

LONG-TERM CARE

HEARING
BEFORE THE
SPECIAL COMMITTEE ON AGING
UNITED STATES SENATE
ONE HUNDRED THIRD CONGRESS
SECOND SESSION

—
MILWAUKEE, WI
—

MAY 9, 1994
—

Serial No. 103-20
—

Printed for the use of the Special Committee on Aging



U.S. GOVERNMENT PRINTING OFFICE
WASHINGTON : 1994

84-657

For sale by the U.S. Government Printing Office
Superintendent of Documents, Congressional Sales Office, Washington, DC 20402
ISBN 0-16-046394-7

SPECIAL COMMITTEE ON AGING

DAVID PRYOR, Arkansas, *Chairman*

JOHN GLENN, Ohio
BILL BRADLEY, New Jersey
J. BENNETT JOHNSTON, Louisiana
JOHN B. BREAUX, Louisiana
RICHARD SHELBY, Alabama
HARRY REID, Nevada
BOB GRAHAM, Florida
HERB KOHL, Wisconsin
RUSSELL D. FEINGOLD, Wisconsin
DONALD W. RIEGLE, Jr., Michigan

WILLIAM S. COHEN, Maine
LARRY PRESSLER, South Dakota
CHARLES E. GRASSLEY, Iowa
ALAN K. SIMPSON, Wyoming
JAMES M. JEFFORDS, Vermont
JOHN MCCAIN, Arizona
DAVE DURENBERGER, Minnesota
LARRY CRAIG, Idaho
CONRAD BURNS, Montana
ARLEN SPECTER, Pennsylvania

THERESA M. FORSTER, *Staff Director*

MARY BERRY GERWIN, *Minority Staff Director/Chief Counsel*

CONTENTS

MAY 9, 1994

	Page
Opening Statement of Senator Russell D. Feingold, acting chairman	1
Statement of Senator Herb Kohl	37

CHRONOLOGICAL LIST OF WITNESSES

Eugene Lehrmann, president, American Association of Retired Persons	3
John Cram, Milwaukee, WI	27
Susan Olson and John Olson	28
Linda Rowley, accompanied by her son Mitchell	29
Sharon Dobrzynski	33
Ann Hauser, Milwaukee, WI	35
Dorothy Freund, Milwaukee, WI	38
Stephanie Sue Stein, Milwaukee County Department of Aging, Milwaukee, WI	41
Tom Hlavacek, Wisconsin Commission on Aging	43
Bev Young, founder, National Alliance for the Mentally Ill	45

(III)

LONG-TERM CARE

MONDAY, MAY 9, 1994

U.S. SENATE,
SPECIAL COMMITTEE ON AGING,
Milwaukee, WI.

The Committee met, pursuant to notice, at 12:30 p.m. at the Milwaukee Transit Center, 909 East Michigan Street, Milwaukee, WI, Hon. Russ Feingold (Acting Chairman of the Committee) presiding.
Present: Senators Feingold and Kohl.
Staff present: Sumner Slichter.

OPENING STATEMENT OF SENATOR RUSSELL D. FEINGOLD, ACTING CHAIRMAN

Senator FEINGOLD. I call this meeting to order. I am Senator Russ Feingold. I thank you very much for coming to our field hearing on long-term care.

Next to me is somebody most of you know, Sumner Slichter, who was the committee clerk of the Wisconsin State Senate Committee on Aging when I was the chairman for 10 years, and now Sumner works with me in Washington on a variety of issues, including health care reform and, in particular, long-term care.

I want to welcome all of you to this field hearing. I am especially proud to be able to hold this hearing in Milwaukee, as Wisconsin generally, and Milwaukee in particular, have done some of the most creative work in long-term care.

As many of you know, First Lady Hillary Rodham Clinton has singled out Wisconsin for the work that we have done in long-term care, and the new home and community benefit in the President's health care plan proposal is modeled, in large part, on the Wisconsin Community Options Program.

In my 10 years in the Wisconsin State Senate, one of the things that we all had to be proud of was the work that we all did on enhancing and expanding the Community Options Program. So I am proud that the President and the First Lady have looked to Wisconsin, and COP in particular, as a model for the groundbreaking long-term care provisions of the Administration's long-term care health plan.

For those who say long-term care reform is a luxury that we cannot afford, I say come to Wisconsin. COP works for the people who need care, for the people who give care, and it saves the taxpayers money every day. We cannot afford not to reform long-term care.

The experience we have had in Wisconsin is clearly relevant to what is being considered at the Federal level, and I hope that our hearing today will lead to a better understanding, not only here,

but across the country, and especially in the halls of Congress, about what is needed and what can be done.

Let me take this moment to thank the Chairman of this Committee, Senator David Pryor of Arkansas. He allowed us to hold this field hearing today in Milwaukee, and he has been a leader on long-term care reform, and I look forward to working with him to include long-term care reform in any health care reform package that we might pass before the end of the year.

I also want to thank my colleague, the senior Senator from Wisconsin, Senator Herb Kohl, for his efforts, and I believe Senator Kohl will be arriving later. He has been a member of the same committee, the Aging Committee, since he was elected to the U.S. Senate in 1988. So he is in his fifth year, sixth year actually, on the Committee. And he, too, has taken a lead on aging issues. It was his field hearing in Madison a few years ago, prior to my being in the U.S. Senate, that led directly to reforms in the Medicare supplemental insurance market. It is a great pleasure to be able to work with him on the Committee, and Wisconsin, of course, is one of the only States—I don't know if it is the only or one of the only—that has both of its Senators on the U.S. Senate Aging Committee.

My thanks also to today's witnesses.

I want to remind you, of course, that in U.S. Senate field hearings we have an invitation system that is required to testify, so I hope no one here will be disappointed that you can't testify. We have left papers on your chairs, so if you want to comment and are not on the list of speakers, that you are able to write or communicate to us, and that will go on the record, I believe, as a part of the official record which will be presented to the U.S. Government offices.

Now, one of the people that will be testifying today is Gene Lehrmann, who was one of the first people to visit me after I became a State senator in 1983. His leadership for long-term care reform in Wisconsin is well-known, and he is the new national president of the American Association of Retired Persons. So he is particularly well-positioned to both lead the fight for long-term care and to truly understand what real reform means in this area.

Finally, I want to thank all of you who took the time to attend today's hearing. Many of you are here because you believe in long-term care reform. But I know some others are here to learn about the issue. An important function of the U.S. Senate Committee should be to educate, and there may be no more important matter on which this Committee can educate both the public and policy-makers than the need for fundamental long-term care reform.

Some of our witnesses like Gene are advocates. Others are long-term care consumers, and others are caregivers. For those of who are learning about this area, you will find that the impact of long-term care on caregivers is one of the pivotal issues, both for understanding the issue and if you want to get anything passed in Washington.

The average American who is caring for a loved one has to miss a week-and-a-half of each year just to provide care, and almost a third of American workers who are caring for a loved one had to reduce their hours or even quit their jobs just to provide care. One-

quarter of American workers over 30 are caring for an elderly parent, and almost half of all workers expect to care for an aging parent in the next 5 years. Some estimate that there are over 10 million Americans that need some level of long-term care, and those individuals are rightly the focus of much of this discussion.

Of course, when we talk about long-term care, we all know that we are not talking only about the elderly but many other people, whether they be developmentally disabled, severely mentally ill, physically disabled, technology-dependent children, and so on. That is what the President's plan is about, as well as the work we have done here in Wisconsin.

Most of the long-term care that is provided in this country currently is provided in the home by family members, and providing that care often takes a toll. We need to consider the caregiver as well as the consumer of long-term care services as we reform the long-term care system.

I believe strongly that health care reform cannot be genuine or complete if we fail to reform our long-term care system. If we partition health care into acute care and long-term care, I think it makes no sense for consumers and caregivers.

Providing coverage for heart disease but not for Alzheimer's disease is entirely arbitrary from the point of view of the consumer, and such a distinction strikes at the very heart of the principle of universal coverage. How can we argue that we have achieved universal health care coverage if the health care problems of 10 million Americans remain uncovered? Of course we cannot. Long-term care reform is an essential and indivisible part of health care reform.

So today's hearing will have a limited set of witnesses. But I do want to hear from you on long-term care or any other matter. You can write to me or call my office if you wish, or please feel free to attend any one of the 72 listening sessions I hold in every county in the State every single year. We have already held 36 of them this year in Wisconsin.

Much of the work I do in Washington has come from ideas presented at one of the listening sessions. In fact, my work in the area of long-term care really began with some listening that I did when, by listening to some of the people in this room, when they first started talking to me about this issue some 6 years ago.

So thanks again to everyone. I look forward to hearing from our witnesses and I greatly appreciate your attention.

We will ask the witnesses to come to this table, and the first panel is composed entirely of my good friend Eugene Lehrmann.

STATEMENT OF EUGENE LEHRMANN, PRESIDENT, AMERICAN ASSOCIATION OF RETIRED PERSONS

Mr. LEHRMANN. Thank you very much, Senator. It's my pleasure to be here and testify on a favorite topic of mine, long-term care.

We very much appreciate your strong interest and leadership on the long-term care issue, both here in Wisconsin, in helping to enact the Community Options Program, as well as back in the Nation's capital. Thank you for holding this important meeting here in Milwaukee.

The inclusion of long-term care in health care reform legislation is vital to Americans of all ages and critical to AARP's support for any health care reform proposal. Too many reform proposals focus only on acute care and simply ignore the long-term care needs of American families, as if these needs were so easily compartmentalized in the lives of these families. Such proposals are fundamentally flawed because they fail to address the need for a full continuum of care throughout an individual's life.

For families, there is no difference between spending \$20,000 on home care and spending \$20,000 on hospital care. It still is \$20,000 they do not have. Without long-term care coverage, no family has real security against the crippling costs of serious illnesses or disability.

Most of us have personal experiences, friends or family, who have had to cope with financial, physical, and emotional stresses involved in meeting long-term care needs.

As policymakers, it's natural to translate the subject into a vision of Federal budget dollar signs. Our families also see dollar signs. They see huge dollar signs when they struggle to pay for home care for a child or a spouse or a parent while still dealing with college tuition costs and a home mortgage.

Caregivers, most often daughters, spouses, and mothers, see not only the direct cost of giving care, but also the income they lose, both now and in their future. Caregivers often forego higher paying job opportunities. They work part-time or give up their job altogether. Each of these decisions means less income now and less pension and Social Security income in the future.

The Government also pays in lost tax revenue and higher assistance costs later. The private insurance market has not provided, nor can it provide, adequate and affordable protection against the costs of long-term care.

Private long-term care insurance that provides meaningful coverage is very expensive and generally excuses people with preexisting conditions or mental disorders. Few people can afford the cost of private long-term care insurance for any length of time, particularly if the policy provides meaningful protection.

Private long-term care insurance policies have done a particularly poor job in trying to cover home care because insurance companies are not confident of their ability to control risks and the demand involved.

The President's proposal for a new home and community-based program recognizes that few families can afford the cost of long-term care. It also recognizes that the need for long-term care extends to all age groups—a child born with a developmental disability; an automobile accident victim in midlife; or a parent with Alzheimer's disease. Appropriately, the proposal focuses eligibility on measures of disability; not age or income. It would give persons of all generations new choices and address the current system's institutional bias by helping families to avoid having to place loved ones in nursing homes.

The President's home and community-based care proposal also would be good for our Nation's economy, providing assistance to working caregivers and helping support out disabled persons to become productive taxpaying members of society, and it would create

new jobs, by one estimate as many as a million, as home care options expand.

For those who think the program is too expensive, it is important to point out that the President's proposal would strictly limit new Federal expenditures for home and community-based care by capping Federal expenditures, imposing stringent eligibility criteria, providing for a long 7-year phase-in period, and providing for income-related copayments.

Most of these criteria are not ideas that AARP would propose if we felt there were any possibility of funding a more comprehensive program. But AARP is realistic about what we may be able to finance as part of a health care reform legislation, and we believe the President's proposal is a very good start.

It is also important to note that most States would realize significant savings from this new program due to Medicaid offsets derived from the greatly enhanced Federal match rate under the proposed new program. The administration has estimated that Wisconsin would save \$389 million between the years 1996 and 2000.

In his State of the Union Address the President said the American public is way ahead of the politicians on the issue of health care reform.

I wouldn't say that about you, Senator, but about most politicians.

We believe this is to be particularly true of long-term care. The findings from each of our four surveys conducted for AARP by an independent firm between April 1993 and January 1994, all show that the public support for health care reform increases dramatically when long-term care coverage is included.

The most recent survey conducted this past January found that 64 percent of the respondents were more likely to support a health care reform proposal that included comprehensive long-term care coverage, and 42 percent were much less likely to support a proposal with no long-term care coverage.

In conclusion, Senator, AARP commends the President and Members of Congress of both parties who have brought the debate to this stage.

The President has made an important, far-reaching step forward toward achieving security against the overwhelming human costs of long-term care.

The proposed new program does not meet the full extent of the need for long-term care, and therefore, we should be careful not to oversell it.

The proposal is, however, a great improvement over our current system and would provide much needed assistance to millions of Americans and their families.

As we go forward, we ask that you always consider the cost to American families of not including long-term care in health care reform.

The President's home and community-based care proposal can begin to provide greater security and protection now and a solid foundation for the future.

There's one thing we must all agree on, the status quo is not an acceptable option.

Senator, AARP deeply appreciates your strong interests and leadership on this issue and looks forward to working closely with you to ensure that long-term care remains an integral part of the health care reform plan.

Thank you very much.

[The prepared statement of Eugene Lehrmann follows:]



Bringing lifetimes of experience and leadership to serve all generations.

STATEMENT
of the
AMERICAN ASSOCIATION OF RETIRED PERSONS
on
LONG TERM CARE

Presented by

EUGENE LEHRMANN

President, AARP

My name is Eugene Lehrmann and I am the President of the American Association of Retired Persons (AARP). I want to thank Senator Feingold for holding this important hearing on the need to include meaningful long-term care coverage in health care reform legislation.

The inclusion of long-term care in health care reform legislation is vital to Americans of all ages and is critical to AARP's support for any health care reform proposal. Historically, many Americans have equated long-term care with nursing home care. Long-term care, however, is much more than just nursing home care. It includes a wide range of home and community-based care as well as residential alternatives.

Long-term care is typically considered a benefit for the elderly. This is a myth. The need for long-term care crosses generational lines. An estimated 10 million persons need some form of long-term care. Approximately one-third of these individuals are under age 65. Many are children. Moreover, the need for long-term care is felt not just by those requiring care, but also by their families -- often those providing and paying for care. This is particularly true in the case of those in the "sandwich generation," caught between meeting the needs of their children and their parents.

Over the past several years we have listened closely to what the American people, including our diverse membership, tell us they want in a health care system. Despite their differing circumstances, the vast majority of Americans, old and young, have consistently stressed the need for broader protections against the high costs of health and long-term care. How is it, they ask, that we cover the cost of a lengthy hospitalization, costing tens of thousands of dollars, but we do not help with the cost of nursing home or home care? Some assume that concern about and support for long-term care coverage is confined primarily to the older population, but, in fact, strong support exists across all age groups. The 50-64 age group is particularly concerned, both for their parents and themselves. It is this middle generation, particularly the women, who see and feel the staggering costs -- financial and emotional -- of long-term care. It is they who bear the costs of providing care in the home and then the costs of institutional care when it can no longer be avoided.

The President has offered a bold and constructive plan for accomplishing reform. The First Lady, Congressional leaders in both parties, and this Committee are to be commended for their commitment to addressing this issue now. The nation has waited too long for comprehensive reform. We must use this unique point in history to enact true reform which covers everyone, includes coverage of both long-term care and prescription drugs, maintains high quality care, and makes health care costs affordable.

AARP is very pleased that the President's proposal includes coverage for home and community-based care for persons of all ages and incomes. The new home and community-based program in the Health Security Act would be a serious start towards addressing the unmet long-term care needs of millions of American families. Too many reform proposals focus only on acute care and simply ignore the long-term care needs of American families, as if these needs were so easily compartmentalized in the lives of these families. Such proposals are fundamentally flawed because they fail to address the need for a full continuum of care throughout an individual's life. Without long-term care coverage, no family has real security against the crippling costs of serious illness or disability.

Health Care Reform Must Include Long-Term Care

While approximately 38 million people lack basic medical insurance, virtually all Americans lack protection against long-term care expenses. With average annual nursing home costs of

approximately \$37,000 (in some areas \$60,000 or more) and home health care costing from \$50 to \$200 per day, the need for long-term care can often devastate a family. For most people, the cost of long-term care is an unmanageable financial burden. Many families are also shocked to find -- too late -- that neither Medicare nor private insurance covers long-term care to any great extent. To a family sitting around the kitchen table, there is no difference between spending \$20,000 on hospital care and spending \$20,000 on home care. It is still \$20,000 they do not have. Therefore, to achieve true security, savings, and quality in our health care system, care must not be limited to the provision of services by a hospital or doctor; long-term care must also be included.

The need for comprehensive services -- It makes little sense to provide financial protection against the cost of an acute illness but leave people vulnerable if they suffer from a chronic and disabling condition, especially since the need for these services often is so interrelated. Results from research conducted on the Social Health Maintenance Organization (SHMO) demonstrations in the late 1980's illustrates why integrated care is so important -- custodial and skilled services are often needed to complement one another. Almost 70 percent of initial referrals for community-based long-term care originated from hospitals and other parts of the medical care system. Moreover, 37 percent of the care plans developed for home and community care included concurrent authorization for medically necessary skilled services. In addition, individuals' levels of disability frequently changed and were tied to acute episodes of illness. Without comprehensive benefits, effective patient care will not be achievable, and costs "avoided" in long-term care may instead show up as costs in the acute care setting.

Caregivers are being unfairly burdened -- Family members, particularly women, provide the vast majority of long-term care to persons of all ages. Caregivers place their own health in jeopardy and frequently are forced to leave the labor market, thereby suffering not only short-term loss of income, but also long-term reduction in Social Security and private pension benefits.

In a recent focus group, a woman in her 50's related her story:

Rose had held a good job with a large corporation until her mother needed long-term care. Unable and unwilling to place her mother in a nursing home, Rose quit her job -- 6 months before her pension would have vested -- to care for her mother. She saw her future income potential and retirement security disappear as she made the painful decision to take care of her mother -- for the next seven years.

There are many stories just like this. They typically involve women in their 50's -- primarily spouses and daughters -- who sacrifice financially, physically, and emotionally to assure that a loved one is cared for. One-half of caregivers spend at least 12 hours per week providing care. At some point in their lives, nearly four out of ten women (37 percent) will care for a disabled adult; approximately 25 percent of these caregivers -- part of the "sandwich generation" -- must simultaneously care for their children. Institutionalization of loved ones often occurs because of caregiver "burnout" if no outside help is available. The Association believes that caregivers deserve strong support.

Private sector solutions cannot work -- The private market has not provided, nor can it provide, adequate and affordable protection against the cost of long-term care. Private long-term care insurance that provides meaningful coverage is very expensive and generally excludes people with pre-existing conditions or mental disorders. Few people can afford the cost of private long-term care insurance for any length of time, particularly if the policy provides meaningful protection. A decent policy bought by the average age purchaser (about 70 years) would cost approximately \$3,000 per year -- too expensive for most prospective purchasers, even if tax incentives were included. Private long-term care insurance policies have done a particularly poor job in trying to cover home care because insurance companies are not confident of their ability to control the risks and demand involved.

Public Support for Long-Term Care

Americans of all ages strongly support health care reform that includes coverage for long-term care. A random sample survey of 2,020 adults conducted for AARP by the ICR Survey Research Group in April, 1993 found that 90 percent of the respondents felt that including long-term care in a health reform proposal was important. Support for health care reform increased from 46 percent to 82 percent when long-term care was included (see Attachments 1 and 2).

The most recent survey by the ICR Research Group, of 2,012 adults conducted between January 26 and February 1, 1994 found that 64 percent of respondents were more likely to support a health care reform proposal that included comprehensive long-term care coverage and 42 percent were much less likely to support a health care proposal with no long-term care coverage.

According to a survey conducted in the fall of 1991 by DYG, Inc., three-fourths of Americans (18 and older) were "very concerned" about paying for the cost of long-term care. The concern, which is felt sharply by both men and women, extends to all income and age groups. In fact, concern about long-term care was greatest among persons age 50-64 -- those most likely to be caring for older parents and worrying about their own futures (see Attachments 3-7).

In a Harris survey conducted during December 1992 and January 1993, 91 percent of the respondents said they could not afford long-term care when they were told it would cost \$15,000 to \$60,000 a year, or \$40 to \$160 a day. With regard to a federal program providing long-term care in the home for the chronically ill or disabled, over 80 percent of these same respondents favored such a program not only for people 65 years of age and older, but for younger adults and children as well.

AARP Views on Long-Term Care

To make long-term care coverage affordable and accessible to all Americans, the Association believes that the ideal solution is a social insurance program, similar to Medicare and Social Security, that would provide a comprehensive set of benefits in the home and community, as well as in nursing homes. A social insurance program would require financial contributions from all members of society and would provide protection to all who need long-term care, regardless of age or income. Such an approach would spread the risks so that the costs to any one person would be small, while offering protection and appropriate care to all. Under such a social insurance system, private sector initiatives would supplement the public system by covering coinsurance, deductibles, and additional needed services.

Other fundamental principles that underlie AARP's views on long-term care include:

(1) provision of a comprehensive range of services, including institutional and home and community-based care; (2) effective cost containment mechanisms; (3) financing which is equitable, broadly based, and affordable to all individuals; (4) coordination between the acute and long-term care systems to assure a continuum of care across an individual's lifetime; (5) assurance of high quality care; and (6) support for informal caregivers.

These principles are at the foundation of AARP's proposal for comprehensive health care reform -- "Health Care America." The proposal, which was developed with the extensive involvement of AARP members across the country, would create a new Medicare-like program to provide comprehensive coverage for both acute and long-term care for individuals of all ages and incomes. The nursing home component of the proposal would be available over the entire length of an individual's stay, excluding coverage for room and board.

AARP believes firmly that any new long-term care should be available to persons of all ages and incomes. The Association strongly opposes means-testing -- tying eligibility for benefits to the recipient's income. We already have a means-tested long-term care program -- Medicaid -- which has proven to be seriously inadequate. A new long-term care program must not repeat these mistakes. Income-related financing, where middle and upper income people are eligible to receive benefits but pay relatively more for them, is a logical way to pay for a program progressively.

There are many reasons why a means-tested program would provide seriously inadequate coverage and leave many Americans in need:

- o Historically, many people do not apply for means-tested benefit programs because of the stigma attached to welfare programs, the complexity of the application process and the lack of information on program benefits due to inadequate outreach. For example, in 1993, 1.8 million low-income older Americans were eligible to receive benefits under the Qualified Medicare Beneficiary (QMB) program but did not enroll. This represents over half of the total eligible beneficiaries. Reasons specifically cited in a January, 1994 GAO report [HEHS-94-52] include welfare stigma, the complicated application process and lack of outreach;
- o Middle income persons have a difficult time affording home care visits, especially if they are needed on a regular basis. For example, a middle class couple with a combined annual income of \$20,000 (the median income of over 65 households in 1992 was \$17,160) must pay for housing, food and other living expenses from this modest income, which is just above 200 percent of the federal poverty line. Annual home care costs of \$5,000 (assuming 100 visits at \$50 each) would be unaffordable, yet this couple would not be eligible for any help under a means-tested system. Ironically, this couple probably would be helping to pay for the means-tested program through their taxes;
- o Means-testing would produce few savings because most people who need home care have low or modest incomes. Only about 5% of the dollars under the President's home and community-based care proposal would be spent on those with an annual income above 400% of poverty (over \$29,600 for singles and \$38,000 for couples -- see attachment 8);

- o Means-tested programs require extensive administrative overhead. They also require that applicants file lengthy and complex forms and comply with burdensome eligibility verification requirements. Moreover, the lack of convenient locations and transportation to the application sites further impedes participation;
- o The public does not support means-testing long-term care. In a survey of over 2,000 adults conducted in April, 1993, 69 percent preferred a government program for long-term care similar to Social Security or Medicare, while only 25 percent preferred leaving it to individual savings and private insurance, with government only providing coverage for the poor; and
- o Because they assist only a segment of our nation's population, welfare-based programs such as Medicaid and SSI do not have as much support in the Congress as Medicare and Social Security. This makes these means-tested programs much more vulnerable to budget cuts.

The President's Proposal for Home and Community-Based Care

The Health Security Act includes a significant, much-needed proposal to provide home and community-based care to millions of American families. The proposal represents a dramatic improvement over our current "non-system."

In basing eligibility for the new home and community-based program on levels of disability, rather than age or income the President has taken a very significant step forward. Moreover, given the limited resources available, it is appropriate that the program target the most severely disabled individuals. An eligibility assessment and determination based on level of disability, when combined with the proposed care plan, would begin to address the serious problems of fragmentation and unmet need that currently exist for disabled persons of all ages. Age is not a viable eligibility criterion because approximately one-third of persons with severe disabilities who need home and community-based care are under age 65. In addition, while the program does ask persons with greater income to pay more for their long-term care services, it is not based on a welfare model. Therefore, those in need would not be forced to bankrupt themselves before getting help, as they must do now, to be eligible for Medicaid.

The President's proposal for home and community-based care would provide much needed support to caregivers who are shouldering enormous burdens by taking care of their loved ones and often missing work to do so. Many caregivers perform these services out of a strong family commitment and a desire to postpone nursing home placement for as long as possible.

The President's proposal also would begin to provide to disabled persons and their families real choices about how to arrange for and where to receive the most appropriate care.

Today, people are forced into nursing homes prematurely or go without care because they do not have access to affordable home and community-based care. Historical patterns in public spending reflect a perverse bias, where approximately four out of five dollars spent on long-term care go to institutional care. This creates situations in which families are broken apart and Americans are denied care in the most appropriate and preferred setting. For the first time, under the President's proposal, many disabled Americans could receive services through the full continuum of care.

The Health Security Act proposal also includes reasonable cost-sharing and low-income protections which will discourage over-utilization and yet help ensure that care is affordable for those who need it.

The President's home and community-based care proposal will also have a positive impact on the economy. For example, Lewin-VHI has estimated that the proposal would ultimately create over one million new jobs. Approximately 85 percent of these jobs would be in the private sector. Working caregivers would be better able to stay in their jobs and absenteeism would decline, thereby improving productivity. Many adult disabled persons would, for the first time, be able to work and become productive, taxpaying members of society with the proposed assistance available to them.

It is important to point out that the Health Security Act would strictly limit new federal expenditures for home and community-based care by (1) not providing an individual entitlement to services; (2) capping federal expenditures; (3) leaving nursing home coverage largely to the private market, with new standards and tax incentives for long-term care insurance policies; (4) imposing stringent eligibility criteria; (5) providing for a long seven-year phase-in period; and (6) providing for income-related copayments. It is also important to note that most states will realize significant savings from this provision due to Medicaid offsets derived from the greatly enhanced federal match rate under the proposed new program (on average, 85 percent vs. 57 percent under Medicaid).

AARP strongly supports the requirement for uniform federal standards for private long-term care insurance. Such reform is long overdue. Findings from studies conducted by the U.S. General Accounting Office, the Office of the Inspector General, and by Project Hope for AARP clearly demonstrate that the current state regulatory system has failed to provide sufficient consumer protection throughout the nation. We do, however, have some questions about the costs and distributional effects of the tax clarifications proposed in this area, particularly for those selling insurance policies.

AARP agrees with many of the proposed standards in the President's proposal. We are particularly pleased by the Administration's approach on two key issues: inflation and nonforfeiture protection. In our view, inflation protection should be offered to all prospective buyers and nonforfeiture protection should be mandatory for all long-term care insurance policies. These views are consistent with the current standards proposed by the National Association of Insurance Commissioners (NAIC).

Suggestions to Strengthen the President's Home and Community-Based Proposal

There are a number of areas in which the proposal could be strengthened. Stronger incentives should be created to encourage states to participate in the program. While we agree that there is merit in state administration of a home and community-based program, provisions should be included to improve state accountability and ensure that tax dollars are appropriately spent. In addition, the reliability of funding within the program's proposed caps should be improved to include some margin for error and to reflect certain limited cost increases that are beyond the control of the states.

Although we are pleased to see even the small Medicaid nursing home coverage improvements, millions would remain vulnerable to bankruptcy due to expensive nursing home costs. Studies show that peoples' greatest fear is impoverishment from nursing home costs, which now average \$30,000 a year, and can exceed \$60,000.

Conclusion

On June 8, 1988, the late Senator Claude Pepper brought a bill covering home and community-based care to a vote on the House floor. Much was said by many members about the need to provide this kind of protection. Even opponents, who argued that the timing was not right, spoke eloquently about the importance of covering services in the home. Just before the proposal was defeated by a 169-243 vote, Congressman Pepper stated:

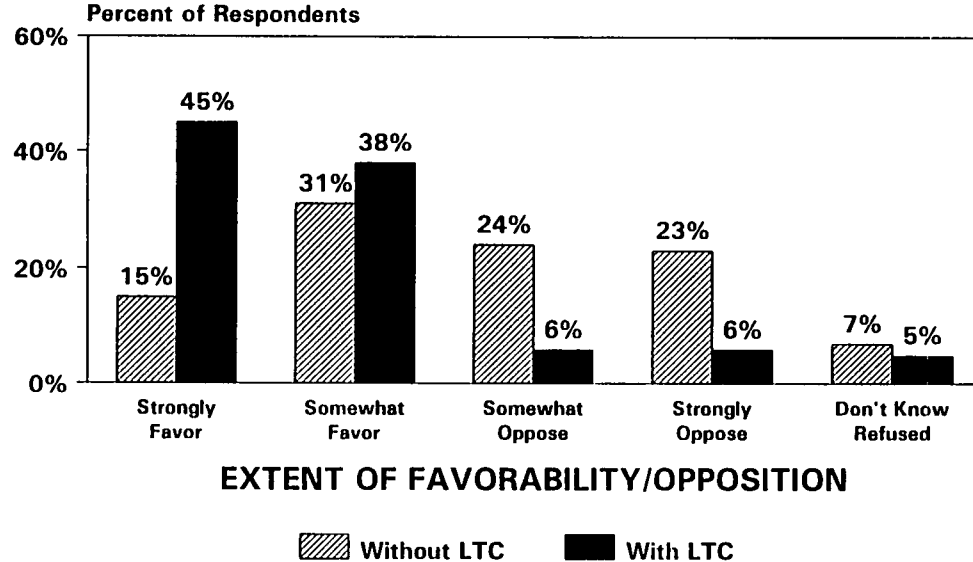
This is a day for which I have waited and worked, and I might say prayed for, for 50 years -- a chance to lighten the burden upon the masses of the people of this country, trying to help those saddled with a long-term illness.... We can help millions of people to meet crises in their homes that are heart-rending in their character. When are we going to have another opportunity if we lose this one?

The opportunity has now come. We have a chance to begin to create a new system that removes the existing bias in favor of placing people in institutions for the rest of their lives; a system that does not force people to bankrupt themselves and go on welfare in order to receive help; a system that does not force caregivers to quit their jobs or jeopardize their own health to continue caring for loved ones; and a system that is not as intimidating for those who need to use it.

As advocates and policymakers we need to be clear with the public that most current long-term care proposals are a beginning. The public must understand the specific benefits of and limits to the President's proposal. The limitations of this program will loom larger in the public's eye in the future if they come to believe that there is more coverage and protection in the program than really exists. But the fact that it does not provide all the answers for everyone in need, cannot be an excuse for doing nothing. The President's proposal is a very important, significant start and a vast improvement over our current long-term care "non-system." Our job is to shape and improve the proposal so that it will provide real protection now and a solid foundation for the future.

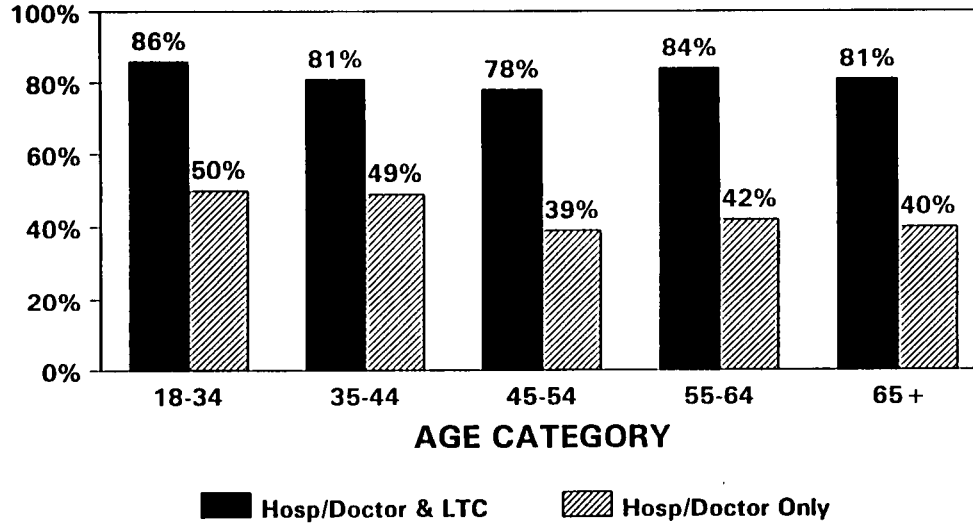
AARP looks forward to working with you, Senator Feingold, to help realize these goals and ensure that long-term care remains an integral part of whatever health care reform package is enacted.

FAVOR/OPPOSE HEALTH CARE REFORM PLAN WITH AND WITHOUT LONG-TERM CARE COVERAGE



AUS/ICR Survey Research Group
Excel Omnibus Study
April 21-27, 1993 (N = 2,020)

**PERCENT FAVORING HEALTH REFORM PLANS
WITH & WITHOUT LONG TERM CARE COVERAGE
(BY AGE CATEGORY)**

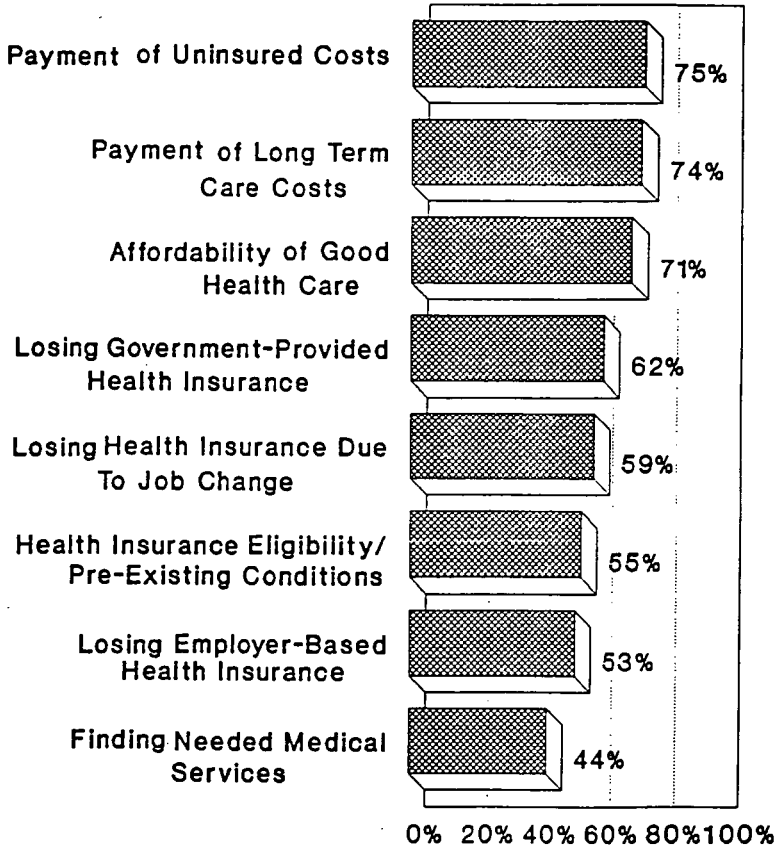


AUS/ICR Survey Research Group
Excel Omnibus Study
April 21-27, 1993 (N = 2,020)

Ratings of Health Care Concerns

Total Sample

Very Concerned About:



ATTACHMENT 4

Ratings of Health Care Concerns

	<u>Total</u> %	<u>Total</u> <u>Women</u> %	<u>Total</u> <u>Men</u> %
<u>Very Concerned</u> ^{1/}			
Being able to pay for costs of health care not covered by insurance/government	75	75	75
Being able to pay for the cost of long term care such as nursing home care	74	76	73
Being able to afford good health insurance	71	70	71

Continued...

1/ Rating of "4" on a 4-point scale

ATTACHMENT 5

Ratings of Health Care Concerns

	Total Women	Women: Age		
		18-49	50-64	65+
	%	%	%	%
<u>Very Concerned</u> ^{1/}				
Being able to pay for costs of health care not covered by insurance/ government	75	74	82	70
Being able to pay for the cost of long term care such as nursing home care	76	72	85	78
Being able to afford good health insurance	70	69	85	60

Continued...

^{1/} Rating of "4" on a 4-point scale

ATTACHMENT 6

Ratings of Health Care Concerns

	Total Men	Men: Age		
		18-49	50-64	65+
	%	%	%	%
<u>Very Concerned</u> ^{1/}				
Being able to pay for costs of health care not covered by insurance/ government	75	75	76	76
Being able to pay for the cost of long term care such as nursing home care	73	69	80	79
Being able to afford good health insurance	71	73	75	58

Continued...

^{1/} Rating of "4" on a 4-point scale

ATTACHMENT 7

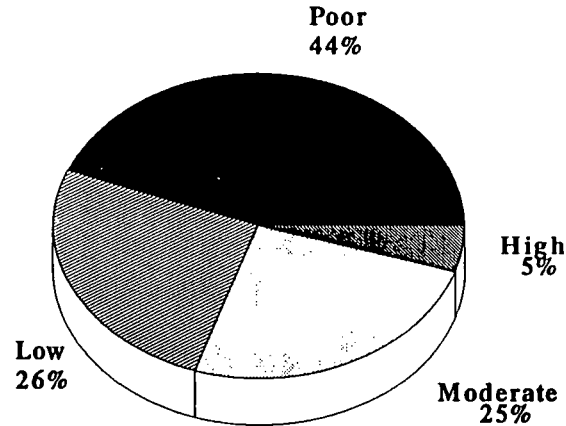
Ratings of Health Care Concerns

	<u>Total</u>	<u>Income</u> <u>(\$Thousands)</u>		
		<u>Under</u> <u>25</u>	<u>25-</u> <u>49.9</u>	<u>50+</u> <u></u>
	%	%	%	%
<u>Very Concerned</u> ^{1/}				
Being able to pay for costs of health care not covered by insurance/ government	75	80	78	59
Being able to pay for the cost of long term care such as nursing home care	74	77	74	68

Continued...

1/ Rating of "4" on a 4-point scale

Projected Expenditures of Public LTC Funds by Income Group Under HSA



Poor: below \$7,400 for singles or \$9,500 for couples; **Low:** \$7,400-\$14,800 for singles or \$9,500-\$19,000 for couples; **Moderate:** \$14,800-\$29,600 for singles or \$19,000-\$38,000 for couples; **High:** above \$29,600 for singles or \$38,000 for couples.

Source: ASPE, prepared by AARP's Public Policy Institute

Senator FEINGOLD. Thank you, Gene. I think for you and me and Sumner and many of the people in this room it's almost a dream come true that we could actually be working on this issue on a national level and yet still be able to be here in Wisconsin, where we see the program work. That doesn't mean we're going to win, but I think that if we use some of the same approaches that we have used at the State level in explaining and working with groups of people to get the message through, we can win this year.

And there are several points that you brought up that I just think we need to reiterate, and everyone in this room has to reiterate to the other Members of Congress of this State and to people in general, because people still don't know, through no fault of their own, what is in the health care plan, the President's plan, and it's already being changed. So there's just a tremendous learning curve for people to get over.

Gene is right that if you want health care reform in general, if you want universal health care coverage, long-term health care coverage is one of the best ways to get a lot of people on board this thing, because almost every family, even those that have basic health care coverage, are very sensitive to and understand the problem of long-term care. So it's politically very important.

It's also important to emphasize what Gene has pointed out. The people say, "How are we going to deal with the loss of jobs in the health care plan?" Well, we don't know if there's going to be a loss of jobs, but we do know that these provisions will provide employment opportunities in the area of home and community-based care, as many as 1 million new jobs across the country.

And I also appreciate the fact that you somewhat criticized private long-term care health insurance plans. I don't think they're as good as a program like this. I think even to the extent that the President's plan tries to do that it might be a mistake, and I appreciate your comments to that effect.

There might need to be some changes in the President's plan, but overall, I think it is clearly a good one. I can tell you whatever else you want to think about the President's plan, it is the only one that lays out a really comprehensive program, with funding, for home and community-based care, and of all those plans, most of the plans in Congress don't really touch the issue.

Let me ask you a couple of quick questions. Gene, you were addressing us, but this is what other Senators say to me. I've made a commitment to speak to every single member of the U.S. Senate about long-term care. I'm up to about 20 of them so far. I'm working my way through. But the question that I'm most often asked is: "How can we afford long-term care?" What would you say to them?

Mr. LEHRMANN. Senator, my response is, we're paying for it now, and I think that that's one of the things that we don't understand. We're paying for it through Medicaid, we're paying for it in just dollars and cents lost, as I indicated, when caregivers have to give up their job, the economy suffers as far as their paying into the economy, their taxes and so forth. We suffer in many different ways.

In addition to that, we're paying for it by using more costly care of one kind or another. An individual who could be cared for in his

or her own home has to go to a nursing home, we're paying an increased amount to care for that person.

So in the long run, Senator, it's just a matter of how we're going to pay for it. Whether individuals are going to try to cope with it, spend their way into poverty before the government kicks in, and then for home care we don't have any program anyway, so I actually—we can wind up saving money for families throughout this country by going ahead with this long-term care proposal.

Senator FEINGOLD. Well, that's an important answer and I need from you and anyone else any proof that we can give of that statement.

We have some evidence from Wisconsin that we're paying for it now and it will make it more cheap, but I can tell you that the most important thing for me to do with these other Senators is to give them any evidence, specific evidence, specific cases or evidence of larger groups of people, that this actually saves us money. That is the key to winning this.

Mr. LEHRMANN. I think, Senator, we will have to try to get some indication for you from individual families that actually demonstrates that.

Senator FEINGOLD. That's probably the best way I can do it.

Let me ask you one other question. One of the principal alternatives to the Clinton plan being discussed in Washington is the one being offered by Representative Jim Cooper of Tennessee.

As it is currently drafted, the plan would shift the long-term care portion of Medicaid entirely on to the States. Are you aware of that and what are your thoughts on it, if you're aware of it?

Mr. LEHRMANN. Yes, I've heard that that's what it would do. Shifting the cost of Medicaid to most States would certainly mean that there would be less home care available to people than there is now.

I would suggest to you that we will have some serious problems as it relates to long-term care; not maybe in Wisconsin, although we do need Federal input to help going, but I can point to many States now where there would be very little financing for long-term care and certainly little or none for home health care, and I think AARP would speak out, will speak out, and has been speaking out, on issues such as that. We're adamantly opposed to such a suggestion.

Senator FEINGOLD. I appreciate that, because Representative Cooper, who happens to be a friend of mine, but he calls his plan "Clinton Lite," trying to make it sound like it's not as hard to swallow.

Mr. LEHRMANN. Right.

Senator FEINGOLD. First of all, the Congressional Budget Office said last week that that plan will increase the deficit over time; second, it will do that and not cover 25 million Americans for health care; and third, as Gene Lehrmann just told you, it will shift the Medicare burden on to States and limit opportunities for home health care.

So don't be easily taken in by Clinton Lite. Thank you very much, Gene.

Mr. LEHRMANN. You're welcome, Senator.

Senator FEINGOLD. The second panel will have several different people, and I think we'll ask all of them to come forward at this time. John and Linda Cram and family, Susan and John Olson, and Linda and Mitch Rowley.

Okay. John and Linda.

Mr. CRAM. No, my wife's not here. It's just me.

Senator FEINGOLD. Why don't you go ahead?

STATEMENT OF JOHN CRAM, MILWAUKEE, WI

Mr. CRAM. First I would like to thank you for holding the public hearings to focus on the issue of long-term care. This is a very important piece of health care reform for many Americans.

I would like to share with you how important long-term care is for my son Matthew. Matthew is 10 years old and enjoys the third grade at 21st Street School. He's also a very big Milwaukee Brewers fan. Matt had a traumatic brain injury when he was 3 months old. This has affected his whole body. His disability resembles cerebral palsy, in that his muscles are very rigid and he is unable to move unassisted. He is also visually impaired and he's fed by a gastrostomy tube. He communicates by using an adapted computer and facilitated communication and by answering the yes and no questions by moving his head. His means of mobility is by using a wheelchair which was especially designed just for him.

Beyond the two 20-minute sessions of school therapy, Matthew also receives hour-long sessions of physical therapy three times a week, occupational therapy two times a week, and speech therapy once a week. These private therapy sessions occur yearround and are necessary for him to remain pain-free and keep to a minimum the number of contractures that he now develops. Contractures are muscles that remain contracted and never let go and cause the body to become very painful and permanently contorted.

All of these therapy sessions we also, as a family, work on at home. We are constantly stretching Matthew, changing his seating position.

We also recognize the need for these formal therapy sessions, because when we go on vacation, as the week goes on, without these sessions he becomes, you know, in a lot of pain, he becomes very uncomfortable.

At present our family insurance would pay for approximately 3 months of therapy per year.

Matt is only able to function because of his therapy. If it hadn't been for Title XIX and long-term care, it would be very difficult to know what sort of life he would be leading now.

We also look at the future. Matt is presently 10 years old. At the moment he probably weighs about 65 pounds. He's still growing. It is becoming very difficult for myself and for my wife and the rest of the family to even be able to lift him or to take care of his personal care needs.

We are presently doing a lot of remodeling. We have to take out a second mortgage to be able to do this, which will, hopefully will, ease things a little bit for a little while, but we do see in the very near future that we are going to need in-home health care to help us on a day-to-day basis.

We also want and anticipate Matthew leaving our home, like our other children, even to go on to school or to just move into his own apartment and enjoy all the things that go with that, but for him to be able to do that he is going to need to have long-term care. He's never going to be completely independent.

We see that there's a good future for Matt despite his many needs. We see a real good quality of life if the supports are in place.

We also ask you to remember that there's no such thing as average need in health care. We feel it's very absolutely individual need.

And I would just like to thank you on behalf of Matt and all the other people with similar health care needs, for taking the time and recognizing the importance of long-term care. Thank you.

Senator FEINGOLD. Thank you, John. I will return after we have heard from everyone and ask some questions of the group, but we'll go on now to Susan and John Olson.

STATEMENT OF SUSAN OLSON AND JOHN OLSON

Ms. OLSON. Senator, I first want to thank you as well for giving John and I the opportunity—and I will be speaking on his behalf as well as mine—to speak today about this issue.

I have to tell you that I have nothing specifically prepared, but I did want to share with you, as you had stated, you're very interested in knowing those of us who live in this situation what actually is going on, and what has gone on. So I just want to tell you where John and I have come from, where we are now, and where we want to be going.

Briefly, 9 years ago this month, my mother died of cancer of the pancreas. At that time, John was living at home and he was the only one of my siblings at home at that time. When she passed away, I rather surreptitiously became primary caretaker of not just John, who has Down Syndrome, but my bereaved father.

And as to your comment earlier and about the fact that work days are lost and such, of caretakers, there were essentially 4 years of my life that I gave for the care of my brother John and my father, that I dropped out of school, I was constantly employed at home and not on the outside. So I was not a contributing member in the work force that way.

Through some unfortunate circumstances John and I left the home situation and have been living together since 1989. During that time John has been able to leave a sheltered workshop here in the city and, through a local VEA and United Cerebral Palsy Organization, be placed in gainful employment for the first time in his life at a local food store.

He has also learned how to take the city bus that he had never taken before, had been always dependent on someone to take him around. That is limited to some extent but, nonetheless, in these times since my mother's death, John has become a very happy, contributing, taxpaying member of society. And by the grace of God, neither of us have had critical health problems up to this point.

Currently, for my part, I continue being his caretaker, but I'm also currently a medical student, and as my studies continue, I'm getting more and more concerned as to what is going to happen in the future. We have been making it thus far. We're surviving day-

to-day, and it's very appreciated that there's an opportunity here, as you've lent an ear to hearing our situation, because when you live as we do, in a day-to-day struggle and not planning far ahead in the future because there aren't options in the future, it's difficult to believe that anyone really cares about what is happening.

So we stand, John and I, sort of at a precipice of what will happen in the oncoming years. As I become a physician, my time will be less and less available to be his caretaker. If something happened to me or if something happened to him, our lives are incredibly enmeshed, and we stand here, just as I said, with no view of what could possibly help us in the future if something were to happen.

I look at the fact that, in retrospect, my actions not only have been those of a loving sister, but someone who also has probably saved, in some way, shape, or form, the expenses that would have been incurred if John had been institutionalized or put into a group home situation, none of which, when I had investigated them, were acceptable.

So to conclude, essentially, I really want to encourage you to continue in this area and I want to see the fruition of this endeavor in the long-term health care plan that is being worked on and proposed to really come to fruition and not be something just continued to be badgered about in a political way.

This is something that critically affects not just my brother's life as a disabled citizen who, himself, is gaining into the elderly population, but me as a primary caretaker as well. So I want to thank you.

Senator FEINGOLD. Thank you. It's good to see both of you here and it's just a perfect example of the kind of thing that we're interested in hearing about here, but also, the President in his speech about health care talked about security and the fact that our health care system needs to provide security to people so they don't have to worry about this all the time.

Our goal here is to extend that concept to long-term care, so that people don't have to wonder on a day-to-day basis whether that is available, as you have to do now.

We'll get back to some questions for you, but I really am delighted to see all of you here.

Finally, Linda and Mitch Rowley. Go ahead.

STATEMENT OF LINDA ROWLEY

Ms. ROWLEY. My name is Linda Rowley, and my son Mitchell is out cruising the hallway. It's a little too warm in here for him.

I'd like to thank you, Senator Feingold, for allowing us to come and speak today, allowing Mitch and I to come talk today about families.

Mitch attends his neighborhood school. He goes to the same classroom he would go to if he didn't have a disability. He's part of his community. He takes swimming lessons, he marches in parades. He's been in an integrated day care since he was 2. At his school he's seen the need for picking up litter because of budget cuts that have cut the custodial staff. So Mitchell has organized a clean-up club. It started out with two people. Now he has 50 kids

and several garbage bags. Once a week they clean up the school grounds.

Conventional wisdom from the medical model and the educational model tells us that children, like Mitchell, a child who is paralyzed from the chest down, a child who has a tube in his brain to help drain fluid, a child who is living on one kidney, a child who has special learning needs, a child who's had 19 surgeries in his lifetime and has many more to look forward to, a child who requires 8 to 10 hours a day of care above and beyond what's considered normal parenting, is a child who doesn't have a very high quality life, is a child who is a burden on his family and his community.

But the reality is, a little boy who's zooming around here today, a little boy who has a wide circle of friends, who has contributed so much to his school already, and his organizational capabilities, his ability to see an issue and rally around it, makes me wonder what he'll be doing at 19. I would say that anyone who gets in his way, watch out.

Yesterday was Mother's Day, and I thought about what it meant to be a mom. I thought about how excited I was my first Mother's Day when I was pregnant. I wanted so much—I wanted so much to have this baby and to be able to take care of him. And if I had to do it all over again, Mitch would be the child that I would choose for my own. I wouldn't change anything about him.

But to be very, very honest with you and everyone here today, this is not the life that I would have chosen for myself or my family. If it had been up to me, I would never know what the inside of a hospital intensive care unit looks like. I wouldn't know anything about the Individuals with Disabilities Education Act or Section 504 or ADA. I would not know what it was like to have professionals come into my home, social workers and nurses and case managers. They invade our privacy and they make judgments, value judgments about how I raise my son, about how we live our lives. If it had been up to me I wouldn't know anything about this. But that's not a choice that we have. So we put up with what we have to get by.

And right now, as a single parent and Mitchell's only caregiver, the only thing that stands between Mitch and an institution is myself. And I know that all it will take is one crisis to put us over the edge. I don't believe that there is any experience more anguishing or bitter for a parent than to come face to face with the reality that you might not be able to do it anymore.

You look at all your friends with their typical children who go through life, who go through, yes, ups and downs, but who never, ever have to question their ability to keep their families together, to keep their lives intact or to take care of their own children. You feel like a failure.

It's hard to step back at that point and realize that what you're doing is performing a minor miracle by keeping this child at home in the community. You realize that if the State had custody of your child it would take over \$100,000 a year and round-the-clock professionals to do what you're doing alone on a shoestring budget.

In our country we have an elaborate system of policies and procedures to ensure that criminals get all the protections they need,

that their civil rights aren't violated. We have the Miranda law. We have free legal counsel. They have the right to have their story heard by 12 of their peers. If they're convicted they have a system of parole where they get out for good behavior.

But in this country where we so esteem the values of individual freedom, self-determination, civil rights, and full citizenship, there are tens of thousands of people who are incarcerated, who have been denied the right to live in the community, who have been denied the right to be part of a family, who have been denied the right to be a full citizen of this country. They haven't committed any crime. They haven't gone to trial. They don't have opportunity for parole. The only thing that they have is that they wear the label of either developmental disability, physical disability, chronic mentally ill, or medically fragile.

For a child like Mitchell, we're looking at a situation right now where he and his ability to live in the community is being compromised by the politics right now of appeasement and concession, to nursing home lobbies and to labor unions.

There seems to be myth right now around Capitol Hill and in the national press that the question of long-term care is an option that we can address or not, depending upon which ways the political winds are blowing at that time. But that's just not true. Unless one of the health care plans floating around Capitol Hill contains a provision for instituting a policy of mass genocide of people with disabilities, we're going to have to find a way to provide long-term care for them.

The choice is not whether we're going to allocate funds for long-term care. It's going to be where the funds are allocated—in institutions and nursing homes or in the community.

I estimate that in order to support Mitch at home it'll cost around \$20,000 a year. To support him in an institution, which is the level of care he needs, it would be around \$120,000 a year. By my estimates, I've saved this government between \$800,000 and \$1 million by keeping my son at home.

In conclusion, I would just like to say that I strongly support what Senator Feingold is doing in looking toward a provision for long-term care.

All I want is to be able to take care of my son and keep him at home, and I know that I can do it much better than any government institution could, and that I can do it at a savings to the government. Thank you.

Senator FEINGOLD. That is a very, very important example of the kind of information I need, we all need, in order to make the case to the Members of Congress that what you're doing is not only difficult, which obviously it's terribly difficult, but that, in fact, it can save money and be a much more appropriate family-oriented approach. And I want to congratulate your son on what he does there in the organizing of the kids.

He has all these organizational skills. It sounds good.

Ms. ROWLEY. Thanks.

Senator FEINGOLD. You all have very important stories to tell. Let me ask whoever wants to answer this question, because Gene Lehrmann brought this subject up.

A number of Members of Congress have offered plans that involve the opportunity, or greater opportunity, to buy long-term care private insurance. Would private insurance cover the long-term care services you need, or have you tried to get private long-term care insurance? What do you think about that alternative?

Ms. ROWLEY. Speaking for myself, my first real experience with the insurance industry was when Mitch was 3-years old, and our insurance company told my employer that their rates were going to go very high if I was kept on the payroll, and I was given a choice of dropping my insurance or getting fired, and I ended up getting fired from my job.

Right now I have to jump through hoops that are extraordinary to get basic care for Mitch that I need. I have never been able to get long-term care supplied. I really don't believe that we will get what we need, that there will always be a loophole that they will be able to get out of to find a way not to provide these services, and to tell you the truth, I'm really tired of having to justify why I need this. And I think that's what I'll end up doing under that kind of plan.

Senator FEINGOLD. If you're stuck with it. Right. Any other comments on the insurance?

Ms. OLSON. Senator, first, for John, of course he is under the Medicaid program, but as you well know, that has limitations whether it's acute or long-term. And fortunately, at this point, with John's God-given health, he hasn't had to demand that kind of care. But this doesn't mean that he won't, as Down Syndrome has been cited to do, develop Alzheimer's disease, so that could be a future. So for him that has been rather unexplored.

But for me, in terms of the caretaker, I can say that I have been uninsured medically for the last 8 years, and through those 4 years of caring for my father and John, because I was not employed, I could not get insurance nor pay the kind of premiums that were required for a single person as I.

When I matriculated into medical school, I went in there without health care insurance, and a stipulation of my matriculation was that I get health insurance. And it was with my insistence that the administration provide health care for medical students because I was one who matriculated with a preexisting condition, and when I shopped around to try and get health insurance, not even long-term care insurance, I was turned down, and no one would write me a rider.

So I had to press the administration at the medical school to seek some source of health care provision for me, and it is only because I'm a student now and the AMA has now approved of this and provides insurance for medical students that, in fact, I'm covered, so again, with a limited long-term care. But again, this just leads us into uncertainty as to what, if a crisis happens in the future, what is going to be covered, what is not going to be covered.

Senator FEINGOLD. Thank you. Do you have any comment on that, on the insurance issue?

Mr. CRAM. I think really the only comment is that my private insurance has paid for things. Through my employer we've had a choice of insurances. I've had to pay a lot more than, you know, the

person at the next desk, because I couldn't go into an HMO, which covers nothing for my son. But there are also the sessions.

Senator FEINGOLD. And you couldn't go into the HMO because?

Mr. CRAM. Because I'd have to give up all the specialists, which took me a long time to get together for him.

Senator FEINGOLD. For your situation.

Mr. CRAM. Right. Exactly.

Senator FEINGOLD. So you really don't have a freedom of choice.

Mr. CRAM. No, not really. And when they have covered services, it's been time limited. It hasn't been—you know, they don't understand the concept of long-term. It's, you know, well, you must have had an injury and it'll be taken care of within 3 months.

Senator FEINGOLD. Right. That is the toughest thing about this, getting policymakers to understand just what "long-term" means. You say long-term to fellow Senators, and most of them say, "Oh, you're talking about nursing homes." So I am just trying to overcome that now. And we have to overcome this all fast.

What you all had to say pretty much speaks for itself and I want to thank all of you for these very important examples to policymakers, but very real and human situations for you and your families. I thank you for coming.

The third panel will include Lillian Storm, Pauline Schaller, Sharon Dobrzynski, Ann Hauser, and Dorothy Freund. Would they come forward.

Senator FEINGOLD. Hello.

Ms. DOBRZYNSKI. I'm Sharon Dobrzynski. I'm speaking for Pauline Schaller, my sister, and about my mother, Lillian Storm.

Senator FEINGOLD. Okay. Why don't you go ahead, Sharon.

STATEMENT OF SHARON DOBRZYNSKI

Ms. DOBRZYNSKI. Okay. Thank you again for hearing us, and this is my first Senate meeting.

I'm talking about my mother, who is Mrs. Harold Storm, who has had MS for at least 17 years and did spend part of that time, 3 years to be exact, in a nursing home. Her care in that nursing home was really quite inadequate.

The aides were asked to work a little harder for her because she could not do anything for herself. She's incapable of any activity or movements.

The aides that did care for her also had between 8 to 10 residents to care for, including my mother, which is a lot of people to attend at one time.

The aides would leave her for a long period of time. When they would come, they would put her on a commode, then they would leave her to care for about five or six other patients. They would not come back and check on her to see if she was okay, to see if she was uncomfortable or needed anything.

I would take my visits at that time of the evening. I was afraid she was going to fall off the commode, so I would extend my visits of seeing her until I was sure she was back in bed. I mean she was just left there alone. I mean that's just the way it was.

If she got sick, a flu or a cold, it took hours to get her an aspirin and, of course, the cost was ridiculous. Her engagement ring of

over 50 years was actually stolen off her fingers and, of course, could never be recovered.

Her meals were inadequate for her. Because of her having MS she could not eat a lot of things and sometimes we had to struggle with getting those things to her.

Because she uses a Hoyer lift, she was used as a practice patient. She always would get new aides. The aides that she did get didn't care to take care of her because she was, of course, too much work. She needed too much care.

If she did express that she liked an aide, they seemed to be given to another area or a different floor. It was unbelievable.

What she did with most of her time at the home, she slept and she didn't know what day it is or what was going on. She always seemed to be kind of in a haze.

The quality of the nursing home is obviously not what we wanted for my mother. My dad did pay more than two to three times, we believe, for the drugs that they dispensed than he could get for himself at home.

We have now, in the last year, got her back home through Medicaid and Title XIX and that COP waiver program. She's been home with my father now for the last year with, of course, aides taking care of her, of which my sister and I are one. We do help take care of my parents at home.

She now has a chance to wear her jewelry, to hear her old time records. She is also a Brewer fan. She has a flower garden which the place she's living has let us build for her outside and, of course, this time of the year she's starting to think what to put out there. She loves to do crossword puzzles but, of course, needs the help of others.

She is definitely a changed, happier person living at home and it's just no comparison to the nursing home whatsoever. The extra time we get through the Medicaid and the COP waiver program, 10 hours of care a day for her. The other care is given to her by myself, my father, and my sister, whatever other care she needs is given happily to her, with no charge except, obviously, a smile from her, which we do get.

Her medication now, we've also gotten for her through my father's HMO, and there is definitely a difference in price there.

As my letter stated that I think you saw, I don't know where anybody else would want their mother, but I certainly would like mine at home where we can help take care of her. And I do thank you for your time and effort in this, trying to get this long-term care taken care of at home for parents.

Mine, obviously, is a little different than most people, because I'm caring for a parent at home and not a child.

Senator FEINGOLD. Well, you know, I wish that each Member of the Senate could just hear, I mean here's an actual example of somebody who was in a nursing home who doesn't have to be there.

Ms. DOBRZYNSKI. Definitely.

Senator FEINGOLD. Who lives in a home, is happier there, in her own home.

Ms. DOBRZYNSKI. Yes.

Senator FEINGOLD. Happier, and obviously must cost everyone less because of all the volunteer personal time you give.

Ms. DOBRZYNSKI. Right.

Senator FEINGOLD. It's also almost an obvious answer. But we've got to somehow get people to start thinking that way.

Ms. DOBRZYNSKI. To try to understand that.

Senator FEINGOLD. Yes. And I will try to take advantage of your efforts to bring this to us.

Ann Hauser.

STATEMENT OF ANN HAUSER, MILWAUKEE, WI

Ms. HAUSER. I want to thank you for inviting me. Hello. My name is Ann Hauser, and I'm here to tell you how long-term home health care gave me back my life. I'm 74 years old. I retired with arthritis after 30 years as a ward clerk at a local hospital. I've always appreciated my independence, but never so much as the day I returned home to live after several unpleasant stays in two different nursing facilities. After being discharged from a 4-week hospital stay for treating an infection caused by Prednisone, my medication for Crohn's disease, I was admitted to a nursing home.

It makes me sad to think that the following story could have been avoided if I had known that my insurance and Medicare would have covered home visits from the Visiting Nurse Association or other agencies. I know I'm not alone in saying that there is a serious need to improve the ways of telling people their care options within the community.

While at this nursing home, I was to continue on IV antibiotics and needed some, but not total, assistance for chair transfers. Before much time had passed, I was assisted in moving around so seldom that I lost my muscle tone. Within 5 months I became bedridden. The Hoyer lift became a cop-out and I learned that it was better to refuse it so that I could keep the use of some of my muscles. The less active I became, the more depressed I became, and I was going down hill fast. I was very, very depressed. How could I be happy in places that allow the aides to switch the TV station on my television to their favorite soap operas?

Furthermore, when I would remind them that I was at their mercy to finish my bed bath, as they stopped to watch just 1 more minute, they would take away my remote control, while I shivered and waited.

How could I be happy or safe where staff members took 17 long, terrifying minutes to answer my call light and cries for help when a confused elderly gentleman came in our room and swung a cane at my roommate and me, when we were helpless in our beds. Or at a place that would rather put me in adult-sized diapers because I used the bed pan too often for their staff's schedules. How could I thrive in an environment that counted on my remaining inactive when I have been so active up until now?

After much therapy, the people at Social Services and the Department of Aging helped me work through the paperwork for getting home care, home health care. My wish for returning home finally came true. I've stayed out of nursing homes since the fall of 1991.

Thanks to the COP funding, I am able to stay in my own apartment because these needs are met:

One person comes in once a week to clean my apartment and do my laundry;

One person does my grocery, drug store shopping;
 My neighbor stops in every day to help me in activities around the house; and
 A therapist comes in three times a week to help me work with my muscle
 tone.

But that's not all. COP also pays for my Life Line, and I've had to use it twice. With this device, I'm in touch with medical help in minutes. It gives me a wonderful feeling of security.

Today my life is so much more active than when I was bed-ridden. With COP's help, I've worked really hard to make enough progress to stay at home. With long-term home health care, that nursing home bed is open for someone who needs it.

Thanks to COP, I'm enjoying life at home. At the nursing homes, I was so depressed and got weaker and weaker. Now my friends and out-of-state family visit often. I cook and entertain; I crochet and enjoy reading. I live every day!

I owe COP my life. And I can even watch my own TV station again!

Thank you all for your time. Do you have any questions?

Senator FEINGOLD. Thank you very much. The comment you made was one of the best ones I've ever heard in terms of the way you've phrased it. How could I thrive in an environment that counted on my remaining inactive, when I had been so active until now. That's just a perfect way to say it.

Ms. HAUSER. I was very active. Very active. In fact, the day that I had been driven to the hospital with this infection, that day I had been to church and volunteered for 7 hours in the office.

Senator FEINGOLD. That's a message we have to get through to people that, you know, nursing homes in this way and other facilities that aren't here to keeping people active. I'm not saying nursing homes could never do that. But a situation like yours. We really cause ourselves much more problems for you and for all of us if we don't allow you to be as active as you can be. And I think this is just a wonderful statement. That quote will find its way on to the Senate floor before long, with your permission.

Ms. HAUSER. Thank you, Senator.

Senator FEINGOLD. Because you certainly said it the way that I would want to say it myself.

As you probably noticed, my good friend and senior Senator, Herb Kohl, has joined us, and I really appreciate his being here. At the beginning, Senator, I mentioned the fact that you preceded me on the U.S. Senate Aging Committee by quite a few years, and before that, I remember giving a speech on Alzheimer's disease here in the greater Milwaukee area where you were the featured luncheon speaker, and you were kind enough to say to the audience that you had a seat open and warmed up for me out there in Washington. And thanks to the good forces out there, that has happened, and when I got there, I was fortunate to be able to join Senator Kohl on the Aging Committee, and to already work with him as a Wisconsin team to try to advance this cause of long-term care. With Dorothy's permission I'll turn to Senator Kohl now and we will come back to you after he's made a few remarks.

STATEMENT OF SENATOR HERB KOHL

Senator KOHL. All right. Well, I thank you, Russ, for giving me an opportunity to come here and say a few words. I'm in the midst of a busy day like you and other people here, but I did not want to miss the opportunity to come here and talk about long-term care, and also to say how fortunate we are in Wisconsin to have Russ Feingold as our Senator. He is just an outstanding guy with great values, great priorities, a tremendous background, an outstanding work ethic, and he's a wonderful guy to work with. You know, there are all kinds of people in Washington, as you might imagine. [Laughter.]

And many of them are people that you don't want to have all that much to do with because they're coming from left field or right field, or whatever, and they're not always playing with a straight deck. [Laughter.]

But Russ Feingold is as direct and honest a guy as you can have, and I can tell you that I really do very much appreciate you and all the other people in Wisconsin who decided to send him to Washington a couple of years ago, and I think that he's a person who is going to have just an outstanding career as a public servant in Washington. I have no doubt that he will be returned to Washington just as often as he wants, because he deserves it. And today's hearing and the turn-out for today's hearing is an example of what he is and what he represents to people who need help in our great State of Wisconsin. So I want to thank Senator Feingold for holding this hearing on a topic that presently affects or eventually will affect every single American.

Long-term care is an intensely personal issue. No other part of the health care system generates as much dissatisfaction as does long-term care, and it is therefore time for this to change.

Senator Feingold has long worked to bring affordable and respectable long-term health care to the people of our great State. As a Wisconsin State Senator, Russ Feingold was the principal advocate for the Community Options Program. Since 1982, the Community Options Program has been the cornerstone of Wisconsin's effort to reduce the incidence of institutionalization of the elderly and the disabled. Because of Senator Russ Feingold's work, Medicaid nursing home bed use in Wisconsin dropped 19 percent during the 1980's, while the rest of the country had a 24-percent increase.

Since coming to the U.S. Senate, Russ Feingold has demonstrated that it is possible to be compassionate and tough on this issue of long-term care. Compassionate to the millions of people who need this benefit, and tough in fighting for their dignity and their rights.

Senator Russ Feingold has at a very young age achieved a great deal: The respect of the U.S. Senate and the personal satisfaction of working successfully for the principles in which he so strongly believes. I share Senator Feingold's support for efforts to provide senior citizens and disabled Americans with affordable long-term care, and I am pleased that President Clinton has introduced long-term care as a priority for any health care reform. In fact, President Clinton's health care proposal modeled its modest long-term care section after the Wisconsin program.

I want to ensure you that I will fight to include home and community-based long-term care as part of any health care legislation that we enact. There is little doubt that our long-term care financing and delivery system is badly in need of reform.

As Winston Churchill once said of the American people, I quote: "You can always count on them to do the right thing, after they have tried everything else."

I hope that we are done trying the everything else, and ready to do the right thing by covering home and community-based long-term care. Senator Feingold's continuing leadership on this issue, I believe, will result in an effective long-term care program for our country. So I want to shake your hand, Russ, for your efforts.

[Applause.]

Senator FEINGOLD. Thank you very much, Herb, and we will now, Herb and I together, go back and continue with this panel.

I believe we've yet to hear from Dorothy Freund, and I appreciate your patience and would like to hear from you now.

STATEMENT OF DOROTHY FREUND, MILWAUKEE, WI

Ms. FREUND. Good afternoon, Senator Feingold, Senator Kohl. My name is Dorothy Freund. I am living in a nursing home in Milwaukee, Wisconsin, waiting to get back into the community.

I have my Bachelor of Arts degree from Ohio State University with a major in English and a Bachelor of Expression degree from a specialized school in Chicago, Maclean College of Drama, Speech, and Voice.

After being graduated from Ohio State, I worked for AT&T doing cost engineering. In the evenings I studied at Maclean and also during vacations. Then I worked as registrar at the school while continuing my studies there, and did a lot of little theater work and later gave song and drama programs for clubs in Chicago.

Subsequently, I worked for the Chicago Motor Club, in the travel field, and did private tutoring in the Chicago area, in Chicago and its suburbs.

In October 1991, I spent 16 days in a Wisconsin hospital for treatment for my ankle, and in mid October of that year, I came to the nursing home, a nursing home in Milwaukee, for further treatment. I gave up my apartment in Butler, Wisconsin, because it was not designed for maneuvering in a wheelchair, and I have been on the waiting list for COP and COP waiver funding in Milwaukee County for a year-and-a-half, since November 4, 1992. I am single with no family. I have an intense desire to be active again in the community and in church, and to become a contributing member of society again.

I'm grateful for this opportunity to speak to you straight from the heart. I've always enjoyed helping people. It makes me feel good to make—it makes me feel happy to make them happy and to give them the educational tools that they need to pursue their high goals.

Let me share with you a recent example. It has to do with someone in the nursing home who has been a very caring nursing assistant, an aide, for 14 years. I'll call her Mary, but that's not her real name.

Recently, she decided that she would like to become a nurse and get her LPN, but she didn't have her high school diploma. She had dropped out of high school during her senior year for personal reasons. So she enrolled in a school where she could study in the evenings and take the courses she needed. When she was making a roommate's bed, we'd go over the rules of punctuation. She'd bring her completed homework to my room early in the morning, and I would go over it, correcting the mistakes and writing down the reasons for the corrections, and then always trying to emphasize the good and giving her encouragement. On her lunch break she would come and we would go over what we could, often finishing later on the phone. Together we worked with her English, her grammar, poetry, writing, then later on geometry, government, and geography. Then that wonderful day arrived when she received, at 39, her high school diploma. I have her graduation picture on my wall, white cap and gown, big smile, so proud.

Recently, she received an achievement award from the high school at a special luncheon. Now she is working on her new goals toward her new study phase, toward her goal. Small, perhaps, but when one life touches another in a meaningful and special way, and then that life utilizes the good received and goes on to touch other lives, we have that magical spread of good which can only take place in a free country such as ours. Then why not stay at the nursing home and help others in the same way? It is not an atmosphere of peace and quiet for any length of time. I'm not deprecating the nursing home or its quality of care. They're always working for ways to improve situations and to solve problems that arise. Nor am I downgrading those who are trying their best to give that care. But when the shouting and moaning and screaming and babbling all go on at the same time, it can be bedlam. It may erupt at any moment.

And so I am on the waiting list for COP and COP waiver programs in order to get back into the community. When I was placed on the waiting list in November 4, 1992, I was told that it would be about a year's wait. It seemed like such a long time, but at least there was hope. And so I set about to, the best I could, to cope with the situation.

The following September, that was September 21, 1993, the news was that the funding would be released after the first of the year. January went by, February went by, and I didn't hear anything, so on March 9 of this year I called my social worker to inquire about it. She was very kind and tried to break the news as gently as possible. There's been no release of COP funding and probably won't be for another year. Another year? Another whole year? But why? She didn't know many of the details and suggested that I talk with Ms. Stephanie Stein, director of the Department on Aging in Milwaukee County. I did talk with Ms. Stein on April 1. What number are you on the waiting list, she asked? 195. Oh, that's low. Low? Yes. Now there are 1,930. She very kindly and patiently explained that a bill had been introduced to the spring session of the Wisconsin State legislature creating 1,700 new slots for the COP program to get people off the waiting lists. That sounds like good news, I said. Not really, she went on. Because when the bill reached the Joint Finance Committee, the dollar appropriation was removed by

amendment, and the bill that actually reached the floor just directed the Department of Health and Human Services to present a study.

What started as help and hope wound up as nothing. It was a big blow. The frustrations of being stuffed in a nursing home, the struggle to ride out the storms and keep my head above the troubled waters can seem overwhelming when there's not even a gleam of hope at the end of the tunnel. But I just can't resign myself to a life of Bingo and Roll-a-ball. Don't give up. There must be a way, I keep telling myself. President Clinton's Health Care Plan, I understand, includes community-based long-term care. For those of us who have been waiting and waiting and waiting, this presents a glimmer of hope.

Distinguished Senators, you are trying to find a balance in this plan to meet everyone's needs. I appeal to you to permit the community-based long-term care portion to remain in the plan.

Senator FEINGOLD. I certainly thank you for your comments in Washington. Senator Kohl and I can tell you that Senators fall all over themselves too often calling each other eloquent. I think they've called each other eloquent for not tripping over their shoes coming down to give their speech sometimes. Senator Kohl and I are a little more restrained in that regard. But what you just did was truly eloquent, and I believe that that kind of a statement which combined humor and a very direct human approach to this is exactly what we're going to need. Yes, you were right. The President's plan is the first national plan that allows the Stephanie Sue Steins and Tom Fraziers of the world to be able to tell you that something can happen to get rid of those waiting lists. They have done, those two people and others in this room, more than any other human beings in this State. To try to be able to say to you that not only that there aren't 1,000 people, that there aren't 200 people on the list, but that everyone's covered, and it's very painful for them and, in fact, a great deal of their life's work to try to get rid of those waiting lists. This plan by this President and this First Lady is the first real national commitment to try to do that. It's in the plan now. Sad thing is, as we've her heard indicated many times today, is a lot of people don't understand why for all the reasons it should stay in the plan. And I sure was moved by your remarks.

Let me just ask the three panel members quickly, since we do need to get on to the other panel, the same thing I asked the last group.

What experiences have you had, if any, with trying to get private long-term care insurance to deal with your needs? Have you tried? Has it been successful and what is your opinion about doing this through the private insurance system? Anybody like to comment on that? Ann.

Ms. HAUSER. When I was in the hospital for 4 weeks, my insurance would have paid for an agency to come in and give me the IV antibiotics at home. I did not know that. So, and the hospital didn't tell me that. My doctor didn't tell me that. They pushed going to the nursing home. But my insurance would have paid for it.

Senator FEINGOLD. For certain services that you needed?

Ms. HAUSER. Yes. For the IV. And when I left the hospital, I could transfer from the bed into my chair on my own. I needed just a little bit of help to transfer back on the bed. When I came out of the nursing home, I could set up for 10 minutes on the side of the bed and roll over on my left side. That was it.

Senator FEINGOLD. Okay. Any other comments on the insurance system? Sharon.

Ms. DOBRZYNSKI. My father did retire, quit his job and obviously lost his insurance when we took my mother home and even before that. So he went into what I referred to earlier as a HMO and it's, you know, it's fairly adequate, it at least gives them the monthly things and the medication that she does need, but it's obviously not adequate.

Senator FEINGOLD. Well, thank you very much. It's an excellent panel, and we will take your stories forward to Washington.

The last panel is a group of advocates in this area who will talk to us about the President's plan and other aspects of what needs to be done for consumers as well as caregivers. Stephanie Sue Stein, Tom Hlavacek, and Bev Young.

All right. We're all set, and we'll start with Stephanie.

**STATEMENT OF STEPHANIE SUE STEIN, MILWAUKEE COUNTY
DEPARTMENT ON AGING, MILWAUKEE, WI**

Ms. STEIN. Thank you, Senator Feingold, and thank you for this opportunity to testify. My name is Stephanie Sue Stein and I'm the director of the Milwaukee County Department on Aging which is the area agency on aging for Milwaukee County, the county aging unit, and also the long-term support unit for all persons over 60 residing in Milwaukee County, of which there are 172,000 people.

We at the Department on Aging know first hand the success of Wisconsin's Community Options Program, as is evidenced by our being able to serve people like Ann Hauser, who spoke to you today, and we also know the heartbreak caused by the inadequacy of Wisconsin's program as evidenced by Dorothy Freund's testimony today. What we need and I think you know this, is a Federal long-term care program which offers our citizens real choices and not waiting lists.

In Wisconsin, as we speak today, we have lost the options in the Community Options Program. We have lost them because there are insufficient COP slots appropriated to meet the growth in the at risk population in this State, and because insufficient money has been appropriated for each individual slot and that there's been no recognition that the cost of buying services for people in the community has risen. And therefore, we have long waiting lists in every county in Wisconsin; 1,930 older people in Milwaukee County alone are waiting for services in the COP and COP waiver programs.

In April of this year, service dollars for the only long-term support program we were able to keep open, the COP Hospital Link Program, were totally used. We knew that the persons we served through this program, persons that were truly diverted directly from institutional to community-based care would use our entire COP allocation, our COP waiver allocation, and our Link allocation

for 1994. And more importantly, our current clients will use our entire allocation of new dollars in 1995.

We now look at 1996 as the year we may be able to serve new clients in any of the 16 different programs that we administer. Meanwhile, almost all of these people will be able to use their Medicaid cards to purchase care which they don't want in an institution. We must have a public program which allows those who need community-based care to purchase that care in their home and in the community.

Yesterday, as Linda testified earlier, was Mother's Day. And I suspect that millions of dollars were spent honoring our mothers with cards and flowers and mementoes of love. And I also suspect that when many families visited their mothers in our community, they realized that things were not quite as they should be. Some of them noticed that mom wasn't getting around just as well as she had been perhaps last year. Or that her clothes looked dirty and not meticulously groomed as mom had been, or that there was spoiled food in the refrigerator, or that a prescription drug bottle hadn't been filled this last month. And some of those concerned people called us today, and when they call us we do two things—we ask informed, caring social work kind of questions about what is going on in mom's life; and then we ask government directed kinds of questions about income savings, and all those good kinds of things, and then we offer advice. If all the questions have answers which lead to the need and the eligibility for care, we offer these families the hope of our services, in 2 or 3 or 4 years. Happy Mother's Day.

Currently our Wisconsin Department of Health and Human Services has decided to do a waiting list survey. This survey is crafted to determine whether we, at the county levels, are correctly assessing the functional and financial eligibility of people who come to us before we put them on these waiting lists. This is to prove, of course, that these stories that we're telling you may be exaggerated.

I believe that a more productive use of our State government's time and money would be to visit these people and to learn their stories. They could then join us in telling these stories to you and to our State legislators in order to eliminate the waiting lists by fully funding community-based care.

We know these programs work. We know that they provide services where people want them and that they save money, and we join you in working for the passage of a national homes and community-based long-term care program in this Congress. Thank you very much.

Senator FEINGOLD. Thank you, Stephanie. As always, and I am particularly interested and troubled to hear about the fate of the COP Hospital Link Program that came out of the good ideas of the people in Milwaukee. It works, we know it works. As you say, it's people that otherwise would have to go to a nursing home, that's the whole principle, and their next stop is the nursing home from the hospital, so it's disappointing to hear that but it also makes the point. When another Senator says to me, well, if you're doing it in Wisconsin, what's the problem? Well, the problem is we can't do it in Wisconsin any more. We do need the Federal dollars to help and

without that we can point to exact cases here in this county where people are going to a nursing home which simply are going there only because the hospitals aren't geared up and linked into the community programs and it's taking away dollars for other things. So that's troubling but it also helps us indicate the urgency of the Federal program.

Now we'll go to Tom Hlavacek.

STATEMENT OF TOM HLAVACEK, WISCONSIN COMMISSION ON AGING

Mr. HLAVACEK. Thank you, Senator Feingold, for once again providing us in Wisconsin with an opportunity to pass on to you our concerns, our ideas, and our personal stories as they relate to this critical national issue.

I just wanted to draw to your attention, too, that in the crowd, this afternoon, are a number of people that have come from different parts of the State, Molly Cisco and Bob Deist, who have brought people from Madison, from the Independent Living Center there, and everybody is interested in this issue, and proud of your leadership on this issue. We feel that it's to our great advantage to have you working on our behalf on this issue for us in Washington just as you did in Madison.

You spoke eloquently, Senator Feingold, as many others have, today, on the interrelationship of long-term care and acute care in the overall health care debate. I would like to focus on something that Linda Rowley touched on a little bit before, and that's another funding link which is the relationship between funding for community-based services and funding for institution-based services. Because when you come right down to it there's a fixed pot of money. That's the problem that we face, that's the problem with the waiting lists, that's the problem with the lack of access that people have. If you take all the money, it is either going to be in the institution pot or the community pot. And you've done a lot of work on that issue in Wisconsin and I think it needs to be exposed more on the national level in terms of this debate because you're right, we're constantly going to be asked this question, where's the money going to come from?

We have to remember that in Wisconsin there were two variables that moved us away from an over-reliance on institutional care toward the progressive posture that we have now. That was the institution of the Community Options Program and the moratorium on new nursing home beds in Wisconsin. Neither of those two variables operating in a vacuum would have led us to the position that we now hold as a leader in community-based models of support. It was the two happening together that led us into a new era. And yet as Stephanie has said and as we know from people in other parts of the state, we have over 5,000 people waiting for COP funds statewide.

I would like to explore two reasons why that's the case. The first is that the moratorium by itself has not done enough to control institutional spending. The institutions have powerful lobbyists and they have the Boren Amendment, which, as you know, guarantees by Federal law that they will get funding increases as they need them every year, as regular as clockwork. What that means is that

if you're a person with a disability on Title XIX, you have an entitlement to a nursing home bed but not to a COP slot. This imbalance not only allows the institution bias of Medicaid to flourish, it has a tragic affect on funding for community living. Legislators have to appropriate funds for institution rate increases before they can consider increases in community funding.

We all know the current status of most State budgets. Right now in Wisconsin there's a rush to take schools off the property taxes and cut back on discretionary programs to do so. Under this scenario, further increases in community funding become more and more remote. And as long as institutional and community funding are tied together with the Boren Amendment on the institution side, the situation will continue to worsen. Especially as the population ages, more and more people turn to this system for help. We therefore believe the scales need to be balanced by either instituting a Boren-type amendment for community funding or by tying rate increases on the institutional side to automatic similar increases on the community side.

When you were a State senator you proposed that amendment in Wisconsin several times in budget debates. We would like to see it debated on the national level. We really think it needs to be exposed, that this is one pot of money that gets divvied up, with the institutions having a huge advantage with the Boren Amendment.

Of course, the answer will be, we don't have enough money for that idea, and that leads me to the Clinton plan. Along with being an expertly crafted idea, as we've talked about based on the COP model, high marks for consumer choice, control and flexibility, it comes with the all-important commodity we all need, which is money. The President's proposal would add 38 billion new Federal dollars by the point of full implementation into the community funding universe. That would mean something on the order of \$760 million in Wisconsin, a State where we fund COP at around \$90 million a year.

In addition, the President's proposal would require that all States provide personal assistance services as a benefit. PAS, personal assistance services, that's the cornerstone for community living, and a national PAS program would be a huge step in the direction we need to go.

We believe the President's proposal would be even stronger if it was coupled with a national moratorium on new nursing home beds. We need to put the bias on the community side of the equation if we're ever to have a reliable and vibrant community living system that meets everyone's needs in the 21st Century and beyond. We can't allow home and community-based long-term care to be seen as baggage in the national health care debate. We have to constantly raise the question, as you have, where should we put our resources? Into nursing homes or into people's homes? And we need to answer that question on a personal level. Not where should they live. The infamous "they." But where would I want to live? Where would I want my parents or my sister or my son or my neighbor to live? When we put it in the personal context we can't justify funding decisions that lead to the door of the nursing home or the State institution.

In closing, thank you again for the opportunity to speak and for the leadership you have shown in Wisconsin on this critical issue. We'll continue to work with you to make sure that home and community-based long-term care remains on the table as the national health care debate evolves.

Senator FEINGOLD. Thank you very much, Tom, and I particularly appreciate the forceful comments on the Boren Amendment and its effects. In fact, that is the case in so much of our Federal policy, that institutional and home-based care are not treated the same way, and the President's plan does begin to change that, but not in any way that would address that matter you just talked about. So we will take a look at that.

Senator FEINGOLD. Bev Young was an original constituent of mine back in my State senate district.

Bev is the founder of the National Alliance for the Mentally Ill. Go ahead, Bev.

**STATEMENT OF BEV YOUNG, FOUNDER, NATIONAL ALLIANCE
FOR THE MENTALLY ILL**

Ms. YOUNG. Thank you. I support everything that's been said and one of the wonderful things about being here today is that, although my mind constantly focuses on serious mental illness, it's good for all of us to hear about the needs of someone who doesn't have a serious mental illness and see the similarities between the needs of various groups of people.

We want and hope that people with serious mental illness, with brain disease, with long-term psychiatric illnesses, will be included in a long-term care package. We advocate that this group be not all people with particularly mental illness, but those with serious functional problems. That group is probably made up of about two-thirds people with schizophrenia, and one-third with illnesses such as manic depression, major depression, obsessive-compulsive disorders, panic disorders. It is made up of probably 1 percent of the adult population, which comes to about 1.85 million people. It has been estimated that the cost today of this group of people is \$20 million. So it is not an inexpensive disability.

Some of the characteristics of our people who desperately need the kind of long-term care is hallucinations, and I think it's simpler to say voices, voices in the head that are persistent and give sometimes wrong messages to the individual. I recall a young man who said, do you hear that, those, that noise, and it was the cars going by the apartment and the sound of the traffic was causing voices in his head.

Also sometimes our people see things that are not actually there, or they think perhaps, and are frightened by, the thought that their, the voices within them, are being heard by the people who surround them.

Our people also have delusions, often strange beliefs, and if you know people with serious mental illness, you know sometimes their speech is disorganized, the moods are not regular, and behavior can be bizarre.

It would be really neat if schizophrenia and these serious illnesses traveled along a nice, neat track. But unfortunately, they do not. And even though the person may be getting excellent care,

there are still acute episodes that require hospitalization, and there are crises.

Some of the problems our people face are problems in concentration. The young man I know best mowed the grass yesterday and stuck with it for 30 minutes, and it's really the highlight of the year, sticking with a job for 30 minutes and not having some kind of interference in his head that would cause him to quit after 5 minutes.

Our people often have difficulty processing information, thinking clearly. Stress is an enormous problem. The young man, I said, why don't you go back to that drop-in center, and he said to me, there's too big a crowd there. And I said, well, how many people were there? And he said three. It was just too many people to deal with when you have another voice in your head.

Some of the kinds of help our people need are basically just skills or information to deal with what's happening to them. They also need help in self-care, because often this, even though the person may look just fine, he or she may have difficulty focusing on the problems such as the need for a shower, the need to do the laundry, food preparation, shopping, and all those things that we just take for granted every day in our lives. The voices can become very severe. Sometimes it turns out they had the radio a little too loud and the neighbors pound on the door. That's when we need the helpers to come over and deal with a landlord, deal with a neighbor. Sometimes we need their help to deal with the police who show up. All these things are a part of the kind of long-term care that's very essential, in order that our people can live in the community and can improve their living skills.

Crucial, of course, is management of the medications and watching to see how the medications are working and if they're changing over time. We in Wisconsin, of course, have developed a fantastic program, which we call Community Support Program, which does keep our people functioning in the community. Helps them improve their way of living and provides for these long-term needs.

This very specific population probably would cost less money if long-term care funds were provided. Dr. Kinalor, whom you know, is estimating that although—that this group might cost from \$16.7 to \$18.5 billion, which is actually less than it now costs in this country, and the decrease in cost, of course, is because if people can live in the community, the cost is less than the extremely expensive institutionalization, hospitalization, and often the extremely extensive court costs. It's also more humane. It means our people will not end up in the shelters, where we figure a certain percentage of our people are. Our people will not end up in the crowded jails or in the prisons, and they can make it in the community.

Above all, in the back of my mind, there is a constant hope that the medications our folks take will improve the end. By so doing, they will improve the way our very ill folks can function. And then I hope that they won't need that long-term care that we're advocating for today, and I think we have reason to hope that that can happen. So let's keep them in our community. Let's let our folks maintain the skills that they have developed in hopes that later in their lives they, too, will have jobs and function like our well family members.

Senator FEINGOLD. Bev, thank you. I think this hearing has very well shown something that is another problem with trying to explain things to people in Washington, and that is they hear long-term care and they think of the elderly only, and even if they talk about people who might have disabilities, they tend to think of the developmentally disabled. There is a lack of sophistication, understanding the differences between people who are severely mentally ill and others, an assumption that there's no way to target those people and try to focus a program.

So there are some deficiencies in the President's proposal. He has a very good long-term care plan, as I've indicated. It's good for elderly in particular, and it provides a system based on activities of daily living, that you need to have three of the five areas that are a problem.

That doesn't necessarily address what you're talking about. It's the natural assumption of a policymaker to say, okay, we can't deal with that now. That doesn't make sense for the reasons you've identified. We can save money and reduce institutional costs and reduce other costs to this system if we tailor this program to this population. And I am as committed to dealing with this particular piece of the problem as I am with the other items you've talked about today.

We have experience in Wisconsin that if we stick together, we get a lot more and better policy than if we separated into different groups. That's what this whole history here has been about, and we need to work together, including those who are concerned about the severely mentally ill, to make sure that the President does what he intends to do. I know that the President and his staff, if they knew all the details of this, which I know they're struggling to do, could certainly make those adjustments, and you and I and others are going to try to make that happen.

A couple of quick questions for the panel. Some people are discussing a means tested long-term care program such as the current Medicaid program. Why shouldn't we have a means testing program for long-term care? Is it a good idea or not?

Ms. YOUNG. Well, in our case we're talking about adults who really live in poverty, so that it really—most of our people who are that severely handicapped are now on SSI or something like that.

Senator FEINGOLD. So you don't think it would matter particularly.

Ms. YOUNG. It isn't going to affect us because our people just don't—if they're that severely handicapped, they don't hold jobs that produce sufficient income to lift them into another area.

Senator FEINGOLD. They would have a problem with the test, is what you're saying?

Ms. YOUNG. Exactly.

Senator FEINGOLD. Tom, do you want to comment on that?

Mr. HLAVACEK. Just that the President's proposal does not require you to become impoverished as almost every other program we've put in place in this country does. And that's a step in the right direction. It's functionally based and it's based on an individual's needs, which we like to see.

The President's program also has sliding copayments attached to it which are something that can certainly be debated but I think

it's important that we do take a look at the President's proposal and what it offers in terms of looking at individual needs instead of just thinking that it's an issue only for poor people, because there's many people for whom poverty is not the issue and, in fact, they have to become impoverished before they can take advantage of any kind of assistance that they need.

Senator FEINGOLD. Appreciate that comment. Stephanie, do you have any comment?

Ms. STEIN. Well, I agree with what Tom just said and clearly the issue is access. People right now on Medicare, which is not means tested, often pay a lot of money in out-of-pocket expenses to get all of the health care that they want or need, and we don't call Medicare means tested. What we do call people with those cards is people who have access to the medical system in this country. And what we need is people who have these needs in daily living to have access to long-term care systems, and some of them will pay a great deal more than others who will pay nothing.

Senator FEINGOLD. Let me just say, I agree with those comments, and I'm pleased to hear your courage in saying it, because there will be a lot of people who will say we've got to means test this from the beginning.

But when I created Wisconsin's Alzheimer's Disease Program, it was not my goal only to provide help to the poorest of people who happened to have Alzheimer's disease in their family. The goal was to not make something that happened to people, through no fault of their own, completely devastating and disrupting to their lives. Yes, we may ask for copayment. Yes, there may be no help after a certain level of income, but eligibility for the program should be available to all Americans regardless of their income. And that is, and I think the other problem is, if you don't do that you end up with it being a Medicaid type program, where people say, as you said, well, that's for poor people. That's not what we're trying to achieve here. What we're trying to achieve here is a social, societal commitment to care about each other. I think Social Security had that quality and I think that we want to achieve the same thing here.

One last point since we are a half hour over schedule. The President's plan, whether you would like it to be or not, is not an entitlement. There's only a certain amount of money proposed to go to long-term care. So if anyone says this is one of these new government entitlements and it's just going to be a spigot that we can't turn off, that isn't how he set it up. He says we're going to give a certain amount of money. Hopefully the States will be able to match that amount. States have to put up I think 15 percent, whatever it is, sliding scale depending upon the situation, and you know when the money's gone, so be it.

But as Tom indicated the dollars in the President's plan alone would make a world of difference for Wisconsin and, I think, get rid of our waiting lists, or at least come very close.

So I want to thank the panel. I want to thank everyone. I'm going to limit my concluding remarks to that because I do have to get going, but I appreciate everyone coming, and the battle is not just started, but it isn't even half over. So I ask everyone in the room to do this. I don't think it's unreasonable. Everyone in the

room should call each of the members of the Congressional delegation. Ten calls if you don't include me. And Senator Kohl was already here. Just call them up or send them a fax and say, please include long-term care. That's all you've got to do. You don't have to talk. Just leave a message. If you do that, it will make a difference. We sometimes receive no more than 10 calls all week out of 2,000 calls on health care. That's all we get sometimes. So if everyone in this room did that, politicians would take notice. Do it and do it now, please, if you really believe in the need for this program.

I thank you and I look forward to working with you.

[Applause.]

[Whereupon, at 2:30 p.m., the Committee was adjourned, to reconvene at the call of the Chair.]



ISBN 0-16-046394-7



90000



9 780160 463945