs to micromanage care from the outside can be avoided. A correlate to this idea is strengthening the performance of the system as a whole by rewarding exemplary performance and promoting continuous improvement of all plans and providers. Finally, for quality improvement to succeed at the local level, clinicians and patients need

America's Health in Transition: Protecting and Improving the Quality of Health and Health Care

In America, we are now in the midst of an historic transition in how we seek and receive health care and in how we finance and deliver that care. Some fear that the changes under way will produce long queues for care, limit the availability of effective treatments and technologies, or lessen the personal commitment of health care providers to their patients. As we try to provide adequate access to health care for all Americans and to reduce the future cost of care, we want also to ensure that we preserve and improve the quality of care that the nation now enjoys. By enhancing the quality of health care, we will also gain greater value for our health care expenditures.

Quality-of-care concerns have often been set aside to tackle the seemingly more pressing problems of access and financing. **The Council of the Institute of Medicine (IOM) believes that quality-of-care matters must be given the same attention in policy and research as the other problems that have led us to the health care reform path on which the nation is now embarked. In fact, the quality of health care can be measured and quality measurement tools can be used to improve care and to help the health care transition succeed.**

For almost 25 years, the IOM has contributed to many pivotal health policy issues. As its 1993 monograph, *Assessing Health Care Reform*, asserts, leaders in both the public and private sectors must ensure that a reformed health care system delivers high-quality care at an affordable price to all and be ever vigilant to the risks to quality of care that change may bring. **Those who are responsible for enacting and enforcing public policy and for determining the future shape of health care in the United States must identify the public agencies and private groups that shall be responsible for overseeing quality measurement and specify to whom those organizations shall be accountable.** Such policymakers must also:

- identify the populations for whom quality of care shall be monitored, from individuals and members of health plans to groups with special health needs, communities, and the nation as a whole;
- confront the full range of quality-of-care problems, including overuse and underuse of services as well as deficiencies in the technical and interpersonal aspects of health care;
- stipulate that quality measurement include evaluation of structural elements, processes, and outcomes of care;
- create reliable uniform data systems and collect consistent data from a variety of sources;
- apply and refine tools and techniques of quality measurement and improvement that will help health care reform succeed;
- devise means of providing valid, useful information on health care quality to consumers, providers, payers, and policymakers; and
- promote communication and education among all elements of society about quality of care and the use of quality measures.

Concerns about quality of care are no excuse to delay or thwart health reform. They are a compelling reason to confront quality matters with the same vigor and sophistication as will be directed at issues of access and cost.

Can Quality of Care Be Measured and Improved?

The answer is "Yes, to varying degrees." Tested approaches already exist for measuring quality of care. Experts have been engaged, for more than 25 years, in creating reliable, valid ways to assess the quality of care for inpatient and ambulatory settings and across a wide range of health services and concerns. In a few areas, well-understood measurement tools can be put to immediate, widespread use. In others, however, the science of quality measurement is relatively elementary, making the validity of comparative assessments suspect.

One conspicuous need is to develop and apply widely accepted standards and criteria for quality measurement tools and instruments that take into consideration factors such as patient age, severity of illness, and the statistical implications of the size of the patient population. Health care reform means that Americans' concerns about quality of care, and people's ability to gather and use data, will evolve over time. Thus, even as existing quality-of-care instruments are applied, new and enhanced measurement tools must be developed.

Good ways also exist for improving the quality of health care. In addition to what we know about good and bad quality care, a "science" of systems and management (involving fields such as organizational behavior, statistics, psychology, and learning) can be used to influence positively the institutions and people who provide health services. Organization-wide quality improvement efforts are just beginning to be adopted in the service sectors worldwide. Promising work is currently under way in health care settings in the United States. Much remains to be learned about linking these concepts and tools, most of which are not yet familiar to clinicians or health administrators, to other, better-known disciplines and approaches in health, such as technology assessment, practice guidelines, clinical evaluation, and medical decisionmaking.

interactions, surgical mishaps, failure to monitor or follow up abnormal laboratory tests, neglecting to provide appropriate education and information to patients, lack of adequate coordination of care, and insensitivity to ethnic and cultural characteristics of patients.

Most quality-of-care issues today are brought to light in the context of personal health care services for individuals, but many critical problems relate to the population as a whole. Public health contributes to the health of the public through assessment of health and health needs, policy formulation, and assurance of the availability of services. This role was clearly stated in 1988 in *The Future of Public Health* and must be reaffirmed. Furthermore, those concerned with the success of health reform must be able to know how reform efforts may differentially affect certain groups of people, especially vulnerable or disadvantaged persons who are most at risk from poor care or inadequate access to care, and they must devise ways to protect such groups from any unanticipated negative effects. These tasks call for applying population-based quality measures to all types of providers in both the private and the public sectors.

Thus, **although success in health care reform calls for attention to the quality of care that individual plans, clinics, and institutions deliver, it also demands monitoring of the quality of care across the entire system.** It is imperative that the nation guard against significantly different levels of performance among the states or among markedly different populations—there are some criteria for quality that should be satisfied everywhere. **Policymakers must be clear about the extent to which national bodies and organizations have responsibilities to protect the quality of care for all populations and plans, to ensure that no particular group falls below acceptable thresholds, and to move everyone up the quality scale.**

Improving the quality of health and health care requires attention to the processes and outcomes of health services rendered to individuals, with adequate adjustments for the different disease, risk-factor, and personal characteristics of those individuals. It also demands consideration of these same elements of process, outcome, and risk adjustment for those with special health care needs and for populations.

Preventive care, promotion of healthful lifestyles, and broader public health activities are critical components of good health. For example, 10- to 24-year-olds, as a group, are likely to gain much more in improved health and survival from preventive and public-health-oriented actions than from traditional illness care. A separate paper will address the key role that public health could play in a reformed health system through population-based services, links with the medical care system to ensure the provision of quality health care to all, and public policies related to environmental health and other areas.

The IOM has demonstrated that many barriers to better health are related to socioeconomic, educational, cultural, and behavioral factors. At times these elements extend far beyond health care or health promotion and disease prevention in the usual sense. In this White Paper, however, the IOM emphasizes the central role that assessing and improving the quality of health care services have in achieving value for health care expenditures.

QUALITY OF CARE AND HEALTH CARE REFORM: KEY QUESTIONS

Can Quality of Care Be Defined?

The answer is "Yes." The IOM stated in 1990 in *Medicare: A Strategy for Quality Assurance* that "quality of care is the degree to which health services for individuals and populations increase the likelihood of desired health outcomes and are consistent with current professional knowledge." This definition has been widely accepted and has proven to be a powerful tool in the formulation of practical

approaches to quality assessment and improvement. Several ideas in this definition deserve elaboration.

The term "health services" refers to a broad range of services that affect health, including those for physical and mental illnesses. Furthermore, the definition applies to many types of health care providers (physicians, nurses, dentists, therapists, and various other health professionals) and to all settings of care (from hospitals and nursing homes to physicians' offices, community sites, and even private homes).

Including "populations" as well as "individuals" draws attention to the different perspectives that need to be addressed. On the one hand, we are concerned with the quality of care that individual plans and providers deliver; this is a traditional, familiar area of assessing and improving the care that individual patients and persons enrolled in specific health programs receive and the outcomes they experience. On the other hand, we must direct attention to the quality of care across the entire system; in particular, we must ask whether all parts of the population have access to needed and appropriate services and whether health status is improving. That focus embraces all groups, whether or not they receive care and whether they are defined by cultural heritage, sociodemographic characteristics, geography (e.g., a state or region), or diagnosis, and it recognizes that such individuals will include the most vulnerable and frail among us.

The phrase "desired health outcomes" highlights the crucial link between the processes and outcomes of health care. It underscores the importance of being mindful of people's well-being and welfare and of keeping patients and their families well informed about alternative health care interventions and their expected outcomes. Focusing on outcomes requires clinicians to take their patients' preferences and values into account as together they make health care decisions.

"Current professional knowledge" emphasizes that health professionals must stay abreast of the dynamic knowledge base within their professions and take responsibility for explaining to their patients the processes and expected outcomes of care. It involves maintaining high standards for licensure, certification, and recertification for all individuals and institutions that provide health care. Finally, it highlights the need for clinicians to contribute to the knowledge base by participating in biomedical and health services research and by developing and using clinical practice guidelines.

Where Do the Quality-of-Care Concerns Lie Today?

The answer is "In many different areas of health care." In accordance with the IOM definition, a reformed health care system must be able to address three fundamental quality-of-care issues:

1. *Use of unnecessary or inappropriate care.* Examples include excessive use of cesarean section, hysterectomy, and open-heart surgery, and overprescription of antibiotics and certain mood-altering drugs. These practices make patients vulnerable to harmful side effects. They also waste money and resources that could be put to more productive use.

2. *Underuse of needed, effective, and appropriate care.* People do not get proper preventive, diagnostic, or therapeutic services if they lack health insurance and delay seeking care or receive no care at all. Even those with insurance often face geographic, cultural, attitudinal, organizational, or other barriers that limit their abilities to seek or receive such care. For instance, mammography and immunizations are not as widely provided as most experts believe is appropriate, and many conditions, including serious depression, are often not diagnosed.

3. *Shortcomings in technical and interpersonal aspects of care.* Inferior care results when health care professionals lack full mastery of their clinical areas, cannot adequately explain key aspects of care to their patients, or cannot communicate effectively and with compassion. Cases in point include preventable medical injuries such as drug

HEALTH CARE REFORM, INDEPENDENT LIVING, AND PEOPLE WITH DISABILITIES



ISSUES IN INDEPENDENT LIVING

HEALTH CARE REFORM, INDEPENDENT LIVING, AND PEOPLE WITH DISABILITIES

A Report of the National Study Group on the Implications of Health Care Reform for Americans with Disabilities and Chronic Health Conditions

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ISSUES IN INDEPENDENT LIVING
A Publication of the ILRU Program at TIRR

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FOR PEOPLE WITH DISABILITIES

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June 1993

Dear Colleague:

In December 1992, ILRU, with support from The Robert Wood Johnson Foundation through its "Improving Service Systems for Persons with Disabilities" program hosted a national study group on health care and independent living.

The purpose of this meeting was to bring together a group of people from various backgrounds to discuss the impact of the present health care system on persons with disabilities, the possible effect of current health care reform initiatives and strategies to bring the disability community into the health care reform debate.

This report is being widely distributed and will go to persons from various fields including independent living, medical rehabilitation, public policy and health care delivery. Our hope is to provide an overview of information in order to facilitate present and future discussions regarding health care reform and its possible impact on persons with disabilities and chronic health conditions.

In the coming months ILRU will continue efforts to collect and disseminate information regarding health care reform, independent living, and disability. In addition, we will work with the National Council on Independent Living and other disability related organizations to ensure that the needs of persons with disabilities are addressed in whatever health care reform package is ultimately adopted and implemented.

Sincerely,

Lex Frieden

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

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REPORT OF A STUDY GROUP ON HEALTH CARE REFORM, PEOPLE WITH DISABILITIES, AND INDEPENDENT LIVING

INTRODUCTION

On December 3 and 4, 1992, ILRU, with support provided by The Robert Wood Johnson Foundation through its program entitled "Improving Service Systems for People with Disabilities," convened a study group to examine health care reform and its impact on people with disabilities. The purpose of the meeting, convened in Houston, Texas, was to draw upon the expertise of individuals from the independent living and disability rights, public policy, and health care fields in (1) analyzing current health care reform initiatives, (2) exploring implications of various initiatives for health care and related services critical to the well being of persons with disabilities, (3) formulating strategies for engaging persons with disabilities and disability rights advocates in the health care reform debate, and (4) identifying the types of resources (e.g., informational materials, technical assistance support) that would be most valuable to individuals and organizations concerned with the health care issues of people with disabilities.

Recognizing that a great deal of work on disability-related health care reform was already underway through the efforts of many organizations, the explicit intent of the study group was to promote substantive involvement of representatives of independent living centers and other independent living service programs in health care reform activities. It was envisioned that such involvement could include (1) grass roots activities at local levels to identify health care issues of particular concern to persons with disabilities served by independent living centers, (2) networking with other local, state, and national health care and disability service and advocacy organizations on key issues, and (3) participation in a coordinated national campaign to ensure that important philosophical concepts from the independent living movement are introduced into the debate on health care reform.

This report presents the recommendations of the study group and a summary of developments that have occurred in the six months that have passed since the study group was convened and the release of this report. This report should be viewed in light of the extraordinarily fluid atmosphere that prevails around the health care reform issue. In the months since the study group was convened, efforts have been undertaken by ILRU, The Robert Wood Johnson Foundation, and the National Council on Independent Living to gather as much information as possible about the status of health care reform initiatives proposed by the Clinton Administration, members of Congress, and others.

In recent months, members of the group have heard from informed sources numerous and sometimes conflicting reports about the chances for serious consideration of one or the other of the approaches ostensibly favored by the White House, members of Congress, and various special interest groups. While some planning details from President Clinton's Task Force on National Health Care Reform have appeared in the popular media, the flow of information can best be called a trickle. All this serves to alert the reader that information provided in this report and in subsequent publications of this and other groups needs to be considered in light of the most current proposals for health care reform that are on the table. For this reason, the currency of any information on health care reform should be questioned by all parties before actions are taken based on such information.

BACKGROUND

In some respects, the interests of the disability community in general--and the independent living movement in particular--in health care reform can be described as ambiguous. The independent living movement emerged in the late sixties and early seventies as a reaction by some people with disabilities to a service system that was dominated by medical, vocational, and other professionals. These professionals, by virtue of academic preparation and professional jurisdiction supported through licensure, accreditation, and payment mechanisms that in many cases required specific provider credentials in order for reimbursement of services, had extraordinary control over the delivery of health care services. Disability rights advocates believed that these professionals often gave little credence to the knowledge or attention to the wishes of the persons they served.

With the emergence of the independent living movement came a strong push by the disability community to "demedicalize" support services needed by individuals with disabilities living in the community. This was accompanied by strongly stated desires by persons with disabilities to play much more active roles in the planning and delivery of services that were intended to address their needs. The rallying cry for the independent living movement became "consumer control," and over the last two decades, approximately 300 community-based service programs operated by and for people with disabilities have been established nationally. Independent living centers provide service options to people with different types of disabilities who want to obtain services in which they, not medical or vocational professionals, make determinations about the goals of the service program, the types of services needed to meet specific goals, and the way in which services are to be delivered.

Given this background, it is not particularly surprising that members of the disability community and independent living movement were somewhat reluctant to wade into the growing debate about health care reform. This debate became increasingly strident in the middle and late eighties as a slumping economy and ever increasing health care costs left more and more people at risk for financial catastrophe from uninsured medical expenditures.

People in the independent living movement have fought hard to establish an identity separate from traditional "professionally" dominated service systems. This fight has included efforts to introduce low cost alternatives, such as peer counseling and independent living skills training, to the expensive services offered by professionals that had been the only option for many people with disabilities prior to the advent of the independent living movement.

Perhaps the issue that contributed most to the reluctance by members of the independent living movement to become engaged in early debates on health care reform centered on personal assistance services (PAS). Personal assistance services for people with disabilities, in the broadest sense, involve the full range of supportive assistance that a person

with a disability might require in order to have optimal independence and to function effectively in home, school, job, and social settings.

During the early years of independent living, when many of the movement's leaders were people with physical disabilities and mobility impairment, the term personal care attendant was used most often to describe an individual who might assist the person with a disability in bathing, dressing, toileting, and doing other life activities. Many people today continue to view personal assistance services from this narrow perspective of addressing the needs of people with mobility impairment. However, as the base of support for the independent living movement has expanded to include involvement by increasing numbers of people with sensory, cognitive, and mental health impairments, so has the meaning of the term personal assistance service. Today it includes the use of readers, sign language and oral interpreters, and other individuals who assist people in carrying out everyday activities that might otherwise be difficult to accomplish.

A critical aspect of personal assistance services is consumer control, including guarding against "overprofessionalization" of personal assistance service providers. With a few exceptions, as in the case of sign language interpreters, a deliberate effort has been made to avoid creating another cumbersome and expensive category of professionals that might ultimately limit the availability of services and drive up service costs associated with credentialing of providers. There is ample documentation that most personal assistance services can be provided by people who have received training by the person with a disability requiring the service or by another individual who may or may not be a health professional with experience in delivering the needed service. Such services include provision of clearly nonmedical assistance, such as dressing and eating. They also might include services such as changing urinary catheters and tracheostomy suctioning, that had traditionally been considered the domain of health care professionals.

Experience has shown that many support services can be delivered safely and reliably by persons with little or no formal health care training. While it may be assumed that consumer directed personal assistance services are more cost effective, this should not be the basis for determining the need for these services. These services, as well as more professionalized services, should be provided on the basis of need and appropriateness for the consumer with the knowledge that resulting improvements in function and quality of life will clearly justify the costs.

Independent living concepts emerged from efforts to create more rational and cost effective nonmedical, noninstitutional, consumer directed approaches to delivery of needed services for people with disabilities. This history has undoubtedly contributed to the relatively late entry of disability rights groups in general and the independent living movement in particular into the health care reform debate. Having worked hard to establish service systems that were consistent with the consumer control orientation of the independent living movement, there was reluctance by some to interject the issue of support services for persons with disabilities into the debate on health care. This reluctance stemmed from concerns related to the risk of having disability support services drawn into a service scenario that was, again,

dominated by health care professionals. The current health care system, in many cases, relies on service authorizations requiring high-cost medical evaluations and diagnostic procedures. Often such authorizations are made only for services deemed "medically necessary," which in some cases translates into having a service performed by someone with a health care credential, even though the service, such as changing a urinary catheter, may be routine.

Notwithstanding concerns on the part of many people with disabilities associated with "professionalizing" routine support services and the impact of such actions in terms of costs for and accessibility to such services, few would argue that many people with disabilities are at greater risk for certain health problems. In the case of people with mobility impairment, risks for skin and urinary tract problems are increased. In the case of people with chronic health conditions such as cystic fibrosis, risks for respiratory disease are increased. Access to affordable health care services provided by professionals who understand the nature of disability and its influence on development and progression of disease is a critical factor if people with disabilities are to maintain optimal independence in community settings.

Similarly, optimal independence cannot be attained if opportunities for employment and career advancement are not available. Health care plays an important and sometimes subtle role in employment and career options available to people with disabilities. People with disabilities may find an employer unwilling to hire them out of fear that the organization's health insurance premiums might increase substantially because of perceived risks of high cost health care needs of people with disabilities. In another case, the individual with a disability may receive a job offer from an employer, but be faced with the choice of giving up existing publicly or privately funded health care coverage in order to accept the job, while taking the risk of going without health care coverage because the prospective employer's insurance carrier will not cover "pre-existing conditions." These conditions usually include all health conditions associated with the person's disability. In still other situations, people with disabilities who are working find themselves reluctant or unable to take advantage of opportunities for career advancement because pre-existing condition exemptions in health insurance plans preclude them from giving up their current employment in order to take advantage of attractive opportunities.

Although the enactment of the Americans with Disabilities Act (ADA) on July 26, 1990 did much to eliminate discrimination against persons with disabilities in employment, public accommodations (e.g., restaurants, theaters), and governmental facilities, it left health insurance virtually untouched. Because employers can continue to deny health insurance coverage to persons with disabilities and chronic health conditions--or require them to pay premiums for coverage far higher than those paid by other employees--the net effect of ADA as a tool for eliminating discrimination against people with disabilities is diminished. De facto employment discrimination against people with disabilities occurs when they are forced to decline otherwise attractive employment offers because the offer does not include comprehensive health care coverage or includes such coverage at costs so high that it makes acceptance of the position infeasible. Although a recent announcement from EEOC provides interim enforcement guidance on the application of ADA to employer-provided health insurance, the impact of this action in eliminating discriminatory employer practices is not yet clear.

Concerns about the availability of quality health care services, as well as limited employment opportunities and the diminished life potential associated with such limitations, created an imperative for disability groups to enter the debate on health care reform. Early leadership on health care reform and disability issues was provided by the Consortium for Citizens with Disabilities (CCD). With involvement of some 41 organizations representing a broad spectrum of health care providers and disability groups, including the National Council on Independent Living, CCD sponsored a series of working sessions on health care reform and disability. The primary product of these meetings was formulation of statements embodying five principles that need to be considered in any health care reform initiative in order to address the needs of persons with disabilities adequately.

These five principles are as follow:

1) Non-discrimination -- People with disabilities and other chronic conditions of all ages and their families must be able to participate fully in the nation's health care system;

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

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

4) 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; and

5) 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.

While the study group endorsed the five principals formulated by CCD, it was felt that a sixth principal should be added. This principal, focusing on the issue of consumer control, is somewhat addressed under "appropriateness" but should stand alone. Consumer control is the cornerstone of the independent living movement, and as such it merits individual attention in any discussion of health care reform and people with disabilities.

6) Consumer Control -- People with disabilities should be involved in directing their health care, including such things as choosing and directing a physician, personal assistant, or other provider. In addition, people with disabilities should play a meaningful role in the formulation of public health care policy, participate in the development and monitoring of medical practice standards, and contribute to decisions about benefits and providers that are to be specified in any reformed health care system that may emerge.

The five CCD principles, along with the principal of consumer control, provide an excellent basis for considering the relative merits of various health care reform proposals. However, these principles were not intended to address specific issues of service coverage, administrative structure, delivery mechanisms, and cost containment methods that will ultimately determine the impact of health care reform on various groups and individuals. These issues must be considered and addressed by the various constituencies--including the independent living field--that know and understand the health care and related needs of the disability community.

Prior to December 1992, the independent living constituency had been involved to a limited extent in health care reform activities. A number of leaders in independent living, including members of the National Council on Independent Living board of directors, have been active in health care reform efforts. In fact, at its May 1992 Annual Meeting a resolution on health care reform, including endorsement of the single payor approach and consumer-controlled personal assistance services, was passed by the National Council on Independent Living membership. However, there was no strategy in place to promote constructive involvement of the independent living constituency in health care reform initiatives.

ILRU's decision to convene a meeting on health care reform and persons with disabilities was a logical extension of its work through The Robert Wood Johnson Foundation-supported project "Improving Service Systems for People with Disabilities." This project, operated through eleven independent living centers around the country, is designed to promote innovative approaches for delivering services to people with disabilities--including health care services. All eleven of the demonstration sites address health care needs--albeit to varying degrees--in their projects. Through its support of a national program office at ILRU, The Robert Wood Johnson Foundation has provided funding to facilitate activities designed to support the sites and to promote replication of service innovations developed at the eleven sites that are shown to be effective in improving independent living service delivery.

FORMAT OF THE STUDY GROUP MEETING

Pre-meeting activities. Prior to the meeting, individuals representing a variety of perspectives and political viewpoints were contacted regarding participation in meeting activities. Many individuals expressed interest in participating in the study group, although some were unable to participate because of prior commitments. The study group that met in Houston consisted of 18 persons. The listing of participants and their current affiliations is provided at the front of this report.

Prior to the meeting, participants were sent a packet of information that included journal articles and papers about problems in the health care system and various approaches to addressing these problems. These documents included discussions of the "managed competition" and "single payer" concepts, as well as manuscripts on health care services and disability by a number of authors. Biographical sketches of participants were also provided.

Meeting activities. The study group convened at 9:00 a.m. on December 3, 1992. Following introductions of each of the meeting participants, Lex Frieden provided a brief overview of the purpose of the meeting and turned the meeting over to Marie Oser, who acted as facilitator for the first day's activities. The first day was devoted to a general discussion of the issues by the large group. Following this large group discussion, the participants were divided into three small groups. Each of the small groups was charged with identifying key issues in health care reform.

The large group was reconvened at the end of the day on December 3, and key issues raised during discussion groups were summarized. At this point, the group decided to alter the plans for the second day of the meeting. The decision was made for participants to self-select into one of three small groups dealing with the topics of (1) policy analysis, (2) formulation of consumer guidelines, and (3) networking and advocacy.

The second day of activities began with consideration of a position statement that had been formulated during the previous evening. The position statement was read to the group and discussed at length by the participants. Several revisions were recommended. The discussion was closed with adoption of the position statement as revised by the group. The revised position statement was overwhelmingly approved by the study group. A copy of the revised position statement is included as Appendix A of this report.

Following approval of the position statement and some general discussion of the format for the remainder of the meeting, the participants went to the small groups that they had chosen on the previous day to discuss the assigned topics. Key points identified by the small groups and refined in the large group discussion that concluded the meeting at the end of the second day are summarized in the following section of this report.

STUDY GROUP RESULTS

The results of the large and small group discussions from the two-day meeting are summarized below under topical headings. Recommendations for action strategies formulated by the group are summarized as well.

- Paradigm shift. There must be a shift away from the current "episodic sickness" model of health care and toward a long-term partnership between provider, consumer, and payor that focuses on achieving the maximum wellness possible for every individual. This is perhaps the most critical issue in the health care reform debate. Rather than continuing a system in which the incentive for providers is to deliver more and higher cost services, the new system should provide incentives for early, low technology, low cost interventions that reduce the likelihood of onset of serious health problems requiring high cost services. Implicit in this discussion is the need to examine the way in which practitioners are used in the health care system. Efforts need to be taken to determine if the least costly professionals who are qualified to deliver primary preventive and interventive care services are being used effectively. More extensive use of qualified non-physician primary care providers, particularly in delivery of health promotion and disease prevention services targeted to persons with disabilities and chronic health conditions, should be given high priority.

- Cost effectiveness. Cost effectiveness needs to be stressed over cost containment. Providing appropriate services at the right time will result in greater savings to the system than will efforts to avoid costs by refusing payment for low-cost prevention and early intervention services. This approach will require consumers to take more control over decisions about when to enter the health care system and what types of services are appropriate. However, a better educated consumer who seeks prevention and early intervention services at appropriate times is a goal that will have substantial long-term payoff for the larger health care system. In fact, many people with disabilities have been forced to become knowledgeable about the interaction between disability and health by virtue of the fact that most health care providers have little understanding in this area. Many people with disabilities are accustomed to having to "educate" health care providers concerning their health status, the impact of their disabilities on their general health, and the types of interventions that are most effective in addressing chronic and acute health problems. The experience of persons with disabilities in taking responsibility for maintaining their health may be a model that should be looked at for the larger population.

- Access and coverage. Universal access and mandated coverage make more fiscal sense than does the current system of limited access and selective coverage. The notion that not providing health care coverage to some individuals is cost effective over the long term is fallacious. Although individuals or certain groups may have lower costs at specific points in time by denying health insurance coverage to some people, the long-term result of this practice is higher cost for everyone. Since people are not denied health care because they do not have coverage under an existing private or public health care plan, the only real impact of the current "patchwork" approach to health care coverage is that a significant portion of people--those without coverage or those with less comprehensive coverage--tend to avoid seeking health care services until their health problems become serious and require high cost intervention. We all pay more for this behavior in the long term.

- Equity. Financing of health care services needs to be arranged in a manner that does not penalize some segments of society in favor of others. At present, individuals who have educational backgrounds or other qualifications that allow them entry into certain job markets are eligible to receive, at little or no cost to themselves, high quality comprehensive health care services. Other individuals, by virtue of diminished educational opportunities and restricted employment options may incur substantial out-of-pocket costs for quite limited health care services from a restricted number of providers. Health care reform efforts should work toward providing a good quality health care plan to every individual. In any plan, costs should be spread equitably so that individuals receiving premium services through a plan that exceeds, either in quality or quantity of benefits, the plan available to the general public incur the costs of premium services. This implies that a mechanism be in place to prohibit the passing on to others the higher costs for premium plans through negotiated rates that favor large employers or groups that intentionally select only those who are in the best of health and are least likely to use health care services.

- Portability. Health care coverage should be portable, so that people can pursue careers and life options without fear of catastrophic financial loss associated with changing jobs or life situations. At present, for many individuals with disabilities and chronic health problems, considering new job offers or thinking of relocating to other geographic locations may be tantamount to playing Russian roulette. A new employer may offer a job and health insurance coverage, including coverage of "pre-existing" conditions after some established waiting period--typically six months or one year. However, for the person with a disability or chronic health condition this may represent a choice between (1) accepting the offer and a significant pay increase or new job challenges, or (2) rejecting the offer to avoid risk of financial disaster related to onset of a health problem that is considered to be related to his or her pre-existing condition. This type of limitation in life options is extremely detrimental to persons with disabilities who are forced to stay in "dead-end" jobs not because they lack job

skills, but because they cannot gamble with their financial futures by "risking" a job change. Any health care reform should include reasonably priced provisions for comprehensive health insurance coverage to be retained by individuals with disabilities wishing to pursue other life options.

- System responsiveness. Any health care reform initiative should include mechanisms to promote professional responsiveness to consumer needs. Although the United States may boast some of the technically best prepared health care professionals in the world, the ability of many health care providers to listen and respond to the needs of consumers is questionable. The independent living movement provides ample evidence of the failure of professionally dominated service systems--both medical and vocational--to respond effectively to the needs of people seeking services. However, there are limitations in the types of services that can be provided through the independent living service model and there will always be a substantial role for medical professionals in service systems designed to address the health care needs of persons with disabilities. An emphasis needs to be placed on revising the educational programs of health care professionals so that as much emphasis is placed on promoting human development--including involvement in making decisions that effect one's life--and on preservation of individual dignity as is placed on technical proficiency in executing clinical procedures. This calls for intervention in entry level professional preparation as well as in the organization and delivery of health care services.

In order to address the key issues summarized above, a number of specific action strategies were developed by the study group. These include:

1. developing and publishing a user-friendly guide on health care reform for persons with disabilities, including an analytical approach for evaluating health care reform initiatives that provides examples of use in assessment of current health care proposals;

2. preparing and disseminating a dictionary of plain language definitions of health care reform terms and examples of their application in debate and discussions;

3. developing and implementing an empowerment-oriented strategy for educating consumers about health care reform;

4. facilitating formation of strategic alliances between disability groups and other groups with shared interests in health care reform issues; and

5. fostering participation of disability consumer groups and advocacy organizations in the health care reform process.

PROGRESS SINCE THE STUDY GROUP MEETING

Since the December meeting in Houston, a number of activities have been completed involving one or more of the five strategies outlined above. First, contact was made with the leadership of the National Council on Independent Living (NCIL) to offer assistance in promoting NCIL participation in health care reform initiatives. The outcome of this offer was that ILRU staff and invited experts on health care reform participated in a one and one-half day information sharing session with the NCIL board of directors in Washington, D.C. on February 20 and 21, 1993. This session was used to provide information to NCIL board members on the two most frequently discussed health care reform approaches (managed competition and single payer), and to facilitate discussion on the health care needs of people with disabilities from the independent living perspective.

At this meeting, the NCIL board reaffirmed its support of the resolution that was passed by its membership at the NCIL Annual Meeting on May 17, 1992. This resolution included support of the single payer approach, as well as inclusion of consumer-directed personal assistance services in any proposed plan for health care reform. The NCIL board also began developing strategies for communicating with its members and other independent living centers on health care reform issues. Subsequent to the February board meeting with partial support from ILRU, NCIL has produced and distributed a position paper on health care reform.

Second, NCIL conducted two sessions on health care reform on May 8, 1993 at its Annual Conference on Independent Living in Bethesda, Maryland. These well-attended sessions involved a panel of experts on health care reform and disability, including an ILRU representative.

Third, ILRU provided a copy of the "Statement of Principle of the National Study Group on Health Care System Reform and Persons with Disabilities" to the National Council on Disability for inclusion in its report entitled, Sharing the Risk and Ensuring Independence: A Disability Perspective on Access to Health Insurance and Health-Related Services, released in March 1993. This document, prepared as a report to the President and Congress, has been widely distributed to disability-related organizations and policy making bodies nationally.

Fourth, ILRU staff provided staff of The Robert Wood Johnson Foundation with names and contact information of people with disabilities who could participate in community meetings set up by the Foundation for the President's Task Force on National Health Care Reform. A number of the individuals contacted were able to participate and Marca Bristo, President of Access Living in Chicago, was a respondent on the panel assembled for the last

of these meetings in Washington, D.C., on March 25, 1993. Identification of individuals who can articulate the concerns of people with various types of disabilities and contribute to deliberations on health care reform issues will continue to be a high priority for ILRU and our colleagues in the study group.

Fifth, the ILRU project on "Improving Service Systems for People with Disabilities" devoted a half day of its annual meeting on March 25 and 26 in San Diego to health care reform and the role of independent living centers. Experts on the managed competition and single payer approaches participated in the session, as did a representative of the NCIL board. Staff of the eleven project sites were encouraged to become actively engaged in health care reform issues at both local and national levels through efforts to identify the health care needs of their constituents and to convey those needs to policy makers and other leaders of the health care reform initiative.

Sixth, ILRU has begun disseminating information on activities around disability and health care reform, using the ILRU Insights newsletter and other mechanisms, such as the DIMENET computer network. These efforts will be expanded as more information becomes available on the health care reform approaches put forth by the Clinton Administration and various members of Congress. The Administration's plan is expected to be released in summer 1993.

Seventh, the development of the user-friendly guide on health care reform is underway, but will probably not be released until the Administration's plan has been announced. The decision to defer release of the guide was based on the rationale that a good deal of information on health care reform is currently available for use in analyzing various alternatives that have been announced to date. This information includes materials developed by various consumer and provider groups, such as Citizens Action and the American Medical Association, respectively. In order to be most helpful to individuals who might use it, the content and language of any guide needs to employ terminology and examples relevant to current proposals. As such, release of the guide will be deferred until the Administration's health care reform proposal is announced.

Likewise, the dictionary of terms will be deferred until the Administration's proposal is released. As was stated earlier in this report, the health care reform effort is very fluid. Since the end of March 1993, news reports have indicated that the term "health insurance purchasing cooperative" (HIPC), used to describe a group of consumers constituted to buy health coverage, has been jettisoned in favor of the term "health alliance." Similar changes in terminology are likely to be forthcoming throughout the planning stages of health care reform efforts and into implementation. Efforts will be made to provide members of the disability community with current terminology and its meaning with regard to various proposals put forth by the Clinton Administration and others.

Efforts to develop effective dissemination strategies and network with consumer and provider groups with similar interests will be ongoing.

CLOSING REMARKS

Health care reform is a critical issue to persons with disabilities. Without adequate, appropriate, and accessible health care, other activities designed to promote individual independence and community integration of persons with disabilities cannot yield desired results. Maintaining the best possible health is crucial to people with disabilities if they are to have reasonable opportunities to pursue school, work, family, and social options taken for granted by people without disabilities.

Just as important as the adequacy, appropriateness, and accessibility of health care services is the orientation of health care providers to the way in which such services are provided. One lesson that has been learned through the success of the independent living movement is that all people, regardless of their disability or functional limitations, can assume responsibility for planning and pursuing life goals. The independent living movement has demonstrated the value of substantive consumer involvement in service planning and implementation. The important concepts of choice, self direction, and individual dignity must be integral to any health care reform plan that is adopted. Leaders from the independent living movement can and should play an instrumental role in assuring that these concepts are not forgotten in the rush to address coverage, containment, and consensus.

STATEMENT OF PRINCIPAL OF THE NATIONAL STUDY GROUP ON HEALTH CARE SYSTEM REFORM AND PERSONS WITH DISABILITIES

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 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 to 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 Consortium for Citizens with Disabilities (CCD). The system as a whole must be: (1) non-discriminatory, ensuring that people with disabilities of all ages and their 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.

APPENDIX B

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 37 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 and counseling services
- habilitation services
- rehabilitation services, including audiology, occupational therapy, physical therapy, 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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Consortium for Citizens with Disabilities

CONSORTIUM FOR CITIZENS WITH DISABILITIES
HEALTH TASK FORCE

"PRINCIPLES FOR HEALTH CARE REFORM
FROM A DISABILITY PERSPECTIVE"

December, 1991
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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
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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

APPENDIX C

SELECTED READINGS

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ABOUT ILRU

ILRU (Independent Living Research Utilization) was established in 1977 to serve as a national center for information, training, research, and technical assistance for independent living. In the mid-1980's, it began conducting management training programs for executive directors and middle managers of independent living centers in the U.S. Since 1985, it has operated the ILRU Research and Training Center on Independent Living at TIRR, through which is conducted a comprehensive and coordinated set of research, training, and technical assistance projects focusing on leading issues facing the independent living field.

ILRU has developed an extensive set of resource materials on various aspects of independent living, including a comprehensive directory of programs providing independent living services in the U.S. and Canada. For more information contact, ILRU; 2323 S. Shepherd, Suite 1000; Houston, Texas 77019; (713) 520-0232, 520-5136 (TDD).

ILRU is a program of TIRR, a nationally recognized, free-standing comprehensive rehabilitation facility for persons with disabilities. Since 1959, TIRR has provided patient care, education, and research to promote the integration of people with physical and cognitive disabilities into all aspects of community living. TIRR is part of TIRR Systems, which is a not-for-profit corporation dedicated to providing a continuum of services to individuals with disabilities.

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