

**LONG-TERM CARE AND THE ROLE OF FAMILY
CAREGIVERS: A RHODE ISLAND PERSPECTIVE**

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

FIRST SESSION

CRANSTON, RI

OCTOBER 4, 1999

Serial No. 106-16

Printed for the use of the Special Committee on Aging



U.S. GOVERNMENT PRINTING OFFICE

62-417

WASHINGTON : 2000

For sale by the U.S. Government Printing Office
Superintendent of Documents, Congressional Sales Office, Washington, DC 20402

ISBN 0-16-060443-5

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LONG-TERM CARE AND THE ROLE OF FAMILY CAREGIVERS: A RHODE ISLAND PERSPECTIVE

MONDAY, OCTOBER 4, 1999

U.S. SENATE,
SPECIAL COMMITTEE ON AGING,
Cranston, RI

The committee met, pursuant to notice, at 10:05 a.m., at the Rhode Island Army National Guard Schofield Armory, 705 New London Avenue, Cranston, RI, Senator Jack Reed presiding.

OPENING STATEMENT OF SENATOR JACK REED

Senator REED. We are going to begin our hearing of the Senate Special Committee on Aging. I want to first thank Chairman Brad Williams, ranking member, for authorizing this hearing and also for your assistance, not just today, but the great assistance and service to the seniors of America and for your many years during your tenure in the Senate.

I'm delighted to be here this morning. I'd first like to thank the Rhode Island Army National Guard for making this facility available to us. General Reggie Centrarchia, our Adjutant General, certainly a talented and dedicated soldier, and he was here already to greet me, but I also want to thank a few other individuals. Command Sergeant Major Jack Ryan. Major Mark Havershaw. Master Sergeant Don Iafrate, who is working the PA system today, which is critical. Sergeant First Class Tom Yuppa. Lieutenant Colonel Tony DeFusco. And also I thank first, she will speak later, Barbara Rayner, for all her assistance and guidance. Kathy MacNamee from the Warwick Senior Services Center. Kathy provided many of the chairs you're sitting upon. We have A. Kathryn Power and Julie Pillozzi from MHRH, and we thank them for the service and support. Claudia Rathbun, who is doing the reporting today. Thanks, Claudia. Also my Seniors Advisory Council, many who are here today. I thank you for your service and also for your help in guiding us through this particular hearing.

I am delighted that we are here today in my hometown of Cranston to conduct this very important hearing about long-term care. We understand it is a critical problem. It is becoming more critical, particularly as our senior population is increasing dramatically.

I would like to thank at this juncture in general our distinguished panel, who will shortly join us, and in particular, I'd like to thank Assistant Secretary of Aging Jeanette Takamura, who is with us today. Jeanette is one of the great leaders when it comes

to seniors' issues in the United States, and I will introduce her specifically in a moment.

Now, we have several objectives at this hearing. First, we want to learn more about the current struggle and challenges that are facing family caregivers in Rhode Island. I want to find out what resources are available and in too many cases not available in health family care.

We also want to discuss several Federal initiatives, which are critical to our response at the Federal level, and, in particular, the National Family Caregivers Support Program, which Jeanette will speak about. This was announced by President Clinton in his State of the Union Address. It is a very important program. It is the subject of the Senate legislation. I'm proud to join Senator Ed Bradley and others as a co-sponsor, including the Older Americans Act reauthorization legislation, and so we want to look at these particular Federal initiatives.

Finally, I hope that this hearing will increase the importance of planning that we all should recognize. This is particularly appropriate for my generation, the baby-boomers who are looking ahead, and they have to also start looking ahead to situations where they're going to be living longer, and they have to plan for a longer life.

Now, let me just also suggest that on this point, long-term care is a neglected topic in the United States today. The American Health Care Association conducted a survey, and they found that 68 percent of Americans responded that they know they're not financially prepared for the burdens of long-term care in the future. That is a staggering admission, and I think a very accurate one. In fact, the local lack of knowledge on how long to support themselves or finance one's self as one gets older. The aging population could not recognize or identify the fact that Medicaid is one of the principal supporters of long-term care in this country, so we have a lot to do when it comes to education.

Now, let me briefly run through some charts we have which will set, I think, the context of the atmosphere for the issues we face today.

In 1997, there was a study conducted by the National Alliance for Caregiving and the AARP. Twenty-two million Americans, one in four households, are involved in caring for family members. So this is not an isolated issue of concern. In fact, every family in America is in some respect, I feel, involved with the caregiving for a relative, maybe directly, maybe indirectly. It might be your brother who is taking care of your elderly parent, but you are certainly involved, also.

Now, we understand how critical this is in the context of seniors. Thirteen percent of the United States population is over 65. Here in Rhode Island, it is 16 percent. We have the third-largest concentration of seniors in the country, and that concentration is going to keep growing, and it is also estimated that there are 12.8 million Americans of all ages who require help to carry out basic needs, so there is 12 million Americans that need some type of daily care. Among those disabled older people who need assistance, 95 percent of them are getting their health care from a family member, only 5 percent are in institutions or have some type of a caregiver that

provides support. So the bulk of long-term care is provided by families in this country, and, frankly, that is probably the way it should be. I think families want to stay together, and they want to be able to support their aging parents or their sick or disabled children. That is what families are about, but they also can't do it alone. We have to recognize that.

Now, we've got another chart which, I think, Lisa will point out for us or point to, and that chart gives us an idea of the impact of family caregiving. In fact, the family caregivers are probably the unsung heroes in this whole issue of dealing with the problem of caring for Americans.

There are more than 20 million caregivers. The vast majority of them are women, daughters, wives, and sisters. Nearly half of all caregivers spend up to 8 hours a week on care, and also, they are spending up to about 20 hours a week, so for many of these individuals, this is a second full-time job. The average caregiver, if you look at the typical caregiver, is a woman about 57, married, working full time, who has been looking after a parent with a chronic condition for a period of 4 to 5 years, so this is not something that is done occasionally, but for many, many people, this is, in fact, their second full-time job.

Now, we also have another chart, which we will talk about the types of care that is given. As you would suspect, this chart suggests that the bulk of what caregivers are doing are those activities of daily living, transportation, taking people to the medical appointments, grocery shopping, housework, meal preparation, financial management, coordinating outside services, and also, ensuring that medications are properly administered; and as another dimension to this situation, too, it is because it is very difficult to care for someone who has a chronic debilitating disease, particularly it is more difficult if that person is also suffering from some form of dementia, and today we're finding more and more situations in which caregivers are dealing with particularly seniors who have evidence of dementia; and if you look at the additional chart we have, it shows the kind of demands that these particular family members place upon the family, and if you look at the people who say they have much less time for their families if they have a senior or someone who is suffering from dementia, they're forced to give up their time. They themselves experience health problems just trying to cope with it, and this is another dimension, another aspect of the problem that we have to recognize.

Now, all of this service comes at a significant cost to individuals. In fact, it has been estimated that caregivers throughout the United States each year provide the equivalent of 45 to \$75 billion worth of services, and that is illustrated on the chart that Lisa has just put up. In Rhode Island, we have 98,000 caregivers. On average, they're contributing in terms of the value of their services something on the order of three-quarters of a billion dollars a year in care. Now, if that care was not given by family members, it either would be lacking totally, and this would be a much more mean and brutal society, or it would have to be absorbed somehow by public funds, so we have to recognize the huge contribution, not just in terms of the climate of our society, but also to the bottom line of our economy these caregivers are giving. As you look in con-

trast, the average nursing home costs \$47 thousand a year. Now, nursing visits and physical therapy visits are \$100 an hour for each visit, so this is not only a tremendously vital service on the human level, but a tremendously valuable service on an economic level, and we have to recognize that, too.

Now, Jeanette is going to talk about the National Family Caregiver Support Program. I hope we can move aggressively and Congress passes on that legislation.

Let me just conclude with a final point. Too often this issue of long-term care is characterized as a seniors' issue. It is not a seniors' issue. If you are a person my age, and you have a senior parent who needs care, it is a middle-age issue. If you are a young child who has a disabling condition and need long-term care, it is a pediatric issue. In fact, the statistics bare this out. Of the individual American citizens needing long-term care, children and adults under 65 comprise 5.7 million of these individuals. People over 65, 5.8 million. So this is an issue that affects every family. It affects seniors. It affects middle-age couples trying to cope with this issue. It affects parents trying to deal with the problems of children with disabilities, and so we're going to be listening later, in our third panel, to caregivers who are dealing with this full range of issues.

I want to thank again everyone for being here today, and I also particularly want to thank our Assistant Secretary. Before I forget, because sometimes in the rush of events you forget to thank everyone. I also want to have a chance to thank our state officials who have helped us, but let me thank a few other people. Moya Benoit Thompson, who is a respected assistant to the Assistant Secretary, tremendous friend of aging, tremendous friend of Rhode Island. In fact, I think she is going to be an honorary citizen she comes up here enough.

I want to thank Gardner Young of AARP of Rhode Island. I want to thank Elizabeth Morancy of the Rhode Island Alzheimer's Association. She has been very helpful. From the Rhode Island Division of Developmental Disabilities, Lynda Kahn and Maya Colantuono. From the Feinstein Adult Day Care Center, Cynthia Conant-Arp. From the Aging Committee I want to thank Jill Greenlee whose staff, along with Senator Breaux, helped with the graphs that we are talking about.

The prepared statement of Senator Reed along with prepared statement of Senator Breaux follows:]

PREPARED STATEMENT OF SENATOR JACK REED

I am delighted to be here this morning. I would like to thank the Rhode Island National Guard Schofield Armory for allowing us to hold our event in their facility. I am very pleased to be able to convene this hearing of the Special Senate Committee on Aging here in my hometown of Cranston to discuss the important issue of long-term care. I believe the issues and challenges associated with long-term care are particularly critical in this state, in light of Rhode Island's fast-growing aging population.

I would like to take a moment to thank our distinguished witnesses. As administrators, advocates and caregivers, you have made significant contributions to improving access and quality of long-term care. I would particularly like to thank Assistant Secretary for Aging, Jeanette Takamura, for being here today.

I hope this hearing achieves the following three goals: First, to learn more about the current struggles and challenges facing family caregivers in Rhode Island and find out what resources are available to family caregivers. We will also hear how

and where available services fall short in meeting the complex array of family caregiver needs.

Second, to discuss current federal initiatives aimed at easing the burdens of family caregivers in providing long-term care. In particular, we will focus on a proposal called the National Family Caregiver Support Program. This plan was first unveiled by President Clinton as part of a four-pronged long-term care strategy during his State of the Union address. Later, the provisions of the plan were introduced as separate legislation in the Senate (Grassley-S. 707) and also incorporated into this year's Older Americans Act reauthorization legislation (Sen. DeWine-S.536). I am proud to be an original cosponsor of S. 707.

Last, I hope this hearing will increase awareness about the importance of planning ahead when it comes to one's own long-term care needs. This final point is particularly important for those of us in the 'baby boom generation'. Most baby boomers are woefully unprepared to pay for their long-term care needs. Moreover, many baby boomers are simply uninformed about how such care is paid for in retirement.

A telephone survey by the American Health Care Association found that 68 percent of respondents, "know they are not financially prepared" to handle anticipated future long term care costs. As for financial assistance, 85 percent of those surveyed could not "name Medicaid as the primary funding source for the vast majority of nursing home residents". Clearly, we can be doing a better job when it comes making informed decisions about future long-term care needs.

According to a 1997 study by the National Alliance for Caregiving and AARP, 22 million Americans—one in four households—is involved in caring for a family member, friend or neighbor. This number is expected to increase as people live longer and the baby boom generation ages. Roughly 13 percent of the U.S. population is 65 and older. In Rhode Island, almost 16 percent of the population is age 65 and over.

In the United States today, an estimated 12.8 million Americans of all ages require help to carry out basic daily activities such as eating, dressing and bathing. Among those disabled older persons who need assistance to remain independent, we know that 95 percent of the time family and friends provide for their care, either exclusively (65 percent), or through a combination of informal and formal care. Only in a small margin of cases (5 percent) is care provided entirely by a paid caregiver. This interaction between formal and informal caregiving will become increasingly important during the 21st century, when the number of older people will increase and the number of younger, working age people will decline significantly.

Family caregivers are truly unsung heroes in this nation. Family caregivers are one of the most effective, and often under appreciated providers of long-term care. Being a family caregiver requires patience, a lot of sacrifices, and tireless hours of work and planning. There are more than 20 million caregivers, the vast majority of them women—daughters, wives, and sisters. Nearly half of all care givers spend up to eight hours a week on care. About one in five spends up to 20 hours, and nearly another fifth are giving constant care to a frail relative, most often a parent.

The average care giver is a woman about 57, married, working full-time who has been looking after a parent with a chronic condition for four or five years. In many cases, family caregivers are responsible not only for assisting their aging parents, but must also juggle the challenges of having a family of their own at home to care for.

Studies have shown that informal caregivers provide a wide range of assistance. According to the 1997 National Association of Caregivers/AARP survey, the majority of tasks caregivers perform are directly related to essential Activities of Daily Living (ADL)—such as transportation (79 percent), grocery shopping (77 percent), housework (74 percent), meal preparation (60 percent), financial management (56 percent), coordinating outside services (54 percent) and medications (37 percent).

Typically, the job of a family caregiver gets harder and more stressful over time, not easier. As the condition of a loved one deteriorates, as is the case with such devastating diseases such as Alzheimer's and Parkinson's Disease, the caregiver must bear not only the emotional distress, but must also face the added responsibilities associated with their care.

As the following chart indicates, caregivers for dementia patients are more likely to have to make sacrifices and experience problems with their health and employment status than caregivers for non-dementia caregivers. A recent study by the National Alliance for Caregiving and the Alzheimer's Association revealed that caregivers for dementia patients typically have less time for their families (56 percent vs. 40 percent); are forced to give up hobbies or other activities (53 percent vs. 40 percent); experience more health problems (23 percent vs. 12 percent); have more lost work days (57 percent vs. 47 percent) or are required to give up their jobs entirely (13 percent vs. 11 percent).

In addition to the emotional toll of being a family caregiver, there is also a significant cost associated with caring for an elderly or disabled friend or loved one. An Administration on Aging survey found home caregivers provide the equivalent of \$45 to \$75 billion worth of professional care each year. In Rhode Island, estimates show over 98,000 caregivers in the state provide, on average, the equivalent of three-quarters of a billion dollars worth of care each year.

Let's compare the cost of some alternative types of care: the average nursing home cost is approximately \$47,000 a year, while home care visits for nursing or physical therapy may typically cost \$100 for each visit.

The burdens and responsibilities borne by family caregivers are certainly great. And while caregiver duties and situations may vary greatly, a common dominator for the vast majority of caregivers is the chronic shortage of resources available to assist them in carrying out their duties.

I hope Congress will enact the National Family Caregiver Support Program this year, so greater resources can be made available to fulfill the critical shortage in services that plague family caregivers and the people for whom they provide care.

Yet, it is important to recognize that long term care is not just about elderly parents and relatives. Today there are almost as many children and adults under 65 in long-term care situations, (5.7 million), as there are people over 65 in long-term care situations, (5.8 million). At this hearing, I will be listening to both children providing care for parents, as well as parents providing care for children.

I would again like to say how pleased I am to have to opportunity to host this hearing. And with that I shall conclude my opening remarks and turn it over to our esteemed and knowledgeable panels of witnesses. Thanks again to all of you for attending.

PREPARED STATEMENT OF SENATOR JOHN BREAUX

One of the most important activities of the Special Committee on Aging has been educating the public about the challenges that our nation faces in preparing for the aging of the baby boomers. When the 77 million strong baby boom generation begins to retire, not only will our national programs and resources be put to the test, but our families will be as well. Already there are over 22 million families in the United States who provide care for a loved one. Their struggles are real and important. And, as our population grows older, the strains felt by families all across the country will only increase.

Caregiving is an issue of particular importance when we think about how to prepare for the new millennium. With the average life-span for men and women increasing, many baby boomers will require long term care at some stage in their lives. This means that more seniors than ever before will have long term care needs, and more families will try as best they can to meet those needs.

As the Ranking Member of the Aging Committee and as an honorary board member of the National Family Caregivers Association, I have learned a great deal about the tremendous strains felt by family caregivers. In March of this year, Senator Grassley and I, along with Senator Reed, introduced legislation that would establish the National Family Caregiver Support Program. This crucial program, designed by President Clinton's administration, would offer assistance to families through the Older Americans Act. Services, support and information would be available to millions of families right in their own communities.

Implicit in the creation of the National Family Caregiver Support Program is the need to reauthorize the Older Americans Act (OAA). The OAA has not been reauthorized since 1992. For three years, the issue has been tangled up in debates and differences of opinion. This year we must move forward to reauthorize and modernize the OAA. The creation the National Family Caregiver Support Program hinges on reauthorization; and as we will surely learn today through the testimony of our witnesses, this program will serve a crucial role in meeting the needs of our nation's families and enable our elders to receive the best and most loving care available.

I commend Senator Jack Reed for chairing this Aging Committee hearing in his home state of Rhode Island and sharing his knowledge with the people of this great state. Senator Reed has been a very dedicated member of the Aging Committee. He has been extremely active in the work of the Committee, whether the issue is geriatric medical education, Social Security or long-term care. Senator Grassley and I both thank Senator Reed for his commitment to ensuring that the needs of seniors in Rhode Island, and across the entire country, are met.

Now, it is my pleasure to introduce Jeanette C. Takamura. Dr. Takamura is the Assistant Secretary for Aging for the Department

of Human Services. She has held this position since 1998. She is a native Hawaiian. While in Hawaii, Dr. Takamura was First Deputy Director of the Hawaii Department of Health. Prior to that, she served as the director of the Hawaii Committee on Aging between 1987 to 1994, where she was instrumental in developing many programs for seniors in her home state. She brings tremendous knowledge of the issues faced by older Americans. She holds a Ph.D. from Brandeis University. She is experienced in the field of health care, dermatology, social issues, and she has been a frontline administrator in the State, so she is somebody who has seen this issue from every perspective. I'm delighted that she, once again, joins us. She, too, can qualify as an honorary citizen of Rhode Island.

Dr. TAKAMURA. Thank you. [Applause.]

Senator REED. Dr. Takamura. Thank you.

STATEMENT OF JEANETTE C. TAKAMURA ASSISTANT SECRETARY FOR AGING, U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES

Dr. TAKAMURA. Thank you, Senator Reed, for the opportunity to testify at this Senate Special Committee on Aging hearing on the long-term care involved in family caregivers.

I am pleased to discuss the Administration's long-term care proposals, including the proposed National Family Caregivers Support Program, and to hear Rhode Island's perspective on an issue that is so important to families across the nation.

At the very outset, I would very much like to commend you, Senator, for your exemplary leadership as a member of the Senate Special Committee on Aging and the Senate Committee on Health, Education, Labor and Pensions. We are most grateful for the support you have provided toward the re-authorization of the Older Americans Act and for your strong support of our nation's family caregivers.

I would also like to recognize Barbara Rayner, director of the Rhode Island Department of Elderly Affairs and her able staff, and commend them for their work on behalf of older citizens of Rhode Island.

Senator Reed, the opening days of the year 2000 are less than 100 days away. In the next century we know there will be more older persons, more caregivers, and greater generational and ethnic diversity in America than ever before. Evolving demographic realities presents our nation with a myriad of challenges and opportunities. I come before you today to talk about an issue that is at the heart of all national public policy discussions related to long-term care, how we, as a nation, as communities, and as families can and will care for our older loved ones.

Earlier this year, President Clinton unveiled a four-part initiative to support Americans of all ages of long-term care needs for the millions of family members who care for them.

First, the President proposed a thousand-dollar tax credit for people with long-term care needs or their families. As a first step, this proposal supports Rhode Island families who are caregiving with financial support.

Second, the Administration has proposed a national campaign to educate Medicare beneficiaries about their long-term care options and how best to evaluate them. Nearly 60 percent of Medicare beneficiaries are unaware that Medicare does not cover most long-term caregivers.

Third, the President proposed that the Federal Government use its market leveraging ability to offer quality long-term care insurance as an option for Federal employees.

Finally, the President unveiled a proposed National Family Caregivers Support Program. If enacted by Congress, and we're looking to your leadership on this, it would provide \$125 million per year to support families caring for older relatives with chronic illnesses or disabilities.

Under our proposal, states would provide critical information about health issues, resources, and community-based long-term care services; assistance in securing appropriate help; counseling, support groups, and caregiver training; quality respite care, supplemental long-term care services, as well, on a limited basis.

Family caregivers have always, as you noted earlier, been the mainstays in the provision of long-term care in this country. Ninety-five percent of all older Americans in the community with limitations in their activities of daily living have family members involved in their care, something you already noted. This degree of caregiver involvement has remained fairly constant over more than a decade, bearing witness to the remarkable resilience of the American family in caring for older relatives.

If Congress enacts the proposed National Family Caregiver Support Program, the Administration on Aging will work closely with the national aging network, including Rhode Island's Office of Elderly Affairs, to plan, coordinate, and provide supportive services to meet the unique needs of caregivers across the country.

We are very pleased with the bipartisan support the proposed National Caregivers Support Program has received thus far in Congress, and I think you know that the House is going to be voting on the authorization of Older Americans Act today at 2.

We're also pleased with the level of support our proposal is getting from the Senate Committee on Health, Education, Labor and Pensions. We are hopeful that continued progress will result in the National Family Caregiver Support Program will become a reality to support families today and in the future.

In conclusion, Senator Reed, I would again like to reiterate our very sincere appreciation to you for your continued support and exemplary leadership and for today's hearing. I look forward to working with you and would be happy to answer any questions that you might have.

[The prepared statement of Jeanette Takaqamura follow:]

**STATEMENT OF
JEANETTE C. TAKAMURA
ASSISTANT SECRETARY FOR AGING
US DEPARTMENT OF HEALTH AND HUMAN SERVICES**

Thank you, Senator Reed, for the opportunity to testify before the Senate Special Committee on Aging hearing on long-term care and the role of family caregivers. I am pleased to discuss the Administration's long-term care proposals, including the proposed National Family Caregiver Support Program, and to hear Rhode Island's perspective on an issue that is so important to American families across the nation.

At the outset, I would like to commend you, Senator, for your leadership as a member of the Senate Special Committee on Aging as well as the Senate Committee on Health, Education, Labor and Pensions, which has jurisdiction over the Older Americans Act programs administered by the Administration on Aging. We are most grateful for the support you have provided toward the reauthorization of the Older Americans Act and for your strong support of our nation's family caregivers.

I would also like to recognize Barbara Rayner, the director of the Rhode Island Department of Elderly Affairs, and her able staff and commend them all for their continued work on behalf of older citizens of your beautiful state. This is my fifth visit to Rhode Island since I was sworn in as Assistant Secretary in 1997. I have been impressed each time by the level of commitment and dedication of Rhode Island's aging network and by the interest and enthusiasm of your older citizens.

Senator Reed, the opening days of the year 2000 are less than 100 days away. We stand on the threshold of an extraordinary time in our country's history. In the next century, we know there will be more older persons, more caregivers, and greater generational and ethnic diversity in America than ever before. Rhode Island's over-65 population alone is expected to increase by 26.2% by the year 2020, and its over-85 population by over 66% (since 1993). These demographic realities present our nation and its leaders with a myriad of challenges, possibilities and opportunities.

I come before you today to talk about an issue that is at the heart of all national public policy discussions related to long-term care; how we as a nation, as communities, and as family members can and will care for our older loved ones. As you know, earlier this year President Clinton unveiled a four-part initiative to support Americans of all ages with long-term care needs and the millions of family members who care for them.

First, the President proposed a \$1,000 tax credit for people with long-term care needs or their families. As a first step, this proposal supports rather than supplants family caregiving and would provide financial support to about two million Americans, including 1.2 million older persons.

Second, the Administration has proposed a national campaign to educate Medicare beneficiaries about long-term care coverage and about how best to evaluate their options. Nearly 60 percent of Medicare beneficiaries are unaware that Medicare does not cover most long-term care needs.

Third, the President is calling upon Congress to allow the federal government to use its market leveraging ability to offer quality long-term care insurance as an option for federal employees.

And finally, the President unveiled the proposed National Family Caregiver Support Program. If this new nationwide program is enacted by Congress and funded at the requested level, it would provide \$125 million per year in federal funding to support families who are caring for older relatives with chronic illnesses or disabilities. Under our proposal, states would provide:

- Critical information about health conditions, resources and community-based long-term care services that might best meet a family's needs;
- Assistance in securing appropriate help;
- Counseling, support groups and caregiver training to help families make decisions and solve problems;
- Quality respite care so that families and other informal caregivers can be temporarily relieved from their caregiving responsibilities; and
- Supplemental long-term care services on a limited basis.

This unprecedented new proposal recognizes that more than seven million people—spouses, adult children, other relatives and friends—are informal caregivers providing unpaid help to older persons living in the community. Family caregivers have always been the mainstays in the provision of long-term care in this country. Ninety-five percent of all older Americans in the community with limitations in their activities of daily living have family members involved in their care. This degree of caregiver involvement has remained fairly constant over more than a decade, bearing witness to the remarkable resilience of the American family in caring for older relatives, despite increased geographic separation, greater numbers of women in the workforce, and other changes in family life.

According to the HHS National Long-Term Care Survey, if the work of these caregivers had to be replaced by paid home care staff, the cost to our nation would be \$45 to \$75 billion per year. The costs to the caregiver—in time, physical and emotional stress, and financial costs—can be significant. We also know that:

- Caregivers dedicate an average 20 hours per week providing care and even more time if an older person has multiple disabilities;
- Caregiving is physically demanding and physically strains caregivers, many of whom are older themselves;
- Caregiving responsibilities place a heavy emotional strain on the caregiver and often this results in depression; and
- Two-thirds of working caregivers report that there are work conflicts resulting in unpaid leaves of absence or rearranged work schedules.

The Administration's proposed National Family Caregiver Support Program is designed to help families with these challenges. Senator Reed, we believe that it is good government to treasure and support family caregivers, so that they do not make themselves vulnerable in the long run; can continue to work without sacrificing their futures; and can continue to be supportive of the younger members of their families as well.

If Congress enacts the proposed National Family Caregiver Support Program, the Administration on Aging will work closely with the national aging network, including Rhode Island's Office of Elderly Affairs, to plan, coordinate and provide supportive services to meet the unique needs of caregivers across the country.

Our proposal for the National Family Caregiver Support Program is part of the Administration's proposal to reauthorize the Older Americans Act, as well as part of the President's budget proposal for FY 2000. If fully funded, Rhode Island will receive over one-half million dollars for caregiver support and services.

We are very pleased with the bipartisan support the proposed National Family Caregiver Support Program has received thus far in Congress. Just three weeks ago, the House Committee on Education and the Workforce reported out H.R. 782, a bill sponsored by the bipartisan leadership of the committee, to reauthorize the Older Americans Act which contains major components of the Administration's National Family Caregiver Support Program as well as our requested \$125 million authorization level. We are also

pleased with the level of support our proposal is getting from the Senate Committee on Health, Education, Labor and Pensions, and the Senate Special Committee on Aging. We are hopeful that progress will continue so that we will have a National Family Caregiver Support Program to support families today and in the future.

In conclusion, Senator Reed, I would like to reiterate our appreciation for your continued strong support for the proposed National Family Caregiver Support Program and for calling for today's hearing. I look forward to continuing to work with you and will be happy to answer any questions you might have.

Senator REED. Thank you. Thanks very much, Dr. Takamura. I am going to ask just a few questions.

First, this notion of family caregiving has been with us for as long as we've had families, but this growing awareness now of the central role that they're playing in our health care system, and if you could just comment upon the national awareness and the growing awareness based upon the President's proposals, the legislature is now supporting, is it helpful to family caregivers?

Dr. TAKAMURA. Absolutely. You know we have been across the country, and during all those visits, I've had the opportunity to meet with people, with caregivers themselves, with baby-boomers, like you and myself, and what we have heard from families all across the country, and certainly in Rhode Island, is that families are very committed to providing support to their older family members, but they cannot continue to do this without support.

The Older Americans Act has done a wonderful job of supporting our older adults, but as I said to one of the reporters from, I believe, the Providence Journal earlier, we know now that in addition to supporting older Americans, we also need to give strong support to their caregivers. There are oftentimes two people who are affected by the aging of our population, two people in each family, and so it is with your great leadership and your support, and hearings such as this, that we are able to get the word out about our commitment to supporting caregivers. We truly appreciate the care that caregivers provide. As a country, as an administration, certainly with the support of people like you, we fully intend to acknowledge their work and we fully intend to support them.

Senator REED. Thank you, Dr. Takamura. The focus in our efforts is a family caregiver, but my sense is that Older Americans Program would help not only just seniors and their families, but also help people who are dealing with, say children with complications, seizures, or adults that might be disabled and are living with a senior parent who themselves are healthy but have to deal with a disabled son or daughter, and is that true?

Dr. TAKAMURA. Well, one of the proposals before Congress actually suggests that we extend the benefits to populations of younger people with disabilities who are being cared for by older people. I think with support for family caregivers, there are many other individuals who are impacted positively, and I would note for you that I think businesses, employers as well, would find support for caregivers will support workers in the workforce. The ramifications are much broader than the legislation might actually articulate.

Senator REED. And a follow-up question, in the proposal that you are suggesting, or the President's suggested, essentially, this would be a state-based level, that it would not be one size fits all from Washington, and the states would have great flexibility. If in Rhode Island, for example, there was a need for respite care to be emphasized and worked out in that way, there would be an information system to inform people they could invest those dollars. Is my view accurate?

Dr. TAKAMURA. Well, I just want your constituent Rhode Islanders to know how well informed you are about our proposal. It is absolutely accurate. And one of the reasons that we wanted to ensure that we preserve and protect state flexibility is because we know

that every state has its own history of developing a service-delivery system, and we don't think that we in Washington know what has to be done in every single state in the country. So as you suggested, we very much believe the states need to take the program and tailor it to meet their own needs.

Senator REED. Madam Secretary, I alluded to some growing demand for family caregivers with demographic changes. One of the startling statistics that I discovered in preparing for this hearing, and I think it excites me in a way, is that of the baby-boomer generation, one million of us are going to live to 100 years old. I hope I am in that million. But that just underscores, I think, that this isn't a transient problem that is going to go away, that it is a demand for caregivers. I think you might speak to that in terms of your perspective, also.

Dr. Takamura. I think you are absolutely right. We will see the need to support family caregivers escalate in the future, and you know another point I think that very strongly supports this proposal: we know all across the country we have some very serious labor-force issues, as well. Because we don't have as many young people, we need to stop and think about where our workers are going to be needed.

Quite frankly, if we can support caregivers, they can continue in the workforce. We would also not have to find ourselves up against the dilemma of trying to figure out where to get many more workers in the area of long-term care. There are multiple concerns being positively addressed by this proposal.

Senator REED. Just a final question, Madam Secretary. You mentioned that today the House is considering the Older Americans Act. We have been trying to re-authorize the Older Americans Act for a very long time. Could you just comment on the consequences for existing programs and these very important issues if the Older Americans Act continues to languish without passage?

Dr. TAKAMURA. You know one of the reasons that I particularly like to come to Rhode Island is because I think you and your delegation understands the significance of the Older Americans Act, and this year we have before Congress a very new proposal for re-authorization. It calls not only for the establishment of the Family Caregiver Support Program, which would help carry all across the country, but it addresses another issue that you alluded too much earlier, and that is, in our re-authorization proposal, we have also proposed to establish something called National Life Course Planning Program. You know, it seems just remarkable to me that we are seeing people live to a hundred, as you just said, 110 and 120, but as a country, and we're not unique in this, we have not really gotten the word out. People need to plan for the possibility of long life. We actually have suggested the Administration of Aging, through a National Life Course Planning Program, established in every state across the country, we can take a leadership role with the Aging Network in making sure our communities are planning for longer-living people. In addition at the level of the family, the aging network would take the lead in making sure that people have access to information and counseling so that they can prepare in five areas of their life; so they have enough information to be able to develop good plans for themselves around health and long-

term care, around financial security, around their living arrangements, because oftentimes people when they are older, need to live somewhere else. The fourth area we think the aging network would play a very strong leadership role in is helping to identifying new roles for older folks.

When you and I become 70 years of age, we are not going to just want to be retirees. We also will want to have a full range of roles available for us, and we won't anyone to tell us that we can't be what we want to be. That is the fourth area.

The final area that we think people need to be thinking about and planning for is consumer protection. As we see more and more older adults in our nation, we know that businesses are going to want to sell products to them. That is great. But we also know that people need to know how to make decisions as consumers. There are five areas that we feel people need to be planning around. Hence, the new reauthorization proposal includes a proposal for National Family Caregivers Support Program and for a National Life Course Planning Program. I truly thank you for understanding both issues because, in fact, I think both issues are critically important and will continue to be in the 21st Century in America.

Thank you.

Senator REED. Thank you very much, Madam Secretary, for your leadership. Thank you.

As you were talking about people in their seventies not being simply content sitting around and being called retirees, I was thinking of my former colleague, John Glenn who, at 75, went up in space, something that I would be daunted by at the age of 49, so you are right, there is a whole new world out there, and we have to be ready for it, and because of you, Madam Secretary, this Federal agency is much better prepared. Thank you so much for joining us in Rhode Island and for your service to your country. Thank you. Thanks very much.

I will now ask the second panel if they would take their places, and we will begin, and that is Barbara Rayner, John Marosy, and Maureen Maigret.

Just as a administrative point, I presume everyone can hear. OK. If you can't, wave your hands and I'll wave back, but Master Sergeant Iafrate will fix it immediately.

Let me introduce all the panelists first, and I will ask Barbara to begin. First, we are joined by Barbara Rayner. Our Secretary Takamura talked about the aging network, and here in Rhode Island the key leader in that network is our director of Elderly Affairs, Barbara Rayner.

Barbara is an old and dear friend. We have known each other for a couple of years, more or less, and we first met when she was the head of Human Services in the Town of Coventry. She did a remarkable job there, and she is doing a remarkable job in the Department of Elderly Affairs.

I think I saw one of her distinguish predecessors today, Anna Tucker. Is Anna here? And Anna is another dear friend. We have been fortunate in Rhode Island to have distinguished leaders in this department, and Barbara is no exception.

She is immediate past chair of the National Institute of Senior Centers. She is also a contributing author of the Senior Centers

Standards and Guidelines. She is involved in national organizations, as well as local organizations. Thank you, Barbara, for being here today.

Next to Barbara is Maureen Maignet. Nice thing about Rhode Island is you know people for a long time, good people. Maureen and I have known each other also for many years.

She is a representative for Lieutenant Governor Charlie Fogarty, who could not be here today, and as you know, Lieutenant Governor Fogarty is the head of the Long-Term Care Coordinating Council. Maureen is the executive director, and we are fortunate in Rhode Island because we have this talent. She has done remarkably good work. It was created in 1987, and it is tasked with developing coordinating policy with respect to long-term care. She has been a great advocate for seniors and for long-term care, and, Maureen, we are delighted that you are with us today.

Finally, we are joined by John Paul Marosy. Mr. Marosy is the founder and president of Bringing Elder Care Home, a consulting firm which specializes in elderly care. It is based in Worcester, MA. He is also a senior consultant to the Planning Department's health plans. He is an author of a new book which is titled, A Manager's Guide to Elder Care at Work, and today Mr. Marosy is testifying on behalf of the National Family Caregivers Association of which he is a volunteer board member. He is an eminently qualified individual, graduating from St. Peter's College, I believe, with a Master's from Boston University, so we are certainly very fortunate to have Mr. Marosy here.

And now Barbara, if you would begin. Thank you.

STATEMENT OF BARBARA A. RAYNER, DIRECTOR, RHODE ISLAND DEPARTMENT OF ELDERLY AFFAIRS

Ms. RAYNER. Thank you. Good morning, Senator Reed. I would like to preface my comments this morning by expressing a very sincere appreciation for your efforts for making possible the Senate Special Committee on Aging hearing in Rhode Island. It truly is a privilege.

My name is Barbara Rayner. I have the privilege of serving as director of the Rhode Island State Department of Elderly Affairs, one of several single state units on aging in the country which also serves area agency on aging for the State of Rhode Island. This cabinet-level post has insured since its inception that the needs of older Rhode Islanders would be heard on an equal footing with other matters of state, and has served well the development and expansion of our State Department of Elderly Affairs and our aging network.

My testimony this morning will focus on the critical issues facing Rhode Island relative to current trends and future needs regarding family caregiving, while, at the same time framing this discussion around the issues of caregiving from the perspectives of public policy, political, and demographic trends, and finally from the view of consumers.

Rhode Island, as you well know, holds the distinction of having the third highest concentration of persons age 65 and older in this country and also leads the Nation in a percentage of elders age 85 and older.

As we look ahead at the continuing demographic shift, we can forecast that by the year 2020, 20 percent of our population will be age 65 and older, however, we will experience yet an even more rapid acceleration to 56 percent in our 85-plus population as our baby-boom cohorts age.

Factors contributing to the future growth in this population, such as low fertility, maturing of baby-boom cohorts, sharp declines in mortality, dramatic increases in minority and disabled elders, and continued growth in the old/old female population forces us to plan strategically for the long-term care needs of older Rhode Islanders. At the same time, however, these demographic trends clearly point to the longevity of our population and provide us with a wealth of wisdom available to us now and continuing at a growing pace in the future, a wealth we must take full advantage of in other arenas.

While we would be hard pressed to articulate the many benefits elders of our state have brought to the quality of our lives in Rhode Island, we can certainly point today to the contributions they have made to our family values. As a population who suffered the trials of the Great Depression and later served our country in the efforts of World War II, they have guided us through the transitions during this century from the extended family to the nuclear family as we now know it. They are a rich mix of many cultures who have sustained pride in the ethnicity and have provided the atmosphere for integration of many additional cultures, who have joined the Rhode Island family. They have found here the opportunity to assimilate to our culture, while sustaining with pride their respective multi-cultural norms. Culturally, therefore, Rhode Island has been and remains a proud melting pot of a range of cultures, and, in fact, has seen a dramatic increase in our Asian and Hispanic elderly populations, now representing 13 percent of the Rhode Island aging experience, and is forecasted to grow significantly over the next twenty years.

All of these issues have major implications on the way in which we move forward in delivering our aging services, and the uniqueness as we decide the family caregiver initiatives here in our state.

As you well know, and as this audience knows, for the congressional record purposes, Rhode Island boasts the leadership of our own Congressman John E. Fogarty and his major contribution in the authoring of the Older Americans Act of 1965. This spirit of leadership and sensitivity to the elderly remains evident in our congressional delegation whose members continue to press forward the national aging agenda, while always sustaining a watchful and protective eye on the needs of their Rhode Island constituents.

Senator, we are deeply grateful for your commitment, and the commitment of your colleagues in Congress, and are confident that we will all be the driving force in the current debate surrounding the re-authorization of the Older Americans Act. In our America, all too often only the negative is recognized by communication, but you need to know that across this state, there is a resounding solid thanks to you for your commitment around the Older Americans Act and your sensitivity to the needs of the older persons, and also that of your congressional colleagues from Rhode Island.

Rhode Island was one of the first states, as you know, to develop this cabinet-level state Department of Elderly Affairs whose founding mission was, and continues to be, quote, "To support the independence, choice, dignity, and safety of our older Rhode Islanders." Over the intervening years, DEA has continued to expand its capacity to serve elders primarily through a network of community-based agencies, second to none in our country and consistent with the philosophy and guiding principles of the Older Americans Act.

Support from state government has been exemplary over these many years and has shifted and expended to address the changing needs of our aging constituents and service-delivery system. The Rhode Island Administration and State Legislature is proud of its support of at-risk clients who were terminated from Medicare funded in-home services as a result of the 1997 Balanced Budget Act and were moved onto state co-pay funded in-home services which continue to sustain many in the community.

The following summary, I believe, highlights the very important characteristics of this population, and the population of persons becomes the targets of these legislative initiatives, and serves as an illustration of the impact of Rhode Island's demography on such programs.

In terms of individuals, the range of age is 65 to 100, however, the average age is 83. Eighty percent of these clients are female; 52.7 percent are living alone; 26.7 are living with relatives; 17.3 are living with a spouse, who is also usually suffering from some health-compromising situations; 23 percent are suffering from Alzheimer's; 24.4 percent have osteoporosis; and 40 percent of the discharges from our program is directed to long-term care facilities, and, again, I would suggest, because of our limited capacity to provide these services to older Rhode Islanders.

In partnership with the community-based agencies and consumer leadership groups such as the Rhode Island Commission on Aging, the aging Forum, The Long-Term Care Coordinating Council, and most recently, the Shared Vision initiative, we have sustained the focus on a consumer-driven agenda. This agenda will provide services through community-based agencies that ensure consumer preference in the least-restrictive environment.

Older Americans Act Funding, combined with other provided Federal, State, and local government and the nonprofit sector provide the resources and support for our community-based industry of senior centers, adult day services, regional case management agencies, home care providers, assistive living facilities, respite care, ombudsman services, and nursing home care. Others providing testimony here today will provide you with a sense of the richness of this agenda and the strength of the partnership between Federal, state, and local government in accomplishing our common goals.

At this juncture, I feel it is important to stress that over 90 percent of Rhode Island elders are not living in institutional care. While the disproportionate 93 percent of our long-term care budget here in Rhode Island is dedicated to nursing home costs, we must acknowledge that this funding is supporting only 10 percent of our elder population.

Over the last several years, initiatives including, the moratorium on nursing home beds, increases in in-home nursing services, enhancement of our home care rate, strengthening of our community agencies, expansion of our nursing home waiver, adult day services, home-delivered meals, and strong regional and community case management services have all contributed to our ability to provide elders quality care.

Although we have developed a system of services, the challenge for Rhode Island is and will continue to be the blending and expansion of these services to support elders and their family caregivers to sustain them within their communities. Such strategies must address and reverse Rhode Island's unacceptable current ranking of 48th in the country for its utilization of long-term care funding dedicated to home and community care. It is only through a formal partnership with caregivers that I believe these goals can be accomplished.

Reflective of national trends, and as a direct result of limited congregate housing resources, the vast majority of older Rhode Islanders continue to live in their homes. While this state has experienced migration of younger family members to other states for economic reasons, it must be recognized that family caregivers have always been and continue to be the mainstay and underpinning long-term caregivers in our state. It is my opinion that our elders' early life investments in teaching us the need for family support and interdependence as the sustaining fabric of the family serves to explain the remarkable resilience of the Rhode Island family in taking care of its older relatives.

The degree of caregiver involvement has remained fairly constant over more than a decade, despite increased geographic separation, greater numbers of women in the workforce, and other changes in family life. This leads us to the reality that while governmental agencies and funding initiatives at the Federal and state level most certainly serve to support these families, family caregiving has been a blessing in many respects, not the least of which is the cost savings to governments who annually face the problem of financing health and long-term care expenses for persons with chronic illness and disabilities.

The Catch-22 of this dichotomy is that the family's commitment to support their elders remains constant, while their time-constrained, two-family work schedules inhibits this commitment. The national profile of caregivers defines them as spending a minimum of eighteen hours per week and as many as forty hours per week in providing critically needed care of their loved ones. Caregivers are more likely to give up free time and time with family, are physically and emotionally stressed, and experience economic hardships. Four in ten caregivers simultaneously care for their children, families, and a majority work full time. Nationally, staff replacement costs to businesses for lost time, extra time off, and work-day interruptions equates to a 30 percent loss in productivity at a cost of up to \$29 billion per year.

Having been a primary caregiver of a handicapped person for a 20-year period during my life, I can personally attest to the role and commitment that is necessary for the entire family to sustain an individual who is chronically disabled within their home. The

role is very tiring, Senator, it is very stressful, and most importantly, it is more often than not in isolation for the new family or the old family, a chronic debilitating disease is a heart-wrenching challenge, one that very few can sustain throughout the life expectancy of that disabled younger person.

Thankfully, medical science has brought rehabilitative and restoring measures for many suffering from chronic disease, such as MS, cerebral palsy, the mentally disabled population; however, we absolutely must have the resources to support that life expectancy, and the family, in order that they can sustain dignity.

The proposed amendment to the Older Americans Act for the National Family Caregivers Support Program clearly addresses the remedial action to the key elements presented here this morning. Specifically, the \$125 thousand annually would provide critically needed support to nationally that we would need to help, over 250 thousand persons.

In closing, on behalf the State of Rhode Island Department of Elderly Affairs, our aging network, and family caregivers, I bring to you with confidence our commitment to continue to optimize our partnership with you in preserving the safety and well-being of our treasured resource, older Rhode Islanders.

As we continue the race against time to sustain high-risk clients in the community, we recognize the need to develop strategies that leverage state and Federal funding, provide information and resources that respond to consumer needs and that support the system of community-based care.

I urge you to press forward and re-authorize the Older Americans Act, and I know we have a full commitment. The passage of the Family Caregivers Support Program will evolve support directly and indirectly to what is our most valuable resource in this country, the American family, and I thank you again for the opportunity to be with you.

[The prepared statement of Barbara Rayner follows:]

Testimony of Barbara Rayner

Good Morning Senator Reed and Senator Grassley. I would like to prefix my comments by expressing our sincere appreciation for your efforts in making possible this Senate Special Committee on Aging field hearing here in Rhode Island. My name is Barbara Rayner, and I have the privilege of serving as director of the Rhode Island Department of Elderly Affairs, one of several single State Units on Aging in the country which also serves as the Area Agency on Aging for the State of Rhode Island. This cabinet level post has insured since its inception that the needs of older Rhode Islanders would be heard on an equal footing with other matters of state, and has served well the development and expansion of our State Department of Elderly Affairs and our Aging Network. My testimony this morning will focus on the critical issues facing Rhode Island relative to current trends and future needs regarding family care giving, while, at the same time framing this discussion around the issues of caregiving from the perspectives of public policy, political and demographic trends, and finally from the view of consumers.

Rhode Island holds the distinction of having the third highest concentration of persons age 65 and older in our country, and also leads the nation in the percentage of elders age 85 and older. As we look ahead at the continuing demographic shift, we can forecast that by the year 2020, 20% of our population will be age 65 and older; however, we will experience rapid acceleration to 56% in our 85+ population as our baby-boom cohorts age. Factors contributing to the future growth of this population such as low fertility, maturing of baby-boom cohorts, sharp declines in mortality, dramatic increases in minority and disabled elders, and continued growth in the old/old female population forces us to plan strategically for the long term care needs of older Rhode Islanders. At the same time, however, those demographic trends clearly point to the longevity of our population, and provide us with a wealth of wisdom available to us now, and continuing at a growing pace in the future, a wealth we must take full advantage of in other arenas.

While we would be hard pressed to articulate the many benefits elders of our state have brought to the quality of our lives in Rhode Island, we can certainly point today to the contributions they have made to our family values. As a population who suffered the trials of the Great Depression and later served our country in the efforts of World War II, they have guided us through the transitions during this century from the extended family to the nuclear family as we now know it. They are a rich mix of many cultures who have sustained pride in their ethnicity and have provided the atmosphere for integration of many additional -cultures, who have joined the Rhode Island family. They have found here the opportunity to assimilate to our culture while retaining with pride their respective multi-cultural norms. Culturally, therefore, Rhode Island has been and remains a proud melting-pot of a range of cultures, and, in fact, has seen a dramatic increase in our Asian and Hispanic elderly populations, now representing 13% of the Rhode Island aging experience, and is forecasted to grow significantly over the next twenty years.

Rhode Island boasts the leadership of our own Congressman John E. Fogarty and his major contribution in the authoring of the Older Americans Act of 1965. This spirit of leadership and sensitivity to the elderly remains evident in our Congressional Delegation whose members continue to press forward the national aging agenda, while always sustaining a watchful and protective eye on the needs of their Rhode Island constituents. We are deeply grateful for their commitment, and are confident they will continue to be a driving force in the current debate surrounding the reauthorization of the Older Americans Act.

Rhode Island was one of the first states to develop a cabinet level state Department of Elderly Affairs whose founding mission was, and continues to be: "To support the independence, choice, dignity and safety for all older Rhode Islanders". Over the intervening years, D.E.A. has continued to expand its capacity to serve elders primarily through a network of community based agencies, second to none in our country and consistent with the philosophy and guiding principles of the Older Americans Act.

Support from state government has been exemplary over these many years and has shifted and expanded to

address the changing, complex needs of our aging constituents and service delivery system. The Rhode Island Administration and State Legislature is proud of its support of at-risk clients who were terminated from Medicare funded in-home services as a result of the 1997 B.B.A., and were moved onto state co-pay funded in-home services which continue to sustain many of them in the community. The following summary highlights important characteristics of these individuals, and serves as an illustration of the impact of Rhode Island's demography on such programs:

- Range of age; 65 - 100
- Average age: 83
- 80% female
- 52.7% living alone
- 26.7% living with relative
- 17.3% living with spouse (frequently health compromised)
- 23% Alzheimer's
- 24.4% Osteoporosis
- 40% of the discharges are to long term care facilities

In partnership with the Community Based Agencies and Consumer leadership groups such as: the Rhode Island Commission on Aging, the Aging Forum, the Long Term Care Coordinating Council, and most recently the Shared Vision initiative, has sustained focus on a consumer-driven agenda. This agenda will provide services through community based agencies that ensure consumer preference in the least restrictive environment.

Older Americans Act funding combined with other federal, state and local government the non-profit sector provide the resources and support for our community-based industry of senior centers, adult day services, regional care management agencies, home care providers, assisted living facilities, respite care, ombudsman services, and nursing home care. Providing testimony today will provide you with a sense of the richness of this strength of the partnership between Federal State and Local Government in accomplishing our common goals.

At this juncture, I feel it is very important to stress that over 90% of Rhode Island elders are not living in institutional care. While a disproportionate 93% of our long term care dedicated to nursing home costs, we must acknowledge that this funding is of our elderly population. Over the last several years, initiatives including the moratorium on nursing home beds, increases in in-home nursing services, enhancement of our home care strengthening of our community agencies, expansion of our nursing home waiver, adult day services, home delivered meals, and strong regional community case management provide elders quality care.

Although we have developed a system of services, the challenge will continue to be the blending and expansion of these services to support elders and their family care givers to sustain them within their communities. Such strategies must address and Rhode Island's unacceptable current ranking of 48th in the country for its utilization care funding dedicated to home and community care. It is only through a formal partnership with care givers that I believe these goals can be accomplished.

Reflective of national trends, and as a direct result of limited congregate housing resources, the vast majority of older Rhode Islanders continue to live in their own homes. While this state has experienced migration of younger family members to other states for economic reasons, it must be recognized that family caregivers have always been, and continue to be the mainstay and underpinning long term caregivers in our State. It is my opinion that our elders early life investments in teaching us the need for family support and inter-dependence as the sustaining fabric of the family, serves to explain the remarkable resilience of the Rhode Island family in taking cue of its older relatives.

The degree of caregiver involvement has remained fairly constant over more than a decade despite increased geographic separation, greater numbers of women in the workforce and other changes in family life. This leads us to the reality that while governmental agencies and funding initiatives at the federal and state level most certainly serve to support these families, family caregiving has been a blessing in many respects, not the least of which is the cost savings to governments who annually -face the problem of financing health and long term care expenses for persons with chronic illness and disabilities.

The catch twenty-two of this dichotomy is that the family's commitment to support their elders remains constant, while their time-constrained two-family work schedules inhibits this commitment. The national profile of care givers defines them as spending a minimum of eighteen hours per week and as much as forty hours per week in providing critically needed care to their loved one&. Care givers are more likely to give up free time and time with family, are physically and emotionally stressed, and experience economic hardships. Four in ten care givers simultaneously care for their children, families, and a majority work full time. Nationally, staff replacement costs to businesses for lost time, extra time off and work day interruptions equates to a thirty percent loss in productivity at a cost of up to \$29 Billion dollars per year.

The proposed amendment to the Older Americans Act for the National Family Care givers Support Program clearly addresses remedial action to the key elements presented here this morning. Specifically, the \$125 M annually would provide critically needed support to approximately 250,000 families across our country by providing them with significant services to meet the long term care needs of their loved ones while, at the same time, caring for our care givers.

In closing, on behalf of the State of Rhode Island Department of Elderly Affairs, our Aging Network and Family Care givers, I bring to you with confidence our commitment to continue to optimize our partnership with you in preserving the safety and well-being of our treasured resource, Older Rhode Islanders.

As we continue the race against time to sustain high risk clients in the community, we recognize the need to develop strategies that Leverage state and federal funding, provide information and resources that respond to consumer needs and that support the system of community-base care.

I urge you to press forward and re-authorize the Older Americans Act and passage of the Family Care givers Support Program, which will evolve support directly and indirectly to our most valuable resource, the American Family.

Senator REED. Thank you very much.

Thanks for your leadership, and we will turn to Maureen now, and I should, as a technical point, indicate that the statements in their entirety will be included in the record, so if anyone wants to summarize or depart from the formal text, the text will be in the record.

Maureen, please.

STATEMENT OF MARGARET MAIGRET, EXECUTIVE DIRECTOR OF LONG-TERM-CARE COORDINATING COUNCIL ON BEHALF OF LIEUTENANT GOVERNOR CHARLES FOGARTY, CHAIRMAN, LONG-TERM CARE COORDINATING COUNCIL

Ms. MAIGRET. Senator Reed, Secretary Takamura, to all those who have joined with Senator Reed this morning and are interested in this important issue of long-term care. My name is Maureen Maigret. I am executive director for the state Long-Term Care Coordinating Council, and I am here today on behalf of the Lieutenant Governor Charlie Fogarty who is the chair of the council. He asked me to extend his greetings to you and his best wishes for a very productive hearing, and also his regrets that he couldn't join in person.

As we speak, he is in Kingsale, Ireland with officials from Newport signing a sister city agreement with that city of Ireland. I think that is the sailing capital of Ireland. He did ask me to read portions of his testimony which he has submitted in full to the Committee, and I will do that. And, again, this is a portion of Lieutenant Governor Charles Fogarty's testimony.

First, I want to thank Senator Jack Reed for convening this meeting today on the issues of long-term care and the role of family caregivers. Given the demographics of the Rhode Island population, the issues of long-term care and support for family caregivers are critical ones for our state as we enter the new millennium.

We are fortunate to have a congressional delegation that has a long history of being sensitive and supportive of the needs of our state's elders and those who care for them. I would especially like to commend Senator Jack Reed for his outstanding commitment to so many efforts to ensure that older Rhode Islanders have access to support programs and services that help them remain independent and living in their own homes and remain in their communities for as long as possible.

The Long-Term Coordinating Council was created by state statute in 1987 to provide for a forum to address long-term care issues, to coordinate policy in that area. Its current membership consists of 37 persons who represent consumers, advocates, state agencies, and providers.

In late 1994, the Council issued the first ever long-term care plan for the state. The comprehensive plan detailed three over-arching goals and a series of objectives to achieve those goals. Not too surprising, and right on point for today's field hearing, support for families was the very first objective set forth in the plan.

The Council's plan identified seven specific action steps to support family caregiving. While I will not discuss each of these action steps, I have attached to the testimony a complete list of them, and I am very pleased to report to you that the state has made consid-

erable progress over the last few years in implementing these actions to support families.

One of our most notable achievements was the passage in 1998 of the legislation I sponsored directing Department of Elderly Affairs to establish a family caregiving resource network to provide and coordinate family caregiving training and support services, to include counseling and respite care. At the time the legislation was passed, the Council was also successful in securing \$150 thousand in additional funds to support the implementation of the resource network and to expand subsidized respite care in the state.

In addition to expanding respite services, these new funds were used to assist in publishing a caregiving resource guide, which all of you who came today received a copy of that, and to support the innovative work in support of families being done by the Rhode Island Alzheimer's Association.

While Rhode Island has made great strides in providing support for family caregivers, much more remains to be done. The National Family Caregivers Support legislation, if appropriately funded, would provide Rhode Island with a wonderful opportunity to build on the strong foundation already laid in the state.

To maximize these opportunities, the Federal legislation must provide as much flexibility as possible for states to implement the program and to use the new resources to strengthen existing state programs, and as an aside, I was most pleased with your question to the secretary this morning and her comments that the states, in fact, would have that flexibility.

I would also urge that states not be penalized when they have already moved forward, such as Rhode Island has, to devote state resources to this important area, and specifically referring to what happened with the CHIP program.

Ideally, funding provided by the National Family Caregivers Support Program could be used to augment the efforts already begun by the Department of Elderly Affairs to establish an integrated information, screening, and referral program, and to develop community-based access points for long-term care. These two critical components of our vision for a long-term care service system have the enthusiastic support of our older consumers and new Federal funds would be of great assistance in moving them forward.

Making decisions about long-term care, especially for those who are frail and not feeling well, is a most difficult task. One of best ways that we can help families is to provide them with accurate and timely information on the face-to-face basis, if necessary, and if their own language whenever appropriate so they can take full advantage of all the choices available to them. I think that this is the exciting aspect of what I see as the opportunities provided under the National Family Caregivers Support Program.

I want to extend my sincere appreciation and thanks to Senator Reed for his strong support and sponsorship of this legislative initiative. I urge members of the Senate Committee on Aging and Secretary Takamura to do all they can to secure its enactment.

Finally, as important as this initiative is for elders and their family caregivers, it is equally important for Congress to begin a serious debate on other issues of critical importance for our elders, and I will touch on just two of those.

Earlier in the year, as Council chairman, I wrote to the chairman of the Bipartisan Commission on the Future of Medicare to support expansion of the Medicare program to include greater opportunities for funding of long-term care services, as well as to add a new prescription benefit program. Seniors across Rhode Island have consistently told us they think these issues are two of the most important ones that policymakers need to address, and I believe it is time for us to meet their challenge.

Some of you may remember the work done by my uncle, the late Congressman John Fogarty, to create the Medicare program. Undoubtedly, many of you remember the yeoman's work done on long-term care by one of the dearest friends of aging, the Honorable Claude Pepper, and most of us were around a few years ago to get excited about the long-term care provisions contained in President Clinton's health care reform initiatives. Well, I believe it is time to put health care and long-term care back on the front burner of our public national agenda.

I am not advocating that Medicare bear the brunt of the burden for funding long-term care. However, I do believe the Federal Government should play a greater role in financing long-term care. Likewise, we know that medicine has changed dramatically since the Medicare program was created. Pharmaceuticals not only play a much more important role in treatment, but also have contributed enormously to the increased longevity that this country enjoys. It is time for the Medicare program to recognize the role of prescription drugs in keeping elders healthy by adding the pharmacy benefit.

Finding ways to begin to include some long-term care and prescription benefits to Medicare should go hand in hand with the review of the Medicaid program and expanded initiatives to encourage personal savings and financial responsibilities for long-term care through expanding the tax incentives. For it is only through the combined approach of enhancing family caregiving capacity, expanding government support, and fostering personal responsibility that this country will be able to meet the needs of its burgeoning elder population.

In closing, let me again applaud Senator Reed for bringing this field hearing to this state and to extend my sincere thanks for having this opportunity to express my views on these important issues, Lieutenant Governor Charlie Fogarty.

[The prepared statement of Lt. Governor J. Fogarty follows.]

TESTIMONY OF LT. GOVERNOR CHARLES J. FOGARTY,
CHAIRMAN
LONG-TERM-CARE COORDINATING COUNCIL

First, I want to thank Senator Jack Reed for convening today's field hearing in Rhode Island on the issues of long-term care and the role of family caregivers. As we all know, Rhode Island has the third highest percent of persons age 65 and over in the country. We also have the second highest percent of persons age 75 and over. In addition, persons age 85 years and older are the fastest growing segment of our population. Given these data, the issues of long term care and support for family caregivers are critical ones for our state as we enter the next millenium.

We are fortunate to have a congressional delegation that has a long history of being sensitive and supportive of the needs of our state's elders and those who care for them. I would especially like to commend Senator Jack Reed for his outstanding commitment to so many efforts to ensure that older Rhode Islanders have access to support programs and services that help them remain independent and living in their homes and familiar communities for as long possible.

The Long-Term-Care Coordinating Council - which I have chaired since December of 1996 -- was created by state statute in 1987 at the recommendation of former Lieutenant Governor Richard Licht to provide a forum to address long-term-care issues and policy and to coordinate the long-term-care programs of four separate state departments and a host of community agencies and providers. Its cur-rent membership consists of 37 persons who represent consumers, advocates, state agencies and providers. Since its creation more than eleven years ago, the Council has served as a forceful and successful advocate to improve long-term care in our state.

In late 1994, the Council, under its chairman, then Lieutenant Governor and now Congressman Bob Weygand, issued the first ever long-term care plan for the state. Over a year in development and subtitled "Working Together: Making All the Pieces Fit", the comprehensive Plan detailed three over arching goals and a series of objectives to achieve these goals. Not too surprising, and right on point for today's field hearing, support for families was the very first objective set forth in the Plan. The report noted the following:

- Most impaired elders prefer to remain at home
- About 80% of impaired elders avoid institutionalization due to personal care, financial support and commitment of family and friends
- Care giving can be extremely stressful for families and more and more families are caught in the so-called sandwich generation juggling care for children and elder relatives.
- The average woman can now expect to spend as many or more years caring for elder relatives than she does caring for her children.

More recent research shows that care giving also results in added cost to business. It is estimated that nationally employers annually spend \$1 1.5 billion due to absenteeism, loss in productivity, and finding replacement workers.

To recognize the importance of family giving and to achieve its objective to support families in their caregiver roles, the Council's Plan identified seven (7) specific action steps. While I will not discuss each of these action steps, I have attached a complete list of them as excerpted from the Plan. And I am very pleased to report to you that the State has made considerable progress over the last few years in implementing the actions to support families in their care-giving role.

One of our most notable achievements was the passage in 1998 of legislation I sponsored legislation

directing the Department of Elderly Affairs to establish, in collaboration with community and aging service agencies, a family care giver resource network to provide and coordinate family care giver training and support services to include counseling and respite services. At the same time the legislation was passed, the Council was also successful in securing \$150,000 in additional funds to support the implementation of the resource network and to expand subsidized respite care services in the State. In addition to expanding respite services these new funds were used to assist in publishing a caregiver Resource Guide developed cooperatively by the Department, the Council and Aging 2000; and to support the innovative work in support of families by the Rhode Island Alzheimer's Association.

While Rhode Island has made some strides in providing support for family caregivers much more remains to be done. The National Family Caregivers Support legislation, if appropriately funded, would provide Rhode Island with a wonderful opportunity to build on the strong foundation already laid in Rhode Island. To maximize these opportunities, the federal legislation must provide as much flexibility as possible for states to implement the program and to use the new resources to strengthen existing state programs. I would also strongly urge you not to penalize those states such as Rhode Island that have already moved forward to devote state resources to this important area by holding back funding, such as has been the case with other new programs such as the CHIP program.

Ideally, funding provided by the National Family Care Givers Support Program could be used to augment the efforts begun by the Department of Elderly Affairs to establish an integrated information, screening and referral program and to develop community-based access points for long term care. These two critical components of our vision for a long-term care service system have the enthusiastic support of our older consumers and new federal funds would be of great assistance in moving them forward.

Making decisions about long term care, especially for those who are frail and not feeling well, is a most difficult task. Barely a week goes by, in which my office does not get a phone call from someone looking for information and advice about what to do regarding long term care services for a loved one. It might be a question about residential care; it could be they want information about purchasing long-term care insurance; it might be to tell us about the complexities of coordinating in-home services. One of the best ways that we can help families is to provide them with timely accurate information – on a face-to-face basis if necessary and in their own language – so that they can take full advantage of all the choices available to them. I think this is the exciting aspect of what I see as the opportunities provided under the National Family Care Givers Support Program. On behalf of the Council I want to extend my sincere appreciation and thanks to Senator Reed for his strong support and sponsorship of this legislative initiative. I urge the members of the Senate Committee on Aging and Secretary Takamura to do all they can to secure its enactment and funding.

As important as this initiative is for frail elders and their family care givers, it is equally important for Congress to begin a serious debate on other issues of critical import for our elders and I will touch on just two of them.

Earlier in the year, as Council Chairman, I wrote to the Chairmen of the Bipartisan Commission on the Future of Medicare to support expansion of the Medicare Program to include greater opportunities for funding of long term care services as well as to add a new prescription benefit program. Seniors across Rhode Island have consistently told us they think these issues are two of the most important ones that policy makers need to address and I believe its time for us to meet their challenge.

Some of you may remember the work done by my uncle, the late Congressman John Fogarty, to create the Medicare program. And undoubtedly, many of you remember the yeoman's work done on long term care by one of the dearest friends of aging, the Honorable Claude Pepper. And most of us were around to get excited about the long-term care provisions contained in President Clinton's health care reform initiatives.

Well, I believe its time to put health care and long term care back on the front burner of our national public agenda.

I am not advocating that Medicare bear the brunt of the burden for funding long term care. However, I do believe the federal government should play a greater role in financing long term care. Likewise, we know that the face of medicine has changed dramatically since the Medicare program was created. Pharmaceuticals not only play a much more important role in treatment but also have contributed enormously to the increased longevity this country enjoys. It's time for the Medicare program to recognize the role of prescription drugs in keeping elders healthy by adding a pharmacy benefit.

Finding ways to begin to include some long term care and prescription benefits to Medicare should go hand in hand with a review of the Medicaid program and expanded initiatives to encourage personal savings and financial responsibilities for long term care through expanded tax incentives. For it is only through the combined approach of enhancing family caregiver capacity, expanding government support, and fostering personal responsibility that this country will be able to meet the needs of its burgeoning elder population.

In closing, let me again applaud Senator Reed for bringing this field hearing to our state and to extend my sincere thanks for having this opportunity to express my views on these important issues.

Senator REED. Thank you very much, Maureen.
John Paul.

STATEMENT OF JOHN PAUL MAROSY, VOLUNTEER AND BOARD MEMBER, NATIONAL FAMILY CAREGIVERS ASSOCIATION

Mr. MAROSY. Good morning, Senator Reed.

Senator Read. Good morning.

Mr. MAROSY. Good morning, Senator Read, and good morning ladies and gentlemen, Secretary Takamura, and the panelists.

My name is John Paul Marosy. I'm a volunteer and board member of the National Family Caregivers Association, a nonprofit member support organization dedicated to improving the overall quality of life of America's family caregivers.

Thank you, Senator, for bringing this important issue to public attention, and for your efforts in the U.S. Senate on behalf of the caregivers and elders.

Our members care for spouses, children, aging parents, and other loved ones. The majority of our members care for someone over the age of 50, and have provided care for 5 years or more. Most of our members have provided care for their family members for an average of about 20 hours a week, so these are intense caregivers within the National Family Caregivers Association, and our members are typical of the eight to nine million of these caregivers who are providing extensive care at home for our neediest citizens.

Caregiving is a family affair. It is a labor of love. Despite the stresses and heartaches that go along with providing care for a loved one, most caregivers, in our recent study, use positive words, like rewarding, happy, enjoyable, and loving to describe their relationships with the people they take care of. As a society, we can do a lot more to make life easier for family caregivers, but it is not all gloom and doom.

I speak from personal experience. When my father was diagnosed with prostate cancer in 1989, I became a family caregiver, and I was involved in arranging his care for the last 2 years of his life. Fortunately, through the efforts of a wonderful Hospice organization, he was able to fulfill his final wish, to die at home.

I was one of the lucky ones. My employer gave me the flexibility I needed in scheduling my work, so I could talk to the doctors and escort my father to appointments without feeling that my job was in jeopardy. However, only about one-third of large employers and fewer than 10 percent of small employers offer any form of elderly care support in the workplace other than what is required by the Federal Family and Medical Leave Act.

In regard to public policy, I would like to make three points today. I would like to comment on two Federal initiatives, President Clinton's four-part proposal to help families caring for those who need long-term care, and Senate Bill 1358 which addresses some of the problems of the cutbacks in Medicare home health care as a result of the Balanced Budget Act of 1997, but first, I want to debunk a common myth that has, in part, held back Federal efforts to assist family caregivers.

This myth is commonly referred to as the woodwork effect. Some policymakers have voiced concern that family members' willingness

to provide care is reduced when public funding increases for home care services. There is a fear that if the Federal or State government makes available support services that the disabled need, the flood gates will open, and we will enter into a black hole of spending for long-term care.

We believe that there is a role for both private long-term care insurance and publicly funded long-term care in addressing families' needs, and we want to point out that there is no empirical evidence to support the so-called woodwork effect on public spending for long-term care. On the contrary, study after study has found that the vast majority of families stay involved in providing care for elders using publicly funded services in the way that the government intended, that is, to support and sustain family caregiving arrangements, unless they're disrupted or they end because the elders had to moved out of their home.

Our Association strongly supports President Clinton's proposal for caregivers, and we feel it is an important next step toward addressing long-term care needs in this nation, and particularly, the National Family Caregivers Support Program, described by Assistant Secretary Takamura, will give family caregivers better access to the information and advice they need, as well as respite care.

The President's proposed one-thousand-dollar tax credit is a move in the right direction toward providing proper incentives to encourage family members to care for loved ones. While a good and worthwhile proposal, it will not completely fill the need that millions of Americans face every day. It will not significantly offset the tremendous costs involved in caring for a loved one. The average cost of a 1-year stay in a nursing home is \$40 thousand and can range as high as \$80 thousand. For a tax credit to be meaningful, it should be several times higher than the proposed one thousand dollars.

The initiatives proposed by President Clinton are worthwhile, but they are no substitute for a national long-term care program based on home and community-based care. Neither should these proposals be viewed as a substitute for any part of the Medicare or Medicaid programs. Congress should not seek to pay for the tax credit through cuts to Medicare or Medicaid services.

Finally, in regards to Medicare home health care, I want to speak in support of passage of Senate Bill 1358, co-sponsored by yourself and Senator Jeffries of Vermont, among others.

When Congress passed the Balanced Budget Act in 1997, it set into motion a series of actions which have had dire consequences for thousands of elders and family caregivers. Congress intended the payment reforms in this act to reduce home care spending by about \$16 billion between 1998 and 2002. Instead, the Congressional Budget Office now says that the Interim Payment System will reduce home health spending by \$48 billion over the same period of time. Studies have confirmed that patients who need the most care are most at risk for the cutbacks in the Medicare home health care.

Since the implementation of the Balanced Budget Act, about 20 percent of all home health agencies in the United States have gone out of business. In New England, 90 home health agencies have closed their doors, and based on the most recent data available,

home health visits are now down 34 percent nationally, and the total number of beneficiaries receiving home health care dropped 15 percent. That is 545 thousand fewer Medicare beneficiaries receiving Medicare home care.

Senate Bill 1358 provides the needed adjustments to the Interim Payment System, which will hopefully enable home health agencies to financially afford to care for people that require ongoing care.

I brought with me, and I will submit to you after my testimony, Senator, a case example of an individual who is 69 years old, a double amputee, and a diabetic who has been denied Medicare home health services because it couldn't be shown that there would be a point at which the home health care would end.

In conclusion, I want to thank you, Senator Reed, for inviting the National Family Caregivers Association's views on these important topics, and for your leadership in calling attention to family caregivers' real and compelling needs in helping them to shoulder the emotional and financial burdens of long-term care.

[The prepared statement of John Paul Marosy follows:]

**Testimony of
John Paul Marosy
Cranston, RI
October 4, 1999**

Senator Reed, Assistant Secretary Takamura, ladies and gentleman, my name is John Paul Marosy. I am a volunteer board member of the National Family Caregivers Association (NFCA), a non-profit, membership organization dedicated to improving the overall quality of life of America's family caregivers. Thank you, Senator, for providing this opportunity to present information about America's family caregivers - and for helping bring public attention to the circumstances of family caregivers, a group whose contributions to the health and quality of life of the elderly and disabled has largely remained invisible - until recently.

NFCA, based in Kensington, Maryland, is the leading voice of America's family caregivers and it is the only national consumer organization that includes all family caregivers, regardless of their age or the medical diagnosis of the recipients of their care. NFCA serves as a catalyst for family caregiver self-empowerment. Our mission is to improve the lives of America's family caregivers by providing information and education, support and validation, public awareness and advocacy.

Today, at least 22 million households - about a quarter of all households - in America include a family caregiver. Our members care for spouses, children, aging parents and other loved ones. The majority care for someone over the age of 50, and have been providing care for five years or more. They are also providing "intense" levels of care. This is defined as helping a loved one with more than two activities and being involved with caregiving responsibilities for more than 21 hours a week. NFCA's members are typical of the eight to nine million of these caregivers who are providing *extensive* care at home to our neediest citizens.

The National Family Caregivers Association defines a family caregiver as any individual that provides non-compensated care to a family member or partner who is chronically or terminally ill or disabled. The care may take any number of forms including physical assistance, paramedical services, financial aid, legal guidance, care management and/or emotional support. At this time there is not a national consensus on the definition of who is a family caregiver. In fact many individuals who are fulfilling the role of family caregiver do not identify with the term. That is one of the reasons it is so difficult to get a comprehensive understanding of the full scope of caregiving's impact.

One thing is clear. Family caregivers are underpinning our health care system by providing 80% of all home care services. One study pegged the average annual value of family-provided services for a care recipient at over \$8,000. Research conducted by the United Hospital Fund of New York estimated the market value of these services at approximately \$200 billion a year.

Caregiving is a family affair. It's a labor of love. Let me say at the outset that, despite the stresses and heartaches that go along with providing caring for a loved one, most caregivers in a recent national study used positive words like "rewarding," "happy," "enjoyable," and "loving" to describe their caregiving experiences. As a society, we can do much more to make life easier for family caregivers - but the picture is not all gloom and doom.

When my father was diagnosed with prostate cancer in 1989, I was 38 years old and very career-focused. My wife and I lived about a two-hour drive from my dad and I was serving as the president of a home health care trade association. We didn't realize it at the time, but our family had become one of the nation's 22 million households involved in family caregiving.

Even though I had worked in the field of aging for fifteen years, when it came time to arrange needed care

for my own father, my whole world turned upside down. Like most baby boomers, I never thought that the ravages of disease and old age would catch up with my parents. I came to a rude awakening. My experience in the elder care field hadn't prepared me for the emotional toll that goes along with trying, on a long-distance basis, to arrange needed help for my dad: the stress, the time lost from work, and the frustration that goes along with attempts to cut through the social service and health care bureaucracies to be sure my father received the best care possible.

I was one of the lucky ones. My employer gave me the flexibility I needed in scheduling my work, so I could talk to doctors and escort my father to appointments without feeling that my job was in jeopardy.

I was lucky, too, because I had a loving aunt who took my father into her home, a sister who visited him daily, and because we found an incredible team of hospice professionals who helped my dad fulfill his final wish, to die at home with his family surrounding him.

At a time when the nation is concerned about the rising cost of health care, government officials and employers need to recognize the role caregivers play in our health care delivery system and to do something to support it. This is particularly true because family caregivers are now being asked to take on new challenges and additional caregiving responsibilities, at a time when it is more difficult for families to do so. The reasons for this are well known and include advances in medical technology that extend and prolong life, changes in Medicare reimbursement laws, the rise of managed care, changes in the traditional family, the mobility of Americans, and the rise of the 85 years + population. With the aging of the Baby Boom generation, our nation will see a sharp rise in the number of persons who need assistance with activities of daily living.

Studies have shown that family caregivers are a population at risk, that they are prone to depression and illness themselves. A recent survey of intense caregivers conducted by NFCA documents the high incidence of negative health effects among this group. I have attached to this testimony a fact sheet summarizing research findings on impact of stress on the health of family caregivers.

Supporting family caregivers is a societal problem, not simply an issue to be dealt with by government or by individual families. There is a role for government (national, state and local), for the healthcare system, for employers, for voluntary community organizations, and, of course, for other family members.

The policies of employers and the practices of the managers have a major impact on family caregiving. Fourteen million family caregivers work outside the home, facing a daily balancing act between job and caregiving responsibilities. A small but growing number of employers have recognized that they can increase employee commitment and avoid unnecessary productivity losses by providing supports for employed caregivers. Among large employers, only about one-third offer any form of elder care support - aside from the unpaid dependent care leave mandated by the federal Family and Medical Leave Act. By comparison, about 75% of large employers offer some form of child care support. The small employer that recognizes and helps family caregivers is a rarity. American business is just beginning to awaken to the magnitude of this issue. A 1997 MetLife study found that business costs (e.g. turnover, absenteeism, distractions at work, increased health insurance costs) related to elder caregiving total between \$11 billion and \$29 billion annually.

In regard to government policy, I would like to comment on two current federal legislative initiatives: 1) President Clinton's 4-part proposal to help families caring for those who need long term care and 2) Senate Bill #1358 which addresses problems created by the large cuts in Medicare home health services set into motion by the Balanced Budget Act of 1997. But first, I want to debunk a commonly-held myth that has, in part, held back federal efforts to provide the relief needed by millions of American families with loved ones needing long term care.

I refer to the myth commonly referred to as the "woodwork" effect. In short, policy makers have voiced concern that family members' willingness to provide care is diminished in response to the availability of publicly funded services. There is a fear that if the federal or state government makes available the support services that the disabled need, the flood gates will open. Family members will abandon their traditional roles as unpaid caregivers and government will face a "black hole" of unlimited demand for publicly funded services.

While we believe there is a role for both private long term care insurance and publicly funded long term home care in addressing families' needs in the future and we want to point out that there is no empirical evidence to support the so-called "woodwork" effect on public spending for long term care. On the contrary, study after study has found that the vast majority of families stay involved in providing care for elders, using publicly-funded services in the ways intended: to support and sustain family caregiving arrangements or provide care during disruptions (usually temporary) of these arrangements in order to keep the elder in the community.

NFCA supports President Clinton's proposal as an important next step toward addressing long term care needs in our nation. In particular, the National Family Caregiver Support Program, described by Assistant Secretary Takamura, will give family caregivers better access to the information and advice they need to continue in their work.

The President's proposed \$1,000 tax credit is a move in the right direction toward providing proper incentives to encourage family members to care for loved ones. While a good and worthwhile proposal, it will not fill the need millions of Americans face every day in caring for disabled loved ones - young and old. It will not significantly offset the tremendous costs involved in caring for a loved one needing long term care. The average cost of a one-year stay in a nursing home is \$40,000 and can range as high as \$80,000, amounts that are prohibitively expensive for most families and which require most elders to spend down their assets to meet poverty-level financial guidelines. To be meaningful, the tax credit amount should be several times higher than the proposed \$1,000.

There is a tremendous need for the proposal to educate Medicare beneficiaries about the program's limits and how best to evaluate their options. There is an equally important imperative to inform the baby boom-aged children of today's Medicare beneficiaries about what Medicare does and doesn't cover. In a recent survey, the National Council on the Aging found that most baby boomers can't even name the Medicaid as the primary payment source for long term care. These baby boomer children are often thrust, unprepared, into the elder care role.

The initiatives proposed by President Clinton are worthwhile but they are no substitute for a national long term care program based on home and community based care. Neither should these proposals be viewed as a substitute for any part of the Medicare or Medicaid programs. Congress should not seek to pay for the tax credit through cuts to Medicare or Medicaid services.

In regard to the Medicare home health benefit, I want to speak in support of passage of Senate bill #1358, sponsored by Senator Jeffries of Vermont and yourself, among others. When Congress passed the Balanced Budget Act of 1997 (BBA) it set into motion a series of actions which have had dire consequences for thousands of elders in need of home health care - and the family caregivers who look after them. While Congress intended the payment reforms in this act to reduce home health spending by \$16.1 billion between fiscal year 1998 and 2002. Instead, the Congressional Budget Office now says that the Interim Payment System authorized by this legislation will reduce the home health program by \$48 billion over the same period of time. Studies by the Commonwealth Fund, the Medicare Payment Advisory Commission (MedPAC) and others confirm that patients who need the most care are most at risk for cutbacks or being

denied access to care. Since the implementation of BBA almost one-third of the home health agencies in the U.S. have closed their doors. In the New England states 90 home health agencies have gone out of business. And, based on the most recent data available, since 1996, home health visits are down 34% nationally and the total number of beneficiaries receiving home health help dropped by 15% - that's 545,270 fewer Medicare beneficiaries served.

S.1358 provides needed adjustments to the Interim Payment System which will, hopefully, enable home health agencies to financially afford to care for persons who require on-going care. In addition, this legislation clarifies the definition of "homebound," one of the criteria used to determine eligibility for Medicare home health benefits. This is important because, presently, the fiscal intermediaries who administer the benefit apply inconsistent definitions. There have been instances, for example, where frail older people have been denied home health care benefits because they left their homes, with assistance, to attend weekly religious services to participate in adult day health care programs - clearly activities which can contribute to, not detract from, the health of beneficiaries and their family caregivers.

In conclusion, I want to again thank you, Senator Reed, for inviting the National Family Caregivers Association's views on these important public policy matters and for your leadership in calling attention to family caregivers' real and compelling needs and helping them to shoulder the emotional and financial burdens of long term care.

Senator REED. Thank you very much.

Let me, if I may, I have just a few follow-up questions, and Barbara, you, in Rhode Island, have been trying to coordinate. I wonder if you might comment briefly about how the National Family Caregivers Support Program would assist you in your efforts.

Ms. RAYNER. As you may be aware, we have instituted an elderly information network to pick up our needs to get accurate information. Currently, we have 12 positions across the state within senior centers. That is an initiative that needs to be expanded.

We also particularly need to bring elderly information specialists into the minority agencies. We have, to a limited extent, taken support groups around the state, I think, the Alzheimer's Association, under Liz Morancy's leadership, and others. We have some very strong, very good support groups. In those types of initiatives, with good leadership, we need to replicate this across the state.

Rhode Island is not alone in their approach to services, and there are certain benefits to that, because they belong to their communities, but the implication—to receive services.

There is a need in other areas to help with training of caregivers, and some of the smallest matters, for example, are helping a person transfer from bed to chair, the implications of dealing with an amputee, the tricks of the trade on how to, the essence and the core of all services we need to bring the caregiver out of that sense of isolation.

I agree with the comments of the National Family Caregivers Association here that there is a very strong role on the part of Rhode Islanders to be providing caregiving. We need to expand respite services desperately. It is amazing what just 2 or 3 hours of leisure time can do to energize a caregiver in that family and also show the dignity of the client, the person being cared for. You know, it is not easy and it is not natural. It is not the way our Americans develop. It is not the way in which we socialize, so I see all of the funding of direct services within our community-based stations bringing the services to as close to the client and their families as possible.

I also think that, while I recognize that the family planning initiative retirement planning may be somewhat separate, it really is not, because the closer we bring families to awareness of services, the better we are educating them on the dynamics of aging and the needs to be planned. I would love to see retirement centers, senior centers across the state to provide the incentives in planning. Those type of initiatives would have a definite effect on the cost of long-term care, and certainly of greater importance to all, the quality of life.

Senator REED. Thank you, and the question, I think, that both you and Maureen might address, I notice that you have, I think in conjunction with the Long-Term Care Council, looking ahead at the Rhode Island long-term handbook which was distributed through the Providence Journal, can you comment about the reaction, positive, negative. That is something that I think is inherent in the present proposal.

Ms. MAIGRET. The reaction to this has been overwhelmingly positive. This came about because we had a situation where the Long-Term Care Coordinating Council had, in a prior year, developed a

brochure which was more of a limited snapshot. The reaction to that was overwhelmingly one of gratitude of people who received it, and so we got together, with the new funding that was provided, with Director Rayner, and published this. So we appreciate Barbara Rayner's support of this publication. It might serve as a model for the rest of the country, I might add, because I just think it is fantastic.

Ms. RAYNER. I think Maureen's comments are extraordinarily timely. I also think that in Rhode Island, we are fortunate that we have one major newspaper so that has been the source of distribution, but also, our senior centers, agent assisted living, and a host of other agencies have been wonderful in disseminating this information, and our elderly information specialists have also used it. This type of publication, this type of opportunity truly in state government is a luxury, but it has endless benefits, so we really appreciate the leadership of the Council in generating the funding and certainly enjoyed the opportunity to respond.

Senator REED. One more quick question, and then I want to ask John Paul. The issue with respect to training of family caregivers, is that an issue that the Long-Term Care Council is involved in?

Ms. MAIGRET. Yes. Part of the charge given to the department, when we passed the legislation, was to provide support for family caregivers, including training, counseling, respite care, and as Director Rayner noted, there are opportunities for training, but much more needs to be done, like Barbara personally had taken care of someone at home, I had the experience of being a community health nurse, and so I had the opportunity to witness firsthand numerous families lovingly care for individuals for 5, 10 years, and it also amazed me the dedication and the devotion that Rhode Islanders have to their family members, but Barbara's right, they need to be taught the skills if someone has suffered a stroke, is having difficulty swallowing food, they need to know the tips on how to help that person feed without choking, asphyxiating, and getting pneumonia, and et cetera, so there is need for that type of program.

I know many senior centers and adult day care centers are doing a very good job with practically no resources in that area.

Ms. RAYNER. Another piece that we would like to add to this with family caregiver funding is we would like to see a nurse case manager attached to each agency so that they could be a resource for these needs which, in turn, would enhance the limited service capacity.

The final piece that I do want to make you aware of, also, is that we have emerged a wonderful partnership with our state Department of Human Services, so that as you are looking at these initiatives coming into our state, I can speak to the partnership with the Department of Mental Health, Retardation, and Hospitals for our young disabled persons, that we have with all of the special interest organizations, but also our state Department of Human Services in getting these services rendered to the people.

Senator REED. If I may, John Paul, a quick question, as briefly as possible, in your testimony you alluded to the societal nature of this issue which is a governmental response the community groups, et cetera. Could you, just very briefly, say a few words about that.

Mr. MAROSY. There is no question in my mind, Senator Reed, that there is no way in the world that today's elder population can look to government for solution to this problem. Eighty percent of the care is provided by the families. What we need to do is stimulate partnerships between voluntary organizations in the community, employers, and government agencies to bring to bear the limited resources that we have in any community to solve this particular problem. The kind of evidence presented here by Barbara Rayner, the Director of the Office on Aging, is exemplary in terms of the type of information put out by the private sector. The government cannot do it alone, employers cannot be expected to do it alone, but together with the volunteer organizations in the communities, I think we can come up with creative solutions in different parts of the country.

Senator REED. Thank you very much. Thank you for your testimony. Thank you very, very much.

At this juncture, I am going to ask that Congressman Weygand please come up to the table and share with us his thoughts.

Congressman Weygand, as you know, is really an advocate for seniors, not only as a member of the House, but also as a Lieutenant Government working closely with the Long-Term Care Coordinating Council, and we are going out of order simply because he has to get to Washington, like I do.

Bob, please go ahead.

STATEMENT OF HON. ROBERT A. WEYGAND, A REPRESENTATIVE IN CONGRESS FROM THE STATE OF RHODE ISLAND

Mr. WEYGAND. First of all, I want to thank you, Senator Reed, for hosting this hearing. This is an extraordinary and very important time for many people that are here, and I unfortunately have to do this very quickly because in about 2 hours, we will be bidding on the floor of the House the re-authorization of the Older Americans Act this afternoon, which we hope will get passed, including many of the aspects of the legislation, so it is very important that we get back to that.

Actually, as you know, prior to my service in the House of Representatives, I was fortunate to serve the people of the State of Rhode Island as Lieutenant Governor for 4 years, and in doing so, the two terms I was there, I served as Chairman of the Long-Term Care Coordinating Council, and I also chaired a panel which developed the long-term care plan for the State of Rhode Island.

This plan was very important because it identified the true need for a continuum of care from acute care all the way down to the home care and the caregivers that you are talking about today, Senator, which are so important to Rhode Island families and American families.

According to a recent national long-term care survey, over 12 million people are caregivers, and that is an extraordinary amount of people. These caregivers are often called the sandwich generation because, while they are providing for one, the aging parents normally, they are also providing for another group of people, their growing children. If the work of these caregivers was to be replaced by health care staff, it is estimated the cost would be between 45

and \$75 billion per year that these caregivers provide to their loved ones.

Caregivers are dedicated people that give an average of over 20 hours per week providing care. Over two-thirds of the working caregivers report conflicts between work and caregiving responsibilities and family responsibilities, and, Senator, I would like to address very quickly and briefly the issue of costs to caregivers, and they come in many different ways. One of them, of course, is the loss of income because they're providing this care, and, as you know in your legislation, which you have been promoting, we need to be able to provide some sort of alternative and incentive, so, indeed, when they do lose income, they can get some sort of supplement and replacement for that through tax credits or some additional support.

Second, we need to provide for the kind of quality of care called respite care that they require. Often, they are taking care of people, their loved ones, for over 52 weeks of the year and they need respite care. Critical information, as Maureen Maigret and Barbara Rayner talked about that gives information to people about community-based, long-term care services, counseling and support, et cetera, but home care is something that I've been very interested in, as I know you have, too, Senator, and that is one of the more expensive costs to many caregivers today.

When they are looking for some additional supplemental care through home care, the Balanced Budget Amendment of 1997, while it provided great improvements to health care systems, it also hurt home care in a way that never was anticipated. I think John Paul alluded to this a little bit earlier. It was anticipated that home care was going to be reduced by approximately \$16 billion over 5 years. Recent numbers came out from the Congressional Budget Office last week that indicated that would be someplace between 47 and \$58 billion over 5 years. It has cut into some of the most valuable services that caregivers require to have them help and supplement the care that they give to their loved ones.

In the State of Rhode Island, and particularly throughout New England, where home care has been the most cost effective and efficient type of care, we were cut down with many of those states that had some of the most expensive home care.

Case in point, Rhode Island was cut down to approximately \$3,400 per year per recipient on an average of home care, yet, the State of Louisiana went from \$9,700 per year only down to \$7,700 per year per recipient for home health care. When you are receiving 9,700 a year, to be cut down to 7,700 a year, it is not a great deal. For Rhode Island, it went from 39 to 34. It was substantial. As you know, many agencies in the State of Rhode Island have been hurt dramatically, indeed, and some have gone out of business. What we need to do is reaffirm our commitment to that.

Last year we were able, through legislation, to remove the 15 percent delay of October 1, 1999, push it back to October 1 of 2000. Your legislation would move it back even another year after that. Last year we spent over \$1.5 billion. Your legislation would help us in furthering and putting it back by delaying the cost, the cutting of the cost to home health care agencies.

Last year, also, we raised the floor for home care agencies from approximately \$2,900 in the State of Rhode Island to about \$3,300, but that is not enough. Your legislation would, indeed, help improve the reimbursement levels of home health care agencies, and also, this year, we have legislation proposed that would help the outliners, those people who fall outside of the normal provisions of home health care reimbursement. They would be given additional funds under the Home Health Care Preservation Act that would provide for additional funds for those outliners. There are over 120 co-sponsors of the House of Legislation that I have put together.

Senator, I want to thank you because I do need to be brief, and I know you have other panelists, and I really do appreciate the great work you have done on caregivers. Family caregivers are an immense resource to this country, providing billions of dollars worth of care that we would have to otherwise supplement with other kind of health care dollars. They are to be rewarded in the best way, and that is by acknowledging them, but also to help provide to them additional assistance on home health care with regard to tax abatements and tax incentives, and other things that you have within your legislation.

Jack, I want to thank you very much for being a great partner in this, and thank you for having this hearing today.

Senator REED. Thank you very much.

Thank you for your testimony. Good luck on your vote this afternoon on the Older Americans Act.

He literally has to run to the airport.

I'd now like to call upon two individuals who represent all of the issues we have been talking about. Merilyn, come forward.

As we do that, let me briefly introduce both. Merilyn deVos is a full-time caregiver for her 86-year-old mother who suffers from Alzheimer's disease. During her 5 years as a caregiver, she has found time to do some freelance writing and has published three cookbooks, and she is currently working on a fourth cookbook, and as a full-time caregiver, Merilyn works for a group of weekly newspapers in Massachusetts.

Ethel Marshall is here today to testify on behalf on her sister, Elizabeth Carvara.

Ethel is the mother of four sons. She worked as a teacher for many years. She is also a volunteer, very active, and her sister has the responsibility for caring for a disabled adult child, so we are looking at, we talked earlier about these dry statistics, the typical caregiver, 50-plus years old, a woman, full-time working, doing all these things, well, we have two ladies here today that are the reincarnation of the statistics, and very thankful that they're here today.

Let me begin with Merilyn. Merilyn, please.

STATEMENT OF MERILYN deVOS, CAREGIVER OF HER MOTHER

Ms. DEVOS. I want to thank you, Senator Jack Reed, and Assistant Secretary Takamura, and all of the other distinguished panelists for the opportunity to share some of my thoughts and story today.

I was struck for the first time listening to everyone that learning about caregiving is really the way most of us learn about this. We get incomplete, inaccurate information, and it takes years to put it all together, and it is a very uncomfortable process along the way.

I have been taking care of my mother, who is a 50-year Cranston resident, for 5 years. I left my own work and home in Massachusetts to come here to care for her in her home because of the quality of the program in Cranston. Overall, what I have found is not that services are lacking, but access to services are lacking on two grounds. The first is that as a family member of someone or close to someone afflicted, you have psychological resistance to accepting the diagnosis, and once you do, you are then, as I indicated, very much, on their own, trying to access where the system can best accommodate you.

Points of entry, whether it is the Department of Elderly Affairs, Council on Aging, the senior centers, the people in those organizations are very forthcoming in extending what knowledge and services are available to you, and then the second barrier comes up, and that is in how to pay for them.

Broadly, just before I get to this piece I wrote up, let me state that my mother's income is about \$1,900 a month, and her out-of-pocket expenses for day care and for very limited in-home assistance through an agency comes to 12 to \$1,500 a month, so quickly it becomes apparent that the only way you can handle these kinds of expenses is through savings, and savings are exhausted, and I think one of the key figures that I picked up here today was given by Barbara Rayner, that 93 percent of the monies spent on long-term caregiving in Rhode Island is used for 10 percent of the population goes to nursing homes. That is a disparity that must be changed, it must be because home-based, community-based support are far less costly, and they go so much further in helping people maintain the commitment that they set out to do.

Senator REED. Your statement will go in the record. You don't have to read it all. You are doing great right now.

Ms. DEVOS. I don't have to read it. I'd rather not read it, just because it is so particular and it narrows somewhat the focus of these issues in a way that I don't think it is really needed.

Again, to be specific, in my mother's own case, she has accessed, I think, every level of elderly care assistance that the state provides, from the local senior center, to visiting nurses, to nursing homes. She was in a nursing home, self-paid, for 23 months, that was 7 years ago, until the 5-year-ago period, when I began taking care of her, and she was put in a nursing home directly from a catastrophic hospital admission, prior to her diagnosis with Alzheimer's, from the manifestation of behavioral changes that made her ill.

She was rehabilitated, and it became apparent to me, oh, 7 or 8 months after her admission 7 years ago, she was no longer in

need of nursing home care and she didn't belong in a nursing home. She was, fairly soon thereafter, downgraded to custodial, but since she had been diagnosed with Alzheimer's since being in the hospital and then almost immediately on her admission, she was not eligible for any kind of reimbursement from her excellent secondary health provider or from Medicare, so from day 21 onward, we were self-pay, and I was very reluctant to change my whole life to take on her care, but it was made very clear to me she needed 24-hour-a-day supervision, and it took me 23 months and about \$120 thousand spent to finally take on this open-ended task of her caregiving; and over the 5-year period, she began very modestly, a few days a week at the Cranston Senior Center, and then was put in their day care program, which provided a full spectrum of services, health care assessment, personal care needs, if that were needed, and activities program. It was a very rich environment at a very modest cost.

As her mental deterioration increased, she became less appropriate for that kind of a setting, which does not have any physical restraints to it, and thank God, the Feinstein Center, the Louis Feinstein Alzheimer's Day Care Center had been in need of and fought for, and when it opened, she was transferred there. However, there was a steep increase in out-of-pocket costs, and it became apparent in this program, which was even more comprehensive in its services, that she would benefit most if she could attend 4, even 5 days a week, so immediately it became a \$1250-a-week commitment. That \$1,900 a month income has cut my mother off from any standard of eligibility for reimbursement for respite care or a downgrade in the fees for any service that we have accessed or for any respite care. Everything that I have provided for her has been out of pocket.

Over these 5 years, when we tried the two main day care programs, she was still a member of the Feinstein Center, the dementia-oriented day care, that was 6 days a week. She had two catastrophic hospital admissions during this 5-year period, one was for a broken leg, one for a broken hip. On both occasions, she was downgraded to self-pay.

Within a matter of days of her transfer from the hospital to a rehabilitation center because, as a dementia patient, the assumption is that you cannot participate in your own rehabilitation because you can't retain the knowledge needed to rehab, even though rehabilitation is primarily physical, and between the therapist and myself, she was getting 8 hours a day of rehabilitation. In fact, my mother was walking independently within 2 weeks of her hip replacement, but on both of those occasions, I had to fight and fight in order to get her Medicare benefits extended for, at least, part of that 100-day period. I was partially successful. I still had to spend about nine thousand out of pocket for those two admissions.

I brought her home, again both times, even though I was encouraged, since her own resources to keep her there had been dwindling, just keep her there because ultimately, she'll have to go back into the nursing home anyway when her funds were exhausted, I was unwilling to do it because I could see how she flourished at the Feinstein day program. She is there approximately 6 hours a

day, 6 days a week, and it gives me a break to do the chores or creative work that I need to do, to get away.

In terms of longer term respite care, I have also accessed assistive living where I had her for brief periods so I could get away and visit my daughter who is abroad. Also, we self-paid two times the nursing home placement for a week, again, for a short-term vacation. None of these services were difficult to access. It was just a matter if you can pay, you can play. And you can participate in anything, but money is needed, and money, on top of money, on top of money never ends.

My mother has adult late onset Alzheimer's. She probably will die of something else, and she is basically a very healthy woman, so it is going to be a very long, slow process.

Right now, we are at the position of having about \$10 thousand left. I have talked to the Medicaid office. I am too early to make a formal application, but I am getting close to the time they told me to come down, and she will have to go in a nursing home because I simply—it has been a 24/7 job all these years, but I cannot take that on because of the day care program. I am not eligible because of her income, and Medicare will pay for a nursing home \$2,500 a month. I naturally will give them the \$1,900. That will be made over to them. And we have no means through which to pay the \$1,300 a month to keep her at Feinstein, and if they could give me a voucher for that money, and they do have Medicaid clients at the Alzheimer's center, I could keep her at home. I could continue to keep her at home. What I was told was, and, again, I am not entirely sure this is accurate, but I was told because of her income, she is not eligible for a voucher payment to offset her fees for an adult day care out of her home, and that would be consistent with the block I found at another point in this journey where, because of that income, that roughly \$25-thousand-a-year income, that she is precluded from assistance, so she will have to go in a nursing home at a greater cost to the state and the Federal Government than it would be to keep her at home with me.

It is madness. It is inhumane. It is unfortunate. I am not accepting that as the final word, but that is the information I have so far, and I would expect that transition to have to take place now within the next 6 months.

[The prepared statement of Marilyn deVos follows.]

STATEMENT of Merilyn deVos

I want to thank Senator Jack Reed for this opportunity to share my story and thoughts. For five years, I have been responsible for the well-being of my mother, Mary De Cesare, a 50-year resident of Cranston, RICK.

As a female only child of middle years I was "ideally" positioned to take on a care giving role when my mother had an early - dementia -induced collapse seven years ago. Except I didn't.

So sudden was her decline, so tightening her now obvious need for total help, that I backed off, even turned my back, for two years.

My father died in 1989. His presence was the glue holding my mother's mind together. He never shared his concerns for my mother's welfare with me though we often discussed the minutia of household accounts and the management of same that would be needed after he was "gone." His archaic sense of unseemly topics of discussion between parent and child was to cost us the very prudence and preparation he so valued in himself.

After my dad died she was mostly alone. He wasn't there to remind her, cover for her. She knew something was really wrong but she made excuses to keep friends and family away, too proud to admit to needing help.

This is when I wish services could first have intervened. But publicly she denied any problem. I was just in for Sunday dinner and then hurried back to my own busy life. She was getting pretty dotty maybe but she survived from week to week, I'd tell myself, so how bad could things be?

Pretty bad as it happened. She had begun buying aspirin and jugs of wine to "help her sleep" and together they led to the massive gastric bleed that felled her.

A visiting nurse might well have picked up on the signs of drinking long before I did. Surely she would have diagnosed the poor nutrition, the thready pulse, the weakness due to internal bleeding. Even a housekeeper would have uncovered physical evidence. Everything was meticulously concealed for my predictable two hour weekly visits.

But there were two barriers to early intervention:

The first was psychological. I wasn't ready for the role reversal that comes with Alzheimer's. I still was asking my mother to do things on her own behalf, see a neurologist, call for Meals-on -Wheels, visit the city's senior center, etc. Worse, I was accepting her refusals to do so. As if she were still the adult and I the child.

The second was economic. Because dementia is a mental disorder, no federal program pays for in-home services. The same default applies to private medical insurance. This bias as put into policy and practice is indefensible. If my mother's behavior had put her at risk of diabetic coma I could have asked her physician to authorize home assessment visits by a nurse. But for her, there were no Medicare payment codes I suspected something was wrong but not so strongly as to pay the nurse's \$85./hour fee out of pocket. Medicare money, saved in the short run, was soon hemorrhaging to pay a two-week hospital stay and beyond. I still believe this could have been avoided, definitely delayed, if more community supports were available.

From the hospital my mother was discharged directly to a nursing home. This was seven years ago. I was

horrified, still in shock. Two weeks earlier my mother and I led separate lives. Now, the hospital social worker said she needed 24-hour supervision if not care and either I had to take that on or let her be discharged to an institution. This was agonizing. I had no basis for deciding anything I didn't even understand what her dementia diagnosis meant.

Mercifully for me after 48 hours of panic and hand wringing, my basic research habits kicked in. I made myself treat it as a reporting assignment and began searching for the knowledge needed to ground any further decisions. It was a pitifully weak lifeline but I had no other way to still the medical institution vortex we had been swept into. Seven years later, public discussion of these situations has increased. I think this will help people be better prepared for their own aging or a family member's demise.

I begged my way into an intense 20-hour crash course on Alzheimer's disease for medical professionals given by the Massachusetts Alzheimer's Association by promising to do a newspaper story on its content. I learned that the way my father left his entire estate in my mother's name was the worst most vulnerable option he could have taken. I learned that decisions or non-decisions we take today shape utterly how we are positioned to resist being obliterated by Medicare and Medicaid rules.

Knowledge of where we were at and where we could go in non-emotional terms took a long time to accrete. It took me 23 months and more than \$120,000 spent before I was finally ready to leave my job and my life in Massachusetts and come to Rhode Island to live full time with my mother in her home, Cranston's senior services surpassed anything available south of Boston where I was living so I came here.

These five years have proved challenging but not in the direct care giving ways I expected. Rather, I have found it hard to understand how we relegate a dementia diagnosis to a further negative than it already is. Certainly in terms of reimbursement of medical, drug and care costs, dementia almost guarantees denial.

A modest income allows us to survive but not to access support services. For these we must use ever dwindling savings without which my mother wouldn't have been taken out of the nursing home to begin with.

Unfortunately, we fall into that vast middle ground of those ineligible for help with costs. Income guidelines for care relief eligibility are unrealistically low. We just miss the upper limit for a reduced fee at the Feinstein, for example. We are also disqualified from any other supplemental respite relief that I have found.

We are ineligible for any reduced drug cost program, too. That expense was more than \$400/month until mother's retirement benefits added a prescription coverage a few years ago. That savings only kicks in only if she is NOT in a nursing home though. Go figure.

While I appreciate Sen. Reed's legislative initiative to reward care givers with up to a \$1000 tax relief, this is a bogus aid for most of us whose income is so low and medical expenses so high that we don't pay any taxes to get relief from. Perhaps it could be structured like the earned income credit whereby we receive a pay out regardless of what we have paid in.

Once the commitment is made, accessing programs is easy. In My case I have repeatedly been pointed in the tight direction by the Alzheimer's Association, the Council on Aging, Cranston Senior Services and others. I began simply by calling Cranston's city hall inquiring about any day programs for seniors.

I got a call from the social worker of the Adult Day Care Program. This type program must offer a full range of services from meals and showers to physical therapy and assessment of needs. A registered nurse is on site. We decided this would be the best option for my mother given her diagnosis and time spent in a

nursing home. My mother was evaluated at home and her name was put on a list. When it came up, I registered her for three days a week at (then) \$30./ day. A TransVan bus was scheduled to pick her up and drop her off. This was free. I was thrilled.

Again, due to the dementia diagnosis, I was never offered any in-home support, nursing or an aide, at her nursing home discharge I got my own list of home health agencies by calling the Council on Aging and eventually settled on one it at a cost of \$12.80/hour for eight to 12 hours a week

The situation was stable for about two years by which time my mother's condition had deteriorated. The city's adult day care program was not specialized for demented folks; so the doors were unlocked and she wandered off. Plus, many activities now moved too fast for my mother to follow.

But, in the meanwhile, the angels were at work and the Louis Feinstein Alzheimer's Day Care Center had been conceived, struggled for and made manifest. From my viewpoint, this place, not my care giving, is the unique and essential foundation of my mother remaining in the community. "The Feinstein," as it is known, is PERFECTLY attuned to the needs of its population, no matter what their mood or state of hygiene. The staff is worth its own case study and is the perfect antidote for all the violent, selfish and material events that fill our daily news.

Some other services we've accessed include resident respite care, twice in nursing homes and once in an Alzheimer's assisted living facility. This was expensive, about \$150/day, but wasn't hard to find. I just kept calling facilities until I found one which would guarantee space for the week I wanted to be away. Those who pay can play.

Twice during these five years my mother has had catastrophic hospital /nursing home admissions due to leg and hip breaks. Both times she was quickly and precipitously downcoded to self-pay due to her dementia "disabling her rehabilitation." Both times I had to fight and fight to get Medicare to pay for more of her time and wound up spending \$9,000 out-of-pocket anyway.

Finally, compared with my experience in Massachusetts, I have found Rhode Island's dementia care givers support groups wanting To be useful, they must meet once a month, nine or 10 times a year at least. They should cover a wide range of relevant issues informed by experts from the community and provide a forum for participant venting of their experiences. If at all possible, they should provide "baby sitting" for the dementia patient during the meeting or, most creatively lead them in their own concurrent support group as they do in Cambridge.

After seven years, my mother is very close to re-admission to a nursing home because we have nearly exhausted her savings. Medicaid will pay her nursing home bill (towards which I'll give them her entire monthly income) but not a day-care stipend costing one-third of that so she can stay in her own home. Does this make economic sense? No. Is it humane? No.

Not that I mind. I've done the right thing. My mother taught me that. And along the way, I've met some of the best people this society has to offer.

Senator REED. Marilyn, thank you very much. And let me just now ask if Ethel could comment, and first, thank you so much for coming here today, both of you.

And Ethel, you are coming on behalf of your sister today, which I think underscores something else. We have heard about family caregivers. This is just not the mother and the father or the son and daughter, it is the aunt, and the cousins and the uncles and everybody else. Please.

STATEMENT OF ETHEL MARSHALL, CAREGIVER OF HER SISTER AND NEPHEW

Mrs. MARSHALL. Good morning, Senator Reed. I am both honored and grateful for the opportunity to appear before you today.

First of all, I want to introduce my son's social worker who is here with me today.

Although it is difficult to tell such a personal and emotional story in a public forum, I believe it is critical for you and your fellow legislators to hear real stories of struggles and challenges of America's senior citizens.

Although I myself am the parent of a 38-year-old son with a developmental disability, the story I would tell today is not my own. My husband and I are fortunate to have our health, as well as a good support system for our son David. We have modified our home to include an apartment for David, and he receives 3 hours of in-home support a day, as well as day support to assist him in his job at the Newport Navy Base.

While we feel fortunate about our own circumstances, we have a firsthand understanding that the commitment to parenting a child with a developmental disability is lifelong. Although opportunities are increasing all the time, self-determination and self-advocation programs are helping people to live much richer, fuller lives, most of these children do not go off to college, marry, or establish their own homes. While other adults with developmental disabilities do move into group homes or their own apartments, many will remain at home with their parents until the parents are no longer able to provide care. This can lead to a phenomenon where a disabled adult, who remained at because he was unable to care for himself, winds up caring for an aging parent.

Today I am here to tell you such a story. It is the story of my sister, Elizabeth Carvara, and her son Steven. Elizabeth is 79 years old and suffers from a medical condition. She is a diabetic, has glaucoma, severe rheumatoid arthritis, and has undergone heart surgery. Elizabeth has chronic pain in her shoulders, neck, knees, and hands. She is unable to dress herself or grasp objects with her hands. She walks very poorly and has great difficulty getting out of her chair.

Elizabeth and Steven have lived together since Steven was born 42 years ago. Due to his developmental disability and mental illness, Steven was not able to move out on his own and establish his own life. He worked for many years at the Maher Center Workshop. Steven always enjoyed this, particularly the social aspects. He relied on his mother to remind him about things like wearing his glasses, dressing in clean clothes, and getting where he needed to go on a daily basis. Steven also depended on his mother to pro-

vide him with balanced meals, assure that he got necessary medical care, and maintained good hygiene.

Over the past few years there have been both gradual and dramatic shifts in who is doing the caring and who is receiving the caring. Let me start by telling you what type of support they do have and some of the challenges associated with those supports. I will then attempt to describe all of the unmet needs that Steven is left to fulfill regardless of the fact that he is not really capable of doing them well.

My sister has a private nurse's aide who comes in 2 hours each morning to get her out of bed, wash and dress her. She pays for this service out of pocket as her Medicaid benefits in this area expired a long time ago. Although she would like someone to come in more often and for a more extended period of time, this is all she feels she is able to afford.

Steven is authorized for 15 hours of in-home support per week through the Division of Developmental Disabilities. The Division funds the Maher Center to provide staff support to assist Steven in learning to be more independent in his daily activities, as well as to have pleasurable experiences in the community. In addition to this, Steven has funding available to attend the Maher Center Workshop Monday through Friday.

Although Steven has adequate support available to him, there have been some real challenges in taken advantage of this support. Steven has stopped going to the workshop because his mother is unable to stay home alone. This has been a real sacrifice for Steven because he really enjoyed going to work, seeing his friends, and just generally getting out of the house to do his own thing. He is incredibly devoted to his mother, however, and almost never complains. Just adjusting Steven's in-home support program has also been a challenge. As my sister's health deteriorated, she became more and more dependent on others for just about everything. The staff who is coming into the home to work with Steven was facing escalating requests for personal and household help by my sister. These staff have tried very hard to be both fair and responsive. They have gone beyond the requirements of their role to help my sister and help around the house. Although the Maher Center is committed to supporting the family unit, they are only officially involved with Steven and are worried that the help they are providing does not exactly fit the criteria or requirement of state's Medicare waiver that provide the Federal portion of funding for Steven's services.

Retaining staff has also been very tricky, because some staff were not comfortable or willing to support my sister as well as Steven. The agency also worries about Steven. They fear he is becoming more and more isolated and often refuses staff's offers to go out for a hamburger or a cup of coffee because he knows his mother fears being home alone even for a little while.

The 2 hours of support each day that Elizabeth is able to afford is just not enough. She is diabetic and must eat something as soon as she wakes up in the morning, and then it is Steven's job to make her a piece of toast. Steven is a capable man in many ways, but he is just not adept in the kitchen. He frequently burns the toast and hands it to her unbuttered and without a plate. My sister

is in a position where she has to be grateful for everything she gets. She is appreciative of Steven's attempts, but she deserves better. They both deserve better.

Elizabeth takes a variety of medication and we do assist her in organizing them each week, but at medication time, she will have Steven take them out of the little compartment for her. He also instills her eyedrops and assists her with administering her own insulin shots. This is pretty scary when you remember Steven is someone who is eligible for support in tending to his own personal care needs.

The thing that scares me the most is that Steven puts his mother into bed at night. She requires a lot of physical assistance for this and is very fragile. Although Steven tries very hard, I don't believe he has the judgment to do this properly.

Once again, my sister will never complain for fear that someone will try to break them up. I believe that this is really her biggest fear. Many parents of disabled children fear that no one will ever be able to care for their son or daughter. Even though Steven has become the caretaker in this situation, I don't think this is the way my sister sees it. She devoted her life to him and can't believe that he would be safe and happy anywhere else. Steven, in turn, realizes that his mother has devoted her life to him and feels deeply obliged to return that commitment to her.

Unfortunately, however, Steven does not have a personal network of his own or any real interests that can sustain him. Most people who are in a full-time caretaker role have family or friends who they can talk to or even seek out others like themselves on the Internet or in support groups. They know enough to say, "I have had it. I need a break," and can seek short respite from their duties.

This is not the case with Steven. All he knows is that he loves his mother, and his developmental disability and mental illness interfere with his ability to process or rationalize the many conflicting feelings that he has deep down inside.

Steven is in the prime of his life and has a good package of support for himself. These supports alone however are not enough to maintain the family adequately or safely. Most family members pitch in regularly. Elizabeth's other son does the marketing and cares for the house and the yard. My other sister comes in once a week to clean house, and I take Steve and my sister to the doctors', pick up medications, and generally help out as needed.

The burden of care really falls on Steven, though, because he is there full time. My sister also hesitates to ask the rest of us for help for fear that we will see how dependent she really is and try to initiate placement in a nursing home. While we will never disrespect her wishes in this matter, she lives with the daily fear that she will be separated from her son, so she tries to act as if everything is fine.

It is not fine. It is far from fine. They need more support and assistance so that my sister can live out her life in her home, and if desired, Steven can continue to live in his own home when his mother is gone. For the time being, they are a unit and should be viewed as one.

The proposed National Family Caregivers Support Program should recognize and provide for the unique and often complex situations that arise when the parents of developmentally disabled adult living at home becomes incapacitated.

Thank you for this opportunity and your kind attention to my story.

[The prepared statement of Ethel Marshall follows:]

Testimony of Ethel Marshall
Bristol, Rhode Island

Good Morning Senator Reed. I am both honored and grateful for the opportunity to appear before you today. Although it is difficult to tell such a personal and emotional story in the most public of forums, I believe it is critical for you and your fellow legislators to hear real stories about the struggles and challenges of America's senior citizens.

Although I myself am the parent of a 38 year old son with a developmental disability, the story I will tell today is not my own. My husband and I are fortunate to have our health as well as a good support system for our son David. We have modified our home to include an apartment for David, and he receives three hours of in home support a day as well as day supports to assist him in his job at the Newport Naval Base. While we feel fortunate about our own circumstances,, we have a first hand understanding that the commitment to parenting a child with a developmental disability is life long. Although opportunities are increasing all the time, and self-determination and self-advocacy programs are helping people to live much richer, fuller lives, most of these children do not go off to college, marry and establish their own homes. While some adults with developmental disabilities do move into group homes, or their own apartments, many will remain at home with their parents until the parents are no longer able to provide care. This can lead to a phenomenon where a disabled adult who remained at home because he was unable to care for himself, winds up caring for an aging parent.

Today I am here to tell you just such a story. It is the story of my sister Elizabeth Carvara and her son Steven. Elizabeth is 79 years old and suffers from a number of medical conditions. She is diabetic, has glaucoma, severe rheumatoid arthritis, and has undergone heart surgery. Elizabeth has chronic pain in her shoulders, neck, knees and hands. She is unable to dress herself or grasp objects with her hands. She walks very poorly and has great difficulty getting out of her chair. Elizabeth and Steven have lived together since Steven was born 42 years ago. Due to his developmental disability and mental illness, - Steven was not able to move out on his own and establish his own life. He worked for many years at the Maher Center Workshop. Steven always enjoyed this, particularly the social aspects. He relied on his mother to remind him about things like wearing his glasses, dressing in clean clothes, and getting where he needed to go on a daily basis. Steven always depended on his mother to provide him with balanced meals, assure that he got necessary medical care, and maintained good hygiene. Over the past few years there have been both gradual and dramatic shifts in who is doing the caring and who is receiving the care.

Let me start by telling you what type of supports they do have, and some of the challenges associated with those supports. I will then attempt to describe all of the unmet needs that Steven is left to fulfill regardless of the fact that he is not really capable of doing them well. My sister has a private nurse's aide who comes in for two hours each morning to get her out of bed, washed and dressed. She pays for this service out of pocket as her Medicare benefits in this area expired long ago. Although she would like someone to come in more often, and for a more extended period of time, this is all she feels she able to afford. Steven is authorized for fifteen hours of in-home support per week through, the Division of Developmental Disabilities. The Division funds the Maher Center to provide staff support to assist Steven in learning to be more independent in his daily activities, as well as to have pleasurable experiences in the community. In addition to this, Steven has funding available to attend the Maher Center workshop Monday through Friday.

Although Steven has adequate support available to him, there have been some real challenges in taking advantage of this support. Steven has stopped going to the workshop, because his mother is unable to stay home alone. This has been a real sacrifice for Steven because he really enjoyed going to work, seeing his friends, and just generally getting out of the house to do his own thing. He is incredibly devoted to his mother, however, and almost never complains. It is important to note here that the Maher Center was

Steven's major source of social contact. Adjusting Steven's in-home support program has also been a challenge. As my sister's health deteriorated she became more and more dependent on others for just about everything. The staff who were coming into the home to work with Steven were facing escalating requests for personal and household help by my sister. These staff have tried very hard to be both fair and responsive. They have gone beyond the requirements of their role to help my sister and help around the house. Although the Maher Center is committed to supporting the family unit, they are only officially involved with Steven, and are worried that the help they are providing does not exactly fit the criteria or requirements, of the state's Medicaid waiver that provides the federal portion of the funding for Steven's services. Retaining staff has also been tricky, because some staff were not comfortable or willing to support my sister as well as Steven. The agency also worries about Steven. They fear he is becoming more and more isolated, and often refuses staff's offers to go out for a hamburger or a cup of coffee, because he knows his mother fears being home alone, even for a little while.

The two hours of support each day that Elizabeth is able to afford is just not enough. She is diabetic, and must eat something as soon as she wakes up in the morning. It is Steven's job to make her a piece of toast Steven is a capable man in many ways, but he is just not adept in the kitchen. He frequently burns the toast and hands it to her, unbuttered and without a plate. My sister is in a position where she has to be grateful for anything she gets, and she is appreciative of Steven's attempts, but she deserves better. They both deserve better. Elizabeth takes a variety of medications, and we do assist her in organizing them each week, but at medication time, she will have Steven take them out of the little compartment for her. He also instills her eye drops, and assists her with administering her own insulin shots. This is pretty scary when you remember that Steven is someone who is eligible for supports in tending to his own personal care needs. The thing that scares me the most is that Steven puts his mother into bed at night. She requires a lot of physical assistance for this, and is very fragile. Although Steven tries very hard, I don't believe he has the judgement to do this properly. Once again, my sister would never complain for fear that someone would try to break them up.

I believe that this is really her biggest fear. Many parents of disabled children fear that no one will ever be able to care for their son or daughter. Even though Steven has become the caretaker in the situation, I don't think this is the way my sister sees it. She devoted her life to him, and can't believe that he'd be safe and happy anywhere else. Steven, in turn, realizes that his mother has devoted her life to him, and feels deeply obliged to return that commitment to her. Unfortunately, however, Steven does not have a personal network of his own, or any real interests that can sustain him. Most people who are in a full time caretaker role have friends or family who they can talk to, or even seek out others like themselves on the internet or in support groups. They know enough to say "I've had it, I need a break!" and can seek short respite from their duties. This is not the case with Steven. All he knows is that he loves his mother, and his developmental disability and mental illness interfere with his ability to process or rationalize the many conflicting feelings he has deep down inside. Steven is in the prime of his life, and has a good package of supports for himself. These supports alone, however, are not enough to maintain the family adequately or safely. Most family members pitch in regularly. Elizabeth's other son does the marketing and cares for the house and yard. My sister comes in once a week to clean house, and I take Steven and my sister to the doctors, pick up medications, and generally help out as needed. The burden of care really falls on Steven, though, because he is there full time. My sister also hesitates to ask the rest of us for help for fear that we'll see how dependent she really is and try to initiate placement in a nursing home. While we would never disrespect her wishes in this matter, she lives with the daily fear that she'll be separated from her son, so she tries to act as if everything is fine.

It is not fine. It is far from fine. They need more support and assistance so that my sister can live out her life in her home, and if desired, Steven can continue to live in his own home when his mother is gone. For the time being they are a unit, and should be viewed as one. The proposed National Family Caregiver Support Program should recognize and provide for the unique and often complex situations that arise when

the parent of a developmentally disabled adult living at home becomes incapacitated.

Thank you for this opportunity and your kind attention to my story.

Senator REED. Well, thank you very, very much. I think this is the most compelling and effective testimony because it is about real people dealing with a real crisis, which is a crisis both in terms of not only time and effort but emotional demands, financial demands.

I want to thank both of you for your testimony and your candor and courage to come forward and talk about your personal issues.

I would also like to point out that the Committee accept additional comments and written testimony, and we have cards that have been distributed with an address and you can also e-mail, so if you have a comment or a question, please submit it to us.

I, too, must go off to get down to Washington tonight. We are voting, not on the Older Americans Act, I would like to vote on that today, we are voting on the transportation appropriations bill. I am going to test the roads right now to see how badly we need this bill. [Laughter.]

But I want to thank Marilyn, I want to thank Ethel, and all of the witnesses today, and let me just conclude this hearing. Thank you.

[Whereupon, at 11:58 a.m., the committee adjourned.]



ISBN 0-16-060443-5

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