

103

CONTROLLING HEALTH CARE COSTS: THE LONG-TERM CARE FACTOR

Y 4. AG 4: S. HRG. 103-203

Controlling Health Care Costs: The...

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

FIRST SESSION

WASHINGTON, DC

APRIL 20, 1993

Serial No. 103-4

Printed for the use of the Special Committee on Aging



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CONTROLLING HEALTH CARE COSTS: THE LONG-TERM CARE FACTOR

TUESDAY, APRIL 20, 1993

U.S. SENATE,
SPECIAL COMMITTEE ON AGING,
Washington, DC.

The Committee met, pursuant to notice, at 9:30 a.m., in room 485, Russell Senate Office Building, Hon. David Pryor (Chairman of the Committee) presiding.

Present: Senators Pryor, Cohen, Bradley, Craig, Burns, Grassley, Graham, and Feingold.

Staff present: Portia Porter Mittelman, Staff Director; Christine V. Drayton, Chief Clerk; Holly Bode, Professional Staff; Anna Kindermann, Counsel; Greg Smith, Investigative Counsel; Mary Berry Gerwin, Minority Staff Director/Chief Counsel; and Katherine DeCoster, Professional Staff.

OPENING STATEMENT OF SENATOR DAVID PRYOR, CHAIRMAN

The CHAIRMAN. Good morning, ladies and gentlemen. The Special Committee on Aging of the U.S. Senate will come to order. We appreciate all of you being here today. We especially appreciate our fine two panels of witnesses. We are very grateful to you for sharing your time and experiences with the Committee.

Before I make my short opening statement and then yield to my colleagues, Senators Cohen and Bradley, I would like to make an announcement that grieves me to a great degree.

Portia Mittelman, the staff director of the Special Committee on Aging—many of you in this audience know her and work with her and love her as I do—is getting ready to leave her post, to go to the Department of Health and Human Services. She will be the Principal Deputy Assistant Secretary to the Assistant Secretary for Aging. We are very proud to have had this experience and relationship with Portia, we wish her well in her new venture, and we hate to see her go. She will continue in her good work, and I think it might even be appropriate if at least the three of us gave a little round of applause for our friend. [Applause.]

Portia, we're going to miss you.

We welcome you this morning to the Committee's hearing on "Controlling Health Care Costs: The Long-Term Care Factor." We have witnesses here today from Maine to Hollywood and places in between to discuss the growing need this Nation has for a comprehensive long-term care system. The United States today is in the middle of a health care crisis—we know that. Costs spiraling

out of control, millions of people with limited or no access to the basic care they need.

Unfortunately, we do not often hear about another equally important part of the health care crisis: The lack of home and community-based long-term care services for the elderly and disabled in our country. It is a problem that is only going to get worse, not better, as our population ages.

Between 9 and 11 million Americans today of all ages need some type of long-term care. Two-thirds of them are elderly, the other third are under age 65. As you will hear today from our witnesses, the vast majority of the long-term care is provided in the home by family and by friends. While most caregivers consider their responsibility a labor of love, it can be an enormous burden. We will hear about that today.

For many people there is little or no relief in sight, either because of financial constraints or the unavailability of care in the community. Most families provide as much care as they are able to give, filling in with whatever they can afford in the community until they are both physically and financially drained. Once it is no longer possible to care for someone at home, nursing home care is more readily available, although much more expensive. However, at \$30,000 or more a year, most people quickly spend what money they have left and in reserve and become eligible then for Medicaid.

It is a sad commentary. American families who are caring for the chronically ill or disabled person are not asking that they be completely relieved of their responsibilities. What they are asking for today is some support and some assistance in providing that care, whether it be respite care, home health services, adult day care, or any number of other alternatives and options that we're going to talk about this morning.

Our current publicly-financed system focuses on nursing home care. Medicaid has become the safety net for people who enter a nursing home, many of whom would not be eligible for Medicaid covered services in the community. Billions of dollars are spent in this country on nursing home care.

Certainly, many people who are in nursing homes need to be there. However, not only is home and community-based care usually less expensive than nursing, it is by far the preferred type of care. How many of us would want to go into a nursing home if it were possible for us to remain in our own home?

I know that the President and the First Lady are going to tackle this issue. Today's hearing is an important step in that process, and I once again want to thank all of the witnesses for coming today. I look forward to hearing their testimony, as I know my colleagues do also.

Senator Cohen, my colleague, I recognize you.

STATEMENT OF SENATOR WILLIAM COHEN

Senator COHEN. Mr. Chairman, I'll be very brief.

First let me say that I hope that our colleagues in the Senate will have an opportunity to watch this particular hearing. As many of you in the audience may know, we are now examining whether or not committees such as the Special Committee on Aging ought

to remain in existence or whether it should be abolished in an effort to reform Congress.

I don't know of another committee that takes the time or devotes the kinds of resources in trying to explore the issues that are most profoundly troubling to our society as this Committee does, Mr. Chairman.

So I hope that at the end of this hearing we will be able to present a record to our colleagues to remind them of the good work that you and the Committee and the staff members perform on behalf of the most vulnerable citizens in our society—older Americans.

A lot of people believe that long-term care is too expensive and it's too complex, but, as you've indicated, Mr. Chairman, there never will be a day in which the answers are going to be easier or the solutions any cheaper. We have to take action now and not next year or the year thereafter to come to grips with this particular problem.

As you pointed out, about 80 percent of the elderly receive care from their families—we talk about family values—80 percent of our elderly receive care from their families, not from institutions. About 12 million people go to extraordinary lengths every day of their lives to help keep loved ones out of an institutional setting, and yet only about 2 percent of those 12 million people receive any kind of support services.

That is not a tolerable situation. It places, as you've indicated, an enormous burden upon those who are providing those services. And I am particularly pleased that we have Mrs. Beverly Hynes from Vassalboro, Maine, who's going to testify today and tell a very compelling story of how she cared for her mother and how her home care saved her family and the government thousands of dollars in nursing home expenses.

Mr. Chairman, I regret that I won't be able to be here for the entire hearing, as we're having a caucus this morning to decide whether or not we can resolve our differences on a so-called stimulus package, and I hope that we can do so.

The CHAIRMAN. Can we assist you in that?

Senator COHEN. I'll make every effort to come back as soon as that meeting is over, but thank you very much, Mr. Chairman.

The CHAIRMAN. Thank you, Senator Cohen.

Senator Bradley.

STATEMENT OF SENATOR BILL BRADLEY

Senator BRADLEY. Thank you very much, Mr. Chairman.

I want to thank you and Senator Cohen for turning the spotlight on this critical and emotionally charged issue. I think for too long it has been neglected and the issue, of course, is family caregivers and long-term care.

There are over 2 million severely impaired adults and thousands of disabled children living in communities throughout this country who need constant care with the most basic functions of life—eating, bathing, dressing. The people who have come here today to testify, those who are on the front line of this daily experience, are a moving testament to the strength of families and provide a glar-

ing example of where Federal policy has behaved short-sightedly and fallen short of the best efforts of its own citizens.

Usually when people think of aging and the functionally disabled, the image of a depressing nursing home environment pops in their mind. But, as Senator Cohen said, four out of five Americans with functional disabilities are cared for, not in institutions, but in homes and by family members.

Family caregivers, as you will hear today, require Herculean physical and emotional strength to be there every day, 24 hours around the clock, providing that kind of care.

The loved ones who provide that care I think have the toughest job I've ever seen—24 hours a day, 7 days a week, they face enormous stress, they need special skills, physical strength, and they earn nothing. They do it out of love.

Caring for loved ones saves thousands of dollars in nursing homes—that's true. But all too often the demands of daily care extract an invisible cost: The demands can become too much, the stress can build, and then something has to give.

If we as a nation are to have any effective long-term care strategy, it will have to build on and support this valuable network of family caregivers. The primary family caregivers can and should be bolstered and supported in their desire to keep their loved ones at home and/or in the community. Even a minimal amount of respite, which is time out from the unremitting task of providing these basic human needs, can head off the disintegration of the family unit and the personal health status of the primary caregiver, herself or himself.

I speak firsthand on this because respite care has been provided for countless New Jersey families under a Federal respite care pilot program over the last several years.

I think of one 82-year-old woman who was given a week of respite so she could attend the wedding of her granddaughter in California—respite from caring for her 103-year-old mother. That's what respite care did for her. Or a recently widowed 68-year-old woman who was able to attend her son's graduation by obtaining caregiver services for her 87-year-old bedridden mother and her 46-year-old paraplegic son.

These are enormous emotional demands that are placed on family caregivers across this country, and some break from that unremitting stress is a minimum, I believe, that we owe families in this country.

With that in mind, I introduced legislation relating to the family caregivers. I hope that we'll be able to include part of it in any kind of package that we talk about in terms of national health care, and I know that the testimony of our witnesses today will give living proof of why this national need must be met.

I thank you, Mr. Chairman.

The CHAIRMAN. Senator Bradley, thank you very much.

I believe now in order of appearance we have Senator Craig.
Senator Craig.

STATEMENT OF SENATOR LARRY CRAIG

Senator CRAIG. Well, Mr. Chairman, let me echo the remarks of my ranking colleague as it relates to the importance of this Com-

mittee, and your leadership in its direction, and especially today as we focus on long-term health care, an area that has not received the kind of attention in the last several months that I sincerely believe it should in examining overall health care reform for this country.

I've just returned from my State. Like many of us, I had held 17 or 18 town meetings, and in those town meetings health care and health care reform was discussed. And often it was brought up: what about long-term care, will it be a complete package, will it address the needs of the elderly in a way that heretofore we have not successfully done so? And I could not honestly tell them at that point that it would.

As we know, Congress several years ago attempted to deal with long-term catastrophic, and it failed, and I think that your and this Committee's willingness to re-examine and re-enter that area is very important to this country.

Let me speak very briefly about the idea of the home care that is important to me and important to my family—my wife's family chose to do that with their elderly and were very successful. Her grandmother died at 97 in the home. Her grandfather died at 99 and 11 months in the home. Now her parents were fortunate enough that they could afford to remodel and reconstruct a home environment so that those elderly could live there and fulfill their lives. But had they not been able to do so, more than likely those loved ones in their later years might have been institutionalized.

Now that's why I've looked at ideas like a medical savings account or some kind of flexibility that across-the-board can give those who choose to provide home care some opportunity that now doesn't exist—certainly, we will go beyond that—but clearly we need to be flexible, and most importantly, Mr. Chairman, I do not believe we need just to look at the government as much as we need to provide those who are so willing to care for their elderly some flexibility and some opportunity to make that care easier to give and with greater benefit.

It's with those thoughts in mind that I am anxious that we move forward in this and hear testimony from those who are before us today. It is a challenging area if we are to, as I know we will and must, deal with the broad parameters of health care. Let us not do it in a piecemeal way. Let us look at it in a broad perspective. The elderly deserve that kind of understanding, and most assuredly, those who would choose to care for their own ought to be given the flexibility within the programs to afford to be able to do that.

[The prepared statement of Senator Craig follows:]

PREPARED STATEMENT OF SENATOR LARRY E. CRAIG

Mr. Chairman, I want to thank you for conducting this hearing today on long-term care. While there has been a great deal of discussion and debate regarding health care reform, long-term care has not been at the core of the debate. Yet families dealing with Alzheimer's disease focus on this issue every day, and they can certainly provide us valuable insight by sharing their experiences. Therefore, I appreciate the opportunity to highlight this important issue and look forward to hearing from the diverse panel of witnesses.

While most of us are familiar with nursing homes or skilled nursing facilities as providers of long-term care, there are many of ways that care is being delivered today. These include residential care facilities, in-home nursing, and family-provided care in the home. All of these components of delivering care are important in meet-

ing the needs of the individual. The delivery of care, whether in a nursing home or patient's home, should be chosen by the family in order to meet the needs and desires of the individual requiring care.

Flexibility in any reform proposal will be an important component, especially for the delivery of care in rural states like Idaho. Idaho has a variety of care providers in the area of long-term care that include different levels of care available in the home and in a hospital or institutional setting. As we look at health care reform and long-term care, we need to be cognizant of the different needs of long-term care patients and shape a system that will be flexible in both the public and private sector.

If a family prefers to provide care for a loved one in the home, and this care will meet the needs of the patient at a reasonable cost, then there should be some sort of support available. Similarly, support should be available for those who need the kind of care provided in a nursing home. Having said that, let me be clear that I think it is important we not focus solely on publicly funded long-term care. There also needs to be a thriving private system supporting these needs as well. One area I have been reviewing is "medical savings accounts," or MSA's. These would work like individual retirement accounts, allowing individuals to save money, tax free, for health expenses. This would include long-term care expenses and would focus on services, not providers, giving it the flexibility to meet individual needs.

I am interested in hearing our witnesses' thoughts on this idea, and any other insights they can provide on this problem today.

The CHAIRMAN. Senator, we thank you for your comments.
Senator Burns.

STATEMENT OF SENATOR CONRAD BURNS

Senator BURNS. Thank you, Senator, and thank you, Mr. Chairman.

I will hand my statement in because we have a meeting. I just want to apologize to our panelists today because I'll be going with Bill. We have a 10 a.m. meeting, but I want to say this before I leave. Nothing touches me deeper than this disease, or home care, and I will tell you why—because it's very fresh in my memory.

And, Walter Dawson, I'm sorry that you're here today but I'm also glad you're here today, that you'll be able to tell a story and a story that my son can tell who is 17 because, you see, last year we went out of the grandpa business quick. My father-in-law died of Alzheimer's in October—in fact, on my wife's birthday. And I lost my father in December, so all of this is very fresh in our minds, and we also notice some things. They got to stay home, they're farmers and ranchers, and I guess we're just old farmer people. We just take care of our own, we just stay at home. But we also understand that we cannot—all of us cannot do that.

So I am happy you are here, young man, and have the courage to come up here and tell your story because I think it's one that has to be told.

At some point in life all of us may touch this terrible disease because we are living longer now, we get older now, and life is extended now. And we have to take that into consideration, and even though this government which prides itself on doing things for people or wanting to do things for people, we are seemingly always behind the curve. We get behind the curve in our policymaking so that it takes a personal touch in order to motivate us into doing some things that we think have to be done.

So home care, we're taking a look at that. I've been involved in telecommunications issues—with interactive TV and this type of thing—where people can stay home, as far as rural health care is concerned and in-home care. The longer we can keep that person

in the setting of the home, the better it is for everybody concerned. We also know that it has its limitations.

So, Mr. Chairman, I appreciate your leadership on this. I will hand my statement in. We're used to having some of our more well-known people that's in the entertainment industry in here. But what is most impressive is this young man who I know will have a story, and I want to apologize that I probably will not be here when you get to tell your story. And that's unfair to you, but I'll be watching this very closely, and I'll be reading what you have to say.

I just want to assure you that even though we have to jump up and go somewhere, we've got too much to do, and we don't get to sit and listen and visit enough in this Congress to really be effective. But I want to thank you, young man, for coming, and I thank you, Mr. Chairman.

The CHAIRMAN. Senator Burns, we thank you and your statement will be placed in the record.

[The prepared statement of Senator Burns, along with the statements of Senators Shelby, Pressler, Simpson, and Durenberger follows:]

PREPARED STATEMENT OF SENATOR CONRAD BURNS

Thank you Mr. Chairman. Let me start by welcoming our distinguished panelists. I am often impressed by the folks that come before our committee, but I think today's first panel is by far the most significant. It shows just how far-reaching the impact of Alzheimers truly is. Having members of the entertainment industry is nothing new here, but it is indicative of the fact that Alzheimers does not discriminate. And certainly, we wouldn't expect a young man of Walter's age to be before the committee to talk about Alzheimers. And yet, this disease has had a very profound impact on his life. I wish you didn't have to be here at all, Walter, but I am glad you have the courage to want to be heard.

At some point in life, we may all have to experience the ravages of Alzheimers. My father-in-law died last fall as a result of Alzheimers, and though he was several States away, I understand full-well the frustrations, heartaches, and financial strain it can put on a family. This devastating disease sapped all the soul and spirit from my father-in-law. I can only hope that the research that is being done will bring help quickly. But until then, we must do what we can to aid those who have Alzheimers, and those who are the caregivers.

As a society, we are living longer these days. This may be a function of living healthier or perhaps just a sign of advanced technology, which can keep us going. In any case, long-term care is becoming a part of health care costs that we can't ignore—it won't let us. I think it is very important that any health care reform package we look at here in Congress contains provisions to deal with long-term care services.

The problem, as you all know, is the high cost of these services. I saw a fact sheet put out by the Alzheimer's Association which states that the cost of Alzheimer's disease is approaching \$100 billion per year. This is just one disease that afflicts our elderly—there are others. And there are other diseases that require long-term care that affects the non-elderly.

So, home care is taking on an increasing importance in all of this. I can tell you from personal experience. I recently lost my dad, but he remained in his home until my mother could no longer take care of him on her own. Allowing folks to stay at home is not only less costly, but it allows the patient to keep their pride and dignity, to be comfortable in their own surroundings, and to keep them in the company of those they love. I don't need to tell you the value of that type of lifestyle for someone who is sick.

I will stop here, Mr. Chairman, because it is clear I am preaching to the choir. These folks live with Alzheimers and know firsthand the effects any type of long-term care has on a family. I will be interested to hear what they have to say, and am especially interested to hear their recommendations. It is easy to point to the problem—it is not so easy to find a solution.

Mr. Chairman, I appreciate your thoughtfulness in calling this hearing and the work of the committee staff in pulling together such a fine group of witnesses. This is one issue that I look forward to some positive action being taken.
Thank you.

PREPARED STATEMENT OF SENATOR RICHARD SHELBY

Mr. Chairman, I commend you for convening today's hearing to discuss the very important issue of controlling health care costs with particular emphasis on long-term care. We are fortunate to have a distinguished panel of witnesses with us this morning who will provide this Committee with some valuable insight into this complex problem. I also am very hopeful that this hearing will identify ways to help us control long-term health care costs whether this care is provided in the home, in a community-based facility, or in a nursing home. In addition, I hope that this hearing will present some creative solutions to the special problems of individuals living in rural communities who in some instances may have fewer options available to them than individuals in urban communities. Moreover, the problems faced by people in rural communities may be exacerbated by the shortage of health care professionals in these areas.

Because long-term care costs disproportionately impact the elderly, few Seniors are able to enjoy the highest standard of medical technology and life-saving medical procedures while many others cannot afford basic health services. Recently, I was saddened as I listened to a woman on television discuss the probability of her death because her medical insurance would not cover a particular treatment when needed. Although this is deplorable, there are many people even worse off than she because they have no medical insurance at all. We must do something about the continuous increase in health care costs while paying special attention to our elderly who are often unable to afford the long-term care they need. Consequently, we are all anxiously waiting to receive President Clinton's health care reform proposal.

According to the Health Care Financing Administration, annual health care spending is expected to rise from \$800 billion in 1992 to \$1 trillion by 1995. If there is no reform of the health care system, it is projected that the 1995 figure will almost double to \$1.6 trillion by the year 2000. In addition, each person will spend an average of more than \$5,700 on health care by the year 2000 compared to only \$2,566 in 1990. This rate of increase is two to three times higher than the expected rate of increase in personal income; consequently, Senior Citizens who live on a fixed income will be disproportionately and substantially affected by these projections in health care costs.

The U.S. Bureau of the Census projects that by the year 2000, persons 65 and older would represent 13 percent of the population, and this percentage could climb to 21.8% by the year 2030. As our population grows older, the demand for long-term care increases. Presently, over 1.5 million Americans reside in nursing homes. This number is expected to increase to 2.2 million by the year 2000, and to 4.5 million by the year 2040. In addition, by the year 2000, 7.2 million Senior Citizens will need some type of long-term care assistance to help them perform daily activities to maintain their independence. This number will increase to 14.4 million by the year 2050.

We have all had a friend or loved-one who may have needed long-term care (You may want to mention something about your mother's stay in the nursing home). I believe, however, that we should not allow the cost of long-term care to penalize the elderly for a lifetime of hard work and saving. We also should not take away the financial and psychological independence of any couple or family when a member of that family needs long-term health care. Obviously, it is an understatement to say we have a lot of work to do to achieve these objectives. Nevertheless, I believe that this hearing today represents an important step in that direction.

QUESTIONS

1. It is my understanding that one reason Medicare has not played a significant role in providing long-term health care is that some fear that federal support in this area would produce a disincentive for families to care for individuals capable of remaining at home. There is some research in this area which disputes this argument. What is your opinion?

2. What type of illnesses should be covered by a long-term health care plan?

3. What kind of approach should be used to protect and preserve people's assets in long-term health care situations. I have heard some individuals use the terms "front-loading and back-loading." Could you define these terms and indicate which you believe is more cost effective?

4. Do you have any short term recommendations for improving long-term health care for the elderly while Congress is deliberating the Administration's health care reform proposal?

5. How likely is it that a Senior Citizen will return to his/her home after a 6 month stay in a nursing home?—a 12 month stay?—an 18 month stay? Could you provide some data in support of your answer?

6. Has the "On Lok" model been replicated in a rural area? If the model were applied in a rural area, what cost savings would be realized?

7. What was the net cost savings in dollars per patient realized in the Rochester experiment?

PREPARED STATEMENT OF SENATOR LARRY PRESSLER

I thank the chairman for holding today's hearing. It is a timely subject and one of particular interest to me.

Between 1980 and 1992 health care costs increased by 106%. Prescription drug prices increased by 123%. Medicare expenditures soared by 272% and Medicaid costs increased some 384%. During the same time period the general inflation rate increased some 68%.

Nearly 37 million Americans are without health insurance. In my state of South Dakota 56,000 individuals are uninsured. Nearly 5,000 South Dakotans are considered uninsurable.

The typical family in South Dakota spends 13.1% of their income on health care costs and insurance premiums. This is the fourth highest rate in the nation.

The Congressional Budget Office estimates that Americans will spend \$912.3 billion this year on health care. This represents 14.6% of our gross national product (GNP). Health care expenditures are expected to exceed \$1 trillion by 1995.

Nearly 39% of all health care spending goes to hospitals. 19% of all spending goes to physicians.

In South Dakota 8,000 individuals reside in nursing homes. Nearly 56% of these individuals are dependent upon Medicaid to pay for their care.

This year Medicaid expenditures are expected to total \$126 billion. This represents 15% of health care expenditures. In South Dakota the Medicaid budget will total about \$232 million. \$72 million or nearly one-third of this budget will be spent on long-term care.

These figures illustrate the need to reform our health care system. More specifically these statistics point to the need to include long-term care provisions in any reform package. Not addressing this issue would be like taking your car in for a tune-up and asking the mechanic not to replace the spark plugs. You'll end up back in the shop when your car won't start. Likewise, if we don't address the long-term care issue we will only provide a short-term health care fix.

Health care reform must be market based. I believe reform should not include price controls and new mandates upon employers. Reform should include long-term care, prescription drugs, primary care, emergency care, and other specialties. It must include malpractice reform, changes in the anti-trust laws, reform of the insurance market, reduction of federal regulation, simplification of claims processing, elimination of waste and fraud, greater emphasis on preventive care and tax incentives to help individuals purchase insurance. This does not prescribe the entire formula for health care reform. However, it lists the principles that I support.

Some have advocated that the federal government pay for the nursing home costs of senior citizens. I favor the use of tax incentives to assist people in purchasing long-term care insurance. In addition, we must provide incentives to help families care for their ailing parents. It is clearly more cost effective to provide care in an elderly person's home.

The long-term care issue has a direct impact on each of us. We may have a parent in a nursing home. We may face entering a nursing home at some point in our lives. We are all the taxpayers who are paying for the Medicaid programs which pays for one-third of nursing home patient care. Long-term care must be included in the health care reform package.

PREPARED STATEMENT OF SENATOR ALAN K. SIMPSON

I want to thank Senators Pryor and Cohen for holding this hearing today on this crucial and timely issue—long-term care for the elderly. I don't have to tell any one here that we are in the midst of a health care crisis in which health care costs are increasing at dramatic rates and millions of people are in need of basic health care. One aspect of this health care crisis that we need to pay more attention to is the need for a more well-defined policy on long-term care—particularly home and community-based care. Long-term care must be addressed in the context of the current

health reform debate and cannot be left out of any comprehensive health care proposal.

Currently, between 9 and 11 million Americans of all ages need some type of long-term care and the Alzheimer's Association estimates that approximately 4 million persons are diagnosed with Alzheimer's disease. As the U.S. population increasingly ages in the upcoming decades, we will need to focus more our resources and energies on the long-term care needs of this growing population.

Unfortunately, I know from first-hand experience about the expense and the heartache of taking care of parents with long-term care health care needs. Both of my parents, who are in their nineties, cannot take care of themselves anymore. My dear father suffers from Parkinson's disease and is in a nursing home and my dear mother needs full-time nursing care provided at home. My brother, Pete and I know full well about the high cost of such care and fortunately, we are financially secure and can share in the high expense of our parents' care. I fully understand that many others are not in the financial position to pay for costly long-term health care expenses out of their own pockets and that some type of Federal program needs to be developed to address these persons' concerns.

One way the Federal Government could address these concerns is to examine the cost-effectiveness of home health care for long-term care needs. No one wants to be in a nursing home if it can be avoided, and for many elderly persons staying in their homes is the last bit of independence they have in their lives. I know my mother prefers being in her own home over being cared for in a nursing home and her quality of life is significantly better. Above all, studies have shown that home care is more cost-effective than nursing home care.

I look forward to hearing from today's witnesses and addressing this important issue as we continue to debate all the components of health care reform including the provision of long-term care.

PREPARED STATEMENT OF SENATOR DAVE DURENBERGER

I'd like to welcome everyone to this morning's hearing and thank our panel for taking the time to share their personal experiences, as family members of Alzheimer's victims.

Minnesota has over 70,000 victims of Alzheimer's disease. But the numbers don't tell the whole story—as we'll hear today from our panel. To complete the picture we need to listen to the family, friends and caregivers of the over 4 million patients nationwide. Each patient has their own story.

While the most tragic and obvious effect of Alzheimer's is the loss of mental and physical functioning, the financial costs are also staggering. Alzheimer's disease is estimated to cost society more than \$90 billion annually. The federal and state governments cover about ten percent of this cost, leaving a tremendous burden on the victims and their families. Since treatment of this disease can stretch over a twenty year period, in some cases, it is crucial that families receive respite care and victims receive needed care services to enable them to remain at home. The cost of nursing home care continues to soar. It's easy to understand that few can afford lengthy stays when the average cost per year ranges from \$24,000 to \$36,000. However, when we look at the cost to the family to keep a victim at home—it's clear that there are no cheap answers. I'm told that the cost to a family averages \$18,000 per year.

When I was Chairman of the Health Subcommittee of the Senate Finance Committee, I authored an amendment in the Omnibus Budget Reconciliation Act of 1986 that provided over \$40 million for the Medicare Alzheimer's disease demonstration project. This legislation currently funds demonstration projects in eight states, including Minnesota. The purpose of this project is to determine the effectiveness, cost, and impact on health status and functioning of providing comprehensive services to Medicare beneficiaries who have Alzheimer's or related diseases. I am pleased that these projects allow Medicare to go beyond its traditional acute care orientation to pay for chronic care services.

Unlike Medicare, which pays primarily for acute care services, Medicaid is a major payer for both short-term and long-term care. Due to this large responsibility and the increase in enrollees, Medicaid's costs are rising in an uncontrolled manner. The Federal government and the states spent \$118.2 billion on Medicaid benefits last year. That was up 25% from the previous year. If this growth continues, total Medicaid spending will over take Medicare expenditures (estimated to be \$148 billion in 1993) within several years. This not only places a severe burden on the elderly but definitely shows the importance of long term care financing.

Therefore, we need health reform that will be comprehensive and address the true source of the problem. Our current financing and medical care systems either ignore these needs or price them beyond the capacity of most individuals in need.

In addition, any positive conclusions that come from research into the prevention or treatment of Alzheimer's disease will help to reduce the cost of long-term care that burdens all of society. Also, research into the effects of Alzheimer's disease on caretakers of Alzheimer's victims could lead to an improved system of respite care, extended leave from the workplace, and overall stress management. Therefore, the benefits derived from an investment in aging research transcends all age groups.

Mr. Chairman, I would like to strongly reiterate the urgency of truly comprehensive health reform. Our delivery system has failed—especially in its responsibility to meet the needs of long-term care. I am pleased that the Special Committee on Aging has focused on this important issue. It is imperative that Congress and the President evaluate the federal government's role in meeting the needs of long-term care.

The CHAIRMAN. Senator Grassley.

STATEMENT OF SENATOR CHARLES GRASSLEY

Senator GRASSLEY. Let me also acknowledge the panel and thank you for coming, and, particularly, thank you for the stories that you tell that are stories of caring. And I'm sure that I, for one, am not fully acquainted first-hand with the problems that you will present, and I'm sure you hope that that would be true throughout my lifetime. And I don't know, but I think that even though we don't experience maybe first-hand, by hearing the stories told so well, it can't help but to make us more sensitive to the problems that families like you face.

I also want to welcome all of the members who are here from the National Alzheimer's Disease Association. I've had an opportunity to work closely with the leadership of the association in past Congresses, particularly on the Federal Government's research program on Alzheimer's Disease. And, of course, I look forward to working with the Association and its members in the future to improve the situation with long-term health care.

Mr. Chairman, the lack of protection against the great financial cost and great heartache that can come with disabling illness or chronic disabling and functional limitations is one of the large remaining gaps in our national health care public policy. I know that many of those who have experienced devastating consequences of disabling illness or who have worked hard over the years in advocating improvement in our long-term health care system hope that the health care reform project on which we're all now launched will also lead to reform in the long-term care aspect as well.

So your hearing, Mr. Chairman, is very timely given that we anticipate a health care reform proposal from the administration next month and anticipate that Congress will spend a great deal of time this summer and into the fall working on that proposal, and, hopefully, adopting a comprehensive proposal before very long.

The focus of this hearing on how cost-effective methods can be developed to care for the chronically ill or disabled is also very timely and important because if we do include a long-term care component in any final reform plan, it seems to me that the shape of that component is going to be influenced by the problem that has bedeviled all of us during our past efforts as we move forward on long-term care. And that problem, of course, is related to the cost of that approach.

So, Mr. Chairman, I thank you once again for the hearing and bringing attention to this problem, and I have a longer statement that I want to include in the record.

Thank you, Mr. Chairman.

The CHAIRMAN. Your statement will be placed in the record, Senator Grassley. We appreciate your statement.

[The prepared statement of Senator Grassley follows:]

PREPARED STATEMENT OF SENATOR CHARLES E. GRASSLEY

Thank you, Mr. Chairman.

I also want to welcome to our hearing today members of the National Alzheimer's Disease Association. I have worked closely with the leadership of the Association in years past on the Federal Government's research program on Alzheimer's disease. I look forward to working with the Association and its members in the future to improve our long term care system.

Mr. Chairman, the lack of protection against the great financial cost and great heartache that can come with disabling illness or chronic, disabling, functional limitations is one of the large remaining gaps in our public policy.

I know that many of those who have experienced the devastating consequences of disabling illness, or who have worked hard over the years in advocating improvements in our long term care system, hope that the health care reform project on which we are all now launched will also lead to reform of that system.

So, your hearing is certainly timely, Mr. Chairman, given that we anticipate a health care reform proposal from the Administration next month, and anticipate that the Congress will spend a great deal of time this session and maybe next year working on that proposal.

The focus of this hearing—on how cost effective methods can be developed to care for the chronically ill or disabled—is also timely and important. Because, if we do include a long term care component in any final reform plan, it seems to me that the shape of that component is going to be very influenced by the problem that has bedeviled all of our past efforts to move forward on long term care reform—and that is the problem of cost.

That is all I have for the moment, Mr. Chairman. I look forward to the testimony.

The CHAIRMAN. And I now yield to Senator Graham of Florida.

STATEMENT OF SENATOR BOB GRAHAM

Senator GRAHAM. Thank you very much, Mr. Chairman. A few comments, first, I commend you for holding this hearing, particularly as we are on the verge of having a major national health reform initiative. In my opinion, it is critical that the initiative include long-term care as one of its principal components.

We know a few facts—First, America is aging. In my State of Florida, according to the 1990 census, we had almost 1½ percent of our population over the age of 85. And early in the 21st century we will have almost 3 percent of our population over the age of 85. It is at those advanced ages that the kind of issues that we'll be discussing today become more prevalent.

Second, we know that the former clear distinction between what was medical and what was social is now becoming blurred. Is it a medical or a social issue to provide an infrastructure of long-term care that, for instance, provides respite services so that the in-home caregiver can have some relief and be able to provide effective care, as opposed to requiring that older Americans be institutionalized in a nursing home?

Third, we have got to have an infrastructure of services that respect the aging process, provide those services that are required but do not take away independence, and which allow the maximum

degree of family and community involvement as the focus of provision of that care.

Fourth, this is a national issue that will require a comprehensive national response in terms of its method of financing and the breadth of services to be made available.

Mr. Chairman, we have a challenging task before us, particularly, to keep the issue of long-term care as an important and urgent component of a national health care policy and not to have it, as some have suggested, left to be considered after a national health care program is shaped.

Your attention today, Mr. Chairman, will help to assure that this issue will not be the forgotten component of national health care reform.

The CHAIRMAN. Senator Graham, thank you very much for your statement. And we do in fact have a real mission before us, and to tell us a little bit about that task and mission is a very distinguished panel, six people who have helped care for a family member with Alzheimer's or a related disorder. They're here to tell us their first-hand stories, their experiences on the front line of long-term care.

The first witness we will have is Mr. James Sikking from Hollywood. He is known as David Howser, from the TV program "Doogie Howser, M.D.," Beverly Hynes from Maine and Virginia Di Manna from Maryland will follow Mr. Sikking.

Next we'll hear from Walter Dawson, age 10, from Falls City, Oregon. Walter, we've had a lot of witnesses before this Special Committee on Aging, but I don't recall any as young as you. We will welcome you in just a moment.

Kojo Nnamdi, the host of "Evening Exchange," a TV show here in Washington, will speak after Walter.

Shelley Fabares from the TV series "Coach," who is also known as Christine Armstrong, will be our last witness on the panel. She will talk about the need for long-term care based on her own personal experience in caring for her mother.

Mr. Sikking, we look forward to your statement, and you may begin.

Let me, if I might, remind our panel that we're going to try to limit our statements to 5 minutes, if we can. And if some of you go over a little bit, we will understand that and we'll try to give you a little leeway here. But we're going to try to limit our statements to 5 minutes.

Thank you, and you may proceed. Now, if you would pull that microphone right up—here I am telling an actor like you to pull your microphone up. [Laughter.]

STATEMENT OF MR. JAMES SIKKING, HOLLYWOOD, CA

Mr. SIKKING. I'll take all the advice I can get, Senator.

Mr. Chairman and members of the Committee, you've been told what I do. I'm an actor. I play a doctor, but I am here to express a disclaimer. I am not an expert in the medical care system or the medical delivery system. I am a citizen, and during the last 10 years I gained valuable expertise on one very important aspect of health care, which is long-term care, as I participated in my mother's struggle with a debilitating disease.

And my testimony is very simple—health care and long-term care must be integrated. By treating long-term care problems as though they are less important than medical care, we are bankrupting our families, we are creating unnecessary expenses for society, and negating a natural and, for most of us, inevitable stage of life.

My personal experience began 10 years ago when my mother started exhibiting serious cognitive problems. It ended last June when she died at the age of 93, a victim of Pick's Disease, a form of dementia that is related to Alzheimer's. Those 10 years were tragic, and, in a strange way, terrific, at the same time. The agony of my mother's decline and eventual death forced me to learn that no matter how hard we try, some things are out of our control, and that at some point you must embrace whatever life sends your way; that tolerance and acceptance are valuable traits to learn in this process.

But there are some things that I cannot accept. I cannot accept the complete lack of information available from the medical profession about our family, what we could expect from this disease, how we might be able to begin to cope with it. Apparently, if a disease like Alzheimer's or Pick's isn't fixable, the medical profession seems to lose a little interest in it. I was fortunate enough to have the resources and I could seek out advice and help. I also have siblings and a family, and they were a wonderful support group. But there was nobody there to tell us what was happening, what we could expect, and the first few years was really an on-the-job training and that was a devastating experience.

I also cannot accept the fact that an experience with long-term care can wipe you out financially. I am financially secure now, but I have been on the other end—believe me, I have—on unemployment without a dollar in my pocket. If my mother's illness had happened then, I don't know really what we would have done. If it were not for my sister's emotional involvement and my financial support, we would have been on the streets with her in a very short time.

I cannot accept the policy of negativism toward long-term care. The bottom line in our society is grow or die. We tend to look at the needs of grandparents separately from the needs of children, and what they both need is a little help.

When dealing with nongrowth issues, nobody is interested. This is really hard to understand for me because nearly everybody is going to grow old and most of us will develop ailments along the way that may cause us to need some help. And, for most of us, it simply isn't there.

I leave it to you and to the experts to figure out how to fix the system. In so doing, I hope you will consider several things—Number one, the destitute must be helped first. In so doing—there is really a huge expanse between the destitute and the wealthy, those wealthy enough to afford the help, and therein falls the shadow. Those who can afford it should pay, but the in-between group must have some assistance to carry on, and that assistance should not force them to be impoverished to qualify.

Number two, we need an integrated and thoughtful health care system that is available if you have a problem, without bankrupt-

ing you or causing you guilt that eats away at you. It should be a system that you can get knowledge and helpful healing. We should start at a level of human relationship and then move to equipment and technology, not the other way around.

And, finally, we must invest in preventive care. Doing so is cost-effective in ways that sometimes it's hard to get accountants to understand. This means helping people to stay at home or in their communities if they can, it means offering some help now to stave off bigger costs later, it means developing custom care that provides what's needed rather than what the bureaucratic rules stipulate.

And my mother was a minister, Dr. Sue Sikking, and she quoted from the Bible. And one of her famous quotes was, "Where your treasure is, there will your heart be also."

So if we stop and look and think about where our treasure is, I hope someday we can say that it is invested in individuals and in families because that's where our hearts should be. Long-term care doesn't have to be a tragedy for us or our families. We can and we must do better.

Mr. Chairman, thank you. Thank you for holding the hearing, and for your compassion and concern for all members of the committee. And if there is anything I can do to help, I'm available.

The CHAIRMAN. James Sikking, thank you very, very much. I know that was not easy, and we appreciate so much your sharing that personal experience with us.

Beverly Hynes from—is it Vassalboro, Maine?

Ms. HYNES. Yes.

The CHAIRMAN. She was the primary caregiver for 12 years for her mother who died in October of this past year of Alzheimer's. She was assisted by family, friends, home health care, and respite care. She and her doctor have stated that her caregiving and use of available community resources saved thousands of dollars in nursing home expenses.

Beverly, I'm going to ask you to pause a second because I know Senator Cohen wanted to be here.

Let us see if we can postpone your testimony a few moments. Senator Cohen is going to come back and not only wants to hear you, I think he may want to ask you a couple of questions.

Virginia Di Manna's husband suffers from Alzheimer's, and she cared for him so long as she was able. She was the primary caregiver, and then she began to suffer a number of ailments herself, and she's going to tell us about that experience.

Virginia, we appreciate your appearing before the Special Committee on Aging this morning.

STATEMENT OF VIRGINIA DI MANNA, GERMANTOWN, MD

Ms. DI MANNA. Good morning, Chairman Pryor.

The CHAIRMAN. Now, you are from Maryland, I believe.

Ms. DI MANNA. I'm from Germantown, Maryland, yes.

The CHAIRMAN. I see. We welcome you to the Committee.

Ms. DI MANNA. I'm a Maryland resident all my life.

I also do not see well—this will not be more than 5 minutes, but they increased the size of my testimony so that I could see it.

The CHAIRMAN. We have to do that up here, I can assure you.

Ms. DI MANNA. I do have some sight problems so maybe you can read it for me.

Good morning, Chairman Pryor and members of the Committee. My name is Virginia Di Manna. I live in Germantown, Maryland. My husband, Daniel, lives in the Coatesville Veterans Medical Center in Pennsylvania. Daniel has Alzheimer's Disease.

When Daniel and I were married in 1953, we had all the makings for the expectations of the American Dream. I was a school teacher; Daniel had a promising career in banking. Daniel and I did realize many of our dreams together. We had four beautiful children, and managed to put them all through college. We were living quite comfortably on a combined income of over \$70,000, and were looking forward to our retirement days. We have enjoyed the security of having saved and invested a good sum of money in preparation for our later years in retirement.

But sometime during my husband's early fifty's, it became clear that something was not right with Daniel. At first, he had difficulty handling stressful situations, remembering what he had just said, and he was not able to use his calculator anymore. At work, Daniel came to depend more and more on his support staff. We both knew this wasn't fair to his employer, but we held tightly to the thread of normalcy in our life, even while I was forced to dress him and drive him to work everyday.

Finally, we could no longer deny reality. In 1985 Daniel submitted to a battery of medical tests, and the doctors came back with the diagnosis, Alzheimer's. At first, we had no idea what the diagnosis of Alzheimer's meant, but we know now. Daniel's disease has taken its toll on most areas of our life. The disease has robbed Daniel of his most basic functions of life. He can no longer feed, bathe, dress himself, or use the toilet. He doesn't recognize me or know my name, and, for that matter, he doesn't even know his own name. My husband, who was a bright and well-educated man, cannot communicate at all now.

The disease has robbed me of a husband I was to share the rest of my life with, the future we had worked so hard for. I was forced to give up my role as Daniel's wife and become his nurse-caretaker instead.

I kept Daniel home with me for about 10 years after the first signs of the illness. We did not qualify for financial assistance for community-based long-term care. So I was forced to bear the burden of the caregiving on my own. Remembering that all four of our children lived to the four winds, from the West Coast to the East Coast, I've borne the brunt of most of this by myself. I lived the 36-hour day you hear about, but it cost me. My physical health and my emotional well-being were shattered.

While Daniel suffered the cognitive decline resulting from Alzheimer's Disease, I suffered the physical decline resulting from the relentless caregiving he required and the failure of our long-term health care system to provide assistance. I have angina, a hiatal hernia, I have esophageal spasms, and other stomach and bowel problems, which I have been told stem from the burden of my caregiving.

Mr. Chairman, I have a letter here from the doctor confirming that my illnesses are stress-related.

The CHAIRMAN. That letter will be placed in the record. Thank you.

ASSOCIATES IN GASTROENTEROLOGY,
Rockville, MD, April 2, 1993.

To Whom It May Concern:

Virginia DiManna has been under my care since 7/17/92. Since that time she has seen me nine times in the office for evaluation of diarrhea, chest pain, abdominal pain, shortness of breath and globus. She has gone through upper endoscopy, colonoscopy, lactose tolerance test, abdominal ultrasound, pelvic ultrasound, esophageal manometry with 24 hour pH monitoring and numerous blood and stool studies. These have served to "rule out" threatening disease processes and have confirmed my impressions that she has stress related symptoms in response to her situation at home caring for her husband.

Unfortunately, a great amount of financial resources are spent in medicine, especially in elderly people where the concern of something "life threatening" brewing is high, ruling out disease processes. In my patient's case I believe that almost all of her medical problems are stress related. It is difficult to decide how to care for people with Alzheimer's disease in these days of growing health care costs. In, Virginia's case, having her husband at home with her has been quite expensive.

Sincerely,

E. SERRIN GANTT, MD

Ms. DI MANNA. When the physical burden became too much, I enrolled Daniel in a day care program costing about \$600 a month, though I really couldn't afford it. This reprieve though came too late. What was supposed to have been free time for me to do the things that needed to be done, quickly became the only time I could attend to my own health needs. I would often take Daniel to day care, come home, and go straight to bed. I finally realized that Daniel's disease might kill me before it took him.

At the doctor's recommendation, I placed Daniel in a nursing facility. Daniel now lives in an Alzheimer's unit of the Veteran's Administration Nursing Facility in Coatesville, Pennsylvania. I cannot say anything bad about the quality of care he receives there. The people are caring. It is worth the 300 miles plus that I drive each week to visit him.

But in 1985 there was a law passed stating that the Veteran's Administration no longer has to cover nonservice-related disabilities, and it has me in a constant state of worry. If he were unable to remain in this facility or if it were closed, his non-V.A. nursing home costs would be between \$27,000 and \$32,000 a year in the community that I live in.

In this situation, the caregiver spouse ends up impoverished, and this is a virtual certainty for me in a very short time.

The insanity of the long-term care system frustrates me. My out-of-pocket expenses for his care are now about \$6,000 a year plus clothing. Moreover, my own medical costs last year were about \$8,700—costs that could have been avoided if I had had more help earlier. If only a fraction of this money could have been spent for more community services for Daniel and respite for me, it would have saved money all the way around.

In retrospect, I know that I kept Daniel home too long and this jeopardized my own health. But knowing what I know now, I am not sure I could have done much differently. I simply didn't have alternatives.

Nothing can bring my husband back nor restore my health, but others who are just now entering the frightening world of Alzheimer's care benefit greatly by preventive services such as home

care and respite, and, eventually, help with nursing home expenses. If our family's struggle can result in help for others, then it will not have been in vain.

Thank you, Mr. Chairman, for inviting me to tell my story and for your concern.

The CHAIRMAN. Thank you, Virginia Di Manna. Thank you very much.

I think there are a lot of cases just like yours across our great land.

Walter Dawson is age 10, and recently he wrote a letter to NPR about the toll both financial and emotional that his father's Alzheimer's Disease has had on his family. He's written to many other people across the country, too, to draw attention to this concern about his family's plight.

Walter Dawson, we appreciate your being here this morning.

STATEMENT OF WALTER DAWSON, FALLS CITY, OR

Mr. DAWSON. Thank you, Senator Pryor and members of the Committee. My name is Walter Dawson. I go to school in Monmouth, OR. I am 10 years old. The name of my school is the Luckiamute Elementary School.

My father has Alzheimer's Disease. He had to pay half his life savings for his care. Now he lives in a nursing home. I miss him very much. I hope you can do something to help people with Alzheimer's Disease.

We were at Disneyland 2 years ago. My dad got very sick. He hated the electric parade because of all the noise and lights. I guess it scared him, and he left. He was gone for over 2 hours. My mom was very scared, so was I.

I told my mom I thought my dad was sick. My brother, Paul, helped us find a doctor. My mom took him to a specialist in Portland, Oregon. They said there was a 90 percent chance he had Alzheimer's Disease. I didn't really understand.

My brother, Paul, was a big help. He helped us find the Alzheimer's support group in Dallas, Oregon, and the Alzheimer's Association chapter in Portland, Oregon. He took us to the beach, and we played football and flew kites. He called me on the phone a lot. Paul was taking radiation treatments and was very sick. He drove over 500 miles many, many times. We loved him very much. He gave me a big teddy bear at Christmas time that I named Paul Bear. Paul died of cancer January 31 of this year.

We moved my dad to a home where they provided good care. It was the best place for him, but it was really expensive. It was \$2,500 a month. In 4 months half of my dad's savings were gone. We had to move him three times. My mother and I visited lots of homes to see what they were like—some were terrible. Now Medicaid pays for his care, but my mom gets bills all the time for things he needs. Medicaid doesn't pay for everything.

At Christmastime we found out my dad had colon cancer. He had to go to the hospital for an operation. He almost lost his bed in the nursing home. We had to pay over \$200 to keep his bed. He has a special account for his money. It has only a few hundred dollars left. The bills seem to keep coming.

It's not fair. There should be a program for the whole country that covers everyone. It should cover everyone from when they're born until they die. It could be paid for by cigarette and alcohol taxes, but we need other ways too. President Clinton has the right idea.

My dad loved books. He used to read to me. Now there are days he can't write his name. There should be more funding for research. Alzheimer's is a terrible disease. Sometimes my dad just gets upset and starts asking me to let him out. Sometimes he thinks I did something wrong when I didn't. He knows my name, but he can't always say it.

This has been really hard for my mom and I. I feel like I'm not sure I want to grow up that fast. My dad is not around to talk things over. My dad is not there to help when we need him. I have to carry in wood and stack wood.

My mother took a part-time job. The State may cut my father's medical health if she earns over a certain amount or the State may have my mom send money to the nursing home. My dad paid the nursing home \$112 out of his Social Security even after he spent his savings. A lot of the money that was for me when I go to college has been spent. It went for my dad's care.

I have written a lot of letters. I wrote to President Clinton, I wrote to my Senators from Oregon, I wrote to a lot of Congressmen, I wrote to the National Public Radio. I hope my letters might do some good.

I have something else I wanted to say.

The CHAIRMAN. Sure, you say anything you want, Walter.

Mr. DAWSON. I think that families who have Alzheimer's patients who are taking care of them at home need help, more help. I hope that there will be more funding for research to find a cure for Alzheimer's Disease. Families shouldn't have to spend all their life's savings for medical help. There should be a program that would pay people to help families care for a family member who is sick.

I hope families will get health care and insurance so that they won't have to pay bills when they're sick.

The CHAIRMAN. Walter, thank you. I have a couple of observations here:

One, Senator Graham, and Senator Cohen, and all the rest of us, we're politicians and so we go around and we make a lot of speeches about these issues. But, Walter, I would like to say that I don't know of a more potent or forceful message that I have ever heard about what we've got to do in our country than you have just delivered. And I want to thank you on behalf of all of us.

The second thing I would like to do is to get a copy of your statement, and at 4:30 this afternoon, I'm going to see Mrs. Clinton. And I'm going to get your statement, and I'm going to say, Mrs. Clinton, I'm handing you Walter's statement, and I hope you will read it. I'm going to give her that this afternoon.

Mr. DAWSON. All right.

The CHAIRMAN. Is that your mom with you?

Mr. DAWSON. Yes.

[Applause.]

The CHAIRMAN. You are two brave people, and we thank you.

Mr. DAWSON. Thank you.

The CHAIRMAN. Senator Feingold has just arrived. We appreciate your coming Senator Feingold. We have just had a very, very eloquent and emotional statement delivered by Walter Dawson. Would you care to make any comment at this time or would you rather wait until we get into the questions?

Senator FEINGOLD. I'll wait until the question time, and I'll make a few comments then.

The CHAIRMAN. Fine.

Senator Graham, did you have a comment?

Senator GRAHAM. Well, I think what Walter has just said and also what Ms. Di Manna said indicates that long-term care is not an age-specific issue. It is one that touches all Americans because we are all affected by either the availability, or unfortunately, in most cases, the absence of an effective system to deal with these needs.

And I am pleased, Mr. Chairman, that you're going to be meeting this afternoon with Mrs. Clinton, and I hope and anticipate that she will be as moved by the messages that we are hearing today as we have been, and that this will reflect itself in an effective provision within any national health care program to assure that there will be appropriate and comprehensive long-term care services for all American families.

The CHAIRMAN. Mrs. Clinton is going to be meeting this afternoon with members of the Senate Finance Committee, and I'll take that opportunity, Walter, to give her that statement.

Shelley Fabares, we welcome you. Do we refer to you as Christine from "Coach"? [Laughter.]

Ms. FABARES. That's very nice, Senator.

The CHAIRMAN. We're very honored that you would come a long way today to be with us, and we thank you for being willing to share your personal experience. It's my understanding that your mother suffered from Alzheimer's, and that you lost your mother last year. We'd like to hear your experiences, thank you.

STATEMENT OF MS. SHELLEY FABARES, VICE-CHAIR, PUBLIC POLICY COMMITTEE, ALZHEIMER'S ASSOCIATION, SHERMAN OAKS, CA

Ms. FABARES. Thank you very much, Chairman Pryor, Senator Feingold, and Senator Graham.

I am here to speak for the Alzheimer's Association, for the 4 million Americans who have Alzheimer's Disease and their families, and for my mother, my darling, Elsa Rose, who finally escaped the clutches of Alzheimer's when she died last September 28.

No one on this panel is here to make a special plea just for people who have Alzheimer's Disease. We are here to make the case for long-term care, services and supports for all persons who need them regardless of age, income, or disability.

Alzheimer's Disease makes that case most clearly because it affects so many people, at least half of all nursing home residents and a similar share of frail older persons living in the community.

It goes on for a very long time; in my mother's case, for 8 years, but in some cases for as long as 20 years. It requires unrelenting round-the-clock care, and there is almost nothing out there to help families provide or pay for that care.

Four years ago, I came to Washington to testify for the first time. Since then, Congress has held many hearings on Alzheimer's Disease and on long-term care, but this hearing today may be the most important one ever because it comes just as we are finally getting serious about health care reform.

President Clinton talks about two goals for health care reform—he wants to give American families security and peace of mind, and he wants to get health care costs under control.

Mr. Chairman, we cannot reach those goals unless we address long-term care. That is the point we are all trying to make here today. I have heard people who say, we just can't do anything about long-term care right now because it is too expensive.

American families don't understand that argument. They don't make any distinction between health care and long-term care. It doesn't matter if your wife gets breast cancer or Alzheimer's Disease. She is sick, and you have to reach into the same pocket or the same life savings to pay the bills.

We cannot give families any peace of mind if we pick and choose the disabilities and diseases to cover. We cannot fix the health care system if we only focus on doctors and hospitals.

If you really want to control health care costs, you have to provide the low-tech long-term care that people with diseases like Alzheimer's and their family caregivers need to stay out of hospitals and expensive nursing homes. And you have to provide the long-term services and supports that many people with disabilities need to live independently.

Other witnesses this morning so far have given evidence of the savings we can achieve with good long-term care. I would like to give you just one figure from a study done in California, my home State. Researchers looked at two groups of people with Alzheimer's Disease. One group lived in nursing homes; the other lived at home.

The cost of care in the nursing home was more than three times the cost of paid care at home. Now, it is not the people with Alzheimer's who live at home need less care. It's that the family and friends with enough help at the right time can provide a very large part of that care. Once a person goes to a nursing home, all of that care gets turned over to the paid provider and the costs explode.

The Alzheimer's Association has been fighting for years for a comprehensive social insurance approach to long-term care, one that asks all of us to pay equally so that all of us are protected equally. We know we cannot do this overnight, but we have to start now. And we have some suggestions for how to begin:

First, you can start with home and community care. We must get rid of the perverse incentives in the system that favor institutionalization. We need to help people with respite care, home care, day care, assisted living arrangements that keep people in home-like environments.

Some people with Alzheimer's Disease need to be in expensive nursing homes because they need skilled nursing care, but many are there simply because they cannot get help at home and because there is nowhere else for them to go. That is crazy. It is wasteful, and, most of all, it is cruel.

Second, you can start with those in the greatest need, the most disabled and those least able to pay. But you must have a clear plan with a specific timetable for getting to the comprehensive program that will assure all American families security and peace of mind.

Third, you must not start with private insurance. We are fooling ourselves if we think that it is the answer to the problem we are talking about here today. Private insurance may have a role to play for people who have a lot of assets to protect. And you are right to require national standards for the policies that are sold. But if we try to build a long-term care system on a foundation of private insurance, it will crumble and people will be unprotected.

If we start down the road with private insurance, we will be inviting the very mess in long-term care that we are now trying to straighten out in acute care. A two-tiered system that insures the well-off, if they don't have pre-existing, of course, provides second-class protection for the very poor, and leaves millions of hard-working families with nothing at all.

Please, let's not make the same mistakes again. With long-term care, we have a chance to do it right from the very start.

Mr. Chairman, members of the Committee, when Alzheimer's Disease strikes a family, you learn how to do things you never thought you could do. Somewhere you gather the will and the resources because it has to be done, because the person you love needs you.

That is the way we approach long-term care. It simply has to be done, and the Alzheimer's Association is here to help you gather the political will and the resources to do it.

I thank you very much, Mr. Chairman, for holding this hearing—again, members of the Committee—and, as I said, I speak on behalf of the Alzheimer's Association, for all of the people that you see in back of us here, and, as always, I speak for my mother. I know she would say thank you very much.

[The prepared statement of Ms. Fabares follows:]

TESTIMONY OF SHELLEY FABARES

Chairman Pryor, Senator Cohen, Members of the Committee. I am here to speak for the Alzheimer's Association—for the four million Americans who have Alzheimer's Disease and their families—and for my mother, Elsa Rose, who finally escaped the clutches of Alzheimer's when she died last September.

No one on this panel is here to make a special plea just for people who have Alzheimer's disease. We are here to make the case for long-term care, services and supports for all persons who need them—regardless of age, income, or disability.

Alzheimer's disease makes that case most clearly:

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It is not that people with Alzheimer's who live at home need less care it is that family and friends, with enough help at the right time, can provide a very large part of that care. Once a person goes to a nursing home, all the care gets turned over to the paid provider—and the costs explode.

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That is the way we approach long-term care. It has to be done. And the Alzheimer's Association is here to help you gather the political will and the resources to do it.

Thank you for holding this hearing.

The CHAIRMAN. Thank you, Shelley.

Beverly Hynes, we're going to receive your statement now. Senator Cohen has returned, and we look forward to hearing your testimony.

STATEMENT OF BEVERLY HYNES, VASSALBORO, ME

Ms. HYNES. Thank you, Chairman Pryor, Senator Cohen, and members of the Senate Committee on Aging. I'm Beverly Hynes, and I'm here from the wonderful State of Maine. I live in Vassalboro with my husband and my granddaughter who I've raised for 22 years, and, until she died last October, my mother who suffered from Alzheimer's Disease.

I was a caregiver for my mother for 12 years. There were times when I wasn't sure I could make it. For 6 of those years my mother couldn't talk, walk, or feed herself. She was bed bound and had to be turned every 2 hours. She had a catheter implant for 6 years. She required total care, but I'm proud to say that my mother never had to spend a day in a nursing home. She was at home until the very end.

My mother had been living in Freeport, quite a ways from us. She was a homemaker and worked very hard for her church, and she was homespun. I used to go down every week to help her balance her checkbook, buy her groceries, and things like that.

One day she called and said she wanted to come live with us. She was overwhelmed by things and wanted to be nearer to us. The first year was pretty good. She was very happy. Then she started acting strange. She deteriorated very fast. She would put on six or eight layers of underwear, five or six dresses. She would talk to the TV and swear people were talking to her. She would receive her Social Security check, cash it, and roll the money up in toilet paper and flush it down the toilet. It became clear she couldn't be left alone.

For the first couple of years, I hired my daughter and I hired other help to assist in mother's care. I am the primary wage-earner in my family, and I have to work. I was able to get home-based care from Senior Spectrum, our Area Agency on Aging. This, plus the respite services from the Alzheimer's Association chapter, were a Godsend. They allowed me to keep my mother at home and keep myself together.

In November 1991, I had to go in for back surgery. For 6 weeks I couldn't do what my mother needed. Fortunately, the home-based care program provided day care and the respite program took over in the evening. They did this until I fully recovered. Without this help, I don't know what I would have done. There was no way in hell I was going to put my mother in a nursing home.

The home-based services program cost me some money, and it involved some government funds. But it also saved the government and me a lot of money. I saw Senator Mitchell on TV the other day, and he said a nursing home bed in Maine is going to cost \$38,000 a year. My doctor has told me over and over, "Bev, do you realize the thousands of dollars you've saved the State?" My aunt was in a nursing home with Alzheimer's, and even though it cost all that money, she didn't get half the care my mother got at home.

Sometimes we are penny-wise and pound foolish. I work for the Area Agency on Aging now, and I see some things that make my blood boil. I went to the home of a woman with multiple sclerosis, and she had a lot of other medical problems, and she had been dumped back into her two-room shack after having her leg amputated. She had no running water, no bathroom. She got no dis-

charge planning from the hospital, no home care. They just dropped her off in a wheelchair and said, live.

I got a small grant from a local agency, got a well dug, a septic tank put in, and a bathroom installed. This gave her a fighting chance. Well, I ran into her in the drugstore the other day, and she threw her arms around me. Now she's got her prosthesis, she drives her truck, she's living independently, and for less than \$10,000 this woman was allowed to maintain her dignity and stay out of an expensive nursing home. All she needed was a bathroom and some running water.

There are lots of examples where a little help goes a long way. Unfortunately, the help isn't there. There are long waiting lists for the home-based care programs in Maine. There's not enough funding. Most people can pay something, but without some outside help, they can't make it.

I hope as part of the President's health reform program we will be able to make this help available to more people. It worked for me, it's working for others, and it saves money. Where I come from, that's a winning combination.

The CHAIRMAN. Thank you, Ms. Hynes.

Senator Cohen, would you like to ask some questions. I know you have to leave again.

Senator COHEN. Well, I would like to ask a few questions to Ms. Hynes.

You said you're now working for the Area Agency on Aging?

Ms. HYNES. Yes, I am.

Senator COHEN. Were you working there at the time you received that home-based care?

Ms. HYNES. I was working there, but it was a few years before the home-based care started.

Senator COHEN. Would you tell everybody the kinds of services that the Area Agency on Aging provides?

Ms. HYNES. My particular job, I'm a resource specialist. I had been an outreach worker for 6 years, going into people's homes in the southern Kennebec area. Now I'm in the central office of the central Maine Area Agency, which is Senior Spectrum, we cover six counties. I take all the referrals from the six counties, and do the screening. People call for help; I try to tell them where to go, advise them of the best source of help. I talk to over 6,000 people a year on my job.

We do have senior centers, and we have adult day care programs, we do have the Meals on Wheels Program, we work with DHS on the Medicaid waiver for home care, and we do have the home-based care program. We also help people that can't afford to pay, we provide PCAs for people that can afford to pay for their services.

Senator COHEN. Is there a long waiting list for people?

Ms. HYNES. There are now. In all six of my counties, there are long waiting lists.

Senator COHEN. How long does it take on average to get these services?

Ms. HYNES. It could take 4 to 5 or 6 months.

Senator COHEN. It takes 4 to 5 or 6 months?

Ms. HYNES. Even longer.

Senator COHEN. Are most people in Maine aware of the services that Senior Spectrum or the Area Agency on Aging provides?

Ms. HYNES. Word of mouth seems to be pretty good. If we can help one person, we're usually going to get calls from five others. I do think more needs to be known; you know, we work very hard. We're very dedicated.

Senator COHEN. Senator Pryor has held some hearings in the past in which we found out that many senior citizens aren't aware of the programs currently available to help them. And, as you indicated in your testimony, the fact is you have saved the State of Maine and the Federal taxpayers thousands of dollars by your own effort.

If we spend a little more trying to inform our senior citizens in terms of what services are available, it may not only result in people staying in their homes—which of course most people want to stay in their homes and receive the kind of family love and care in those final days—but it also saves the taxpayers thousands, untold thousands of dollars. I think we have to do a better job at that.

You also mentioned you got a grant from a local agency to help a woman who had multiple sclerosis to get a well and a septic tank and a bathroom so that she could live at home.

What agency was that?

Ms. HYNES. I went to the FHA. I got a \$5,000 grant from them, and I went to Voc Rehab and got a \$5,000 grant from them. Then I went to lumber companies and—you know, I separated them so I wouldn't hit the same one all the time. [Laughter.]

I got some stuff for her roof. They gave me shingles, and then the man I got to do it said, no, we don't need shingles. So I took the shingles back, and I said, can I have some tar? And he said, sure. Then I went to another lumber company and I got some lumber and some nails, and I said you put it in front of the Town Hall and we can get select men to build it. And they built her a ramp.

The CHAIRMAN. Would you be interested in coming to Washington? [Applause.]

Ms. HYNES. That lady today, as I said, she has multiple medical problems. And to see her in her truck and going and independent—and she is in her 80's now; she was in her 70's then—it makes you feel good. You know that she has a quality of life now that she didn't have before.

Senator COHEN. Mr. Chairman, last week in my home town of Bangor, I held a hearing dealing with prescription drugs. I know it's a subject that's very dear to your heart. We heard testimony from Rosamond Potter, who's also of Senior Spectrum, and she testified that she often has to use very creative means, to find money to help the seniors pay for their drugs. I assume that you have to do the same sorts of things regarding what we are talking about here today. I think perhaps Jim Sikking understands the nature of the Maine people.

Beverly Hynes is indicative of the kind of people that we have in Maine who are not only very, very self-sufficient, but very creative in making do with very little. She typifies many, many of the people that we have. If we can take her as an example and show the Federal Government how you can take a little bit of money and

turn the energies and the creative intuition of the people of country loose, we can do a lot more than we're currently doing.

Final comment, I was interested in your statement about the woman who had MS. She got very little information. I think you said she was just sort of dumped out into a little shack when she was released after amputating one of her legs.

Again, at the hearing last week, Senior Spectrum found the same problem for patients being discharged who couldn't afford prescription drugs. There is no source of information that is given to them to help them cope with the manifold problems that they have to confront. I think that also is true with this situation here as far as patients who are discharged from hospitals to help them deal with home care, what services are available.

We can do a lot more than we are right now, Mr. Chairman. I think a lot of it has to do with education, and with the people like Beverly Hynes and the other panelists who have testified here this morning, maybe we can make some inroads.

Thank you very much for your testimony.

The CHAIRMAN. Thank you very much, Beverly Hynes, and thank you, Senator Cohen. I know that you have another meeting that you've come from and you have to go back.

But I'm going to call on our last witness this morning, Kojo Nnamdi.

You're a famous person around Washington, D.C., and you're no stranger to us. But what you have been doing in your own personal life is of great interest to us, and we hope you will share this experience.

Thank you for being with us.

STATEMENT OF KOJO NNAMDI, HOST OF "EVENING EXCHANGE," WASHINGTON, DC

Mr. NNAMDI. Thank you very much, Mr. Chairman, members of the Committee.

My name is Kojo Nnamdi, and I'm the host of "Evening Exchange," a television program on matters of public policy that airs nightly in Washington on the Howard University-owned PBS affiliate WHMM-TV.

In July 1982 while I was working as a radio correspondent here in Washington, my wife died as a result of an aneurism. We had two young sons, twins, both 9 years old at the time. In order to assist me with the care of my sons, my mother, Gladys Paul, then 74 years old, came to Washington to live with me.

She immediately took charge, as was her way. She held herself responsible for all domestic responsibilities in the home, delegating chores, and educational functions to my sons and to me. For about 3 years, everything went smoothly, as smoothly as things go when a 40ish father is forced to pretend that his mother is completely in charge of his home. Indeed, that pretense was often amusing.

However, by 1985 we began to notice that my mother was getting more than a trifle forgetful. There were too many pots being forgotten on a lit stove and too many complaints of money stolen by the, quote, "cleaning woman," whom we all knew by experience to be scrupulously honest.

Nevertheless, forgetfulness being one of the expectations of aging, I was not overly concerned—merely making a mental note at the time that before long, I should undertake all meal preparation myself. But I said, “we’re a long way from that.”

I was wrong. By the dawn of 1986, my evening arrival home was all too frequently marred by the smell of smoke from the vicinity of the kitchen, and by my sons’ accounts of granny’s efforts to put the fires out, complicated by her confusion when the smoke alarm went off.

In 1987 my mother’s mild forgetfulness had clearly deteriorated into something more pathological. Her characteristic good humor was often reserved only for visitors, and a noticeable mean streak began to permeate her conversations and family relationships. She became so paranoid about the housekeeper that she refused to leave her room while this good woman worked, and, eventually, refused to speak to her at all.

After 1988, my home had to be transformed to accommodate my mother’s condition in much the same way that a home has to be arranged to accommodate its habitation by a frisky child under 3 years old. Because my mother had no memory but retained just about all of her motor skills, she seemed to be everywhere all at once, going in and out of every room in the house, hiding, replacing, or rearranging everything in sight.

The gas had to be cut off from the stove if no one was nearby, locks had to be changed on the front and rear doors to the home, and my sons and I—they by then teenagers—had to coordinate our schedules to ensure that someone was at home virtually all the time.

A typical day’s schedule had my sons preparing my mother’s breakfast before they went to school, I getting up to fix dinner, then my sons would look after her in the late afternoons after they got home from school while I was at work. As a result of this, only three of their friends those who had grown up with them and understood their grandmother’s condition—ever visited our home during a 3-year period. Their other friends could not handle my mother’s bouts of paranoia nor her outbursts. Neither of my sons had a steady girlfriend through high school. Their schedules didn’t allow them the time. I could not have cared for my mother during those years without the help of my sons, but we all paid a very dear price, socially and financially.

As my mother’s physical health also began to deteriorate and visits to the doctor’s office and the hospital became increasingly necessary, my financial condition also began to deteriorate, as my mother was not eligible for Medicare. She came to me from Guyana, South America, and was in the process of applying for permanent residency in this country. I, of course, worked for the Public Broadcasting System.

The financial, physical, and emotional pressures began to bear heavily on my sons and me as all relationships in the household became infected with the strain of it all. It was at that point that I sought out the assistance of the Alzheimer’s Association of Greater Washington, and the care giver support groups, which have been so helpful to so many primary caregivers.

But we were fortunate compared to many families. My mother became incontinent only during the last 2 months of her life in 1991, and we were never forced to seek respite care or the more expensive nursing home care for her.

However, when she passed in December 1991, we were in the process of seeking such care, overwrought over how she would adjust to it, and with hardly a clue as to how it would be paid for. God apparently intervened, took her while she was still beautiful, and laid her to rest.

Thank you very much.

The CHAIRMAN. All of the testimony today has been deeply personal and very emotional, very meaningful, and we know they are going to serve to be very constructive in the policies that this Congress and this administration enunciate with regard to long-term care.

I would just like to ask a few questions, if I might. Let me start with Kojo. He sat here longer than the rest listening, and thank you for your statement.

What was the number one thing that you were needing during those 3 or 4 years while you and your sons were taking care of your mother in the home? What did you need most? I'm going to ask the other panelists this same question.

Mr. NNAMDI. Respite.

The CHAIRMAN. For yourself?

Mr. NNAMDI. For both myself and my sons. It was a period during which we never took any vacations, we couldn't go any place for any length of time, we were never able to get the kind of rest and recuperation that primary caregivers so badly need. I was happy to hear of the incident in which the 82-year-old who was caring for her 103-year-old mother was able with the assistance of respite care to go to a wedding someplace else because the stress builds up. And even if people can afford it financially, the stress not only has a mental effect on the primary caregiver, it ultimately has a physical effect.

My own blood pressure rose significantly during the time of caring for my mother. In our case, respite.

The CHAIRMAN. When you ultimately asked for, and I assume, received the support system of the Alzheimer's Association here in the District, did this furnish you any type of respite.

Mr. NNAMDI. No, what it was able to furnish me was a certain emotional support of being able to share experiences with others who were undergoing the same thing at the same time. And, as Jim Sikking pointed out earlier, we as a society are so ignorant about Alzheimer's that it takes people who are involved in the experience to inform others, including the medical community, about what's going on and what needs to be done.

That for me was particularly important.

The CHAIRMAN. Very good.

Shelley, what did you find that you needed during those trying times? What was your number one need?

Ms. FABARES. I was sitting here thinking—gosh, there are so many things.

But I agree with Kojo. I think respite was certainly needed, and also I needed answers in terms of how I was going to care for my

mother on a long-term basis, which again brings us back to the need for long-term care.

I, like James, was in a position at this time in my life to be able to take care of my mother. If I had not been, if it had happened at another time in my life, as James again alluded to, where I was unemployed, I could not have done it. It would have been simply terrifying, and I needed to know that there was—and in the business that I'm in, you can be working on Tuesday and totally out of work on Wednesday and stay that way for the next 10 years—and so I really needed to know that there was something out there in terms of long-term care for my mother. And it wasn't there.

The CHAIRMAN. Thank you.

Walter, what was your number one need, you and your family's need when you were trying to help your father? Would you like to comment on this? I think you've made some mention of some of this in your previous statement.

Mr. DAWSON. Well, that's a good question. Some of the things were—well, we immediately moved him to a nursing home so what he needed was financial support. We didn't have all the money to pay for it, and half of his money was spent in 4 months. And it was really hard, and you have to have support from families too, from other family members.

The CHAIRMAN. Walter, you made mention of the fact that you lost—I wasn't quite following you well enough—you said that you lost the nursing home bed or you were almost about to lose the bed. Explain that to us, please.

Mr. DAWSON. Well, when he went to hospital for an operation, he was away for over 5 days, and the State only pays for 4 days. So we had to pay \$200 for another 2 or 3 days. If we didn't pay that, he would have to leave.

The CHAIRMAN. And where would he have gone at that time?

Mr. DAWSON. Well, we didn't know. There was no place for him to go really. There's a 2-year waiting list on that nursing home too to get back in.

The CHAIRMAN. Walter, you're 10 years old, and I promise you there are members of this Committee and my colleagues in the Senate that don't know half of what you know about some of these regulations and laws that we all have. [Laughter.]

And I might also say that the Medicaid program is such a patchwork quilt of different rules and regulations. And in our State of Arkansas, we have different rules, for example, than you have in Oregon, or than Shelley has in California, or in Maryland, or in Maine.

Mr. DAWSON. Also, if you're on Medicaid in Oregon, you're only allowed to have \$2,000 at the most.

The CHAIRMAN. That's what we call spending down. You have to spend yourself into the poor house, and it's a crazy system. Hopefully, we're going to do something about it, and hopefully we're going to listen to your message and the other messages that we have.

Virginia, what was your number one need with your situation?

Ms. DI MANNA. I think in the early stages the thing that was most needed was the community—use of the Alzheimer's support groups that give the individual the emotional and psychological

support that you need to get through this. It's very—I feel that part is very important for everybody who goes through this because you get to the point where you are completely—the word I use often is isolated from the community.

And the second thing, talking about the same things that we have been discussing along the line here, money is a funny thing. You work all your life and you figure you're a nice middle-class family. Back when my husband got this, \$70,000 was a lot of money. And now because we take in too much Social Security and his retirement and my retirement add up to too much, we will never be eligible under any circumstances for any kind of community help.

And I don't know what the answer to that part is, but I do know that we are impoverishing people like me down to the point where who's going to take care of me. And my husband is healthier than I am. I'm 66 years old, and he has full head of black hair. Look at me, and I can't see straight, and I put half my teeth in a glass at night. And I say to myself, look at this man; he's so strong. Fourteen years now he's been living with this disease, and he's just totally incapable of taking care of himself.

I think the third thing that we need is a type of respite for the income bracket in which most of us middle-class people fall in; it's respite. In the State of Maryland, I could get respite, but it cost me \$11 an hour on a sliding scale because of what we earned between the two of us. And some programs we were not eligible for at all because of the income, so what you do is you start using up your assets.

If you take him to day care or if you have extra medical bills, you just start draining your assets. And in the situation like this young fellow, we had, when my husband started into this, we had two kids in college. And we had set money aside for that, and both of us decided when this thing came down that we were not going to touch that college money. So we did manage to get them both through—all four of them—through college.

And it still did not—the funds are not going to be there for when I need them, and I can't buy a health care policy because I have pre-existing conditions. A catastrophic long-term health care policy, I can't buy it. The only one that will sell me anything is AARP, and they do have one that they will sell you even if you're maybe half dead. They would sell you that policy. [Laughter.]

My insurance bills are catastrophic. They're really bad, and the thing with the VA system, I think, to me is a wonderful thing is that even though I'm on the means test there, if they just don't close those two experimental Alzheimer's sections into Coatesville, Veterans Medical Center, maybe some day God will be good to me and to my husband and relieve him of his body.

The CHAIRMAN. Thank you, Virginia.

Beverly Hynes, what was your greatest need or what is?

Ms. HYNES. Well, I think the long-term care. As I said, my husband has had four heart attacks. He isn't able to work, and I am the primary wage earner. We do have to eat, and we do have to pay taxes, and I do have to work 8 hours a day. And having the home-based care in there, knowing that I could go to work and not have to worry was a godsend, more respite would have been nice.

My husband and I just started courting again after 12 years because if one of us went, the other had to be home with my mother. And she had to be turned every 2 hours, and that was 24 hours a day, and you just didn't have a lot of time to be the family that we wanted to be, you know.

The CHAIRMAN. What about for your husband with the four heart attacks? What about prescription drugs? Did this—

Ms. HYNES. We paid through the nose.

Ms. DI MANNA. The State of Maryland has—don't most States have medical assistance, and if you apply for it—

Ms. HYNES. Do you mean the worldwide drug—

Ms. DI MANNA. Maryland Medical Public Assistance—I have been a caretaker for my mother for 37 years, besides the fact that I lived with her for 26 years before we were married. But with her, because she had nothing, the State of Maryland—there are programs in the State of Maryland to take care of her.

The CHAIRMAN. I don't think that every State has such a program.

Ms. DI MANNA. They supplied her a little bit of spending money, and they took care of all her medications, and there was one other specific thing that they attended to.

She was a resident of the Asbury Methodist Home, which is a full health care facility. But the State of Maryland, I think, does have in place something that would help somebody who doesn't have it.

The CHAIRMAN. I understand.

James Sikking, what was your greatest need during all of this?

Mr. SIKKING. I needed Beverly is what I needed. [Laughter.]

The CHAIRMAN. Well, we all do.

Mr. SIKKING. You probably would have too.

I think the greatest need, and I am thinking about it in retrospect, because when it happens, you're so confused and it's so insidious. You don't now it's happening to you until you're 2 years into it.

I think I needed to know that I wasn't alone, that it was okay to be angry with my mother, that it was okay to feel guilty about being angry with my mother, that it was a process that we all go through. I saw Virginia smile when talking about a mean streak.

Alzheimer's patients are not a day in the park. There's a lot of real life that you have to learn to deal with, and that causes you emotional problems because you think you shouldn't feel that way. That support system, that knowing that it's okay, that you'll get through it, and you'll begin to know how to deal with it, would have been quite helpful.

I think part of the problem is, which I had to a certain extent, I resent having to choose in my resources between taking care of the grandparent, my mother, and using those resources to take care of her and not having the resources to educate my children.

So you are in a screw vice that helps, which is all part of the stress, and people don't realize—this is public information—now, what does a Senator make, \$125,000 a year?

The CHAIRMAN. I think so.

Mr. SIKKING. You think so. [Laughter.]

Let's say a Senator makes \$125,000 a year and after your employer, and our government, gets through with you, plus tax, license, parts, and labor, if you're lucky, you will come out, let's hope, with \$65,000 or \$70,000. If you have, as I did for 10 years, a parent that went into a home—she went into three of them—somewhere between \$28,000 and \$32,000 a year, you are now touching living on maybe \$38,000 or \$40,000 a year.

And making that choice of what about college, what about the other things that you need to have in your life, and the anger that you have against this disease, which you quite frequently take out on the individual, and I think the hardest issue to come to grips with is not to judge that person you love by the last few years of their life in Alzheimer's.

The CHAIRMAN. Thank you, sir.

Senator Cohen.

Senator COHEN. I don't have any questions, Mr. Chairman. I think the panelists have all presented the panoply of testimony, which is important for us to understand.

What occurs to me is that our system, our health care system, has all of the simplicity of the tax code.

I mean, the fact is that Senator Pryor and I are sitting up here. If we had to confront that issue tomorrow, he is correct in pointing out that Walter Dawson knows far more about the issue than we do. We wouldn't know where to turn, as most people don't know where to turn.

And, Kojo, you mention you went through this for several years perhaps before you even heard of the association here in Washington. We need to simplify our health care system. We've got to have a single entry point so that people can go to a single point of information, and that we have health care providers that can say, you need to go to a hospital, you need home health care, you need nursing home attention. These are the services that are available—a single point of information so that we can make people's lives easier and they can understand the choices that are available.

And that's not even dealing with the issue of fiscal relief on the financial side. The physical relief, which is the one you've all talked about here today for the caregiver, but just the idea that we have to know what is available and not go through this labyrinthine process of figuring out is it Medicare, is it Medicaid, who pays, who doesn't, how much, can I afford it, can't I afford it, do I have to spend down, do I have to spend myself into poverty?

We have a system that it's as if we have taken a sledge hammer and shattered a glass top into thousands of fragments, and no one can put this piece together to make any kind of coherent sense out of it.

So, hopefully, as a result of your testimony and the panel that will follow, it will help us at least to present to our colleagues and to the administration, which is working very hard on this issue, and I commend President Clinton for undertaking to come up with a health care reform package, and Mrs. Clinton, who is doing a stellar job, in my opinion, in gathering the kind of information that's necessary, that we can hopefully during the course of this year resolve whatever that remain within Congress. And there will be many.

Shelley, you talked about a public program. The estimates are it may for long-term care cost \$100 billion, and President Clinton has been floating some trial balloons about value added taxes among others to say how do we pay for it?

So we've got some very tough issues to resolve on the financial side, but I think we've got to get back to some basic concepts about the role of government and the private sector. But, more importantly, how do we construct a system which everyone can reasonably understand? And I thank you all for your testimony.

The CHAIRMAN. Thank you, Senator Cohen.
Senator Feingold.

STATEMENT OF SENATOR RUSSELL FEINGOLD

Senator FEINGOLD. Thank you, Mr. Chairman.

I am delighted to be here. I got here a little bit late because I could not get in here last night. But I did get up at 3:30 in the morning today in Wisconsin to get here. I hoped to be here for the beginning of the testimony. I missed a little bit, but I just want to begin by saying a couple of things.

I ask unanimous consent that my written statement go in the record. I just want to talk for a minute or two.

The CHAIRMAN. Your statement will be placed in the record.

Senator FEINGOLD. What I do want to say is that there was an attempt a few weeks ago to eliminate this committee in the U.S. Senate. I was very proud to stand on the floor of the Senate and support the Chairman and support the Committee precisely because of the kind of thing we're listening to right now. This is extremely important testimony, not just with regard to Alzheimer's Disease or even long-term care, but with regard to the whole health care system. It is very compelling, and it might not happen in the appropriate forum if it were not for this Committee.

So I can already see the benefit of having won that vote before the Senate, and I want to just say a couple of other words.

I have had the opportunity to work on this issue with long-term care for 10 years, and since 1984 have worked with the Alzheimer's Association having authorized Wisconsin's Alzheimer's Disease legislation, working with people like Steve McConnell, who is here today, and others. I apologize for not being at your kick off today on the Hill at 8 a.m. I was supposed to speak but there were no planes leaving Wisconsin last night. I want to say thank you for the work that we've done together. And I am very, very eager to get started on working here at the national level where I now have the opportunity to serve.

I also want to say a special thanks to one of the witnesses here, Shelley Fabares, who doesn't just come to Washington to fight for this cause. Here's a southern Californian who was willing to come to Wisconsin in the middle of February to help us with an Alzheimer's Disease Mardi Gras Ball, having to serve as the queen while I was the king of this ball. It was a long evening, and she did a wonderful job of helping us even in a smaller environment like that because of her true commitment to this issue.

And so I'm just going to say a couple of other words, but I wanted to say those personal words of thanks to the organization and to this individual.

I have believed for many years, as does the Chairman and the ranking member, that long-term care is just critical to any true health care reform. I've heard the First Lady say that if we're really going to deal with the deficit, that one of the key elements of this in the mind of the President is health care reform. And we in Wisconsin through our Community Options Program and the Alzheimer's program have begun to show how this program will be paid for—by doing it.

You're already paying for it. We're already paying a ridiculous fortune in nursing home care when many individuals, as the witnesses have shown, could be in the community.

In Wisconsin alone, we've saved, we believe, hundreds of millions of dollars by having a home-based alternative. I could go on far too long on this, Mr. Chairman, but let me just say that I consider this to be one of my most important priorities as a new member of this body, and I look forward to working with you and the members on it.

[The prepared statement of Senator Feingold follows:]

PREPARED STATEMENT OF SENATOR RUSSELL D. FEINGOLD

Mr. Chairman, members of the Committee, I am delighted to participate in this morning's hearing. The issues relating to long-term care are of great importance to me and my state; it is an area to which I devoted a considerable amount of time as a member of the Wisconsin State Senate for ten years and I intend to be actively involved in these issues at the federal level.

In convening this hearing, Chairman Pryor has identified one of the critical reasons we need to include long-term care reform as part of an overall health care package, namely the need to bring health care costs under control.

Although there is disagreement on the specifics of health care reform, with over thirty-five million Americans lacking coverage and the cost of care exploding, the need for acute care reform is widely acknowledged.

What has not been adequately recognized, however, is the critical need for long-term care reform.

Though long-term care benefits have been included in some health care reform plans, few of the proposals have offered the fundamental reform that is needed. This is a serious mistake. The demographic imperatives of health care dictate that if we are ever to get health care costs under control, we must include long-term care reform in the health care reform package.

The elderly are the fastest growing segment of our population, and those over age eighty-five—individuals most in need of long-term care—are the fastest growing segment of the elderly. The over eighty-five population will triple in size between 1980 and 2030, and will be nearly seven times larger in 2050 than in 1980.

At the same time, the working base of the country—those people whose tax dollars are supporting the growing population needing government-financed long-term care services, and whose earnings help support family members needing long-term care—is shrinking relative to the population of long-term care consumers.

In 1900, there were about seven elderly individuals for every one hundred people of working age, by 1990, the ratio had grown to about twenty elderly for every one hundred people of working age. In the near future, though, that ratio will grow even more quickly, increasing to twenty-nine elderly for every one hundred people of working age by 2020, and to thirty-eight elderly for every one hundred people of working age by 2030.

Failure to reform our current long-term care system will mean a growing population of long-term care consumers served by a dwindling set of costly alternatives, and supported by a relatively shrinking population of workers and taxpayers.

It isn't sufficient simply to include long-term care benefits in a health care package. We need fundamental long-term care reform. We need to rethink the way in which we provide long-term care to people. We need to create a long-term care system that is consumer-oriented instead of an entitlement for providers.

We need legislation emphasizing community- and home-based flexible services that respond to individual consumer choice and preference, and that will relieve pressure on the federal deficit and on families, who are often forced to spend their life savings to pay for the long-term care of a loved one.

We must move away from the current regulatory-intensive medical model, and emphasize that the consumer of long-term care services is more like a customer than a patient. The system should be flexible enough to respond to the individual preferences of the customer, from the initial assessment right on through to ongoing services, with case managers and others regularly consulting with the customer and family members to be sure their needs are met in a satisfying manner.

In my own state of Wisconsin, we have created just such a program—the Community Options Program—and it has saved taxpayers hundreds of millions of dollars. The Community Options Program is responsive to consumer needs and preferences without relying on an overreaching bureaucracy.

For example, the program doesn't rely on government certified providers to do things like homemaker or chore services. Those services can be provided by family, friends and neighbors.

In contrast, the bureaucracies of current long-term care programs have often been much more responsive to provider desires than to consumer preferences. Taking a regulatory approach, they have driven up costs to consumers and taxpayers, and have lacked the flexibility needed to respond to consumers.

We need to abandon the unspoken but ever-present belief that underlies most government long-term care programs, that regulation equals quality.

Quality is meeting the expectations of the customer.

That doesn't mean we abandon sensible safety requirements. It does mean that we must think in terms of what the long-term care consumer's needs and preferences are. Long-term care programs should be driven by that principle, not a book of regulations.

Though cost containment must be an important feature of long-term care reform, emphasis should be placed on who becomes eligible, not in creating a structure of reimbursement schedules. We want people to enter the program because they truly need long-term care, not because they are tired of cleaning their home or doing grocery shopping.

The experience in my own state of Wisconsin shows that a flexible, consumer-oriented long-term care system will reduce health care costs while providing better services for individuals in need of long-term health care.

We must work to ensure that this kind of fundamental long-term care reform is included in the overall health care reform package that will be considered by Congress later this year. Failure to include these kinds of long-term care reforms will severely impair our overall efforts to control health care costs.

The CHAIRMAN. Senator Feingold, thank you. And we are proud that you're on this Committee, and we appreciate so much your getting up at 3:30 this morning to attend this hearing in Washington, D.C. all the way from your home State.

I want to thank our panel this morning, and although I don't think I've ever done this before, but I think it's appropriate today. Because of the tremendous courage that these statements made, I think it's appropriate for the audience to give them a little round of applause. [Applause.]

Thank you very much. We are indebted to you, thank you.

We will call our second panel, please—second and final panel, I should say.

Ladies and gentlemen, let's proceed; it is 11:15. Senator Cohen and I have a meeting that we each have to attend, and we must leave here by 10 minutes to 12. We have three distinguished panelists today, and we're going to hear from them at this moment.

Let me introduce for the audience our panelists. This is our final panel.

Herb Sanderson is the director of the Division of Adult and Aging Services from the Department of Human Services in Little Rock, and we appreciate your coming, Herb. You're no stranger to this Committee, nor, certainly, to this issue. Dr. T. Franklin Williams, former director of the National Institute on Aging. He is a Professor of Medicine now at the University of Rochester School of Medicine and Dentistry, Rochester, New York. Beverly Baldwin,

Dr. Baldwin, Professor of Nursing, University of Maryland at Baltimore, Baltimore, Maryland.

We thank you both for coming, and, Herb Sanderson, we will call on you at this time.

We're going to try, to the best of ability, observe the 5-minute rule. We'll understand if you go a few minutes over.

Your full statements will be placed in the record.

STATEMENT OF HERB SANDERSON, DIRECTOR, DIVISION OF AGING AND ADULT SERVICES, DEPARTMENT OF HEALTH AND HUMAN SERVICES, LITTLE ROCK, AR

Mr. SANDERSON. Thank you, Senator Pryor. I'll edit down my written comments to move this process along.

I do wish to thank you for the opportunity to testify before the Senate Special Committee on Aging today.

We have many things in this great Nation of which to be proud, not the least of which is an opportunity like this where citizens are heard and government responds. But this hearing exposes a deficit in our society. For those who have access, the best health care in the world is available in the United States. Too many do not have access, especially those needing long-term care. Speaking plainly, the lack of a long-term care system in this country is a political and social scandal. It need not be this way. Home and community-based care is not only preferred by most, it holds down health care costs.

Attachment I to my testimony shows that despite a rapidly rising 85-plus population, the most frequent users of nursing homes, and despite the fact that Arkansas licensed over 4,000 new nursing home beds, the State has been successful in keeping the number of Medicaid recipients in nursing homes nearly constant for the past 11 years.

The cost of nursing home care has doubled not because of utilization, but because of rate increases. If utilization had risen, many millions of additional dollars would have been required.

Arkansas has been able to contain the growth of nursing homes by offering people choices; choices of how and where they receive long-term care. This includes supporting family members and other caregivers who provide the bulk of long-term care in this country.

Key components of the Arkansas plan include ElderChoices, this is our home and community-based care waiver, which does provide respite among other services; Medicaid personal care, which assists with a variety of activities of daily living; case management, which we've heard testimony about how complex the system is, and case management simply helps people figure out what they're eligible for and helps them receive those services. There's an example in my testimony of a 60-year-old person that was not going to be able to go home, not for medical reasons from a hospital, but for social reasons. And the case manager helped her to be able to return to home.

Medicare—and my printed testimony misstates this. It says Medicaid, but our Medicare skilled home health care system has been very important.

There's been much debate over the issue of cost-effectiveness of home and community-based long-term care compared to long-term

care provided in institutions. Comparison of home and community-based care with institutional care shows the cost-effectiveness of our ElderChoices program. The cost of providing care to an ElderChoices client including prescription drugs, hospitalization, and doctor visits, is less than half of nursing home care.

While all of the above components serve to provide quality home and community-based care, they also serve to point out what is wrong. Home health benefits are limited in duration. Personal care is a wonderful service, but available only to the poorest of the poor, those on Medicaid.

Much of case management is needed because the current, quote, "system," is fragmented and anything but user friendly. Medicaid waivers are limited and demonstrate there is clearly a bias toward institutionalization.

To overcome these weaknesses in our current systems, the following principles should be adopted:

Funding for services should not be oriented to providers, but should be client-driven and flexible enough to meet people's needs;

Administration of the program should be primarily the responsibility of the States, the government level with the most experience in this area;

The first Federal dollar of any new program should be for home and community care to overcome the bias in the current Federal financing mechanisms toward institutional care;

Covered services, regulations, and standards should be family-oriented and biased toward the least intrusive home and community-based assistance; and

Eligibility for receipt of benefits should be based on functional capacity, not medical diagnosis or physician prescription.

As this country debates health care reform, home and community-based care must not be forgotten. If home and community-based care is not part of the new system, we will be saying to millions of Americans of all ages, do without care or use more expensive acute or institutional care.

The former is inhumane; the latter is fiscally irresponsible and inhumane.

Thank you.

[The prepared statement of Mr. Sanderson follows:]

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Director, Division of Aging and Adult Services
Arkansas Department of Human Services

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The cost of nursing home care has doubled. Not because of utilization, but because of rate increases. If utilization had risen, many millions of additional dollars would have been required.

Arkansas has been able to contain the growth of nursing homes by offering people choices - choices of how and where they receive long term care. This includes supporting family members and other caregivers who provide the bulk of long term care in this country.

Key components of the Arkansas system include:

1. **ElderChoices.** This is the name of our state's 2176 Home and Community Based Care Waiver. As the name implies, it is designed to offer choices to those needing care. This program is specifically designed to keep people in their home who otherwise would be in a nursing home. ElderChoices is client driven. An array of services is available that fit the special needs of each client. Services include adult day care, adult day health care, respite care, home delivered meals, chore, home maker, emergency response system and adult foster care. Clients eligible for ElderChoices are also eligible for personal care, case management, prescription drugs and primary health care.
2. **Medicaid Personal care.** This service includes assistance with bathing, dressing, hair and mouth care, toileting, meal preparation and light house cleaning. This service is an extremely vital part of Arkansas' home and community based care system.
3. **Case management.** Obtaining public benefits is more often than not a time consuming, complex, demeaning journey. Frail, bed ridden or demented citizens cannot navigate their way through a fragmented hostel environment. Simply put, case management helps figure out what services are needed and helps secure these services. What does this mean in human terms? A 60 year old Arkansan was living independently until she had to go the hospital. Because of the condition of her house, just as much as her medical condition, it appeared she would not be able to return to her home. Her house was basically uninhabitable; there were holes in the floor, garbage was stacked up in every room, and the plumbing did not work. A case manager arranged for volunteers to come in and clean the house, repair the

plumbing, haul off the garbage and fix the floor. The case manager arranged for home delivered meals, an aide to assist the person in her home and a payee to manage the individuals finances. Today she is a new person. She is happy, living at home, not in a nursing home.

4. Medicaid skilled home health care. Arkansas, like the rest of the nation, witnessed a rapid growth in home health care during the late 70's and 80's.

There has been much debate over the issue of cost effectiveness of home and community based long term care compared to long term care provided in institutions. Comparison of home and community based care with institutional care shows the cost effectiveness of ElderChoices. The cost of providing care to an ElderChoices client, including prescription drugs, hospitalization and doctor visits is less than half of nursing home care.

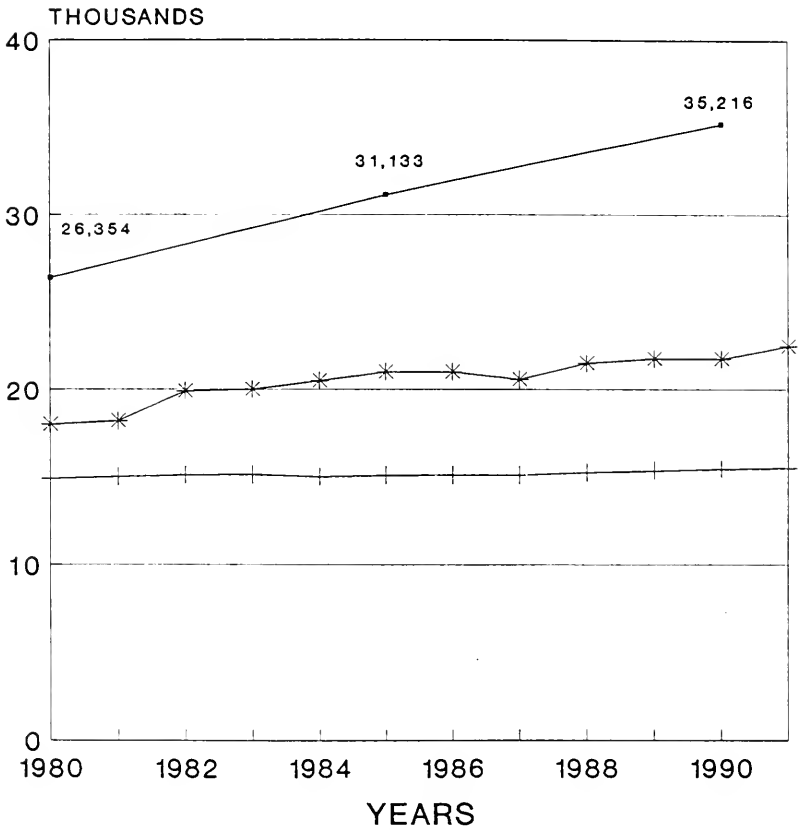
While all of the above components serve to provide quality home and community based care, they also serve to point out what is wrong. Home health benefits are limited in duration. Personal care is a wonderful service, but available only to the poorest of the poor. Much of case management is needed because the current "system" is fragmented and anything but user friendly. Medicaid waivers are limited and demonstrate there is clearly a bias toward institutionalization.

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- Funding for services should not be oriented to providers, but should be client-driven and flexible enough to meet people's needs.
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- Eligibility for receipt of benefits should be based on functional capacity, not medical diagnosis or physician prescription.

As this country debates health care reform, home and community based care must not be forgotten. If home and community based care is not part of the new system to millions of Americans of all ages, do without care or use more expensive acute or institutional care. The former is inhumane, the later is fiscally irresponsible and inhumane.

Growth of Arkansas' 85+ Population, Nursing Home Beds and Medicaid Nursing Home Population



+

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85+

+
 Nursing Home Residents

*
 Beds

Population: 1980 Census; 1985 estimate from Arkansas Institute of Economic Advancement
 Division of Demographic Research, University of Arkansas at Little Rock; 1990 Census. Beds:
 Licensed beds certified for Medicaid. Residents: Medicaid clients in nursing homes 6/30.

The CHAIRMAN. Mr. Sanderson, thank you very, very much for coming a long way today. We appreciate very much your statement. We'll have a few questions in a moment.

Dr. Franklin Williams.

STATEMENT OF T. FRANKLIN WILLIAMS, M.D., PROFESSOR OF MEDICINE, UNIVERSITY OF ROCHESTER SCHOOL OF MEDICINE AND DENTISTRY, ROCHESTER, NY

Dr. WILLIAMS. Senator Pryor, and Senator Cohen, and other members of your committee, I will summarize my written statement. I might also just mention that I'm a member of the Public Policy Committee of the Alzheimer's Association.

I welcome this opportunity to present my perspective, supported by factual evidence, about the importance of integrated health care for chronically ill older Americans, including specifically persons with Alzheimer's Disease, in controlling our total health care costs.

I have three key points I would like to emphasize:

One is that the only way we can control—and even decrease—rising total health care costs, which are related predominantly to our increasing numbers of chronically disabled older people, is to take full advantage of what we already know about integrating chronic and acute services such as on the On Lok model that I'll return to, comprehensive assessment, and systematic care management.

Second, numerous demonstration programs show clearly that total costs, and especially hospital costs, which are the largest component of health care costs, can be significantly reduced through appropriate long-term care services, which are also more clinically effective and more preferred by the public.

And, third, it's essential that we take advantage now of what we've learned and encourage and support such comprehensive services for chronically disabled persons and their families as a key component of health care reform.

Now, as you know, persons aged 65 and older constitute 12 percent of our population, but perhaps you may not remember that they account for 55 percent of our total hospital costs. And also our chronically disabled older people who need long-term care account for 40 percent of all health care costs. We can only expect these costs to rise unless we change our ways.

What have we learned that can help us improve this picture? An overall leadership approach is being taken by the National Chronic Care Consortium consisting of 20 participating settings across the Nation, which are experimenting in various models of comprehensive health care. One of the models is the On Lok model, and I want to refer specifically to that because we have a particularly good example in Rochester called Independent Living for Seniors.

This is built like the original On Lok program started in San Francisco more than 20 years by Marie Louise Ansak, and in our program it accepts—as in the others—it accepts only very frail persons who would otherwise need admission to nursing homes.

At the center of this service is team evaluation and care management with a heavy emphasis on the adult day health center, as the core setting; a setting to which the enrolled persons come, with transportation as needed, most or all days of the week for support-

ive, rehabilitative, and social programs closely linked to home care and any other type of necessary service, including hospital or other services as need.

Quite frail persons can be discharged sooner from hospitals into this program and can continue to live in their own home settings either alone or with working family members because of the support that this program can give.

Thirty-five percent of the Rochester participants have dementia of the Alzheimer type. The program receives from Medicaid funds a capitated rate, which is 5 percent less than the average rate for nursing home reimbursement in our area of New York State, and this pays for all care that people need and any type of care, including hospitalization.

Among the most noteworthy accomplishments of this program is the reduction in hospital admissions and hospital days, and this is shown in the left-hand chart up here. For the first 204 initial participants, their use of hospital days in the year before they entered this program amounted to an average of 21 days per year. In the first year of the program that they were in it, the number was reduced to 11, and when the capitated program was put into effect, it's been reduced to 5 days per year—a four-fold reduction in hospital day use through the activities of this program. There's a similar experience in On Lok in San Francisco and the other settings.

Our present goal in Rochester is to replicate this program in several other areas of the community. Overall, a small proportion of Medicare insured persons are higher users of hospitalization and account for a large proportion of the high hospital costs. A number of demonstration programs have shown that through comprehensive multi-disciplinary assessment and care management, emphasizing home health care, as we've already been hearing about, hospital days can be reduced 20 to 40 percent. There's an accompanying table in my testimony that shows the many references on this subject and the high hospital users.

A current demonstration program directly addresses the goal of assisting families of persons with Alzheimer's Disease to continue to provide their care at home through limited support services. This is the Medicare Alzheimer Disease demonstration, which is underway in eight sites around the Nation, and, unfortunately, faces premature ending unless funds already available are permitted to be used by Congress.

In this program, there are already some striking results.

For example, in the randomized trial of the West Virginia program, the Alzheimer's affected persons are enabled to continue living at home in the community an average of 146 days longer, almost half a year, before needing nursing home admission than the control patients in this randomized trial.

Overall, in these eight sites the caregiver families of the affected persons have been using only about half of the modest funds set aside to enhance the home care services; that is, only \$150 to \$300 a month, or four times less than nursing home care would cost.

When the families are assured of some help and are assisted by competent care managers to choose the help they need, they are capable and content with using much less home care services than might have been thought.

Another experimental program is illustrated in the other graph up here, which through a more enhanced counseling and support groups has materially reduced the rate of admissions in nursing homes by about 50 percent compared again to a randomized controlled sample of admissions among the group who didn't receive this additional enhanced counseling and support. There are references for all of these findings in our material.

Other examples could be cited, and it is clear that we need to continue to learn more from ongoing new research and demonstrations. But I simply return to say that we must move on to take advantage of what we already know how to do if we're really going to save money, as I think we can in our chronic care costs.

Thank you, Mr. Chairman.

[The prepared statement of Mr. Williams follows:]

PREPARED STATEMENT OF T. FRANKLIN WILLIAMS, M.D.

Senator Pryor, Senator Cohen, and members of the Committee: I am Dr. T. Franklin Williams, Professor Emeritus of Medicine at the University of Rochester and Monroe Community Hospital in Rochester, New York, and former Director, National Institute on Aging, of the National Institutes of Health. I welcome this opportunity to present my perspective, supported by factual evidence, about the key importance of integrated health care for chronically ill older Americans, including specifically persons with Alzheimer's Disease and related dementias, in controlling our total health care costs.

The key points I want to emphasize are these:

1. The only way we can control (and even decrease) rising total health care costs, which are related predominantly to our increasing numbers of chronically disabled older people, in particular those afflicted with Alzheimer's Disease, is to take full advantage of what we already know about integrated, chronic, and acute services such as the On Lok model, comprehensive assessment, and systematic care management.

2. The numerous demonstration programs that have been conducted based on such integrated care show clearly that total costs, and especially hospital costs which are the largest component of health care costs, can be significantly to markedly reduced through appropriate long term care services which are also more clinically effective and more preferred by the public.

3. It is essential that we take advantage now of what we have learned, and encourage and support such comprehensive, integrated services for chronically disabled persons and their families as a key component of comprehensive health care reform.

As background, we need to keep constantly in mind that persons aged 65 and older, 12% of our population, currently account for 55% of our total hospital costs, and that long term care expenditures, which are predominantly although not totally for older people, account for approximately 40% of all health care costs. With the predictable rapidly increasing numbers of very old persons in our society, many of whom face problems of chronic disability including dementia despite our best efforts to date, we can only expect that hospital and long term care costs related to their needs will continue to rise rapidly unless we are successful in changing the ways we provide for their care.

What is going on and what have we learned that can help us improve this picture? An overall leadership approach is being taken by the National Chronic Care Consortium, a consortium now consisting of twenty participating settings across our nation, with the aim of developing models for providing integrated health care services to people with chronic conditions. These integrated approaches include all elements: preventive, primary, acute, and long term care services, in which the comprehensively developed long term care component is a key feature. These settings are involved in replications of the On Lok model of long term care, social HMO programs, capitated long term care insurance, and developing advanced information systems. Each member of the Consortium is committed to providing a complete continuum of hospital, nursing home, assisted living, clinic- and home-based services. The Consortium recognizes that, because of the very common discontinuities in care and conflicting care goals as well as conflicting financing provisions, persons needing long term care very often do not have the opportunity to make a choice with guidance for appropriate care or appropriate continuity of care. Unfortunate results

include long and expensive hospitalizations, excessive readmissions, and unnecessary admissions to nursing homes.

I want to describe in particular the On Lok model of comprehensive care for severely disabled and frail older persons, as illustrated in one of the replication sites of the On Lok model, namely, the program called, "Independent Living for Seniors", in Rochester, New York, which is a member of the National Chronic Care Consortium. This program is modeled after the original On Lok program, developed in San Francisco more than 20 years ago by Marie Louise Ansak. Like all of the 14 sites around the nation now engaged in the PACE (Program of All-inclusive Care for the Elderly) program, the Rochester program accepts only very frail persons who would otherwise need admission to nursing homes. At the center of this service is team evaluation and care management, the team consisting of geriatrically prepared physician, nurse, social worker, and other staff. The key service site is the adult day health center, a setting to which the enrolled persons come, with transportation provided as needed, most or all days of the week, for supportive, rehabilitative, and social programs. The services are closely linked through the same organizational approach to home care as needed, to primary care, to restorative therapies, specialty consultations, laboratory services and, when needed, nursing home care or hospital admission.

These comprehensive services enable quite frail persons to be discharged sooner from hospital, and to continue to live in their own home settings, either alone or with family members, with home support services as needed. The day program component also makes it possible for working families to continue to have a frail relative live at home, spending the working day in the day health center.

The Independent Living for Seniors program in Rochester, which has been underway for more than two years, now has 140 participating very frail older persons, utilizing two day center sites, all of whom would otherwise require nursing home care. Thirty-five percent of this group have dementia of the Alzheimer type, a proportion which is more or less similar to the proportion of demented persons in the other On Lok replication models. Once this program in Rochester was fully underway, the reimbursement for almost all of the enrolled persons has been incorporated in a capitation system worked out with the Health Care Financing Administration and the State of New York through waivers. The program receives, from Medicaid funds, a capitated rate which is 5% less than the average rate for nursing home reimbursement in this area of New York State. The program is able to cover all of the health care expenses of the enrolled people with this arrangement, which is obviously less costly than most nursing home beds would be.

Among the most noteworthy accomplishments of the Independent Living for Seniors Program, the On Lok model, is the reduction in hospital admissions and hospital days as a direct result of the integrated, comprehensive services program. The accompanying graph illustrates the point. For 204 initial participants, their use of hospital days in the year before they entered this program amounted to an average of 21 days per year. In the first year in the program, the number of days per year was reduced to 11, and for those enrolled in the capitated payment system, the number of hospital days has been reduced to 5 per year. There is similar experience in the original On Lok site in San Francisco and in other participants in the PACE program.

The present goal in Rochester is to replicate this program in several other sites, through the County-wide Community Coalition for Long Term Care. A number of studies have documented the fact that a small proportion of Medicare insured persons are high users of hospitalization and account for a large proportion of the high hospital costs. A number of demonstration programs have addressed the challenges presented by these chronically ill persons, through approaches to comprehensive, multidisciplinary assessment and care management, and other care management approaches by emphasizing home health care. A summary table from a review by Eggert and Friedman is attached and indicates that most of these demonstration projects have decreased the hospital days among those with very high or high hospital use, typically by 20-40%.

One current demonstration program directly addresses the goal of assisting families of persons with Alzheimer's disease to continue to provide for their care at home through limited support services. This is the Medicare-Alzheimer Disease Demonstration, which is underway in eight sites around the nation, and unfortunately faces premature ending unless funds already available are permitted to be used. In this program, there are already some striking results.

For example, in the randomized trial of the West Virginia program, the Alzheimer's-affected persons are enabled to continue living at home in the community an average of 146 days longer, before needing nursing home admission, than the control patients.

Overall, the caregiver families of the affected persons have been using only 50-60% of the modest funds set aside for the enhanced home care services: it seems clear that when families are assured of some help and are assisted by competent care managers to choose the help they need, they are capable and content with using much less home care services than might be thought. Typically, the costs of these home care services in this project have been in the range of \$200-\$300 per month, far lower than nursing home costs would have been.

Another experimental program has substantially delayed nursing home admissions of Alzheimer's disease patients through enhanced counseling of caregivers and participation in the support groups.

Other examples could be cited. It is clear that we can continue to learn more from ongoing and new research and demonstration efforts. I return to my key points in summary, namely, that an integrated approach, including comprehensive long term care services for older chronically ill persons, must be included in any move towards health care reform that is to be both clinically and cost effective; we do have adequate experience and documentation from a variety of demonstration programs to know how such integrated approaches can be accomplished; and we should move to make these widely available, with appropriate ongoing financing.

Thank you very much for this opportunity to be a part of this hearing.

MEMBERS OF THE NATIONAL CHRONIC CARE CONSORTIUM

- Baylor University Medical Center—Dallas, Texas.
- Benjamin Rose Institute and University Hospitals—Cleveland, Ohio.
- Beth Abraham Hospital—Bronx, New York.
- Beverly Hospital—Beverly, Massachusetts.
- Carondelet St. Mary's Hospital—Tucson, Arizona.
- Fairview Hospital and Ebenezer Society—Minneapolis, Minnesota.
- Hunting Memorial Hospital—Pasadena, California.
- Intermountain Health Care—Salt Lake City, Utah.
- Lutheran General Health Care System (Parkside Senior Services)—Chicago, Illinois.
- Lutheran Health Systems (Mesa Lutheran Hospital, Valley Lutheran Hospital)—Mesa, Arizona.
- Lutheran Hospital, Lutheran Homes, Lutheran Social Services, St. Joseph's Hospital—Fort Wayne, Indiana.
- Philadelphia Geriatric Center and Albert Einstein Medical Center—Philadelphia, Pennsylvania.
- Rochester General Hospital, Park Ridge Health Systems, Community Coalition for Long Term Care—Rochester, New York.
- St. Mary Medical Center—Long Beach, California.
- The Eddy—Troy/Albany, New York.
- Group Health Cooperative of Puget Sound—Seattle, Washington.
- Henry Ford Health System—Detroit, Michigan.
- Mount Zion Health Systems—San Francisco, California.
- Provenant Health Partners—Denver, Colorado.
- Sutter Health—Sacramento, California.
- Sites participating in the Medicare Alzheimer's Disease Demonstration: Miami, Florida; Champaign/Urbana, Illinois; Minneapolis/St. Paul/Duluth, Minnesota; Rochester, New York; Cincinnati, Ohio; Portland, Oregon; Memphis, Tennessee; Parkersburg/Wheeling, West Virginia.

Hospital Days Per Person Per Year: Comparison of ILS and Medicaid Cohorts

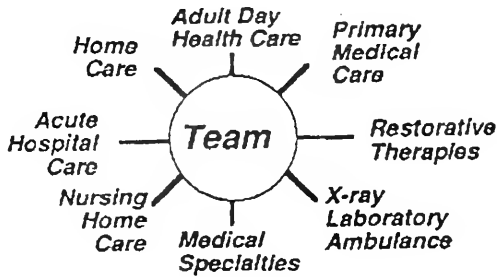
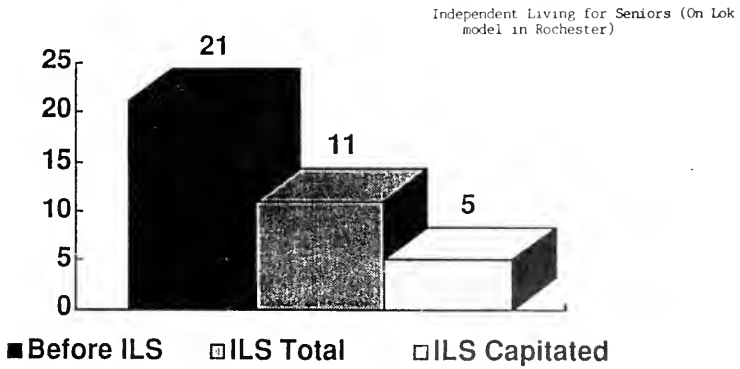


Table 2
Hospital use among home care, community-based care, and geriatric assessment and/or followup studies and demonstrations: 1984-88

Name of study or demonstration	Hospital days per person per year for control/comparison group	Treatment group use compared with control/comparison group use
Very high hospital use		
	Number	Percent
ACCESS Medicare (Medicare/Medicaid Group)	60.1	-78
ACCESS Medicare (Medicare/Private Pay Group)	59.0	-26
Bristol, England, Acute Stroke Study	50.4	-2
Rochester, New York, Home Health Care Team	39.5	-38
Johns Hopkins Post-Hospital Support	38.4	-24
Seputveda VA Geriatric Evaluation Unit	36.4	-42
High hospital use		
Channelling Financial Model	26.8	-4
ACCESS Neighborhood Case Management Team	26.0	-26
South Carolina Community Long-Term Care	20.0	-10
Channelling Basic Model	19.8	-3
Monroe Community Hospital Geriatric Ambulatory Consultative Service	18.9	-40
Nursing Home Without Walls (NYC)	18.2	+8
National Center for Health Services Research Homemaker	18.0	+12
Nursing Home Without Walls (Upstate)	15.9	+17
New York City Home Care	14.9	-25
Moderate hospital use		
Chicago Five Hospital Homebound Elderly	14.0	-11
National Center for Health Services Research Day Care Chronic Disease	13.0	-23
Benjamin Rose Hospital Home Aide	11.8	+6
San Diego Allied Home Health Care	11.4	-40
San Diego Allied Home Health Care	9.1	-8
Rosdovre, Denmark, Preventive Visiting	7.5	-24
Alarm Response	6.8	-4
Highland Heights	6.4	-8
White River Junction VA Outpatient Continuity	6.1	-38
On Lok Senior Health Services	5.4	-13
Congestive Heart Failure	5.4	+2
Low hospital use		
Middleton VA Geriatric Evaluation Unit Followup	4.2	+55
Worcester Home Care	4.0	0
Georgia Alternative Health Services	4.0	+50
Triage	3.4	+118
Oxford, England, Geriatric Screening and Surveillance	2.0	-29
Kaiser Portland Home Care and ECF Program, Age 65 or over	1.8	-28
Palo Alto VA Geriatric Clinic	1.8	+60

SOURCES: Hospital Days from Table 8 in Weisert, Cready, and Finkel, 1987, and from Berkeley Planning Associates, 1987; Zinner, Groh-Junker, and McCusker, 1985; Rubenstein et al., 1984; Eggert et al., to be published; Williams et al., 1987; Hendriksen, Lund, and Stromgard, 1984; Watson et al., 1984; Karst et al., 1987; Tulloch and Moore, 1979; Murado et al., 1972; and Yeo et al., 1987; Treatment group use calculated from Tables 5 and 6 in Weisert, Cready, and Finkel, 1987, and from the other studies listed above.

Senator COHEN [assuming Chair]. Thank you very much, Dr. Williams.

Dr. Baldwin.

**STATEMENT OF BEVERLY A. BALDWIN, PH.D., R.N., FAAN,
SCHOOL OF NURSING, UNIVERSITY OF MARYLAND AT BALTI-
MORE, BALTIMORE, MD**

Ms. BALDWIN. Thank you, Senator Cohen, and members of the Committee for the opportunity to address you today and talk about some research I'm conducting with the University of Arkansas, Dr. Cornelia Beck related to the types of experiences that the caregivers you've heard from this morning for to deal with; that is, the managing of the behavior of the people who have Alzheimer's Disease.

I think we've come full circle this morning because not only I come to you as a professional, but I too am a caregiver of elderly parents, a long-distance caregiver of elderly parents from the State of Florida—Senator Graham's State. And we are now beginning our journey with home health care within the last 6 months.

But I come to you today to talk about research we are doing on behavioral management with Alzheimer's patients, particularly patients who need help with bathing, feeding, dressing—the activities of daily living—and with patients who need help with behavioral disturbances or problematic behaviors.

I'd like to emphasize three key points in my testimony and move very rapidly because I would have a videotape to share with you today.

I want to emphasize that our research is not the only type of research going on in the United States which relates to behavioral management. But it is one in which we're trying to use concepts that we've known since the 1940's and basic behavior treatment and management to apply to helping caregivers on a systematic basis to deal with the kinds of things, the simple tasks, that are needed to help Alzheimer's patients have high quality of life and well-being.

The three points:

Number one, basic behavioral interventions with elderly with dementia can improve their level of functioning, particularly in areas of ADLs like bathing, dressing, eating, grooming, and toileting.

Number two, behavioral measures can be used with elderly with dementia to reduce and prevent disruptive behaviors, and these are the behaviors that seem to be most problematic for families—the hitting, the biting, the kicking, the spitting, the kinds of things that are very problematic that I think any of the caregivers here today could testify to. It reduces the amount of time and the number of caregivers that are required to monitor the elderly.

And systematic behavioral approaches can be used in the home, in the community, and in the institutional settings by both family members and other caregivers. The outcomes are very positive, and they're observable because our research is in nursing homes and in no way implies that anything that we're trying to do as far as behavioral management is limited to nursing homes. And, in fact, many of these approaches may be much more applicable in the

community setting, in adult day care, and home health care setting, and assisted living.

Dr. Beck has conducted over the last 5 years a number of behavioral studies that help people with dressing, eating, and toileting. We're now including in our study dressing, bathing, eating, toileting, and grooming. The basic premise is that we help caregivers to provide basic cues, prompting—both verbal and nonverbal prompting and cuing, and demonstration to keep the person with Alzheimer's with dementia as independent as long as possible.

We take people who are totally dependent in these activities and coax them through behavioral techniques to become more independent, to begin to dress themselves again as much as possible, to begin to bathe themselves again as much as possible, to maintain the functional ability that they have.

Activities of daily living tend to be the most difficult for many caregivers because these are the things that Alzheimer's and other dementia residents seem to lose most rapidly.

I have been working collaboratively with Dr. Beck on a number of structured one-to-one activities with dementia residents who are particularly disruptive; that is, who will not comply with instructions, who are withdrawn, who are very verbally or physically aggressive.

This one-to-one time that we are spending with the residents might be either structured or unstructured, and we're testing that out. Again, we're using basic behavior cues to help these people, a lot of prompting, a lot of cuing, a lot of positive regard.

In my testimony, I expand on the reason that many of these behavioral techniques have worked so well in other settings, psychiatric settings, work with mentally retarded. There's no reason to think that it would not work with this particular group.

Let me just cite one case vignette, and then a second one which will be on videotape, and I will not give any more of my written testimony.

We had a woman in her mid-80's who was very petite, and when we went into the nursing home setting, we were told—by the way, we were in seven nursing homes; four in Arkansas, and three in Maryland. We have almost 150 people, residents, who are in our clinical trials. We have a very large sample.

This petite woman was in her mid-80's. The staff described her, and I quote, "completely dependent in all ADL's and unable to participate in any activity." They protected her by anticipating and taking care of her needs without allowing her to be independent in any functional tasks. She paced the halls when upset or anxious; most of the time she followed staff members around the unit, mumbling and picking at her clothes.

Within 2 weeks after being assigned to the experimental ADL intervention and our study, this resident was assisting with her shower, combing her hair, brushing her teeth, and participating in dressing—sounds like a small miracle. It's not hi-tech, it's not very glamorous.

In addition, she would spend time in short activities with the project nursing assistants. By the end of the 3-month intervention, this resident was less disruptive with staff and other residents, and

she was actively participating in feeding herself, bathing, and dressing, thereby reducing the amount of time that staff had to spend with her.

The second vignette, although I've included several in my testimony, has to do with a videotape that we are going to see, which is very short. The resident you're going to see is a tall lean woman in her mid-80's. She has been described as someone who mumbles and whines with a sharp tone, according to staff members. One of the main disruptive behaviors she has is she will not follow directions of staff, and, if left to herself, she does not eat. And I must emphasize this because we're going to see what happens in the videotape.

Very often, she's found in other residents' beds, which is very disconcerting both to staff and to residents. She will strike out if staff force her to comply. She often refuses to shower or dress unless totally assisted.

After 1 month of working with the project nursing assistant on both the activities of daily living and the activity protocol, this resident was participating actively in bathing, dressing, grooming, and toileting, and particularly you're going to see her feeding herself.

If prompted and cued, she would participate for up to 20 minutes in the various tasks presented to her. Her conversation improved as she became more involved in the structured activity. She was less resistant to ADL's and responded well to the prompts. These measures are cost-effective, they reduce staff time, and increase the quality of life and the quality of care for these residents.

I'd like to present this video for you this morning, and indicate that we're going to show just a very short clip of the woman not following directions, not wanting to get out of bed, and then the trained nursing assistant will prompt her and get her to feed herself.

[Videotape shown.]

Ms. BALDWIN. Let me just close with the fact that this represents a very small vignette of the kinds of things that can be done, and I know all of the caregivers on the first panel can identify with some of the behavior you just saw.

Dr. Williams made the point to me that the caregiver was calling her by her first name, and I think this is one of the issues that we probably could discuss.

Unfortunately, many people who are institutionalized for a long time have been called by their first name, and they won't respond to their last name. And so the response, whatever that is and whatever is familiar to her is important.

My point today is these are simple measures, they're cost-effective, they're pragmatic and very basic. We, of course, need more research in this area, and we need to help caregivers, whatever the setting, to be able to do these.

[The prepared statement of Ms. Baldwin follows:]

TESTIMONY OF BEVERLY A. BALDWIN, PH.D., R.N., FAAN, SONYA ZIPORKIN
GERSHOWITZ PROFESSOR, GERONTOLOGICAL NURSING

Mr. Chairman, members of the Committee, thank you for giving me the opportunity to testify today. My name is Beverly Baldwin. I am a Geropsychiatric Nurse and a Sociologist. I currently hold an endowed chair in Gerontological Nursing and Professor in the School of Nursing at the University of Maryland at Baltimore.

I am a fellow of the American Academy of Nursing and a fellow of the Gerontological Society of America. For the last twenty years, I have been involved in research, education and program development and evaluation in the area of aging and mental health. During this time, I have worked collaboratively with nurses and other health care professionals to develop and research behavioral approaches to meeting the needs of the cognitively impaired elderly. My research has included families, staff and elders in adult day care; families, staff caregivers and residents in nursing homes and other long-term care settings; and family members providing care for their elderly in the home.

My testimony today focuses on collaborative research with Dr. Cornelia Beck, Professor and Associate Dean, College of Nursing, University of Arkansas for Medical Sciences, Little Rock, Arkansas. Dr. Beck is Principal Investigator and I am Co-Investigator of a three-year National Institute of Aging funded study of behavioral management of disruptive behaviors of nursing home residents with dementia. The majority of these residents have Alzheimer's Disease. We began the second year of the study January 1, 1993. Dr. Beck and I have worked collaboratively over the last five years to develop and test simple, pragmatic behavioral measures that family and staff caregivers can use to reduce some of the disruptive or problematic behavior that accompany this devastating chronic illness.

Although we are just entering the second year of the current study, case examples from this and data from previous studies confirm the efficacy of behavioral approaches to working with the elderly with dementia, whether in the community (home and assisted-living), acute and or nursing home settings. These low-technology strategies are easily transferable from one setting to another and can be successfully implemented by both formal and informal caregivers.

I want to emphasize three key points which our research and that of others in the field confirm:

Basic behavioral interventions with elderly with dementia can improve their level of functioning, particularly in areas of bathing, dressing, eating, grooming, and toileting.

Behavioral measures can be used with elderly with dementia to prevent and reduce disruptive behaviors, thus reducing the amount of time and number of caregivers required to monitor these elderly.

Systematic behavioral approaches can be used in home, community, and institutional settings by both family and other caregivers with observable positive outcomes and increased independence for the elderly.

Description of the Behavioral Approaches.—Trained nursing assistants have been working with dementia residents in the current study to test two approaches to enhance resident independence and self-esteem. These interventions are videotaped and I have an example to use with my testimony today.

Dr. Beck has conducted a number of systematic studies which test behavioral strategies for increasing dementia residents' independence in bathing and dressing. We are also including eating, grooming, and toileting in the current study. Nursing Assistants are trained to use simple behavioral commands with residents to promote participation in their own care. These strategies include using one or two work commands; consistently using the same word for the same object; and giving verbal praise after the completion of each step. The assistants also try to provide a consistent environment for completing these activities of daily living; reducing external stimuli (noise, excess activity or staff); and physical prompts if the verbal prompts fail (by demonstration, touch with verbal confirmation). The caregiver (nursing assistant, family, or other helper) focus on the specific tasks involved in activities of daily living, thereby facilitating the resident's ability to perform functional tasks.

All activities of daily living (bathing, dressing, eating, grooming, and toileting) are concrete, task-oriented activities providing purposeful interaction for dementia residents. Encouraging them to be involved with ADLs helps residents meet the needs for territoriality, self-esteem, safety/security, autonomy and personal identity, potentially decreasing disruptive behaviors. In addition, involvement in ADLs meets the need for meaningful communication and cognitive understanding and helps prevent premature loss of contact with the environment. Over time, the amount of time and number of people to care for the resident decreases, resulting in a cost-effective approach to enhancing resident functional abilities.

I have been testing a structured activity intervention that nursing assistants can use with disruptive dementia residents to provide a systematic, short (20 minutes or less) daily approach to meeting the resident's basic needs for communication, self-esteem, safety/security, autonomy, personal identity, and cognitive understanding. The goal is to maximize the resident's strengths through a supportive, structured, therapeutic activity. The intervention provides positive reinforcement and control enhancement in addition to reinforcing alternative positive approaches to resident's

disruptive behavior (hitting, biting, slapping, wandering, pacing, etc.). The visual, physical and verbal components of the activity regime encourage expression of feelings and thoughts. If a dementia resident receives no assistance in processing and expressing thoughts and feelings, he/she may become frustrated and agitated. This planned, behavioral measure is viewed as a preventive model of care.

Concrete, reality-based activities keep residents involved in the world around them and are among the most important needs of persons with dementia. The dementia resident, if left alone, may seek out solitary activities such as wandering, moving objects, pulling at clothing, moaning, rocking or repetitive mumbling. Purposeful activity keeps them active. Verbal, visual, physical, tactile and gustatory/olfactory modalities are tapped. The content focuses on improving memory, expression of thoughts and feelings, recreation and learning. Examples include discussions of family, children, occupation; using word games or puzzles, clapping hands to different rhythms, massaging own face and discussing the contents and preparation of a food snack, such as a cupcake.

These behavioral approaches can be easily taught to nursing assistants, family members, volunteers, and other caregivers. We provide a two-week intensive training program for the nursing assistants employed for the study, with ongoing monitoring and positive reinforcement. Altering the behavior of caregiver often alters the behavior of the resident toward more independent and functional outcomes. In addition, we are examining the effects of these strategies on reducing disruptive behavior of dementia residents. Forty-five behaviors have been identified and are being monitored on all shifts of the seven research nursing homes (four in Arkansas and three in Maryland).

Case Vignettes to Illustrate Outcomes.—Numerous vignettes from specific residents in the clinical trial to date illustrate the potential of these basic interventions. Residents in our study are considered to be the most disruptive, therefore, "difficult" to manage, as reported by the staff.

Mrs. M. is a small, petite woman in her mid-eighties. The staff described her as "completely dependent in all ADLs" and unable to participate in any activity. They protected her by anticipating and taking care of needs, without allowing her to be independent in functional tasks. She paced the halls when upset or anxious; most of the time, she followed staff members around the unit, mumbling and picking at her clothes. Within two weeks after being assigned to the experimental behavioral ADL intervention, Mrs. M. was assisting with her shower, combing her hair, brushing her teeth, and participating in dressing. In addition, she would spend time in short activities with the project nursing assistants. By the end of the three-month intervention, Mrs. M. was less disruptive with staff and other residents and was actively participating in feeding herself, bathing, dressing, and grooming activities, thereby, reducing the time the staff had to spend with her.

Mr. G. is a tall, thin man also in his mid-eighties. He was described by staff as withdrawn, "uncooperative", and unable to follow instructions for completing ADLs. He was hospitalized for a fractured hip and returned to the nursing home for physical therapy and rehabilitation. Within one month after working with a project nursing assistant on the activity protocol, Mr. G. was more social, would spend more time outside his room, was more cooperative in physical therapy and described by staff as "a different person." He appeared to enjoy the structured activities and became more verbal as the three-month intervention progressed. He responded well to physical therapy and is mobile. Labor costs in terms of staff time are decreased.

Mrs. G. is a small, frail woman in her early eighties. She wanders about the facility, rubbing her abdomen and asking for a "heart pill". The staff describe her as "irritating" to other residents and staff, entering other residents' rooms and sometimes climbing into bed with them. She has a short attention span and becomes angry and threatening when confined. Within one month of working with a project nursing assistant in structured activities, she was capable of sitting for up to thirty minutes looking at picture books and naming objects and individuals, participating in an exercise class and sitting and talking with staff members. She would eat her meals if a staff member prompted the activity and reduced external stimuli. Left to herself, she would not eat, took other residents' food and often was confined to a geri-chair during meal time.

Mrs. H. is a tall, lean woman in her late eighties. She mumbles and "whines" with a sharp tone, according to staff members. She will not follow directions of staff and if left to herself, often does not eat or is found in another residents' bed. She will strike out if staff force her to comply; she often refuses to shower or dress, unless totally assisted. After one month of working with a project nursing assistant on both the ADL and activity protocol, Mrs. H. was participating actively in bathing, dressing, grooming, and toileting. If prompted and cued, she fed herself totally. She enjoyed the activity time, and would participate for up to twenty minutes in the var-

ious tasks presented to her. Her conversation improved as she became more involved in the structured activity. She was less resistant to the ADLs and responded well to the prompts for independent action. These measures are cost effective in reducing staff time to provide care.

Summary.—Simple behavioral interventions can work, regardless of setting, to enhance the abilities and wellbeing of elderly with dementia. Consistency in approach and attitude are key issues, but caregivers can be trained and reinforced to work with residents using these measures. Keeping the elderly independent longer not only improves quality of life and enhances physical and mental wellbeing, but the amount of time required to provide care is reduced and the caregiver (whether staff, family or volunteer) has greater satisfaction, due to the reciprocity of the relationship with the resident. Behavioral strategies work and can provide a cost-effective method for dealing with the complex and interactive needs of older adults with dementia.

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Dr. WILLIAMS. I simply think that people should be called by the name they prefer to be called by, and I think people should start by referring to people as Mr. or Mrs. and respect them as we would anybody else.

The CHAIRMAN. What breakthroughs are out there? Are we looking at any potential or possible breakthroughs in the near years? What prospects do we have, any?

Dr. WILLIAMS. Well, I can comment and perhaps others can too.

I think, as you know through your strong support of the research in this area, both the Senators and this whole Committee, the advances in research are really moving very rapidly, and we see great promises for more medications that will make a difference. We see great promises for understanding the underlying disease causes.

But, in addition, we see great promises for improved care of the types you're hearing here where we've already learned how we can do much better with the examples shown here, and at less cost. And I think that by taking advantage of what we already know in some systematic ways that Congress can guide and that the administration can guide that we can vastly expand the types of services we can help people obtain in their homes and at literally less cost, and especially reducing the high cost elements.

The CHAIRMAN. Dr. Williams, I am a real layman, and I apologize for this layman-type question, but I'm amazed right now. Maybe it's because I'm getting older and I'm suddenly becoming more sensitive to my surroundings, or what have you, and thinking about where I'm going to spend my golden years, so to speak. And all of a sudden it seems like in the last 5 or 6 years that the whole world has Alzheimer's Disease.

Is this a new disease, is this an old disease, was it called something else 10 or 20 years ago? What is going on here that I have missed?

Dr. WILLIAMS. Well, Senator Pryor, I think you've had the same experience that most of our Nation or the world has had, is that

we've just awakened to the fact that what used to be called senility or arterio-sclerotic brain disease really in most instances was actually a specific disease, which we call Alzheimer's after the person who first described it almost a century ago now. It just wasn't recognized as being the common cause of loss of mental function.

Fortunately, not everybody gets it. I mean, we're very fortunate that many people over 100 have very well-preserved cognitive functions. But, as others have said, it's the most predominant cause of disability in our country at any age in total numbers, and I think that we've just begun to realize that we've got a big challenge here, and I think we are moving toward addressing it.

The CHAIRMAN. Is there an average age when this disease begins?

Dr. WILLIAMS. Well, Senator Pryor, it goes up exponentially with age. There are relatively few people who have the disease under the age of 50—a few, but rare. It begins to rise in the 60's usually, and by the time we reach people who are in their 80's and 90's, some estimates make it as high as 40 to 45 percent have this disease.

Now, there isn't complete agreement about that, but it certainly goes up to 20 or more percent in that age range.

Ms. BALDWIN. Senator Pryor, may I interject an answer to your previous question on what breakthroughs we're seeing in the area, and I think, certainly, Dr. Williams can speak to the areas of finding the cure and the cause of the disease.

I think the other breakthroughs that we're seeing within the last 5 years have been in improving the quality of life of these people. As you've heard this morning from caregivers, some of these people live 10, 14, 15 years with this disease. This did not happen 20 years ago. They died very quickly because of infection or other problems.

But now with Federal regulations in which we're looking at the use of chemical and physical restraints, the overuse of drugs, and physical restraints to manage behavior, the door has been opened for us to really begin to look at measures to improve the quality of care of these people. And I think those are some of the new avenues that are going to open up in the next few years.

We're not relying on chemical methods to deal with helping someone who will not comply with care or who refuses to take a shower. We're going to have to look at other measures that are much more simple, and much more basic, that improve not only the quality of care, but the well-being of the person who has the disease. We have to do something to keep the person from becoming the disease, keep the person the person.

The CHAIRMAN. Senator Cohen.

Senator COHEN. Regrettably, Dr. Baldwin, you just removed the whole basis for my question.

Ms. BALDWIN. Oh, sorry.

Senator COHEN. But let me say, Mr. Chairman, I think what the panel has indicated is that we have known over the years that there are options to nursing homes or other types of institutional settings. We have found many people, for example, in fact are kept in hospitals not because they need that level of care, but because there are no available options in the community. It's an act of car-

ing to keep that person in the hospital because they have no other way of surviving.

We now also know that there are many people currently in our nursing homes who don't need that level of care. Some still do even though we're all dedicated to reducing costs by trying to keep people where they really want to be—in their homes. The fact is there are still millions of people who will need institutional care and nursing home care.

The one thing that has struck me as the result of the hearings we've been having over the years is that we are just beginning to find out what role the mind plays with respect to our health.

We have had hearings, for example, on music as therapy; that music has a tremendously positive therapeutic value in our lives; meditation is also a technique that is being explored by more and more people. It's not being seen as something that is on the fringe of medical science, but rather a fairly important and integral part in terms of our treating people.

Bill Moyers has a best-selling book. I envy his best-selling status. [Laughter.]

He has a best-selling book on this very subject matter of the relationship between the mind and the body. Perhaps, the ancients knew it far better than we do.

You have just touched upon it, Dr. Baldwin, and that is talking about providing care. Way back in the 1960's, we used to have nursing homes that were labeled by then Chuck Percy, former Chairman of this Committee, or ranking member of this Committee. He called them warehouses for the dying because all we did was put people in those homes and keep them drugged up. We were caring for them in a physical sense, and we were taking care of their bodily needs, perhaps, but we weren't dealing with their minds.

And, as a result of that effort, to expose the kinds of situations that did in fact exist in our country at that time. To the extent that it continues even today, we have a continuing scandal, as you pointed out, Mr. Sanderson.

But, nonetheless, providing care means providing more than just physical care. It means really providing loving care, and that means really touching the mind of the individual as well as the body of the individual. I think for too often now we've always treated people as sort of fungible items. They're all interchangeable, and they're like weed, or whatever; that there's no difference. And, in fact, each individual is different, each individual may respond to different types of stimuli.

I have a former administrative assistant of mine who had a son who's autistic. He had no communication with the outside world for a quarter of a century or more. They've just realized he's a very highly intelligent individual. In a breakthrough they discovered that this individual has been sitting there in total silence for a quarter of a century, but has understood everything that's been going on in the world from watching television, listening, and observing. They have finally found a way to communicate with him and break through that barrier of silence.

We have a lot of exploration of space, and it's not only in the stars. It's inside the human mind, and I think as a result of the

effort that all of you have been engaged in, hopefully we can have more breakthroughs and provide a more decent, more humane—to use your word, Dr. Sanderson—a more humane method of dealing with the people that we love.

Thank you very much.

The CHAIRMAN. Senator Cohen, I think you will agree with me, this has been one of our better hearings of the Senate Special Committee on Aging. It's been meaningful, and, ultimately, I think it will be so constructive once again in helping to shape the policy of the Congress and of the new administration.

I truly don't believe that we're really going to be able to call our health care reform package real reform unless we address long-term care. [Applause.]

I'm not attempting to take anything away from the proposal that will come from the White House but I am saying that I truly believe our President and Mrs. Clinton would like to see—I believe this—I believe that they would like to see long-term care a part of that package.

We all know that is very expensive, but today we have seen that the system we have now is very expensive in terms of the human costs, the physical, and emotional costs that are out there today in our country.

And for not only you as panelists, but the preceding panel, and all of the groups who are supportive of long-term health care reform, this Committee and, the Congress are very indebted for their efforts. Because like the many caregivers across the America, they're not getting paid extra to do this. They're not getting paid extra to come to Washington and to be a part of this momentum that is being created to support and forge ahead with long-term health care reform.

We're overdue in this country for health care with reform and long-term health care. We've got a big mission, a major mission. I hope that we have the will, and I hope that we have the commitment, the know-how, resources, to do it.

I was just sitting here, and I was thinking, well, how do we pay for this? I said, well, we found a way to pay for the S&L bailout. When Hurricane Hugo and with the tornado hits and the earthquake hits, we found a way to pay for those catastrophic events that affected our country and our people. We just found ways to do it, and I think this is once again an area where we've got to find ways to do it, and we must have the will to do it. And the commitment, I believe, must be there, too.

So we want to thank all of our panelists. You made a very major contribution, and provided a step forward for all of us.

With that said, we will keep the record open for a few days to have any additional follow up questions from members of the Committee who may or may not have been present. We are once again indebted to all of you, and our meeting stands adjourned.

Thank you.

[Applause.]

[Whereupon, at 11:55 a.m., the Committee adjourned, to reconvene at the call of the Chair.]

APPENDIX



AMY

A

April 1993
98 APR 26 AM 8:15

Senator David Pryor
Russell Building, Rm 267
Washington, D.C. 20005

Dear Senator Pryor -

The Alzheimer's Association requested several children of family members attend the Long Term Care Demo. held by your sub Committee on aging to support Walker Dawson.

Enclosed please find testimony prepared by my eleven year old daughter which I request you consider including in the record.

I appreciate your consideration to these important issues.

Sincerely

Janet Randall
15418 Floyd St
Omaha, Nebraska 68144

COMMITTEE TESTIMONY

MR. CHAIRMAN AND COMMITTEE MEMBERS

MY NAME IS ABBY RANDALL , I AM 11 YEARS OLD

I LIVE IN OMAHA NEBRASKA AND I'M IN 5TH GRADE AT HARVEY OAKS
ELEMENTARY SCHOOL

I AM A ALZHEIMERS VOLUNTEER BECAUSE MY GRANDFATHER HAD
ALZHEIMERS DISEASE

MY GRANDFATHER WAS THE SENIOR EXECUTIVE VICE PRESIDENT OF
MUTUAL OF OMAHA INSURANCE COMPANY, HE WAS IN CHARGE OF
SELLING GROUP INSURANCE ALL OVER THE WORLD, HE HAD MORE THAN
4000 PEOPLE WHO WORKED FOR HIM.

MY GRANDFATHER WAS A VERY IMPORTANT BUSINESSMAN BUT HE HAD TO
RETIRE WHEN HE WAS ONLY 61 YEARS OLD BECAUSE HE COULDN'T
REMEMBER HOW TO DO HIS JOB ANY MORE.

GRANDPA WAS STILL AN IMPORTANT MAN TO ME BECAUSE HE WAS MY
FRIEND-- HE COULDN'T DO HIS JOB ANYMORE--- BUT HE WAS AN
ARTIST--HE DREW PICTURES OF ME AS A BABY-- HE COLORED WITH
ME--AND WE USED TO GO FOR WALKS.

I HAD TO GO WITH MY GRANDPA WHEN HE WANTED TO GO FOR A WALK
BECAUSE HE DIDN'T REMEMBER HOW TO GET HOME ANY MORE.

COMMITTEE TESTIMONY

WHEN MY LITTLE BROTHER WAS BORN MY MOM AND DAD AND I WERE STAYING WITH MY GRANDPA AT HIS HOUSE BECAUSE MY GRANDMA WAS IN THE HOSPITAL AND GRANDPA COULDN'T STAY ALONE. MY PARENTS WERE VERY EXCITED THAT THE ADOPTION AGENCY HAD CALLED THEM TO TELL THEM WE WERE GOING TO HAVE A BABY BOY. THERE WAS A LOT OF CONFUSION-- BUT ESPECIALLY FOR GRANDPA. HE WAS SURE THAT HE AND GRANDMA WERE HAVING A BABY BOY INSTEAD OF MY PARENTS AND HE DIDN'T THINK IT WAS SUCH A GOOD IDEA.

BEFORE GRANDPA DIED HE NEEDED SOMEONE TO STAY WITH HIM ALL THE TIME. HE COULDN'T REMEMBER MY NAME, OR HOW TO DO ALMOST ANYTHING,--

WE WERE LUCKY--GRANDPA DIED BEFORE HE HAD TO GO TO A NURSING HOME, BUT THAT WAS AFTER MY FAMILY TOOK CARE OF HIM AT HOME FOR 5 YEARS. MOST FAMILIES AREN'T AS LUCKY AS MINE--NO ONE HAD TO QUIT THEIR JOB TO TAKE CARE OF MY GRANDPA AND WE COULD AFFORD TO HAVE SOMEONE STAY WITH HIM WHEN EVERYONE NEEDED TO GO OUT. PLEASE HELP FAMILIES WHO AREN'T AS LUCKY AS MINE BY INCLUDING LONG TERM CARE IN THE HEALTH CARE REFORM PACKAGE.

THANK YOU...

Mrs. Gail L. Kelley
 43852 Laburnum Square
 Ashburn, VA 22011
 (703) 729-0651
 February 19, 1993

Mrs. Hillary Rodham-Clinton,
 First Lady
 1600 Pennsylvania Avenue
 Washington, D. C. 20500

Dear Mrs. Clinton:

I am writing this letter on behalf of my husband and all others suffering from Alzheimer's disease. My intent is to bring your attention to a health issue that is not given a great deal of media attention, not nearly as much as AIDS or Cancer, but is, in fact, the 4th largest killer of mankind, and equally as devastating, if not more so.

Your involvement in health issues, your interest in humanity, and your intelligence in grasping situations leads me to hope that perhaps we (the victims and our families) might have a chance of strong support from you.

As I write this letter, I think of how wonderful it is for you and your family to have achieved the goals that you have and to know that you have bright futures ahead of you. I wish to ask you, though, what would you do if your husband, as young as he is, instead of becoming President had been told that he has Alzheimer's, that there is no known cure, nothing to stop its progression, and that you and your family would become just as much victims of the disease as your husband; in fact, maybe more? This is what my husband and I have faced since 1992, when he was diagnosed at the age of 46. What I am trying to impart to you is that Alzheimer's is a descent into Hell - and I don't want my husband to make this trip! For that reason I am writing to you.

In April we, the Alzheimer's Assoc., will be having a public forum in Washington, D. C. dedicated to the victims and families of Alzheimer's, bringing people together from all over the country. Would it be possible for you to attend as a show of support? I assume our national association will be contacting you to request your presence. As an individual member of the local Northern Virginia Chapter, I believe your attendance would bring more attention to this disease and perhaps help us gain much needed funding for research, long-term health care, respite care, etc.

My daughter and I attended last year for the first time, and it would be impossible to tell you the feeling that came over me when we waited on the steps of the Capitol to have our pictures taken, and in the distance I saw masses of people affected by this disease in some way or another coming towards us. It was overwhelming, and I knew I was not alone - and yet I am.

Your appearance and comments would help make the public more aware of this disease and, hopefully, educate them that this is not an old people's disease, nor a young person's disease, and that no one is immune. If a cause and cure are not found soon, by the year 2015 14,000,000 people will be afflicted.

I send this letter with a measure of hope that it will do some good. I'm fighting for my husband's life Mrs. Clinton. If it were your husband, wouldn't you?

Sincerely yours,

Mrs. James P. Kelley
 (Gail L. Kelley)

Contemporary Housing Alternatives of Topeka, Inc.
 534 South Kansas Avenue Suite 910
 Topeka, Kansas 66603
 (913) 232-8338

April 9, 1993

Members of Congress
 c/o Portia Mittelman
 Senate Special Committee On Aging
 Senate Dirksen-G31
 Washington D.C. 20510

Subject: Written Testimony Regarding Solutions
 For Long Term Care Alternatives

Members of Congress,

There is a terrific need as you know for specialized care and housing for those afflicted with Alzheimer's Disease. We may very well have some answers to help you with questions regarding the BUDGET DEFICIT, and OPTIONS to providing better LONG TERM CARE!

Background establishing our efforts stem from 15 years of housing development. Randy, my husband has developed specialized housing in 13 states for the ELDERLY and DISABLED populations and Independent Living Centers. He has also developed the majority of the GROUP HOMES for the MR/DD population in the state of Kansas. Myself, I was attending Washburn University obtaining my degree in Psychology when in March, 1990, my mom was given the diagnosis of Alzheimer's Disease.

Mom was recommended for Nursing Home placement. It was at that time I started looking into how this population could benefit from the GROUP HOME environment.

Mom was just like you and me. She was a very neat, clean, and attractive lady with what everyone said were exceptional social skills. I could not put this vibrant little person in a nursing facility! Not to neglect the fact that she was perfectly healthy otherwise.

The few community services we had, and her being early stage, did not work. Meals on wheels would bring lunch and she would answer the door and say she couldn't eat another bite when actually I had just reminded her they were coming and she put the lunch she had fixed back in the freezer. She thought she had just eaten.

Since mom was not a wanderer, I chose to move her into an Independent Living Apartment. Her total income per month was \$429.00 so we helped with the rents as they were \$650.00 per month. Mom's apartment walked right out into the dining room. There she had nutrition and socialization which I felt were the most important elements to deal with at that time! There were no services except for a continental breakfast and a full lunch. I did worry that she could have left the stove on or she could have wandered off but still felt what COULD HAVE happened was not worth INSTITUTIONALIZATION.

I created a respite program that worked for her and her long term memory. I had four of her friends take mom to lunch every Thursday to her favorite restaurants. I paid for their meals and moms. They would alternate weeks so I knew someone was going to be with her and she would have something to look forward to. Mom never knew I was involved and to retain her pride and dignity she didn't need to know! This was also a relief to me knowing someone else was taking some of the worry off my shoulders! Being her only caregiver, the worry was at times overwhelming! There hasn't been a day that I felt any type of normality with my own family. They also have felt the despair of having a grandmother with Alzheimer's Disease.

Our children are 3, 10, and 16 years of age. I can remember being in pre-mature labor with Trent (my 3yr.old) and being hooked up to a heart monitor while arguing with an insurance company regarding a car accident mom had prior to my hospital admission. The Dr. gave me drugs to hold the baby until he finally came 3 weeks early. I knew with my pregnancy, I couldn't deal with moms diagnosis until after having Trent. (Trent was also a child who would be up 3 to 4 time a night and with mom on my mind, I was constantly trying to figure alternatives for her well being---I have to say these last 3 years have not been easy!)

Needless to say I have a very dependable and understanding husband. Without his support and help with our family, through the time of moms diagnosis, I could have never been able to check into options as thoroughly as I have, nor thought about the possibilities for better housing and care through Group Homes!

Shannon was seven at that time. I look at her now and wonder how I could have missed out on so much of her last three years, trying to attend to both a mother with Alzheimer's disease and a toddler requiring so much constant attention! She has grown up so much! But she has been my strength. One day she asked me "mommy, when grandma dies are you still going to work with the Alzheimer's Association"? I said yes as long as there is still a need and she said "maybe when you can't do it any longer I'll take over and help"! I was so proud of her! She's only 10 years old!

And our oldest, Trisha, has spent countless hours babysitting and worrying about her grandmother and HER OWN MOM! She is a real tower of power. She has had to take on more responsibility than others her age. I'll never be able to thank her enough for the times she's had to endure!

I have watched my mom go through all ages and stages and some of the same behavior of my two youngest children. Only they have matured noticeably and mom had digressed--noticeably! Dr. Barry Reisberg, Aging and Dementia Research Center in New York, addresses the behavioral similarities the best! (See Attachment)

Mom fell this last August hiding her purse on the top shelf of her closet. She broke her upper right arm and this prompted nursing home placement. Being only 69 years of age, mom is still aware enough that she definitely did not like the social atmosphere of a nursing home, after a month, she started declining in her disease. With four long hallways and so many doors she would take three steps out of her (then private) room and show so much fear that she became childlike and felt this dreaded fear of being left alone. (similar to taking a 2 year old to a hospital and saying goodbye--you can imagine the fear of not knowing what's going to happen next, who will love her, feed her, dress her, or even fearful of who may harm her.) Mom has spent the last 6 months being a guinea pig to different medications trying to calm her anxiety. And this is at one of the nursing homes with the best reputations. I feel they do try and do care, but they don't have the staff ratio to spend the time or the ALZHEIMER'S TRAINING to work with these Alzheimer's residents as is needed for proper care! (But because their care was genuine, this home was my best option.)

Even the staff can't stand to see the suffering she's gone through. She has fallen because of the medications and been restrained in a wheel chair, become incontinent, and at Christmas time I didn't know if she would live another month. She had also gone from 137 pounds in August down to 113 pounds in January. I finally said "take her off all this stuff"! I couldn't stand to see her like this and she would say "Kathy I just want God to take me" and I would say "I know mom". She is now off all that medicine and can walk again and is free of her incontinence problem and can carry on a pretty normal conversation.

She still gets anxious and I feel much of the anxiety is and has been related to the IMPROPER ENVIRONMENT, which can be devastating to those with this disease, but also the STAFF RATIO and ACTIVITIES relating to her LONG TERM MEMORY should be considered for proper care. ALZHEIMER'S TRAINING is an important compomant to QUALITY AND HUMANE CARE! (I could not get a nursing home that offered this type of care when looking for placement because she soon would be on MEDICAID. I remember feeling desperate!!)

We have obtained our 501(C)(3) NOT-FOR PROFIT status and have developed (2) Group Homes (Residential housing) designed and researched specifically for Alzheimer. They will have 24 hour staffing and the residents will remain as independent as possible with modifications made as to their progression through the stages.

Three years of research have gone into the development of this demonstration project which is targeting populations at or below 80% of the median income and those on MEDICAID! Day Activity Services and In-Home Respite Programs are also planned with future expansion and education to rural areas. Research is now being planned with the AREA AGENCIES ON AGING to develop a DAY ACTIVITY CENTER adjacent to our first GROUP HOME.

***** See Attachments *****

The National Alzheimer's Association has definitely gained my respect by the RESEARCH, RESOURCES, AND COMMITMENT they have shown and I feel proud to serve as Vice-President for our local Alzheimer Association to serve on the Public Policy, Education, and Nominating Committees. Donating as much time as possible, I serve as Respite Coordinator researching services in the counties our association serves so we can help caregivers when they call in. I also am there for CAREGIVER TO CAREGIVER SUPPORT, AND HOPE TO SOON SEE MANDATORY ALZHEIMER'S TRAINING for anyone offering care to an Alzheimer's person.

!!!!!!!!!!!!!!MEDICAID BUDGET QUANDERERS LISTEN UP!!!!!!!!!!!!

40% TO 60% OF THOSE PLACED IN NURSING HOMES TODAY HAVE DEMENTIA OF SOME FORM!

RESEARCH MONEY NEEDS TO BE APPROPRIATED to finding a cure! An Alzheimer person can live 15 to 20 years and most end up on MEDICAID--Look at the Federal and State dollars that can be saved if funds are available to find a cure!

ABUSE is happening for those in their early to middle stages who try to adjust to such confusing environments as INSTITUTIONS AND NURSING FACILITIES. These are also the stages nursing homes are being quoted as "having the most problems with these people." And understandably! Either raise reimbursement rates to these homes OR allow OPTIONS for better care!

MATCHING GRANT MONEY is desperately needed to help give programs start up costs and funding to keep our loved ones out of Nursing Homes. Give these SENIOR CITIZENS something to look forward to. DAY ACTIVITY CENTERS, CLUBS AND SOCIAL PROGRAMS PROVIDED BY TRAINED ALZHEIMER'S CENTERS AND PLEASE--

HELP GIVE THE ALZHEIMER'S CAREGIVERS OF OUR NATION RELIEF KNOWING THERE ARE SOME CAPABLE PEOPLE OUT THERE WHO UNDERSTAND THIS DISEASE AND CAN GIVE RESPITE AND TIME OUT SO WE CAN POSSIBLY START LIVING RELATIVELY NORMAL FAMILY LIVES!

MEDICAID IMPROVEMENTS AND WAIVERS TO PROVIDE LONG TERM CARE SERVICES!!!--EXAMPLE: The state pays approximately \$1,000.00 per month for mom to be in a nursing home. I asked the state if I moved her into our Group Homes if they could pay us just 80% of what they were paying a nursing home and they said NO that there was already a waiver written for Alzheimer which was included in the HOME AND COMMUNITY BASED PROGRAM and as we are licensed under Health and Environment as a Personal Care Home we can only receive \$12.00 per day! This \$12.00 a day is also to include activity for her. ---How can someone who has been recommended for ICF nursing facility and we, having found a better alternative to nursing home care and at a LESS COST to the state be turned down!! Especially when the state agencies agree with everything we are doing and say they are in full support!!

Please help us be able to provide HOUSING AND SUPPORTIVE SERVICES to LOW INCOME senior citizens. BETTER CARE can be provided at LESS THAN NURSING HOME REIMBURSEMENT RATES!!!!!!!!!!!!!!

Our GROUNDBREAKING CEREMONIES are scheduled for April 25, 1993.

With the response to the articles in the paper (See Attached), three of these Group Homes could be filled now.

THE "NEED" IS SO GREAT FOR THESE ALTERNATIVES THAT WE WILL BEGIN CONSTRUCTION AND PRAY THAT CONGRESS WILL HELP TO PROVIDE SERVICES TO THIS TOTALLY MISUNDERSTOOD POPULATION.

Sincerely,



Kathy Speaker

A Comparison of Developmental Ages and the Changes in Behavior Observed in Patients with Alzheimer's Disease

Approx. age in development and level	Behavior
Level 1 (adult)	Essentially normal adult behavior.
Level 2 (Adult)	Minor changes have occurred, but usually are attributed to the normal aging process, i. e., mild forgetfulness.
Level 3 (12+ years)	Ability to function in job is diminished. Can perform the repetitive tasks, but has difficulty with abstract ideas and new tasks.
Level 4 (7-12 years)	Ability to handle simple finances limited.
Level 5 (5-7 years)	Difficulty selecting proper clothes.
Level 6 (5 Years)	Has difficulty putting on clothing correctly.
(4 years)	Unable to bathe without assistance Needs some assistance with toileting.
(3 years)	Incontinent of urine at times.
(2-3 years)	Incontinent of feces at times.
Level 7 (15 months)	Only speaks 5-6 words.
(1 year)	Speak one word. Unable to walk independently.
(6-9 months)	Unable to sit up independently.
2-3 months)	No longer smiles in response to contact with caregivers.

Adapted from Reisberg, B. (1985). An ordinal functional assessment tool for Alzheimer's type dementia. *Hospital and Community Psychiatry*, 36(6), 593-598.

2-B The Topeka Capital-Journal, Saturday, December 12, 1992

Alzheimer's creates frustrations for those seeking care for parent

■ Either take care of them or put them in a nursing home. There's no in between.

By PHIL ANDERSON
The Capital-Journal

Kathy Speaker had to put her mother into a nursing home recently.

It nearly tore her apart — because she believed a group-home setting would have been a better option.

Unfortunately for Speaker, no group home was available for her 69-year-old mother, Margaret Mary Kelly McMullen, who was diagnosed with Alzheimer's Disease 2½ years ago.

Particularly upsetting was the fact that Speaker has been working on a group home for Alzheimer's Disease patients for more than two years.

Alzheimer's Disease is a progressive, degenerative condition that attacks the brain and results in impaired memory, thinking and behavior. An estimated 4 million people nationwide have the disease, including 3,000 in Shawnee County.

After she was diagnosed with the disease, Speaker's mother lived in a Topeka retirement apartment complex until recently, when she broke her arm in a fall.

She recuperated in a Topeka convalescent center, then McMullen's family members placed her in a Rossville nursing home.

It wasn't an easy move for McMullen — or for her children and grandchildren.

"Right now, families don't have many options," said the 38-year-old Speaker, who has three children, ages 15, 9 and 2. "Either they take care of their family members with

Alzheimer's Disease or they put them in a nursing home. There is no in between."

Speaker made it clear that she had nothing against nursing homes.

But she quickly added that people in intermediate stages of Alzheimer's Disease could benefit more from living in a group setting, rather than in a nursing home.

She realizes group homes aren't the solutions for all Alzheimer's Disease patients. But group homes can help avoid premature nursing home placement and act as a "stepping stone" between a patient's own home and a nursing home.

Studies also have indicated that conditions of Alzheimer's Disease patients may deteriorate more rapidly after they are placed in nursing homes.

The frustration level has hit Speaker especially hard because she had believed a new group home for Alzheimer's Disease patients could have been built by now, if she and her group had been successful generating support from state officials.

Late last year, Speaker and her husband, Randy Speaker, announced plans to build two group homes for Alzheimer's Disease patients in Topeka.

Speaker's husband is chief executive officer of Contemporary Housing Alternatives of Topeka Inc., a not-for-profit corporation which designed the Alzheimer's Disease group homes. The corporation was formed 2½ years ago and has been working on the group-home project since then.

Randy Speaker also has helped groups build apartment complexes for low-income older adults and for people with disabilities.

According to plans released late last year, two homes were to be built, each providing care for six to eight Alzheimer's Disease patients. The construction cost of each home was to be \$225,000.

One of the homes was to be built

on city-donated land near S.W. 21st and Randolph. The other home was to be built on another parcel of land in the city.

Rooms were to be made available both to private-pay patients as well as for Medicaid-eligible patients.

Around-the-clock care was to be available, with a ratio of one Alzheimer's Disease-trained staff member for every four patients, a lower ratio than most nursing homes offer. Individual program plans would be made for each patient.

Group leaders said the cost to the state would be less than the cost of nursing-home placement.

More than \$500,000 in funding was secured from several sources, including Capitol Federal Savings, the Federal Home Loan Bank of Topeka, the Kansas Department of Transportation and the city of Topeka.

However, state lawmakers didn't approve funding during the 1992 Legislature. State funding could have been used to help pay for Medicaid patients' expenses. Speaker and her group hoped half the group home residents would be Medicaid recipients.

Both homes combined were projected to serve more than 100 Alzheimer's Disease patients, preventing many from having to enter an institution through a long-term care program as well as daycare and respite programs.

Building supporters say a group home setting could prolong the life of an Alzheimer's Disease patient, while allowing the patient to maintain a sense of dignity and self-worth.

For instance, Speaker said, a group home would allow the patient to cook a meal for visiting family members, with minimal assistance from a staff member.

The group homes also were to be designed specifically for Alzheimer's Disease patients, to minimize confusing building traits such as long hallways with many doors.



—Jeff A. Taylor/The Capital-Journal

Margaret Mary Kelly McMullen, 69, received a warm hug from her daughter, Kathy Speaker.

Speaker said she and others involved in the project sponsored a bill requesting state funding during the 1992 Legislature. That bill passed the House of Representatives but was voted down by the Senate.

She said those working on the project were disappointed — especially when they initially were led to believe that the state was behind the project.

State funding would be used for the day-to-day facility operation. Speaker is still hopeful the state will come up with a funding mechanism, even though she feels like the project has gone “back to square one.”

Had the state told building supporters early on that the answer to their funding request would be “no,” construction could have started on the project as a private-pay facility, Speaker said.

Now, the ground sits vacant and those wanting to build a home for Alzheimer's Disease patients remain frustrated.

Capitol Federal Savings and Federal Home Loan Bank each required that construction begin by March as part of the loan agreement. Unless the state helps fund the project, it will start as a private pay facility.

Robert L. Epps, commissioner of income support and medical services for the Kansas Department of Social and Rehabilitation Services, said the Speakers' project is a worthy one. But that doesn't mean state funding will be granted without legislative authorization.

“The Speakers, I think, are very deserving of commendation,” Epps said. “They're trying to provide a new and valuable service for victims of Alzheimer's Disease and their friends and families.”

“I guess where we find ourselves in an incompatible situation is in terms of financing.”

Epps said Social and Rehabilitation Services isn't able to provide a grant for the group home project. To do so would be to set a “horrendous

precedent,” Epps said.

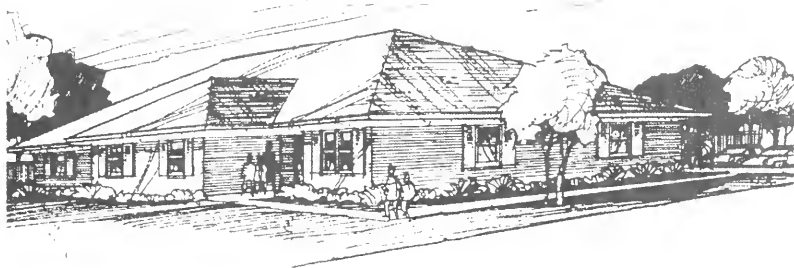
“We have almost a \$1.2 billion budget,” Epps said. “But nowhere in that budget is there discretionary funding for grants like this.”

Epps said if Social and Rehabilitation Services were “to spring” a couple of hundred thousand dollars for such a program, the legislative intent of the decision likely would be called into question, since the Legislature denied funding during the 1992 session.

To get state funding, Epps said, group home supporters likely will need to obtain a line-item appropriation — specifying a certain amount of money — from the Legislature.

Kathy Speaker said group home supporters would try to gain legislative approval in the upcoming session.

Call Contemporary Housing Alternatives of Topeka at 232-8338 for more information.



This architect's drawing shows a group home for people who have Alzheimer's disease. It will be built at 2111 S.W. Randolph by Contemporary Housing Alternatives of Topeka Inc.

Group home designed for needs of Alzheimer's patients

■ Couple designs living quarters for special needs of adults not yet ready for nursing homes

By DON MARKER
The Capital-Journal

What started as a personal quest to understand how Alzheimer's disease was affecting her mother has led Kathy Speaker and her husband, Randy, to achieve their dream of seeing a group home built for Alzheimer's patients.

Construction start is planned for March on the group home at 2111 S.W. Randolph that will provide eight rooms specifically designed for Alzheimer's patients. The home is scheduled to be occupied by July 1. A second, similar group home is planned for later this year.

They are being built by Contemporary Housing Alternatives of Topeka Inc. Sherman Parks Jr. is chairman of the board and Randy Speaker is president. The organization is a not-for-profit corporation that was founded in November 1990.

The city of Topeka donated the site to Contemporary Housing and donated \$50,000 toward the expected construction cost of \$190,000 per home. The remainder is being funded by a grant from the Federal Home Loan Bank Board under its Affordable Housing Program. Capitol Federal Savings and Loan Association is the first mortgage holder.

Speaker said he expected another \$35,000 would be needed to equip and furnish the first home. Public donations will be accepted for furniture and to defray 30 percent of the cost of two vehicles donated by the

Kansas Department of Transportation.

This Alzheimer's patient group home is the first of its kind in Topeka.

"It will provide an alternative environment that is less confining than a nursing home," Randy Speaker said.

Kathy Speaker added that the home "is designed to make

it easy for them to cope with everyday living and to help them maintain the style of life they are used to."

The Speakers' initial exposure to Alzheimer's disease came when her moth-



Kathy Speaker



Randy Speaker



The Topeka Capital-Journal, Saturday, February 6, 1993 3-C

Alzheimer's progresses slowly

The Capital-Journal

Alzheimer's disease is a progressive condition in which nerve cells degenerate in the brain and brain tissue shrinks, says the American Medical Association Encyclopedia of Medicine, published in 1989.

There is no cure and no way to arrest progress of the disease.

The cause of Alzheimer's is unknown, the AMA says, but onset is rare before age 60. Thereafter, incidence increases steadily with age, and up to 30 percent of people older than 85 are affected.

The early stage of Alzheimer's will find the individual noticing increasing forgetfulness, the AMA says. The individual may try to

compensate by writing lists or by asking others to help. Problems with memory often cause the patient to feel anxious and depressed, but these symptoms generally go unnoticed.

A second phase involves severe memory loss, particularly for recent events, the encyclopedia says. The patient will also become disoriented about time and place and get lost easily even in familiar surroundings. Concentration and ability to calculate decline.

"Anxiety increases, mood changes are sudden and unpredictable, and personality changes become apparent," the AMA says.

The third stage involves severe disorientation and confusion. There may be hallucinations and

paranoid delusions, with symptoms usually worse at night. There may be incontinence. The patient may become demanding, unpleasant and sometimes violent. Some become docile and helpless.

Full-time hospital or nursing care is often inevitable, the encyclopedia says.

"Once the patient is bedridden the complications of bedsores, feeding problems and pneumonia make life expectancy very short."

The AMS says, "Ideally, care is best provided at home, but this may be impossible. Although efforts are being made to expand facilities, a shortage of suitable places exists for elderly people with dementia. Research into drug therapy is continuing."

Home for Alzheimer's patients

Continued from page 1-C

er, Peggy McMullen, was diagnosed about three years ago as having Alzheimer's disease.

"They told us to put her in a nursing home," Kathy Speaker said.

They didn't. McMullen lived successfully in a retirement complex until last August, when she moved to a nursing home.

McMullen's illness brought home to the Speakers that there needed to be a stepping stone between independent living and a nursing home. The group home is that stepping stone. It will enable the person who needs a structured, supervised environment to live without having to experience the more confining and confusing nursing home environment.

The home will provide 24-hour residential care -- with two staff people on each eight-hour shift -- for people in the early to middle stages of Alzheimer's. People in those stages "can get around pretty well," Randy Speaker said.

Six of the rooms in the home will be private rooms, each with a lavatory and toilet. There also will be a large bathroom with toilets and an area for supervised bathing.

Two of the rooms will be designed for couples and will have fully

equipped bathrooms. An Alzheimer's resident and a healthy spouse could live in those rooms.

Initial plans call for 24-hour care to be offered in six rooms, with two rooms being used to provide day care in four-hour increments for Alzheimer's patients.

A program also will be offered to provide respite care in Alzheimer patients' homes so their regular caregivers can take breaks.

The first group home will have 3,900 square feet and will be built by Neighbors Construction Co., Edwardsville.

Architects are Knight and Remmele, Topeka.

The exterior will be vinyl sided and designed to fit into the neighborhood.

The rear yard will be fenced. Inside the fence will be walking paths, recreation areas and a place where residents could plant a garden.

Inside, there won't be hallways that could confuse an Alzheimer's resident. Interior areas will be painted different colors to help patients identify their own quarters. A canopy will mark the entrance to the bathroom-bathing area.

Residents' rooms will have exterior walls and windows.

In the center of the home will be a kitchen, recreation room, dining

room and place for playing cards and television viewing.

Other space will be for a laundry room, utility room, staff space, office and a library.

Randy Speaker said he anticipates four of the units will be for low income patients, and that cost of home residency hasn't been determined.

"Being a not for profit corporation, we'll establish it at cost or below," he said.

The home's occupants will be determined on a first come, first served basis, Speaker said. Inquiries about residency or donations may be made to his office at 232-8338.

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