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S. HRG. 107–291

WOMEN AND AGING: BEARING THE BURDEN OF LONG-TERM CARE

JOINT HEARING

BEFORE THE

SPECIAL COMMITTEE ON AGING

AND THE

SUBCOMMITTEE ON AGING OF THE COMMITTEE ON HEALTH, EDUCATION, LABOR, AND PENSIONS UNITED STATES SENATE

ONE HUNDRED SEVENTH CONGRESS

SECOND SESSION

WASHINGTON, DC

FEBRUARY 6, 2002

Serial No. 107–17

Printed for the use of the Special Committee on Aging

U.S. GOVERNMENT PRINTING OFFICE

77–850 PDF WASHINGTON : 2001

For sale by the Superintendent of Documents, U.S. Government Printing Office
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JOINT HEARING ON WOMEN AND AGING: BEARING THE BURDEN OF LONG-TERM CARE

WEDNESDAY, FEBRUARY 6, 2002

U.S. SENATE,
SPECIAL COMMITTEE ON AGING,
AND COMMITTEE ON HEALTH, EDUCATION,
LABOR, AND PENSIONS, SUBCOMMITTEE ON AGING,
Washington, DC.

The committees met jointly, pursuant to notice, at 9:35 a.m., in room SD–106, Dirksen Senate Office Building, Hon. John Breaux (chairman of the Special Committee on Aging) presiding.

Present from Special Committee on Aging: Senators Breaux, Lincoln, Stabenow, Carnahan, Craig, Santorum, and Hutchinson.

Present from Committee on Health, Education, Labor, and Pensions: Senators Mikulski and Dodd.

OPENING STATEMENT OF SENATOR JOHN BREAUX, CHAIRMAN

The CHAIRMAN. The committee will please come to order. Good morning, everyone. Thank you for being with us this morning for indeed a very special opportunity and a special joint hearing of our Senate Special Committee on Aging joined together with the Subcommittee on Aging of the Senate Committee on Health, Education, Labor and Pensions, chaired by our colleague, Senator Barbara Mikulski, who will be making opening remarks in just a moment.

I think that it is unique that two committees concentrating on this very important subject have come together to hear from a very distinguished group of colleagues who have special information and special concerns about the subject matter before the committee today.

We are meeting here today because America really is in a crisis. And the good news is that people are living a lot longer. The bad news is that people are living a lot longer without adequate long-term health care. So it truly presents a crisis of monumental proportions when you consider that the difficulties we have today will only be compounded many times over as the 77 million baby boomers become eligible for senior programs, entitlement programs, and still face a nation without adequate long-term health care for our nation's seniors.

America is clearly the strongest nation in the world, perhaps the strongest nation in the history of the world, and yet the only really long-term care program that we have available for our nation's sen-

iors is a program that was never intended to provide long-term health care for seniors, and that is the nation's Medicaid program.

The Medicaid program was really a national health program combined with the Federal Government and the states designed to really provide health care for indigent low-income seniors. Because of the absence of any other program, Medicare has become the main program to provide long-term health care for everybody. So you find the unusual and unfortunate and oftentimes extremely embarrassing situation where seniors in this nation have to become poor so they can enroll in a program where they can find health care in a program that was never intended to do so.

It is interesting now that Medicaid now pays for about 40 percent of all the long-term health care delivered in this country, and it was a program that was never intended to do that. So the real challenge before our country is to find out what solution can we reach to help our growing number of seniors live not only longer lives but live better lives, particularly in the last years of their lives.

So what we are here today is to hear from a special group of our lady colleagues in our Senate to give us information about their experiences or any ideas or suggestions that they have.

We are truly in a sandwich generation. Everyone in this audience and probably everyone testifying and all of our members up here know what it is to be in a sandwich generation. My own situation is very similar to millions of other Americans. My mother-in-law, who has diabetes, had breast cancer, lives with us at our home. I have a daughter at the same time who is in her third pregnancy and has been bedridden since the very first day, requiring a great deal of care because she has two small grandchildren—we have two small grandchildren. She has two small children.

So we are in that sandwich situation where we are taking care of people in our parent's generation, my mother-in-law, at the same time trying to provide assistance to my daughter and her children. And guess what? My wife does most of it.

You know, that is the situation where we find more and more Americans in the female population who are providing most of the care to people who need healthcare in this country. Three-fourths of all the caregivers are women. And all the problems that that presents, special needs that they have, is really what we are trying to talk about today and find out how we as the strongest nation in the history of the world can do a better job.

This is something that we can no longer ignore and sweep under the carpet. I am delighted that we have this joint hearing. I am delighted to recognize our good friend and leader in the Senate, the chairperson of the Senate Committee on Health, Education, Labor and Pensions, their Subcommittee on Aging. Senator Mikulski, comments.

[The prepared statement of Senator John Breaux follows:]

PREPARED STATEMENT OF SENATOR JOHN BREAUX

I am pleased to be here today with Senator Mikulski and the Health, Education, Labor, and Pensions (HELP) Subcommittee on Aging. Hearings such as this to highlight long-term care and caregiving are more important now than ever as we anticipate the retirement of the baby boom generation.

I am pleased to have with us our women Senators, representing those that bear the greatest burden of long-term care and caregiving. I know many of the Senators testifying today will have their own personal experiences of grappling with these issues. I also want to welcome the Older Women's League and the National Alliance for Caregiving who have been working on these issues for many years and have innovative ideas for addressing them.

Women make up a disproportionate share of caregivers in this country, with very little public support. For example, women comprise more than 80 percent of the family caregivers for chronically ill elders. The average American woman can expect to spend 17 years caring for a child and 18 years caring for an elderly parent. I know that my own wife has this experience. In addition, women live longer than men, and therefore will need to personally access long-term care more frequently. And yet our public policies do very little to provide a network of support to caregivers.

We lack a cohesive long-term care system in this country and we will pay a dear price for this when the baby boomers retire. What we do have does little to support long-term care programs that promote independent living such as home and community based care. Addressing the need for a comprehensive long-term care system in this country requires most of all creating policies that recognize the role of caregivers. Otherwise, we will face a national crisis when the baby boom generaion retires.

Knowing the primary role women play in caregiving and in our long-term care system, I am pleased to hear from our women Senators who will be integral to this debate as we seek to create better long-term care policies in this country.

OPENING STATEMENT OF SENATOR BARBARA MIKULSKI

Senator MIKULSKI. Thank you very much, Senator Breaux, for organizing this hearing and for it to be a joint hearing of this Special Committee on Aging, on which you have provided such wonderful leadership, as well as our Committee on Health, Education, Labor and Pensions. We have a Subcommittee on Aging, which I chair, and my colleague Senator Tim Hutchinson is the ranking member.

We look forward to really working with you and coming up with a framework and the funding for long-term care because we also know you are on the Finance Committee, and at the same time I am the senior woman in the U.S. Senate, I want to thank you for inviting all of the women of the Senate to participate in this very unique conversation.

Each and every one of them, as you will soon hear, brings their own perspective, their own expertise, and their own recommendations for solutions.

We the women of the Senate do not have a caucus, but we meet regularly to brainstorm on how we can look out for the day-to-day needs of the American people, convert that into public policy, and at the same time look at the long-range needs of our country in terms of national security, economic security, and health security.

So I am glad that you have the women's brigade here today, and I am looking forward to hearing from my own colleagues and introducing them. Like you, Senator, my own family has faced the crisis of long-term care. My very dear father suffered from Alzheimer's. My family and I watched him die one brain cell at a time. This was the man who saw to our education, took me to cowboy movies and bought me those good old cowgirl boots when I wanted to be a Dale Evans. When a fire took his own business away from him and as he rebuilt his business, he and my mother sacrificed for me to go to college.

How heartbreaking it was to see the man who cared for me and protected me now needed my care and my protection along with my sister's and my mother. What we saw was like all families; what

did we find when we saw what we needed in terms of long-term care? We believe that the family is the first caregiver and ought to remain so. But America's families face a fragmented system. They do not know where to go and often where to start when they face the needs of a family member who has a chronic and often progressive illness like Alzheimer's or Parkinson's.

They also then are shocked by how expensive it is, and that no matter how hard they work, no matter how hard they saved, no matter how hard they prepared, that in order to qualify for any financial help from anywhere that they had to spend down.

So here they are, bewildered, overcome with grief about the situation, not knowing where they can go to get help, and not knowing where they can get help to pay for the help. We have got to give help to those who practice self-help and support the American family. In our own situation, I had access to the resources of Johns Hopkins Hospital where I could take my dad for a geriatric evaluation to make sure we had the right evaluation for his situation.

We had hoped that it was a vitamin deficiency, and all he needed was vitamins and for the family to pitch in and send mom and dad on a love boat cruise. Alzheimer's was the diagnosis.

But we used other support services like adult day care before we had to face the need for a nursing home when dad became so ill the family was facing that incredible 36-hour day that Alzheimer's families face. So we need to really come back to the family and how we can support them.

I believe that honor your father and mother not only is a good commandment to live by, but a good policy to govern by. Almost the only down payment we have had on long-term care was the Spousal Anti-Impoverishment Act that I authored in the U.S. Senate in my very first term with the wonderful help on a bipartisan basis of the Finance Committee.

AARP tells us we have kept one million people out of poverty and prevented liens on the family farm or the home because of that. We have also worked on a bipartisan basis with Senator Hutchinson, Senator Gregg, Senator Jeffords, Senator DeWine, and Senator Kennedy to create the National Family Caregiver Support Program under the Older Americans Act. That is to provide information and assistance, counseling and support groups, respite care and supplemental services to family caregivers.

We have tried to take a look at the VA because everywhere we go when they talk about veterans healthcare, they now talk about long-term care. The greatest generation in America is faced with wondering how they are going to pay for their prescription drugs, and how are they going to pay for their long-term care. And we have had a quiet program going on at the Veterans Administration. I think we need to be louder about it.

So, Mr. Chairman and colleagues, I think we have tools with which we can give help to those who practice self-help, and particularly to those Americans who have gone before us and saw us through tough times, and we need to be sure that now when they have their tough times, we need to get going and support them. So, Mr. Chairman, I look forward to the rest of the hearing.

[The prepared statement of Senator Mikulski follows:]

PREPARED STATEMENT OF SENATOR BARBARA A. MIKULSKI

I'm very pleased to join with Senator Breaux to bring together the women of the Senate, the Subcommittee on Aging, and the Special Committee on Aging to focus on women, long-term care, and caregiving. I'm also pleased to welcome Ms. Gail Gibson Hunt, Executive Director of the National Alliance for Caregiving in Bethesda, Maryland.

Many Americans do not think about their long-term care needs until a tragedy strikes. When a person needs long-term care, it is a tragedy for the person who is ill, for the family who is the caregiver, and for the taxpayer who has to share the burden.

My dear father suffered from Alzheimer's disease. My family and I watched him die one brain cell at a time. I know what families live through when a loved one ages and needs more care, eventually more than you alone can provide. Everywhere I travel around Maryland, people come up to me and tell me what a big issue long-term care is for their family.

Women are more often the ones who provide care to loved ones and who eventually need care themselves. Three-quarters of caregivers are women. Women live longer than men and are more than twice as likely to live in a nursing home. Caregivers and their families face mental, emotional, physical, and financial stresses and strains. Some caregivers work three shifts—caring for children, working a full-time job, and caring for an elderly parent at home.

In the 20th century, we made more scientific and medical breakthroughs than we have during any other century in American history. People are living longer. More Americans can remain in their homes and communities, delaying or preventing institutionalization. But our country's approach to caring for this growing number of aging Americans is piecemeal and fragmented. We have some good down payments to build from, but we must do more.

I believe that honoring your mother and father is not only a good commandment to live by, but also good public policy to govern by. One of the accomplishments that I am most proud of is my Spousal Anti-Impoverishment Act. From my own family's experience, I saw how cruel rules forced elderly couples to go bankrupt before they could become eligible for Medicaid to help pay for nursing home care. I changed those rules so that a spouse living in the community could keep enough income to pay the bills and live at home, while the other spouse is in a nursing home.

I fought hard on a bipartisan basis to establish and fund the National Family Caregiver Support Program under the Older Americans Act. It provides information and assistance, respite care, counseling and training, support groups, and supplemental services to caregivers who need them. These are vital supports to thousands of caregivers across the country.

I'm also the Senator for the VA. One of the biggest future needs of the VA health care system is long-term care. There is a great desire for these services. States are building VA nursing homes, but there is no continuum of care. There must be assisted living and other ways for veterans to be able to live their last years with their families and age in place. On the Medicare side, some of our biggest budget battles have involved Balanced Budget Act givebacks to nursing homes, home health care agencies, and other providers who care for our aging population.

Our first responsibility is to the family and those that practice self-help. Tax credits, spousal anti-impoverishment, long-term care insurance for Federal employees, and the National Family Caregiver Support Program are parts of what should be the long-term care mosaic. But many pieces are missing—there is no comprehensive approach. First there is the family caregiver, but no one can care for someone by themselves for years and years. Family caregivers need advice, counseling, and support. Helping those who plan and practice self-help is a downpayment. But we must do more. This is about getting behind our nation's families.

I look forward to hearing from the other women Senators and all our witnesses for their insights and ideas about the best ways to help women and families better prepare for the burdens of long-term care.

The CHAIRMAN. Thank you very much, Senator Mikulski. Any comments, Senator Hutchinson?

STATEMENT OF SENATOR TIM HUTCHINSON

Senator HUTCHINSON. Yes, thank you, Chairman Breaux and Senator Mikulski. I am pleased to serve as your ranking member. This is an excellent statement and you are absolutely right. The way we best honor our parents, our mothers and our fathers, is not in word, but in deed, and that is being done by millions and millions of caregivers, who are primarily women. I want to thank you for holding this hearing and highlighting the role of women as caregivers.

Recent results, and to me this was stunning, of a survey conducted by Bruskin Research for the National Family Caregivers Association, the NFCA, shows that the number of persons who provided care for an elderly, disabled or chronically ill friend or relative during the past year is more than twice as large as what had been previously thought.

Survey results indicate that 26.6 percent of the adult population was involved in caregiving during the last 12 months, and that translates into about 54 million people, of whom over 60 percent are women.

So I am very pleased to have this very distinguished panel of our colleagues here today. I know Senator Lincoln, my colleague from Arkansas, will elaborate on this, but in Arkansas, almost one-quarter million caregivers provide assistance to friends or family members, and if that were paid through insurance, it would cost taxpayers and policyholders over $1.8 billion a year, according to our Department of Health in the State of Arkansas.

Most of this caregiving is given willingly and given lovingly, and it is a rewarding experience, but caregivers face many, many challenges. Poor health, depression, a sense of burden, concerns over financial costs are common among caregivers. Most over half of caregivers, work outside the home in order to help pay for out-of-pocket expenses because there is no public assistance available.

Long-term care is an increasingly important issue, as we all know, as we go into the 21 century, as the baby boomers age. It is going to impact all of us. This is an issue that deserves our full consideration and attention, and I applaud Chairman Breaux and Chairwoman Mikulski for holding this hearing today.

[The prepared statement of Senator Tim Hutchinson follows:]

PREPARED STATEMENT OF SENATOR TIM HUTCHINSON

Chairman Breaux, Chairwoman Mikulski, I want to thank you for holding this hearing highlighting the role of women as caregivers.

Recent results of a survey conducted by Bruskin Research for the National Family Care-givers Association (NFCA) shows that the number of persons who provided care for an elderly, disabled or chronically ill friend or relative during the past year is more than twice as large as previously thought.

Survey results indicate that 26.6 percent of the adult population was involved in caregiving during the past 12 months. Based on Census data, this translates into approximately 54 million people, over half of whom (at least 60 percent) are women.

Family members and other informal caregivers are the main fabric of our long-term care system in the United States. In most cases, they provide uncompensated care to family or friends with chronic illnesses or disabilities.

In Arkansas, almost one quarter million caregivers provide assistance to friends or family members, and if paid for through insurance would cost tax payers and policy holders over $1.8 billion annually (according to the Arkansas DHS Division of Aging and Adult Services).

Most caregiving is willingly undertaken and can be a rewarding experience for the giver. But caregiving can also result in great financial, physical, and emotional hardship—a burden which is borne primarily by women. Women on average live at least seven years longer than men, and they comprise 70 percent of the population age 85 and older.

Caregivers commonly experience poor health, depression, and a sense of burden. Concerns over the financial costs of caregiving are a major source of worry for many middle-income caregivers. They are often not eligible for public assistance, but cannot afford the out of pocket expenses associated with such care.

It is estimated that as many as 50 percent of family caregivers also work outside the home which can potentially result in work disruptions and lost productivity, both personally and in the workplace.

Caregiving will continue to be an issue well into the 21st century as the baby boomer generation ages. This has brought the concerns of caregivers into the public policy debate both on Capitol Hill and in State Legislatures around the country. Many decision makers in both the public and private sectors are even themselves directly or indirectly affected by this issue, as we will hear more about today.

This is an issue that deserves our full consideration and attention.

The CHAIRMAN. Thank you, Senator. Senator Dodd, any comments?

STATEMENT OF SENATOR CHRISTOPHER DODD

Senator DODD. Well, Mr. Chairman. We have a big panel with us here this morning. Let me just ask unanimous consent that I will be able to put a statement in the record and to commend both of our colleagues here for holding this hearing, and thank our distinguished panel of colleagues and witnesses who are going to share some thoughts with us.

This is a wonderful subject matter for us to be engaged in here in the Senate, and obviously the statistics speak for themselves. The numbers leap out at you. Rhetoric is wonderful, but just you read the numbers and the problem is clearly evident. When you are talking about 70 million Americans in the next 30 years that will be over the age of 65, over 85 years of age the fastest growing segment in the country, and then looking at the disproportionate number of women who are already but will be asked to bear the responsibility of caring not only for themselves, because they will live so much longer than their husbands. They will spend 17 years, the average woman does, caring for children and 18 years caring for a husband or a parent.

So it is pretty startling, the numbers, and clearly cries out for some solutions. I would just mention briefly, I have often said there are many things each one of us can claim, that we are proud of having served in public life, but as long as I live I will never forget the day in February 1993 when I stood in the Rose Garden of the White House and watched President Bill Clinton sign the very first law that he signed into law, the Family and Medical Leave Act, which many of my colleagues here made possible.

And that little piece of legislation which said you did not have to lose your job if you took care of somebody, including a parent. It is unpaid leave and so it is awkward for people living with limited means, and we are trying to draft legislation now to make this paid in some way without obviously putting tremendous burdens on people, but it ought to be available to people who are living on the margins economically as well.

But the FMCA and the legislation that Senator Mikulski has talked about, the National Family Caregiver Support Program,

have made a difference for an awful lot of Americans, and we need to try and figure out how we can make that available to more and more people. So I thank you both for doing this.

[The prepared statement of Senator Dodd follows:]

PREPARED STATEMENT OF SENATOR CHRISTOPHER DODD

Chairwoman Mikulski and Chairman Breaux, thank you for convening this important joint hearing. As we now know, over the next 30 years, our nation will dramaticaly change as the baby boom generation enters their retirement years. By 2030, the number of those aged 65 and older will more than double to an astounding 70 million Americans. Also, the number of those age 85 and older is expected to grow faster than any other age group. And as this morning's hearing will make evident, the problem's presented by the aging of America are particularly critical for women, as they represent a growing majority of the population as age increases above the age of 65. Recognizing this, the role of women as both caregivers and recipients of long-term care services as they age themselves is a matter of great concern and I appreciate the opportunity to examine this critical issue.

As we'll learn today, the majority of those that provide care for our elderly are women. In fact, research shows us that approximately 75 percent of those providing care to older family members and friends are women. And even though some studies show a relatively equitable distribution of caregiving between men and women, the same studies tell us that women caregivers spend 50 percent more time providing care than their male counterparts. Combined with the fact that women also represent a significant majority of our elderly population, it is clear why this morning's hearing is so important. As both caregivers and recipients of care themselves, any examination of the issue of how to best care for our senior citizens must consider the important role of women in long-term care. Already lacking, the need for increased access to valuable long-term care services will only become more critical for many of our nation's seniors. This is clearly a problem that is not going to go away.

Today, women are thrust into many demanding roles, such as mother, professional, doctor, researcher, teacher, and caregiver. As statistics have shown us, it is women who mostly take on the role as caregiver. They willingly take on the responsibility of providing care for loved ones, seeking information, listening, often taking on financial responsibilities, along with their many other responsibilities. This is laudable—though often thankless—very difficult work. Those that provide care to an elderly family member or friend need to be recognized and supported for the valuable work that they are doing. Providing assistance to another is one of the greatest gifts that a person can give. I believe that the federal government should do all within its power to support long-term caregivers and examine new ways to support their efforts.

I was particularly pleased to have the opportunity to author the Family and Medical Leave Act (FMLA)—legislation that has afforded millions the chance to take valuable time away from work so that they can care for a sick or elderly family member. The FMLA grants the opportunity to caregivers to take up to 12 weeks of unpaid leave during any 12-month period to care for an immediate family member with a serious health condition. When I first began looking at the issue of family and medical leave, I was surprised to learn how many among us take on the responsibility of caring for a sick or elderly family member. In fact, a study conducted in my state of Connecticut last year asked participants, "during the past month, did you provide regular care or assistance to a family member or friend who is elderly or has a long-term illness or disability to someone 60 years or older?" Approximately, 15.2 percent or roughly 382,000 of Connecticut's adults are engaged in elder care in any given month.

The problem of insufficient long-term care resources has both great present and long-term implications. A decade from now, we know that the baby boom generation will begin to retire. With this our healthcare systems will be placed under tremendous strain. Clearly this is a problem that we must begin to think about today. I look forward to hearing from our witnesses this morning concerning the question of how to best develop a comprehensive long-term care infrastructure.

So, it is with great interest that I attend this morning's hearing. I am also particularly interested in other issues that will greatly affect our nation's senior citizens in the future. Access to prescription medicines, Social Security and Medicare reform, and access to safe and affordable long term care services are all issues that must be closely examined if we as a society are going to be prepared for the great increase in aged Americans.

The one thing I am sure of, is that if we do nothing to address this problem, it is our own loved ones requiring long-term healthcare that will suffer. At its core, our discussion this morning is about the quality of care we provide to some of the most vulnerable among us. We owe it to both our seniors and those that provide for their care to address this problem.

The CHAIRMAN. Thank you, Senator. Senator Santorum.

STATEMENT OF SENATOR RICK SANTORUM

Senator SANTORUM. I too will put a statement in the record in deference to my colleagues who are here who have prepared testimony. I just want to congratulate you for holding this hearing. We have a huge problem right now, but as Senator Dodd alluded to, it is going to get much, much bigger. We are going to see an 80 percent increase in the number of elderly in this country over the next 20 years, 80 percent increase.

And as Chris said, the fastest growing group of people in America are people over the age 85. I had a little girl a couple of years ago. I found out at that time that she has a one in three chance of living to be 100, and one in six women in this country alive today will live to be 100. This is an incredible problem that is out there that is not—obviously the human cost is obvious, but the economic implications for our economy and with women such a vital part of our workforce and the burden that we are placing on women as a result of the aging population. It is a big issue. It is an important topic, and the point that I just want to stress here, it is not that bad right now compared to what it is going to be like 10, 20, 30 years from now.

And we really need to look at this in a comprehensive basis and see what we can do about it, and I want to congratulate you for doing this and all of you for testifying. Thank you.

[The prepared statement of Senator Santorum follows:]

PREPARED STATEMENT OF SENATOR RICK SANTORUM

Thank you, Chairman Breaux, Chairwoman Mikulski, fellow colleagues, and invited guests. If there is one thing that unites all of us here today, it is perhaps the sentiment that this hearing could not be more timely or necessary.

We all know of the tremendous fiscal pressures that the coming baby boom retirements will impose on our public healthcare and retirement programs, and that steps we take today to reform programs like Medicare and Social Security will go a long way to help meet the needs of our beneficiary population down the road.

But a far less understood attendant policy challenge stemming from our aging society is the growing costs and need for long-term care services, and the unique factors that come into play with regard to the well-being of women. So I again thank the Committee members for holding this forum today.

Perhaps more than any other socioeconomic group, women are disproportionately affected by long-term care. For many centuries, women have served as the traditional, primary caregivers of long-term health care. Today, women still bear the responsibility of caring for their parents or loved ones when they need attention.

And due to the fact that women are living longer than men, they are more likely to develop the sort of functional ailments that require long-term care services. Today, the average woman can expect to live some seven years longer than her male counterpart (to the age of 80 from birth, and to 85 if she surpasses 65 years of age)—all the while increasing her demand for vital long-term health care that ranges from help with day-to-day activities to sophisticated therapies. In addition, more women are working outside the home than ever before, and with those professional responsibilities come the personal responsibilities of essentially serving as another parent to some loved family member. So we are witnessing a confluence of disturbing trends that comprise the challenges that are currently facing and will continue to face women and long-term health care services.

The social costs of emotional strain and anguish that often arise when daughters, granddaughters, sisters and nieces are faced with such burdens are concerning in and of themselves, to say nothing about such burdens' effects on personal financial well-being and productivity in our economy.

I know that there are numerous proposals that many Members of Congress and President Bush has put forth to help ease the financial burdens of financing long-term care. Many of these are bipartisan ideas, and have a lot of merit, such as providing a tax deduction for long-term care premiums, giving employees the opportunity to purchase group long-term care insurance policies through their cafeteria plans, and offering tax credits to help qualifying caregiving families pay for supplies, home improvements and other services so vital to keeping a loved one at home.

As for my own efforts, one facet of the long-term care equation in which I am particularly interested and on which I have been working with Senators Rockefeller, Lincoln, and McConnell is legislation to allow Medicare home health beneficiaries the option to receive some or all of their Medicare home health services in an adult day setting. The idea behind the Medicare Adult Services Alernative Act is to allow caregivers more flexibility in attending to other things in today's fast-paced family life, knowing their loved ones are well cared for in a social and thereapeutic setting.

I look forward to hearing the experiences and perspectives that each of these witnesses will provide. And I hope that they will help illuminate the issues facing women and long-term care, and help us identify what immediate and longer-term steps we may take to prepare our country for the increasing costs and need for long-term care services.

The CHAIRMAN. Thank you. Thank all of the members of the committee, and I wanted to add that when I was talking about my wife taking care of my mother-in-law, and our children, she also has the real challenge of trying to take care of me, which is probably the biggest problem of all.

Senator DODD. I was going to make that point. [Laughter.]

The CHAIRMAN. She is also doing that which is a real challenge. And women find themselves as homemakers in many, many cases trying to do all of that and which is incredible.

We have a very distinguished group of our colleagues and we are just delighted. I will try and introduce them first as they arrive. I was going to say that our colleague from Arkansas, Senator Blanche Lincoln, and I are joined at the hip. I mean I want to make it clear it is the political hip. [Laughter.]

And we are members of the New Democrats together, the Centrist Coalition together. She is a member of the Aging Committee. She is a member of our Finance Committee. So we work very closely together on a regular basis. I am delighted for her leadership and pleased to have her comments. Blanche.

STATEMENT OF SENATOR BLANCHE LINCOLN

Senator LINCOLN. Thank you. Well, a very special thanks to you, Mr. Chairman, and to Chairwoman Mikulski, for having the foresight of bringing this very important issue up. It is certainly a pleasure to testify today, and we want to thank you all and both of the committees and the members of the committees for their hard work on this very important issue.

I am glad to be in the company of other women senators on such a distinguished panel that I sit with here, sharing our experiences and our point of view. As we all know, the face of caregiving is female. Caregiving for the elderly and children falls predominantly to women in our society. In our society, we women care for our children, our parents and often our husband's elderly relatives.

Caregiving is an issue I care about deeply. Over the past year, I have hosted several forums on aging, long-term care, and

caregiving issues in Arkansas. Arkansas ranks fifth highest for its population of 55 plus seniors and second for the percentage of seniors living in poverty. Three out of five elderly Arkansans are women.

As a baby boomer, I consider myself part of that sandwich generation that Senator Breaux mentioned, a group obviously responsible for caring for children and aging parents simultaneously. And, in fact, I am actually a part of another group called the "club sandwich" generation, whose members are also taking care of their grandparents. My husband's grandmother is now 104, living in an assisted living apartment and unbelievable in terms of her abilities to get around.

But it certainly does put us in a situation of not only having a generation on either side, but a second generation on either side of those generations. I am a proud mother of twin 5-year-old boys who are extremely active, and as any parent knows, just keeping up with two small children is as challenging as it is rewarding, and I know that Senator Dodd can add to that a great deal since his recent appearance on the scene of fatherhood.

But, obviously, my typical day of making sure that lunches are packed, both for my husband and my children, meeting a bus, getting children to school, making sure that meals are planned so that we do have somewhat of a resemblance of a normal family home in terms of sitting down to dinner, involvement with getting kids to soccer and karate practice. Thank goodness for cell phones because in addition to my two boys and my husband, I also help monitor the health of my aging parents, particularly my 73-year-old father who is in the later stages of Alzheimer's disease, and more important, his primary caregiver, which is my mother.

And I know you all will not believe this, but she is an extremely strong-willed woman and very independent-minded. Don't know where it comes from. [Laughter.]

But it is often difficult as we deal with our parents and those who are caregivers. We must consider not only their sense of independence, but their sense of pride and their ability to provide dignity to the individual that they are taking care of. As Senator Mikulski brings to mind, the idea of looking at someone who in my lifetime has been that strong provider, the one who taught me how to fish or how to scalp cotton and chop soybeans, the man who was there for me at every turn in my life, now recognizing that he needs almost every second of his day to be cared for by one of us.

And I can tell you from personal experience that these responsibilities can seem awesome at times, not only from the physical strength that is called upon by my mother in order to be a primary caregiver, but also certainly the emotional strength. I know that I am not alone in this, so I have been an advocate for passing legislation supportive of the growing number of frail elderly Americans as well as their caregivers.

As a member of the Finance Committee and the Special Committee on Aging, I have a special interest in working with others here in the U.S. Senate to prepare healthcare providers and Medicare for the inevitable aging of America. I think the numbers that were mentioned by all of our colleagues in their opening statements, par-

ticularly Senator Santorum on the 80 percent of where we are going, is just phenomenal.

We also have the Geriatric Care Act of 2001, which calls for increasing the number of geriatricians in our country through training incentives and Medicare reimbursement for geriatric care.

Our nation's healthcare system will face unprecedented pressure as our population grows older. Demand for quality care will increase and we will need physicians who understand the complex health problems that aging brings. I had a phone call from a constituent the other day in Jonesboro, AR who is caring for her aging husband, and she had been seeing five different physicians in five different places.

She had finally discovered the Don Reynolds Center on Aging in Little Rock, and she called me with unbelievable delight that she had actually found a place where she could take her husband and all of her needs could be met.

The doctors talked to one another. The physicians as well as all of the other medical professionals talked and exchanged ideas and concerns about that one patient in order to give them the ultimate of care. As seniors live longer, incidences of disease and disability increase. Conditions such as heart disease, cancer, stroke, diabetes, and also Alzheimer's disease occur more frequently as people age.

The complex problems associated with aging require special training of physicians in geriatrics. Geriatric medicine provides the best healthcare for frail older persons.

Geriatrics promotes wellness and preventive care with an emphasis on care management and coordination that helps patients maintain functional independence, improve their overall quality of life, and reduce unnecessary and costly hospitalization, institutionalization and other complications.

Today, there are fewer than 9,000 certified geriatricians in the United States. Only three medical schools in our country, the University of Arkansas for Medical Sciences being one of them, have a department of geriatrics. This is incredible considering that all 125 medical schools in our country have departments of pediatrics. Why would only three of them have a department in geriatrics?

The number of geriatricians is expected to decline dramatically in the next several years. In fact, most of these doctors will retire just as the baby boomer generation attains Medicare eligibility.

I will speak more about my bill later this month in a Special Committee on Aging hearing devoted solely to that issue, but I encourage my colleagues to look at it and the great need that we have out there. I have also supported enactment of other legislation to assist caregivers and to help our growing elderly population to prepare for their long-term care needs.

I helped enact the National Family Caregivers Act which will provide funding to help caregivers gain access to support groups, counseling and respite care. I appreciate the work that Senator Collins did on that bill and that she worked with us on it. What is important about this bill is that it focuses squarely on the caregivers in the family, most often the daughters and wives who make tremendous sacrifices to care for their spouses, parents, and loved ones in their senior years.

By helping these caregivers get the support they need, we open the door for more effective care and create greater opportunities for people to age in their homes rather than in nursing homes or institutions. Recently, we also made long-term care insurance available.

Senator MIKULSKI. Senator Lincoln, we do not want in any way to limit your testimony. The time has expired, and Senator Murray has to leave.

Senator LINCOLN. Certainly. What I would like to emphasize in my testimony today, as well as in my written remarks, as I refer to pieces of legislation, is that in these legislative remedies we are looking for innovative and creative ways of addressing our seniors' needs in long-term care.

Our hope is is that we can keep our loved ones in their homes and that we will look for those innovative ways through legislation in order to be able to make that happen. Thank you.

[The prepared statement of Senator Lincoln follows:]

PREPARED STATEMENT OF SENATOR BLANCHE LAMBERT LINCOLN

Good morning. It is my pleasure to testify today. I want to thank Senators Breaux and Mikulski for calling for this hearing on such a significant topic. I am glad to be in the company of other women senators, sharing our experiences and our points of view. As we all know, the face of caregiving is female. Caregiving for the elderly and children falls predominantly to women in our society. In our society, we women care for our children, our parents, and often our husband's elderly relatives.

Caregiving is an issue I care about deeply. Over the past year, I have hosted several forums on aging, long-term care, and caregiving issues in Arkansas. Arkansas ranks fifth-highest for its population of 55-plus seniors and second for the percentage of seniors living in poverty. Three out of five elderly Arkansans are women.

As a baby boomer, I consider myself part of the "Sandwich Generation" a group responsible for caring for children and aging parents simultaneously. In fact, I belong to the "Club Sandwich Club," whose members are also taking care of their grandparents. My husband's grandmother is now 104 years old.

I am the proud mother of twin 5-year-old boys. As any parent knows, just keeping up with two small children is as challenging as it is rewarding. In addition to my boys, I also help monitor the health of my aging parents particularly my father, who is in the later stages of Alzheimer's disease.

I can tell you from personal experience that these responsibilities can seem awesome at times. I know that I am not alone in this, so I have been an advocate for passing legislation supportive of the growing number of frail elderly Americans and of caregivers.

As a member of the Finance Committee and the Special Committee on Aging, I have a special interest in preparing health care providers and Medicare for the inevitable aging of America. I am the author of the Geriatric Care Act of 2001, which calls for increasing the number of geriatricians in our country through training incentives and Medicare reimbursement for geriatric care. By improving access to geriatric care, the Geriatric Care Act of 2001 takes an important first step in modernizing Medicare for the 21st century.

Our nation's healthcare system will face unprecedented pressure as our population grows older. Demand for quality care will increase, and we will need physicians who understand the complex health problems that aging brings. As seniors live longer, incidences of disease and disability increase. Conditions such as heart disease, cancer, stroke, diabetes and Alzheimer's disease occur more frequently as people age.

The complex problems associated with aging require special training of physicians in geriatrics. Geriatricians are physicians who are first board certified in family practice or internal medicine and then complete additional years of fellowship training in geriatrics. Certified geriatricians pass a certificate of added qualifications administered by either the American Board of Internal Medicine or the American Board of Family Practice.

Geriatric medicine provides the best healthcare for frail older persons. Geriatrics promotes wellness and preventive care, with an emphasis on care management and coordination that helps patients maintain functional independence, improve their

overall quality of life, and reduce unnecessary and costly hospitalizations, institutionalization and other complications.

Given our seniors' dependence on prescription drugs, it is increasingly important that physicians know how, when, and in what dosage to prescribe medicines to older persons and have knowledge of possible interactions with other medications.

Today, there are fewer than 9,000 certified geriatricians in the United States. Of the approximately 98,000 medical residency and fellowship positions supported by Medicare in 1998, only 324 were in geriatric medicine and geriatric psychiatry. Only three medical schools in the country the University of Arkansas for Medical Sciences (UAMS) being one of them have a department of geriatrics. This is incredible, considering that all 125 medical schools in our country have departments of pediatrics.

The number of geriatricians is expected to decline dramatically in the next several years. In fact, most of these doctors will retire just as the baby boomer generation attains Medicare eligibility. I will speak more about my bill later this month in a Special Committee on the Aging hearing devoted solely to this issue.

I have also supported enactment of other legislation to assist caregivers and to help our growing elderly population to prepare for their long-term care needs. I helped enact the National Family Caregivers Act, which will provide funding to help caregivers gain access to support groups, counseling, and respite care. What's important about this bill is that it focuses squarely on the caregivers in the family most often the daughters and wives who make tremendous sacrifices to care for their spouses, parents, and loved ones in their senior years. By helping these caregivers get the support they need, we open the door for more effective care and create greater opportunities for people to age in their homes, rather than in nursing homes or institutions.

Recently, we also made long-term care insurance available to Federal employees. This is a major step forward in making long-term care insurance affordable and accessible for as many as 13 million people. That's 13 million people who will have an opportunity to protect themselves and their families against financial ruin as they age. What's also important about this law is that it's going to serve as a benchmark for the private sector. The government is setting a standard by offering this insurance, and I'm confident that we have created a model that industry will want to follow.

Also, I co-sponsored the Long-Term Care Security Act, which will allow taxpayers to deduct the cost of long-term care insurance premiums and would provide tax credits for long-term care expenses.

An initiative I am also interested in pursuing is doing more to shift a greater portion of Federal funding from institutional care to community-based care. Currently, we spend 75 percent of federal dollars on institutional care. We must create opportunities for home care, adult day services, and hospice centers to flourish. By channeling more federal funding to these community-based services, we can develop a variety of options for care that are more responsive to the needs of our seniors.

Adult day services meet an essential element in the continuum of care for elderly persons. Last year, the Arkansas Center for Health Improvement was asked by the Arkansas Division of Aging and Adult Services in collaboration with the Robert Wood Johnson Foundation to develop information on the status of adult day services in Arkansas. I was disturbed by the finding that the general public has a very limited knowledge of the program and that many health care providers have a limited understanding of adult day services as a community-based option to nursing home or residential care facilities. We must do more to make sure that the elderly and those providing their care are aware of community-based services, such as adult day services.

I am also concerned that our Nation's veterans and their dependents may not be fully aware that they are entitled to benefits and services through the Department of Veterans Affairs. One of the most important benefits the VA provides is comprehensive health care, including low-cost prescription medications. Last year I submitted a Senate resolution calling on the Secretary of Veterans Affairs to work with the Commissioner of the Social Security Administration to better inform the Nation's veterans and their dependents about benefits available from the VA.

What I want to emphasize in all of these legislative remedies is that we're looking for innovative and creative ways of addressing our seniors' needs for long-term care. Whether it's tax credits, deductible insurance premiums, community-based care, or focusing on caregivers, we need to find new ways to encourage people to prepare for their long-term care needs and to explore options besides institutions.

Again, I am grateful to Senators Breaux and Mikulski for organizing this hearing. I also appreciate sitting beside other women senators who each bring a unique perspective to their duties in the Senate, and particularly on the issue of women and caregiving. I look forward to working together to come up with workable solutions.

Senator MIKULSKI. Thank you and we will look forward to your hearing as well and your ongoing and continued leadership.

I am apprised that Senator Murray has to leave, and I would like to suggest that she speak and then Senator Collins to make sure the other party gets a chance to speak, and I would like to bring to the committee's attention that Senator Snowe might be appearing, but both Senator Snowe and Senator Kay Bailey Hutchison have had long-standing leadership in this area.

The CHAIRMAN. Well, Senator Murray, obviously, thank you very much for being with us. I mean you have been a leader in this area on the Senate Health, Education, Labor, and Pension Committee, and you have a story that we are aware of, and we look forward to hearing you and know that you have been a terrific leader in this area, and thanks for participating. Patty.

STATEMENT OF SENATOR PATTY MURRAY

Senator MURRAY. Thank you very much, Chairman Breaux, Chairman Mikulski, for your leadership on this issue and for calling this very important and unique hearing. When I look at the issues of long-term care, I really think back to my own experiences in my family, starting with my mother.

My mother was my hero. She was the best basketball player at five feet tall on her team when she grew up in Butte, MT. She went to college to become a pharmacist. She loved every Notre Dame team and could name all the players and list all of the scores.

She raised seven kids on a shoestring budget. When I was 15 with siblings ranging in age from one to 16, my father was diagnosed with multiple sclerosis and had to quit his job and soon became wheelchair bound and homebound. My mom went back to work, she got every one of us off to college, and she worked full time as my dad's caregiver.

When other moms were taking trips to Hawaii after their kids were grown, my mom was lifting my dad out of bed and dressing him every single morning. When my mom's friends learned to play bridge and golf, my mom learned how to get a motorized wheelchair in and out of a car.

When other moms cared for their new grandchildren, my mom was making dinner and feeding my dad. My mom never became a pharmacist. She only took one trip in her life, and that was here to Washington, DC., when her daughter became a United States Senator.

My mom never went to the opera, saw a movie, or went to lunch with her friends, and, you know, she never complained, even when it affected her own health. She accepted her role as a caregiver, but I think for many families, like my own, caregiving is cloaked in silence. Caregivers like my mom cannot speak out for one simple reason: they do not want the person they are caring for to ever feel that they are a burden. So we have to speak out for them.

Today, both my parents are gone, but thousands of people at home are silently taking care of someone they love, and they need us to speak out. I see two proposals that I think could help.

First, we need to double funding for the Family Caregiver Support Program. Senator Mikulski has proposed this and I strongly

support it. Second, I think we need a respite care benefit under Medicare. You will recall that in 1997 President Clinton proposed that idea and it would provide really needed support and relief for family members who are caring for a relative in their home. Even if it only provides up to 72 hours of respite care a year, I can assure you it would be a life line for thousands of families. Seventy-two hours a year for my mom would have been an incredible miracle.

My mother was a hero because she worked in silence, but today we can break that silence and give families the support they need as they care for loved ones. I am very grateful to you, Chairman Breaux, Senator Mikulski, members of this committee, for holding this hearing and allowing us to do the right thing for so many people who are caring for a family member in silence. Thank you.

The CHAIRMAN. Thank you very much, Senator Murray, and we appreciate your being with us, and if you do have to depart, of course, we understand that.

[The prepared statement of Senator Murray follows:]

PREPARED STATEMENT OF SENATOR PATTY MURRAY

Thank you Chairman Mikulski and Chairman Breaux for your leadership on this issue and for calling this unique hearing. When I look at issues like long term care, I think back to my own experiences in my family starting with my mother. My Mother was my hero. She was the best basketball player on her team where she grew up in Butte, MT. She went to college to become a pharmacist. She loved every Notre Dame team and could name all the players and could recite all the scores. She raised 7 kids on a shoestring budget.

When I was 15, my Dad was diagnosed with Multiple Sclerosis and had to quit his job, so Mom worked. She got every one of us kids off to college, and then she worked full time as my Dad's caregiver. When other mothers were taking trips to Hawaii after their kids were grown, my mom was lifting my dad out of bed and dressing him every single morning. When her friends learned to play bridge and golf, my mom learned how to get a motorized wheel chair in and out of the car. When other moms cared for grandchildren, my mom was making dinner and feeding my dad.

My mom never became a pharmacist. My mom only took one trip—one that she treasured forever——when she came to Washington DC to see her daughter become a U.S. Senator. My mom never got to go to the opera, or see a movie with friends, or go out to lunch with her neighbors. You know: she never complained even when it affected her own health. In my memory, she was one of the happiest people alive. She accepted her role as a caregiver. But I think for many families like my own, caregiving is cloaked in silence.

Caregivers like my mom can't speak out for one simple but important reason: they don't want the person they are caring for to ever feel they are a burden. So we must speak out for them.

Today both my parents are gone. But thousands of people are at home today silently taking care of someone they love. They need us to speak out. And I see two proposals that could help.

First, we should double funding for the family caregiver support program. Senator Mikulski has proposed this, and I fully support it. Second, I still think we need a respite care benefit under Medicare. You'll recall that in 1997, President Clinton proposed this idea. It would provide vital relief for family members who are caring for an aging relative in the home. Even if it only provides up to 72 hours a year of respite care, it would be a lifeline for thousands of families.

My mother was a hero because she worked in silence. But today, we can help break that silence and give families the support they need as they care for loved ones. I'm grateful to Senators Mikulski and Breaux for holding this hearing and allowing us to do the right thing for so many people who are caring for a family member in silence.

Senator MIKULSKI. Thank you. Mr. Chairman, I want to introduce Senator Susan Collins, a dear friend and colleague. I also need to acknowledge the role of the Republican women in the

economic security and health security facing families and women. Senator Kay Bailey Hutchison has been a strong advocate particularly on the economic security issue. She and I worked, when she took the leadership, on the issue of expanding spousal contributions to IRAs, recognizing the role of the homemaker and she has also worked on other issues.

The senior senator from Maine, a member of the Finance Committee, our own colleague from the House of Representatives, has long been a champion of long-term care, making sure that women have access to the health care they need, and also for a very sensible prescription drug benefit. So they are going to try to get here, but I want everyone to know that we really worked on a bipartisan basis. We are going to hear from Senator Sue Collins, her own ideas, but though they are not here at the hearing, I want you to know that the Republican women are at the table when we discuss these issues.

Senator Sue Collins has been a champion of making sure the elderly have the benefits that they need. She has been a real advocate in terms of the issues of Medicare givebacks, in terms of the spartan reimbursement for nursing homes, and particularly the skimpy ones for home health care. She and I teamed up because we had visiting nurses visiting in Maine and in Maryland in snowmobiles in order to make sure people got their home health care.

She has been an advocate in these areas, and she has also worked very hard on the issue of diabetes, which is a chronic and progressive illness, that if not properly managed, requires long-term care from kidney dialysis to other support services. She is the "Legislator of the Year" of the Visiting Nurses Association of America and the Juvenile Diabetes Foundation has recognized her. I introduce Senator Sue Collins.

STATEMENT OF SENATOR SUE COLLINS

Senator COLLINS. Good morning, and thank you very much, Madam Chair, and for your very gracious invitation to testify and your very kind introduction. I want to commend you and Senator Breaux and all of the members of this committee for your leadership in holding this very important hearing.

As we have heard so eloquently this morning, this is an issue that touches every American family. Each of us has had the experience of trying to figure out how to ensure compassionate care for a much loved elderly relative, but the simple fact is that this issue affects women even more than men.

Women can expect to live 7 years longer than men on average so we are more likely personally to need long-term care. In addition, as has been mentioned, 75 percent of all caregivers are women. Senator Santorum mentioned that his daughter has a one out of three chance of living to 100. She also has a very good chance of ending up taking care of her father. [Laughter.]

That should give us all pause. The challenges for women are particularly great because it comes at a time when more women than ever before are working outside of the home. The fact is that the average caregiver in the United States today is a 46-year-old woman who works full time outside of the home and yet spends an additional 18 hours a week caring for her 77-year-old mother.

Long-term care is the major catastrophic healthcare expense faced by older Americans. It is therefore particularly troubling that while women are at greater risk of needing long-term care than men, they are usually far less prepared for the financial consequences. In a recent poll of baby boomers, 33 percent of the women surveyed reported having less than $25,000 in their retirement plans.

That amount would not even cover a single year of nursing home costs. To help address this problem, I have joined with Senator Mikulski in calling for a doubling of funding for the National Family Caregivers Support Program authorized by the Older Americans Act. I have also joined with my colleagues, Senator Lincoln, Senator Grassley, Senator Breaux, and a bipartisan group in sponsoring the Long-Term Care and Retirement Security Act.

This important legislation would give a tax credit for long-term care expenses of up to $3,000 to help families already struggling to provide long-term care to a loved one. It will also encourage more Americans to plan for their long-term care needs by providing a tax deduction to help them afford private long-term care insurance.

Finally, I cannot let this opportunity pass without noting that we still have work to do to prevent an additional cut in home healthcare payments from going into effect in October of this year.

Home healthcare is a less expensive alternative to nursing home care for many older Americans. Moreover it allows them to receive the care in the security, privacy and the comfort of their own homes. So I want to also remind all of our colleagues that we still have work to do in that area as well.

Just as women have more at stake when it comes to long-term care, we also stand to gain the most from public policies that help families meet their long-term care needs. As a member of both this distinguished committee as well as the Health Committee, I look forward to continuing to work with my colleagues to address these important issues. Thank you for the opportunity to appear today.

[The prepared statement of Senator Collins follows:]

PREPARED STATEMENT OF SENATOR SUSAN COLLINS

Mr. Chairman, Madam Chairman, thank you for your leadership in calling this hearing on an issue of critical importance to us all, but of particular concern to women long term care.

The simple fact that women can expect to live as many as 7 years longer than their male counterparts puts them at far greater risk of needing long-term care. Moreover, not only are women far more likely to need long-term care, but they are also the ones who most often shoulder the burden of providing long-term care to their loved ones. Today, almost 75 percent of our nation's caregivers are women wives caring for husbands, daughters caring for parents, even daughters-in-law caring for parents-in-law.

And this is at a time when more women are working outside the home than ever before. The average caregiver in the United States today is a 46-year old woman who works outside the home and spends 18 hours a week caring for her 77-year old mother.

Long-term care is the major catastrophic health care expense faced by older Americans. It is therefore particularly troubling that, while women are at greater risk of needing long-term care than men, they are usually far less prepared for the financial consequences. In a recent poll of baby boomers, only 27 percent of women surveyed had more than $100,000 in their retirement plans. Thirty-three percent of the women surveyed reported having less than $25,000, an amount that would not even be sufficient to cover 1 year of nursing home costs.

To help address this problem, I have joined with Senator Mikulski in calling for a doubling of funding for the National Family Caregiver Support Program authorized by the Older Americans Act. I have also joined with Senators Grassley, Breaux and a bipartisan group of our colleagues in sponsoring the Long-Term Care and Retirement Security Act. This critically important bill will give a tax credit for long-term care expenses of up to $3,000 to help those families already struggling to provide long-term care to a loved one. It will also encourage more Americans to plan for their long-term care needs by providing a tax deduction to help them purchase private long-term care insurance.

Just as women have more at stake when it comes to long-term care, they also stand to gain the most from public policies that help families meet their long-term care needs. As a member of both the HELP Committee and the Special Committee on Aging, I look forward to working on these issues and thank the Chairmen for the invitation to testify.

The CHAIRMAN. Thank you, Susan.

Senator MIKULSKI. Let me turn now to Senator Debbie Stabenow, and by the way, Senator Lincoln, we like that phrase "the club." We talked about the sandwich generation. Is that "club sandwich" your line? We are going to start to talk about that and make sure it has got the bacon in it.

Senator Stabenow is our next witness. Senator Stabenow is a sister social worker. She has a master's degree in social work. She is essentially a certified do-gooder, but brings incredible background from experience in the Michigan legislature and also the House of Representatives and now in the Senate where she has really championed the issues of the elderly from a prescription drug benefit to the issue of home health care.

The National Committee to Preserve Social Security and Medicare has recognized her with a top award, and the National Association for Home Care has named her a "home health hero." A national magazine has also named her one of the ten powerhouses in Washington. So let us hear the kilowattage.

STATEMENT OF SENATOR DEBBIE STABENOW

Senator STABENOW. Well, good morning, and I want to thank my colleague, Senator Breaux, for your leadership on the committee, as well as Senator Mikulski. I am here today sitting at the witness table as opposed to sitting in my usual seat which would be as a member of the committee, and I look forward to joining the committee as we move forward on these issues.

My colleagues here have spoken very eloquently about the fact that we share a bond as mothers, sisters, daughters, grandmothers, who all are playing a role in long-term care for our loved ones. My mother also is my hero, and my father was ill when I was growing up, and she was, in fact, a nurse, a director of nurses at the local hospital, but, in addition to caring for us, cared for my father and she really is my hero. She is now at 75 on two golf leagues and doing water aerobics and so my guess is she will be caring for me rather than me caring for her. And I am very pleased to have her genes.

But there is no question that while women constitute far and away the highest number of consumers of long-term care in both the community-based services and facility-based settings, we also comprise an overwhelming percentage of both the formal and informal caregiving workforce, and it is so critical that we understand that, and I would hope that we would have the same sense of ur-

gency on a policy level that we have in our homes when our mothers, or fathers, or grandparents need care.

When something happens in our own family, I know for us the world stops until you fix it. There is a sense of urgency about healthcare, particularly long-term care, and I would hope that we could engender the leadership on our two committees that same sense of urgency in the policy arena of what it means to say to a family we will have to wait a year, or 2 years, or 5 years, or 10 years.

Our families are struggling everyday, whether we are paying attention to the issue or not. We have all heard the statistics. I have very specific information that I would like to leave in the written testimony as it relates to Michigan and what has been happening. My great concern is that we are seeing at every level cutbacks, both because of downturns in the community we have seen in the Michigan economy and downturns and cutbacks in Medicaid and the challenges of Medicare and so on.

But we are going in the opposite direction of where we need to be in terms of the need. We are seeing under Medicaid waivers that we are seeing cutbacks, and in fact we are in a situation where we have also seen 18 nursing homes closed in Michigan since 1998, half of them voluntarily, and one of them, in fact, is being closed by the State of Michigan this week due to performance deficiencies.

I also would join with my colleague, Senator Collins, in speaking about the critical needs of home healthcare and the cutbacks that occurred through the BBA and the need to continue to restore those funds, and I would remind all of us that another 15 percent cut is scheduled for this fall and would devastate services, absolutely devastate services available to families nationwide.

I think probably more than any other combination of issues, the one I hear the most about and have heard about from years from the people I represent have been requests for home healthcare and the challenges of prescription drug costs. And I need to mention that today because I believe they are combined as more and more people are attempting to be at home rather than in a nursing home or a hospital. Much of that relates to their ability to have access to prescription drugs, and that is an incredibly challenging issue for us, and I believe underlines the majority of the cost increases that we are seeing in all level of healthcare today, and one that we certainly need to address.

There are many positive things that we have been trying to move forward on as a Congress. In 2002, we reauthorized the Older Americans Act, as we all know, and included a National Family Caregivers Support Program, which is very positive, and I think one of the most important things is that we included respite care, which again we all hear over and over again, and I know we have experienced in my family the need for that time out so that when you are the caregiver and have the day-to-day pressures of caregiving, it is very important to give those caregivers a time out.

In conclusion, I would just say again it is a privilege to be here with my colleagues, each of whom including Senator Mikulski, who is on the dias, who have been champions on this issue, both because of our own personal experiences, but also because of the peo-

ple we represent, and I am hopeful that we will be able to address the challenges and create the sense or urgency that is needed and the sense of urgency that is felt in each family struggling with issues of long-term care and that we will be able to bring that sense of urgency here to the U.S. Senate. Thank you.

[The prepared statement of Senator Stabenow follows:]

PREPARED STATEMENT OF SENATOR DEBBIE STABENOW

It is a pleasure to join my colleagues today at the witness table rather than in my usual seat as a member of this Committee. We women are here today to emphasize the role that we, our mothers, our sisters, our daughters and our grandmothers play in providing long-term care for loved ones.

While women constitute far and away the highest number of consumers of long-term care services—in both community based and facility based care settings—they also comprise an overwhelming percentage of both the formal and informal care-giving workforce.

You all have heard the statistics and what they tell you is that wives are caring for husbands, mothers are caring for children, and grandmothers are caring for entire extended families. Our economy is reliant upon this uncompensated care provided by loving family members, most of who are women. Many of these woman face difficult choices between family and work and because of time away from the workforce may jeopardize their retirement savings, as well. Unfortunately, Michigan's women are facing ever decreasing choices in acquiring or retaining long term care services and help for themselves or their families.

For instance:

- In-Home Care: The Center for Medicare and Medicaid Services (CMS) started the Medicaid waiver program for the elderly and disabled as an optional Medicaid program in 1981. Michigan was one of the last states in the nation to implement a statewide waiver in 1998. In FY 2001, the waiver served almost 15,000 clients. However, that same year, the Michigan Department of Community Health (DCH) decided to stop new enrollments in the waiver program, except for people transitioning out of nursing homes. In FY 2002, the DCH decided not to provide waiver slots to people moving out of nursing homes. The waiver program is now closed to anyone in the community who qualifies for Medicaid and is in danger of moving to a nursing home. The only options for such an individual are enrolling in the Medicaid Home Help program (which uses the most restrictive Medicaid income and asset tests) or moving to a nursing home.

  The DCH has also placed restrictions on the amount of care that can be received by the waiver clients that are still being served. The DCH has only provided enough funding for an average stay of 270 days, and waiver agencies estimate that the average stay will greatly exceed that figure this fiscal year. For this reason, waiver agencies have been forced to cut back on the services received by frail elders and younger people with serious disabilities.
- 18 nursing homes closed in Michigan since 1998—half of them voluntarily—and one of which is being closed by the State of Michigan this very week due to performance deficiencies.
- Assisted living facility beds—both licensed and unlicensed—remain unaffordable to many in the long-term care market, which again is predominated by women.

Other poorly funded community services face even greater cuts and reductions as the current state budget crisis in Michigan deepens. As with so many issues and systems, the major problem with long-term care is that there is a serious deficiency in funding—and consumers in this area are uniquely unable to pay for it.

While I know I must keep my remarks short, I must also briefly mention that funding for home health care was severely cut in 1997 by the BBA and I have been working ever since to restore funding. I would like to remind everyone that another 15 percent cut is scheduled for this fall that will devastate services available to families nationwide.

This is the bad news. But, there are positive stories to tell, as well. In 2000, Congress reauthorized the Older Americans Act. In the reauthorization a new "National Family Caregiver Support Program" was created. It provides funding to states (which pass the funding on to Area Agencies on Aging) to provide information and services to family caregivers. A key component of the services provided is respite care. Respite care can take many forms, but in essence it is there to help relieve the burden of family members caring for loved ones. While this includes help for

elderly spouses caring for an ill husband or wife, it also includes providing support for a growing trend in our country—grandparents caring for grandchildren.

Last year, Michigan received its first allotment for the Family Caregiver Program, $3.8 million dollars. Area agencies on Aging held forums and roundtables throughout the state to make sure resulting services and programs would be tailored to meet the needs of the community. I am already getting positive feedback about this program and I hope that it continues to grow and provide much needed help to families.

In conclusion, I feel is a privilege to join with my Senate colleagues today—both women and men—to voice a concern that families are facing across the nation. Long-term care needs are not being met and women bear much of the burden of filling in the gaps that currently exist. I am hopeful that today's hearing can begin the debate that will lead to offering more choices and affordable solutions for families.

The CHAIRMAN. Thank you very much, Senator.

We are pleased to have Senator Hillary Clinton as our next presenter, fresh from glowing accolades from her opening night performance at the Correspondents' Dinner last night where she was a terrific hit. It is hard to believe that almost 10 years ago, you were before Congress testifying as the chair of the Task Force on Health Care over on the House side. I remember it quite well when you were advocating a national health policy and really talking about some of the same issues that 10 years later we are still talking about, and it shows you the urgency of Congress trying to find a solution to these very difficult problems, which only get more difficult everyday.

So we are delighted to have you back with us and look forward to your suggestions. Hillary.

STATEMENT OF SENATOR HILLARY RODHAM CLINTON

Senator CLINTON. Thank you very much, Senator Breaux and Senator Mikulski and my colleagues. I am pleased to testify along with so many people who have made a real contribution to the ongoing discussion about how we are going to deal with the inevitable transformation of the baby boom into the senior boom, and we are going to be faced with decreasing resources as we look forward. The increasing needs of a population that will become much more dependent, not only on their families but on society.

We have heard some extremely moving testimony as well as stories from the senators on the panel about their own families, and we can only multiply that literally millions and millions of times over to understand the extraordinary pressure that exists today on so many caregivers, and it is not only something that has to be borne by individual families who are heroically dealing with the challenges of caring for not only older relatives but in many instances children with long-term disabilities, people in the prime of life who are struck down, and I hope that this hearing bringing together the resources of the Senate will begin to address the problems.

We have already touched on the number of women who far outnumber men in the aging population, and these women suffer disproportionately from our failure to develop a coherent long-term care financing system, and many women who are not only caring for the loved ones, but are also facing their own deteriorating health and frailty, because older women are twice as likely as men to live in nursing homes and twice as likely to live in poverty.

Because we have an inability in our system to finance and support long-term care, we rely on informal unpaid caregiving and the brunt of that is borne by women. Seventy-five percent of unpaid caregivers are women who on average provide 50 more hours of informal care per week than men.

Third, and finally, an underlying reason why our caregiving systems are in disarray and why these important functions are undervalued, underfinanced, and too often uncompensated in our society is because it is work that women perform in their homes. We too often take for granted the contribution that women make as caregivers, and for too long this work has been invisible. No one paid for it. It did not show up in the GDP.

Now just because family caregiving is unpaid does not mean it is costless. The costs include not just time and lost economic opportunities, but also the personal and emotional strain, fatigue and very frequently poor health. These costs should be recognized. These caregivers must be supported through respite care and other services.

Now, we have made progress, and I particularly applaud my colleagues, especially Senator Mikulski, for taking the leadership position on this, but as economists and as our own common experience tells us, when work is undervalued, it will unfortunately be undersupplied, and we are quickly realizing that our country is suffering not just from a budget deficit but what Mona Harrington has called a "care deficit." In nursing, in child care, in the teaching profession, and in long-term care, we see shortages and looming crises that threaten the provision of care on which our children, our parents, our families, and our society depend.

We have estimated that in New York alone, we have 3.5 million informal unpaid family caretakers. Now thanks to the vigorous advocacy of leaders like Senator Mikulski and others, Congress has passed the National Family Caregiver Program. I think we should expand on the successes of this program. I am working on a bill to extend the concept of the National Family Caregiver Program, which has worked so well for the elderly to other populations, parents who care for chronically ill children, families of disabled individuals, many of whom report to me that they desperately need respite services.

We also should address the need for greater long-term care financing. Medicaid now pays for nearly 40 percent of all long-term care spending, but Medicaid, originally designed as a safety net healthcare coverage system for low-income families, was not designed as a long-term care financing system for middle-income families.

Yet the expenses of long-term care can wipe a family out and many middle class families find themselves quickly spending down their savings and ending up on Medicaid for publicly financed support. I believe that will only increase the problem if we do not address it.

We need new financing tools that are better suited to middle income seniors and families with modest incomes and assets. I have talked with many New Yorkers about what we want out of such a system. I remember talking to a 72-year-old woman who just looked at me with just this great sort of expression of what am I

going to do? I am taking care of my 94-year-old mother with Alzheimer's and my 52-year-old daughter just had an automobile accident and I am now taking care of her.

These stories are not unique anymore. And what we believe would work is a joint state-Federal program to help make long-term care affordable. We want to have a program separate from Medicaid with flexibility so that individuals can decide what services to buy, whether it is paying for home health, an adult day care program, transportation services, or nursing home, and I look forward to working with my colleagues on a bill to capture the features of that kind of flexible plan.

And let me just end by saying that this conversation has to take place within the context of our current budgetary situation. Every option that we think would be needed for available healthcare is going to become harder to provide if we look into the future and see that we are spending the Social Security and Medicare surpluses to pay for operational expenses today. That will put not only our individual families but our entire society in a much more difficult hole to dig our way out of.

So I hope that as we look at a broad array of the needs of the aging and include those who are the unpaid informal caretakers, we recognize that we all have a stake in working out a system that will provide for the help that we need so people can keep their loved ones at home. When necessary, there will be social supports, but I think realistically we are not going to be able to come up with the options that we should if we do not have the resources to provide that help. Thank you very much.

[The prepared statement of Senator Clinton follows:]

PREPARED STATEMENT OF SENATOR HILLARY RODHAM CLINTON

Thank you Senator Mikulski, Senator Breaux, Senator Hutchinson and Senator Craig for your leadership on issues concerning the provision of long-term care in our society.

I am so pleased to be able to testify today, and I look forward to hearing the testimony of other to gather insights on how, as a member of the Subcommittee on Aging, I, along with my colleagues, can help address this urgent challenge.

Our country's piecemeal long-term care financing system is in dire straits, and this system will be under increasing strain in coming years as life-spans increase, and as the Baby Boom becomes the Senior Boom.

And the reason this is of particular importance to women is three-fold. First, women outnumber men among the aging pouplation. Thus women suffer disproportionately from our failure to develop a coherent long-term care financing system, a problem that is exacerbated by the fact that older women are also twice as likely as men to live in a nursing home, and twice as likely to live in poverty.

Second, our the inability to finance and support long-term needs in this country means that many must rely on informal, unpaid caregiving, and you can guess who bears the brunt of that burden: women. Seventy-five percent of unpaid caregivers are women, who on average provide 50 more hours of informal care per week than men.

Third and finally, an underlying reason why our caregiving systems is in disarray, and why these important functions are undervalued, under-financed, and too often uncompensated in our society is because it was work that women performed in the homes. We too often take for granted the contribution that women made as caregivers. For too long, this work was "invisible," no one paid for it, and it didn't show up in the GDP.

Just because family caregiving is unpaid does not mean it is costless. The costs include not just time, and lost economic opportunities, but also personal strain and fatigue, and poor health. Thes costs should be recognized and these caregivers must be supported, through respite care and other services.

But we've made some progress, and now confront new challenges. Women have more opportunities now than they did then, and more responsibilities. So many women in New York have told me how they feel there's not enough time in the day to do everything—holding down a job, shuttling kids to soccer practice and taking a parent to the doctor; helping a child with homework and bathing a parent at night. Some who can afford to purchase care do, and we need to look at how we make high quality care available and affordable, but the many who continue providing care informally, need our support as well. These responsibilities should, after all these years, finally get the visibility they deserve, rather than being taken for granted.

As economists will tell you, when work is undervalued, it will unfortunately be undersupplied. And we are quickly realizing that our country is suffering not just from a budget deficit, but what Mona Harrington has called, "a care deficit." In nursing, in child care, in the teaching profession, and in long-term care, we see shortages and looming crises that threaten the provision of care on which our children, our parents, and our families all depend.

Thanks to to vigorous advocacy of leaders like Senator Mikulski and others, Congress passed the National Family Caregiver Program, and we must expand on the successes of this program. I am working on a bill that would extend the concept of the National Family Caregiver Program, which has worked so well for the elderly, to other populations as well—parents who care for chronically ill children, families of disabled individuals, many of whom report to me how desperately they need respite services.

We must also address the need for greater long-term care financing. Medicaid now pays for nearly 40 percent of all long-term care spending. But Medicaid, originally designed as safety net health coverage for low-income families, not as long-term care financing for middle-income families. Yet the expenses of long term care can wipe a family out, and thus many middle-class families find themselves quickly spending down all their savings and end up on Medicaid for publicly financed support. Now a large bulk of Medicaid spending consists of long-term, not acute care expenditures.

We need new financing tools that are better suited to middle-income seniors, and families with modest incomes and assets. I have talked with many New Yorkers about what they want out of such a system. They like the idea of a joint state-federal program, to help make long-term care affordable. They want to be responsible for their share of costs, but they don't want to lose all their assets either. They like having a program separate from Medicaid, and they also like flexibility, so they can decide what services to buy—whether it's paying for a home health aide, or an adult day care program, or transportation services, or nusing home care. I am working on a bill to capture the features of the plan that would best meet their needs.

Again I thank the Committees for exploring the imporant intersection of gender, long-term care, and caregiving, and I look forward to working with both committees to explore these and other ideas for improving long-term caregiving not just for women, but for all Americans.

The CHAIRMAN. Thank you very much.

Senator MIKULSKI. Excellent.

Now we would like to turn to our colleague Senator Jean Carnahan of Missouri, also a member of this Special Committee on Aging. Senator Carnahan comes with extensive experience from the State of Missouri. She has been long an advocate for Missouri's families. As first lady, she was well-known for being a champion of the needs of children and the needs of parents to be able to care for their children as well as the elderly. She has received numerous awards for her positions on public policy including the state's Martin Luther King Special Achievement Award, the March of Dimes and others.

But I think we have all admired the way Senator Carnahan has just come to the Senate, picked up her responsibilities, has put Missouri first, and made sure that the Missouri families are thought of everyday when she is doing her job. We look forward to hearing from you with your background.

STATEMENT OF SENATOR JEAN CARNAHAN

Senator CARNAHAN. Thank you, Senator. Missouri author Adele Starbird writes about a visit she made with her mother in a nursing home. The conversation went like this. Her mother says, "Well, things are going well for me. I am on an entirely new tract. I am just trying to be pleasant all the time."

Adele responds, "Is it a great effort?"

Her mother says, "Did you ever try it?"

Adele: "No, I'm going to wait until I'm your age before trying anything so drastic."

They both laughed, and then she grew serious. "It is the only thing that is left now that I can do for anybody. I can't read or write, but I can at least be pleasant and not add to the troubles of others. You know I think that every human being is already carrying about as much as they can bear, and I don't want to make it harder."

Adele concludes: "Pleasant. She was more than pleasant. She was gallant."

Well, I tell this story as a prelude to my remarks today because today's hearing focuses on women as caregivers, but you cannot truly understand what it means to be a caregiver until you look at the whole picture, and the whole picture includes a human being who is a recipient of that care. Whether that person is your husband, or mother, or father, chances are they do not want to be a burden. Chances are they do not want their kids caring for them when it should be the other way around.

The first stage in the caregiving process occurs when the aging family member moves from independence to dependence, and for many seniors this involves leaving their home of some 30, or 40, or even 50 years. The decision is usually precipitated by an event that forces the change to occur. The reason can be declining health or finances, a fall or an accident or the death of a spouse.

While it may be clear to the family that their loved one can no longer live on their own, it is not always clear to the individual. I speak about this from personal experience. After my mother passed away, it was clear to me that my father would be better off in my home. The problem was I lived in Missouri, and he had lived all of his life in the Washington area.

He was asthmatic, he was diabetic, and he was subject to insulin reactions. He needed reliable care to make sure that he ate properly and that he exercised regularly. Most of all, he needed the love and support of his family. While I recognize that he should move in with me, that was not at all clear to him. In fact, it was a real test of my powers of persuasion. I gave him all the logical reasons why he should come home with me, and although he listened, he was not convinced.

Finally, in one desperate appeal, I took him by the hand, I looked him in the eye, and I said, "Dad, remember what you hear in church on Sunday morning, that sometimes you have to make a decision based on faith, and this is one of those times. You need to believe that this is going to work."

Well, there was a pause and finally he looked at me, and he said where is my suitcase? Well, I am happy to say that my father lived with me and my husband, and our four children for the 7½ years

before his death. I cherish the memory of those days and I would not trade them for anything. Thank you.

[Prepared statement of Senator Jean Carnahan follows:]

PREPARED STATEMENT OF SENATOR JEAN CARNAHAN

Thank you, Mr. Chairman.

Missouri author Adele Starbird writes about a visit with her mother in a nursing home. The conversation went like this:

Mother says: "Well, things are going well for me I am on an entirely new track. I'm just trying to be pleasant all the time."

Adele: "Is it a great effort?"

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Adele: "No, I am going to wait until I'm your age before trying anything so drastic."

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"It's the only thing that's left now that I can do for anybody.

"I can't read or write, but I can at least be pleasant and not add to the troubles of others.

"You know I think that every human being is already carrying about as much as he can bear, and I don't want to make it harder."

Adele concludes: Pleasant. She was more than pleasant she was gallant.

I tell this story as a prelude, because today's hearing focuses on women as caregivers. But, you cannot truly understand what it means to be that caregiver unless you look at the whole picture. The whole picture includes a human being who is the recipient of that care. Whether that person is your husband, mother, or father, chances are they do not want to be a burden. Chances are they do not want their kids caring for them when it should be the other way around. The first stage in the caregiving process occurs when the aging family member moves from independence to dependence. For many seniors, this involves leaving their home of some 30, 40, or even 50 years.

The decision is usually precipitated by an event that forces a change to occur. The reason could be declining health or finances, a fall or an accident, or the death of a spouse. While it may be clear to the family that their loved one can no longer live on their own, it is not always clear to the individual.

I speak about this from personal experience. After my mother passed away, it was clear to me that my father would be better off in my home. The problem was I lived in Missouri, and he lived in the Washington area all his life. He was asthmatic and diabetic and subject to insulin reactions. He needed reliable care to make sure he ate properly and exercised regularly. Most of all, he needed the love and support of his family.

While I recognized that he should move in with me, this was not clear to him at all. In fact, it was a real test of my powers of persuasion. I gave him all the logical reasons why he should come home with me. Although he listened, he was not convinced.

Finally, in one final desperate appeal, I took his hand and said this to my father: "Remember what you hear in church on Sunday morning? That sometimes you need to make a decision based on faith. This is one of those times. You need to believe that this is going to work." There was a pause. He replied to me "Where's my suitcase?" I am happy to say that my father lived with me and my husband and our 4 children for the remaining 7½ years of his life. I cherish the memory of those days. I would not trade them for anything.

Thank you.

The CHAIRMAN. Thank you very much, Senator Carnahan. Thank everybody on the panel. I mean these were just, Barbara, terrific personal experiences, and there are millions just like all of ours that are out there, and to add to the question now, you know, what do we do? I mean, you know, Senator Clinton was here 10 years ago talking about this, and we have all been talking about this.

You know as the strongest nation in the history of the world, we ought to find a way to help take care of elderly. I have just one question. Senator Dodd and I were talking about this. I sponsored and have worked on trying to make long-term health care insur-

ance more affordable, and it is very expensive now. Nobody can afford it hardly.

We have legislation in with Senator Gramm, Senator Grassley, myself and others that provides a $3,000 tax credit for family caregivers that is phased in, also up to $5,000 tax deductions for the purpose of long-term healthcare insurance.

Senator Dodd and I were talking, and Chris was making the point that the president's budget calls for tax credits for tuition for private schools, tuition tax credit, and if, as which is clear, we have a very tight budget situation, what about offering, as an alternative to a tuition tax credit, offering tax credits for the purchase of long-term healthcare insurance?

Do any of you have any thoughts about that? I mean everyone does not have to—Susan, what do you think? Let us start there.

Senator COLLINS. Well, I have been a cosponsor of your bill for a long time so I am a strong supporter of it, and I think it would make a real difference. What I have found with a lot of my constituents is that they have assumed that Medicare is going to pay for long-term care, and despite the fact that that has never been the case other than for that short period of time after hospitalization, I think that perception is still out there.

One of the things I like about your bill is I think it would start to encourage all of us who do not have long-term care insurance to start buying it now and that would help with the affordability.

The CHAIRMAN. OK. Anybody else?

Senator STABENOW. I would just add to that. I think it is an excellent idea. When I was in the House of Representatives, I also sponsored similar legislation, but the common comment that I heard on the bill that I had introduced was that it was not a large enough amount. I think the real concern is whether or not $3,000 will be able or $5,000 will truly be able to make a dent as we look at the costs long-term, and I would go back along with this because it certainly is a start, and I certainly would support it.

But that is the most common comment that I heard regarding the $3,000. The other piece, though, really does go back to the whole question of prescription drugs, and I think we have to, when we look at long-term care, also be looking at the fact that the majority of these people are looking at very large, hundreds of dollars a month, prescription drug costs, and that that is very much a part of what is happening.

So I would hope as we do this, and I know, Senator Breaux, you have been focused on that, as well as many members have. But the tax credit makes sense, but somehow we have got to also address this huge issue, which is more out-of-pocket costs even than long-term care.

The CHAIRMAN. Senator Mikulski.

Senator MIKULSKI. Well, I just wanted to thank my colleagues for their outstanding testimony and to say a couple of things. I think we have issues really that we could do this year. If we are going to talk about tax breaks, then we ought to talk about targeted ones and I think this whole idea of giving help to those who practice self-help is really important.

The other is I want to remind my colleagues that again working on a bipartisan basis, because this is the way we get it done, we

passed the long-term care insurance opportunity for Federal employees so that Federal employees can buy long-term care insurance. They will receive no government employer subsidy, but because we are buying it in bulk, we will be able to reduce those rates.

That is coming out—the legislation passed 18 months ago. It was done with our colleagues here. Senator Grassley was a leader, our colleague Senator Cleland, others on the Government Affairs Committee. The point that I am making is Federal employees will be able to buy this, Federal retirees will be able to buy this, and then we are going to get lessons learned on really what is the best way to fund long-term care also through private insurance. So that is a good match.

The National Family Caregiver Support Program passed because we were able to reauthorize the Older Americans Act that had not been reauthorized in almost a decade. I am going to be holding a hearing, Senator Breaux, on the National Family Caregiver Support Program. I welcome advice and insight on an oversight hearing. Is it working and how can it work better?

But I do think the issue of BBA givebacks continues to be a toxic cloud that is over our nursing homes, our home healthcare, and even our own acute care facilities, and I think we really need to address that along with this prescription drug benefit.

But, you know, when we really work together, each and every one of my colleagues, both at the witness table and up on the dias here, has made a difference, but when we work together, we can make change, and I look forward to doing that.

The CHAIRMAN. Thank you. Now, our ranking member of the Senate Aging Committee who has been here and working with us very closely, Senator Craig.

STATEMENT OF SENATOR LARRY E. CRAIG

Senator CRAIG. Well, Mr. Chairman, chairmans, chairpersons, thank you very much, but certainly to Senator Collins and Senator Stabenow, let me thank you and your colleagues for your phenomenal testimony today. I think all of us were not only interested in hearing it, but you began to share with us the leadership roles you have taken on some of these critical issues.

As I for a short period of time chaired the Aging Committee before Senator Breaux picked it up, and I began to focus more clearly on the issues of aging, there were some figures that stood out in my mind that spoke to me more loudly than anything I had seen or heard. And that was that we tend to focus on those in need of care in the aging community that are visible to us, and those are a small, small minority of those that are truly being cared for in the homes of Americans.

Within our culture is a marvelous commitment, and that is to care for our own as best we can. It is not just a sense of obligation. I do believe it is a part of us, and what we have focused on and what you have focused on, and I heard Senator Mikulski say it, to try to help those who help themselves. Clearly, the cost of care today to that busy person out there, and you are right, in most instances it is the woman that gives the care, is not only expensive

from a true dollar standpoint, it is phenomenally expensive from a time commitment.

While I do not think it is in this country's best interest to want to change that culture, it clearly is in this country's best interest to help it, to improve it where we can, because my guess is that providing all of the resources, there will still be that great sense of obligation on the part of the daughter or the son to want to care for his or hers as best they can as long as they can. And, yes, there are a variety of options out there for those who have more, but clearly as a baseline in this country, for those who feel it necessary to keep their aging parents or relative within their homes, there ought to be some benefits that help them assure that care can be given.

I think one of the most important hearings that Senator Breaux and I held was a hearing that spoke of the need to know and how to be able to handle and cope with an aging parent who develops disabilities and becomes a physical burden as well as an emotional burden, and how to train and be trained and to be educated in how to handle this in a way that with some limited skills can certainly improve the time spent and lessen the pressures borne.

We can help there, though, and all of you have offered legislation or have spoken out in leadership roles for that purpose, and let me thank you all so very much for doing that. That is part of what we can do. Sometimes it is the little incentive. Sometimes it is the bigger incentives.

Senator Stabenow, I cannot disagree with you on the issue of prescription drugs. This Senate in a bipartisan way must lead on that issue. It is without question the driving force in healthcare costs today, and that is probably the larger issue that has to be dealt with and should be dealt with, as the other issues of creating the incentives and/or the help for those who want to keep their aging parent or relative within their home. Thank you all very much. Susan, thank you. Mr. Chairman, thank you.

The CHAIRMAN. Thank you, Senator Craig, for your contribution.

Senator CRAIG. Let me ask unanimous consent that my opening statement be a part of the record.

[The prepared statement of Senator Craig follows along with prepared statements of Senator Landrieu, Senator Snowe, and Senator Cantwell:]

PREPARED STATEMENT OF SENATOR LARRY CRAIG

Good morning. Thank you for attending this Joint hearing between the Senate Special Committee on Aging and the Health, Education, Labor and Pensions Subcommittee on Aging.

We are all aware that women play a role in addressing the long-term care needs of their family members and loved ones. In fact, Idaho, consistent with the national average, has almost one quarter of its households providing care to family and friends over the age of 50. Through this hearing, we will all get a better understanding of the vast amount of care that is actually provided and the large toll that it can take on women providers.

We have the honor today of hearing testimony from many of my female colleagues who will share their unique experiences in caring for their own family members and friends. These individual stories, I believe, will be representative of the stories of thousands of women across this country.

On our second panel, we will be hearing from two of the outstanding advocacy groups on this issue. The Older Women's League will share with us specific financial and health concerns that can be raised for females when assisting a family member

with their long-term service and support needs. And the National Alliance for Caregiving will speak about the role of women caregivers.

The title of this hearing the "Bearing the Burden of Long-Term Care." This is not meant to imply that caring for family members and friends is something that is univiting and should be avoided. In fact, in my experience, most individuals want to help take care of their family members. Instead, we are holding this hearing to shed light on the issue so we can begin to assist the many daughters and wives who are struggling with the daily task of caring for older family members.

Again, I would like to thank the witnesses for testifying and I look forward to hearing your testimony.

Thank you.

PREPARED STATEMENT OF SENATOR MARY LANDRIEU

Good Morning. I would like to thank the committee for allowing me the opportunity to testify on women and aging, a subject that affects all Americans today, either directly or indirectly. I would especially like to thank my Senior Senator John Breaux who has been an extraordinary leader in this area. He is relentless in his pursuit of common sense solutions to the issues involving the elderly and for this he should be commended. I am proud to join him in his fight to address the needs of aging women.

The statistics on this issue confirm what common sense has told us for some time. The first of the baby boom generation will turn 65 in just ten years and with the advances of medicine more of them are living longer. It is expected that by 2040, there will be nearly four times as many Americans over age 85 as there are today. While these numbers affect the elderly population as a whole, they have a disproportionate effect on women. On average, women outlive men by seven years. On the other end, three quarters of all caregivers are women.

Because women live longer, they are exposed to more chronic diseases and disabilities—heart disease and lung cancer, osteoporosis and breast cancer. In addition to supporting programs aimed at better research and treatment of these diseases, Congress must do all that it can to ensure that the programs that serve women with these diseases are as up to date and effective as possible.

This is particularly true of Medicare. Fifty-seven percent of Medicare's 39 million beneficiaries are women. As we know, our Medicare system has not kept pace with medical advancements and as a result has become outdated. Medicare should adopt the best management, payment, clinical and competitive practices used by the private sector to help maintain high-quality services and keep spending growth in line with private sector spending. In addition, strong and effective federal administration of Medicare should be assured.

We also must do what we can to help improve education and accessibility to long-term care insurance. Less than 1 percent of long-term health care expenditures are paid for by insurance. As a result, seniors are plagued by an ongoing concern about the cost of long term care for themselves or a loved one. These are not decisions that our parents and grandparents should have to make alone. We must strengthen programs that help provide greater access to insurance programs for these purposes.

Finally, I would like to stress how important programs like independent living services, rehabilitation services and community based support programs are for our senior citizens. Many elderly women have spent their lives engaged in the service of others, whether serving as a wife for their spouse, a mother to their families or a leader in their communities or their professions. It is often very hard for them, because of health needs, to become "dependent" on others. There are many very successful programs that provide the assistance support and care these women need in a setting that allows them to continue to be independent and productive citizens.

Again, I am proud to join my colleagues in support of this important hearing. I hope it is the first of many opportunities forus to engage in a discussion of future solutions to what is a very real problem.

Thank you.

PREPARED STATEMENT OF SENATOR OLYMPIA SNOWE

I would like to express my appreciation to the Chairman and Ranking Member of the Special Committee on Aging, Senators Breaux and Craig, and to the Chair and Ranking Member of the HELP Subcommittee on Aging, Senators Mikulski and Hutchinson, for holding this hearing and bringing attention to the dual challenges women face when it comes to long-term care. Women not only have to worry about

their own long-term care arrangements, they are also the predominant caregivers for their family members.

The fact is, long term care is a women's issue. First of all, these issues affect women the most, as women are the primary recipients of long-term care. Two-thirds of home care consumers are women, and women are three-fourths of all nursing home residents over age 65. More than 80 percent of family caregivers for chronically ill seniors are women and the average woman can expect to spend 17 years caring for a child and 18 years caring for an elderly parent. Women also make up more than 90 percent of paid long-term care workers in the U.S.

Long-term care issues have been of critical interest to me throughout my tenure in Congress. As the Co-Chair of the Congressional Caucus on Women's Issues for 10 years and as a member of the House Select Committee on Aging, I focused on issues affecting the health and economic equity of women. In fact, Senator Wyden and I served together on the Select Committee on Aging and have worked together on issues ranging from long- term care, to funding for Alzheimer's disease and osteoporosis research.

Improving the availability and quality of care for patients with Alzheimer's disease has been a priority for me. In 1984, my efforts resulted in a requirement for the Administration on Aging to place a priority on grant applications from students who specialize providing care for Alzheimer's patients. In 1987, I introduced the Alzheimer's Disease Coordination Act, which was included in the Older American Amendments of 1987.

Another concerning of mine has been the quality of care that long-term care patients receive, and in 1987, I introduced the Long-Term Care Patient's Rights Act, which was including in the Budget Reconciliation Act. As a result, states are now required to inform people of their rights when they become a patient in long-term care facility. And, my good friend Senator Mikulski and I both worked on the spousal impoverishment issue in 1987 one of the very few provisions of the Medicare Catastrophic Coverage Act that Congress did not repeal in 1989.

More recently, my focus has turned to providing tax credits to family caregivers to reduce the financial burden of caring for a loved one at home, and providing additional Federal support for respite care services. As a member of the House in 1986, I introduced the first resolution to designate National Family Caregivers Week with Senator Glenn, who was a member of the Senate Aging Committee, in an effort to bring attention to the needs of our family caregivers.

My interest in increased funding and emphasis on Alzheimer's disease resulting in the Alzheimer's Disease and Related Dementias Research Amendments, which was signed into law in the 102d Congress. I was also successful in expanding the Older Americans Act to provide supportive services for family caregivers. These services, which caregivers can now receive today, include training, access to support groups, respite care and information and referral for other related services. Through my efforts the Older Americans Act also now provides improved services to protect the rights of older individuals who are in a guardianship.

To make long-term care policies more affordable, I have worked to improve the tax deductibility of long-term care insurance policies and introduced legislation to accomplish make this a reality. In 1996, as part of the Health Insurance Portability and Accountability Act, Congress expanded the tax treatment of long-term care policies so that they are treated the same as other health care insurance coverage expenses. I was also successful in ensuring that long-term care policies that offer per diem benefits, which offer a set dollar amount each day for services, are treated the same as policies that provide reimbursement for specific long-term care services.

Today, we need to refocus and reinvigorate our efforts on long-term care. The challenges will only grow more difficult, and it has been nearly 10 years since Congress took a comprehensive look at long-term care during the health care reform debate. When Americans were beginning their love affair with the automobile in 1900, there were three million people in the U.S. over age 65 and the average life expectancy was 47. Today, there are 35 million people over age 65 and the average life expectancy is 79 for women and 74 for men. Between now and 2050, the number of people over age 65 will more than double to 82 million seniors—1 in 5 Americans—56 percent of whom will be women.

And, the number of people afflicted with Alzheimer's disease now will almost double by 2020 to seven million—with 70 percent receiving care at home. The number of patient's with Alzheimer's disease will double again to 14 million, reaching epidemic proportions, by the year 2050 unless scientists discover preventive therapy or a cure. We are in a race against time, a race against the aging of the Baby Boomers and the diseases of aging, and a race to find solutions to a pending national crisis in long-term care.

We used to think about the retirement of the Baby Boomers as if it were a far off event like the arrival of the 21st century. Now, here we are, with only ten more years before the first Baby Boomers retire, which is the leading edge of a large storm front of Baby Boomers who will follow them into retirement. This issue won't just go away, and there is no simple one-size- fits-all solution.

What must drive our effort is the reality that while Congress debates the issue, thousands of family caregivers have stepped forward to take care of their loved ones. These family caregivers mostly women are caring for chronically ill family members or those with disabilities on a 24/7 basis because they want them to be able to stay at home in a loving and caring environment. More than 26 percent of all adults in the U.S. have taken care of a loved one or close friend during the last year. With Alzheimer's disease alone, there are more than 5 million families caring for their loved ones three times more than in 1987 and, almost 4 in 10 have been providing that care for more than 5 years. The average caregiver provides care for 8 years, and one-third provide care for 10 years or more. Family caregivers put aside vacations and hobbies, have less time to spend with other families members, pass up job promotions, incur substantial out-of-pocket expenses, and many suffer from physical and mental health problems as a result of their caregiving. And, at some point, the caregiver deserves a break, a respite, from their compassionate commitment.

When Senator John Glenn and I introduced the first legislation on Family Caregivers in 1986, we did so in order to bring attention to the important work they do and the crucial role they play in the nation's long-term care system. And we have made some progress. Two years ago, Congress established the National Family Caregiver Support Program as part of the Older Americans Act reauthorization. States can use these funds to provide respite care in the home, or in an adult day care center, or even over a weekend in a nursing home or assisted living facility.

But we need to do more. And one key area where we can help right now is to change the tax code to provide assistance with respite care costs. Family caregivers not only take care of their loved ones, but in fact they save us a lot of money. If federal, state, and local governments were suddenly faced with providing this care through paid home care staff, they would have to find an additional $196 billion each year in their budgets. One key area where we can help right now is to change the tax code to provide assistance with respite care costs. We should take an important step toward lessening the financial and emotional cost of Alzheimer's disease by providing relief to patients and their families. Legislation that I have introduced would permit families to deduct the cost of home care and adult day and respite care from their Federal income taxes, if care is provided to a dependent suffering from Alzheimer's disease.

We also should expand the dependent care tax credit to apply to respite care costs. I have introduced a bill to accomplish this and in so doing also restore the original intent of the credit to provide the largest possible benefit for low-income individuals by expanding the credit and making it refundable. My legislation would increase the percentage of work-related dependent care costs that qualify for the tax credit from 30 percent to 50 percent for families earning $15,000 or less, and phase the credit down to a 20 percent tax credit for those earning $45,000 or more annually. The dependent care tax credit was created in 1976 to help low- and moderate-income families alleviate the burden of employment-related dependent care. We need to update the credit so it reflects today's world.

Respite care, while important, is just the tip of the long-term care iceberg. In order to address the serious and growing long term care challenges, we owe it to current and future generations of women and their families to make long-term care our priority.

We should take steps to ensure the long-term care that seniors receive today is of the highest quality. We need to have effective regulatory and enforcement procedures and more focused attention on those providers with a history of compliance problems and poor quality care. We need to examine Medicaid funding for long term care services, and we need to permanently eliminate the 15 percent cut in home health care payments.

Next, we need to look at longer-term solutions that will benefit future generations of retirees. We should provide tax incentives for people of all ages, but especially younger people, to purchase long term care insurance. Then, we need to support a national campaign to get the message out that people need to consider purchasing long-term care insurance and invest in the security of knowing you will be cared for when you need long term care.

Finally, I believe we need to take a comprehensive look at long-term care issues because a piecemeal approach, by definition, will leave important issues unaddressed.

This should be our nation's long-term care agenda, and I would like to thank you again for holding this hearing and calling attention to these important issues and how they affect women. These issues will not go away, but will only become more difficult to address as time goes on. I sincerely hope this hearing can generate a new spirit of interest and cooperation encouraging us to work together to move these important issues forward. Thank you.

PREPARED STATEMENT OF SENATOR MARIA CANTWELL

Thank you, Senator Mikulski and Senator Breaux. I appreciate the opportunity to testify at today's hearing, and I want to express my gratitude for the leadership you both have shown on this topic over the years.

I believe that Congress has a responsibility to ensure that families have adequate resources to care for their loved ones. I know that I am extremely lucky—I have the honor of representing the people of the State of Washington here in the Senate, and my mother is healthy. But not everyone is as blessed as I am. Women are major stakeholders in the debate on long-term care policy because we are over-represented as both caregivers and recipients of care.

As the Committee knows, with only about 1.6 million individuals residing in nursing homes, most people who need long-term care receive it in home and community-based settings. In fact, the American health care system relies heavily on informal caregiving—to the tune of $200 billion in uncompensated care annually. And there is no doubt that as the baby-boomers retire in the coming decades, as well as continue to tend to their own parents' needs, long-term care services will be in much greater demand.

Issues surrounding long-term care—availability, quality, cost, and other public policies—have a disproportionate impact on women. And worries about long-term care do not begin when illness or disability strikes women personally. Because women make up nearly three-quarters of the informal, unpaid caregivers in this country, the worries begin when middle-aged women start to provide care for their elder parents, parents-in-law, other family members, or friends.

Most informal caregivers are in their mid-forties to mid-fifties, work full time, and may also be primary caregivers for their children or grandchildren. In order to accommodate the extra hours and commitment required of them, informal caregivers often must curtail their own professional advancement, reducing both their current earnings as well as future retirement benefits. And while women are most likely to need respite from our caregiving duties, we are least likely to receive it.

Many factors exacerbate the problems facing women when we decide how to address our long-term care needs. We live an average of seven years longer than men. We are more likely to live with multiple chronic health problems requiring long-term care services such as arthritis, hypertension, or osteoporosis. And we are also more likely to face poverty than men during retirement, making purchase of private long-term care services difficult if not impossible.

I believe both state and federal policy makers have a duty to ensure the long-term care security of our constituents. I wholly applaud the work done in the last few years by Senators Mikulski and Breaux to establish the National Family Caregiver Program. And as today's hearing demonstrates, this will not be the end of the debate. We need to continue to focus on how to improve access, how to ensure quality, and especially how to lower both private and public costs of these vital services.

Thank you, Senators Mikulski and Breaux for inviting me to testify at this hearing. I am confident that together we will be able to ensure that women and our families have adequate resources to care for our loved ones.

The CHAIRMAN. Without objection, so ordered.

We have another panel that we would like to welcome up at this time: Dr. Laura Young, who is Executive Director of the Older Women's League, known as OWL, which is a wonderful acronym, which is the only national grassroots membership organization to focus solely on issues that are unique to women as they age.

It is now in its 22nd year. The group has established itself as a reputable source for information on caregiving and long-term care. Dr. Young is representing OWL as its Executive Director. Before that, she was a Senior Vice President for the National Mental Health Association. And I look forward to Dr. Young's testimony.

Senator Mikulski, you want to do a joint introduction because you have to leave?

Senator MIKULSKI. Yes. I am very happy, first of all, to welcome Dr. Young, and also excited that Gail Gibson Hunt is going to testify. She is the Executive Director of the National Alliance for Caregiving. It is located in Bethesda, Maryland along with the home of the National Institutes of Health. The Alliance plays a very important role because it supports family caregivers through research, outreach and public awareness. It does it by bringing together organizations like AARP, the National Council on the Aging, even the Department of VA, to get everybody in the same room to really talk about the same issues. That in and of itself is to be commended.

Ms. Hunt herself is an expert on aging and elder care. She has worked tirelessly to improve the quality and availability of those services, and before taking her position with the National Alliance, she was the president of a management consulting firm specializing in aging issues.

She oversaw the first National Caregivers Survey in 10 years and three studies on the impact of caregiving in the workplace. This is exactly what we need to know, and again I would like to say to both of you, we will be holding an oversight hearing on the National Family Caregiver Support Program later on in the spring, and we really want to have your participation.

Mr. Chairman.

The CHAIRMAN. Dr. Young, we have you going first.

STATEMENT OF DR. LAURA YOUNG, EXECUTIVE DIRECTOR, OLDER WOMEN'S LEAGUE, WASHINGTON, DC

Dr. YOUNG. Thank you. Chairman Breaux, Chairwoman Mikulski, and distinguished members of the committee, I appreciate your invitation to testify today on the critical issue of women, caregiving, and long-term care reform.

The Older Women's League, or OWL, as we are known, commends you for addressing the concerns of America's caregivers and especially for your recognition of women, who bear the burden of caregiving. As the executive director of OWL, the only national grassroots membership organization dedicated exclusively to the unique concerns of women as they age, I can assure you that our members have a very personal stake in the issue of caregiving, as caregivers and care recipients.

Allow me to paint you a picture of the typical informal caregiver. She is a married woman in her mid–40's to mid–50's, employed full time, spending an average of 18 hours per week on caregiving. In addition to juggling her career with caring for a parent, partner or spouse, she may well be primary caregiver for her children and increasingly her grandchildren as well.

While society owes a huge debt to these women, here is the reward we offer. Caregivers risk their own financial security, face emotional and physical health challenges, and have few affordable accessible services to turn to for support.

The financial picture for caregivers is not pretty. About half of caregivers in the paid labor force report their career is affected by caregiving: arriving late for work, leaving work early, or taking un-

scheduled leave days. Often the consequence is a move to part-time or more flexible jobs, and about one in five caregivers end up leaving the workforce entirely.

A cut in work hours equals a cut in wages, a tradeoff women can ill afford since we still make only 73 cents for every dollar a man earns. Midlife is often a woman's peak earning period, yet it is also the time her wage earning is interrupted by caregiving. It is estimated that caregivers lose an average of half a million dollars in lifetime wages. You cannot save what you do not earn.

Social Security benefits are also affected by caregiving. Caregivers suffer an average loss of $2,100 annually, and given that the average older woman in America today has little over $15,000 in annual income, these lost Social Security benefits have a significant impact.

It is not just wages that are affected. Part-time or more flexible jobs are less likely to offer benefits such as health insurance or pension coverage, and while the gap has been shrinking, women still have not caught up to men in rates of pension coverage, and caregiving with its interruption of work patterns is one of the culprits.

Mental and physical challenges are also part and parcel of caregiving. A substantial number of adults who provide care to a parent, age 65 or older, report symptoms of depression. This can impair a caregiver's ability to provide care and endanger her own health as well. The incidence of depression is higher among informal caregivers and women are diagnosed with depression twice as often as men.

There is physical impact as well, and studies show that two out of three informal caregivers are in ill health. Routine caregiver tasks can cause acute and chronic physical strain, particularly when caregivers lack appropriate training.

As a result of all of this, women are more likely than men to face poverty in retirement: 12 percent vs. 7 percent. As the number of women who provide informal caregiving increases, the number of poor older women will inevitably increase.

The sad truth is that America assumes women will continue as informal caregivers. As long as words like "love" and "commitment," "duty" and "family" are used in relation to caregiving, society will always see it as women's work and devalue it. My written testimony lays out nine policy recommendations to support caregivers, protect their health and retirement security, and I hope you will consider such changes.

But we also must confront difficult and pervasive social norms that expect women to care for others more than they care for themselves. It should not be lost on us that today's caregivers end up as tomorrow's care recipients. Women make up more than two-thirds of nursing home residents, and the typical nursing home resident is a 75-year-old woman.

Ninety percent of women ages 65 and over report one or more chronic conditions, and 75 percent have two or more. Women's increased longevity means that we make up 60 percent of adults over 65, and by age 85, there are more than twice as many women in America as men.

So what does this mean for the long-term care debate? Simply, the current long-term care structure needs a major overhaul as it does not work for women. Women's lower lifetime earnings make most long-term care insurance policies unaffordable, and since Medicaid only assists the poorest of seniors, many low income women cannot seek assistance until they spend down virtually all their savings and assets. With the average nursing home costs running about $30,000 a year, this solution does not work for most women.

OWL is also gravely concerned about the caregivers inside the long-term care industry: home health aides, nursing home aides, and other paraprofessionals who provide the bulk of day-to-day care. This workforce is 93 percent female and paid very little. Although we ask these workers to care for our frail elders, paid caregivers face poverty level wages, inadequate training and little opportunity for advancement with sometimes dangerous working conditions.

There is extremely high turnover rate in these jobs that further threatens the delivery of quality care. Thus, the cycle continues with our formal caregivers unable to provide the best care to our elders and ill-prepared to afford their own long-term care needs later in life.

OWL believes we need to build a new paradigm for long-term care policy that values caregiving and caregivers, without requiring women to sacrifice their economic security and retirement to achieve it. The picture painted of women caregivers and long-term care appears very bleak. It is now time to paint a new picture. Thank you for picking up the brush.

The CHAIRMAN. Thank you, Dr. Young. Appreciate your testimony.

[The prepared statement of Dr. Young follows:]

Women and Aging: Bearing the Burden of Long-Term Care

A Joint Hearing of

Special Committee on Aging
&
Aging Subcommittee
of the Health, Education, Labor, and Pensions Committee

U.S. Senate
February 6, 2002

Testimony of Laurie Young, Ph.D.
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Mr. Chairman, Madame Chairwoman, and distinguished Members of the Committee:

I appreciate your invitation to testify today on this critical issue of women and caregiving. The Older Women's League (OWL) commends you and your respective committees for engaging in the important discussion of addressing the critical needs of America's caregivers, and especially for your recognition of women, who bear the burden of caregiving.

My testimony today will focus on how caregiving affects women, including its long-term financial and health consequences. I will also highlight a few policy recommendations that OWL believes would greatly assist caregivers.

As the executive director of OWL, the only national grassroots membership organization dedicated exclusively to the unique concerns of women as they age, I can assure you that our members have a very personal stake in the issue of caregiving.

Women Are America's Caregivers

OWL's 2001 Mother's Day Report, *Faces of Caregiving*, released last May on Capitol Hill, addresses the value, scope and consequences of informal caregivers' work. "Informal caregiving" is a catch-all phrase that refers to unpaid care and financial support provided by family members or friends to people with chronic illness or disabilities. It is the backbone of long-term care and support in America.

The report reminds us that women provide the majority of informal caregiving — and often pay a steep price for their efforts. Caregivers suffer reduced wages and job security, which inevitably lead to diminished retirement security. Informal caregivers also experience emotional and physical stress that can take a toll on their own health.

When we speak of caregiving, OWL uses a broad definition that encompasses raising children, assisting people with disabilities, and caring for frail elders. As the voice of midlife and older women, OWL stresses that caregiving truly spans the generations. We also underscore the one common denominator to all forms of caregiving — women do the majority of caregiving work, both paid and unpaid.

I would like to begin by describing the scope of informal caregiving in America. We know that as many as 52 million Americans, or 31 percent of the adult population, are informal caregivers. Almost one-quarter of American households provide care to friends or relatives age 50 or older. We also know that informal caregivers provide an irreplaceable service, estimated at nearly $200 billion annually. When formal home care expenditures are added to the $200 billion "public good" of informal care, the economic value of community-based care dwarfs the value of institutional care by a ratio of nearly three to one. In fact, informal caregivers provide more care in the home — free of charge — than the federal government provides in all settings combined.

Gender makes a difference when it comes to informal caregiving. Nearly three-quarters of informal caregivers to seniors are women. Women on average provide 50 percent more hours of informal care per week than men. Women also provide informal care for longer periods of time than men — in many cases, for more than five continuous years.

The typical informal caregiver is a married woman in her mid-forties to mid-fifties. She is employed full-time and also spends an average of 18 hours per week on caregiving. In addition to juggling her career with caring for a parent, partner, or spouse, she may be the primary caregiver for her children and, increasingly, for her grandchildren as well. Between 20 and 40 percent of caregivers are members of the "sandwich generation," caring for children under age 18 in addition to other family members. Because women are more likely than men to assume caregiving roles, they are also more likely to be sandwiched by the needs of two or more generations.

Beyond the averages, we cannot forget that different communities tackle their own unique caregiving challenges in different ways. African Americans women have higher rates of providing informal care than women in general, and are more likely to be raising grandchildren. Hispanics are the fastest-growing segment of the population and face unique language barriers to accessing formal services. The gay, lesbian, bisexual, and transgendered community faces its own set of issues regarding caregiving, especially because they are less likely to have certain sources of support, such as government and employer assistance policies. Meanwhile, Asian American caregivers tend to be younger, which lends a unique twist to their needs. In our efforts to respond to the needs of caregivers and those they are caring for, we must remember that such needs are as diverse as the faces of those who provide the care.

The common denominator is that the majority of caregivers in all of these communities are women. It is women who provide the unpaid care and support to parents, children, grandchildren, spouses, and partners. And it is women who pay a financial, emotional, and physical price for the care they provide.

Caregiving Affects Women's Financial Security

So we know that caregiving is a gender issue. But OWL also sees caregiving as a retirement security issue. Women's earnings and retirement security are put at risk by informal caregiving, increasingly so the longer women provide care.

Informal caregivers often curtail their professional opportunities and thereby imperil their financial security in retirement. Fifty-four percent of caregivers in the paid labor force report their career is affected in some way by caregiving, which may require them to arrive for work late, leave work early, take unscheduled leave days, or have intermittent absences during the workday. Seven percent of informal caregivers who are employed report they moved from full-time to part-time work or took a less demanding job in order to accommodate their caregiving work. It is extremely difficult to balance caregiving with a career given society's reluctance to value informal caregiving and paid employment equally. Yet informal caregivers are expected to find this balance.

For many women, caregiving influences their employment from the very first job. As a result of their caregiving patterns, most women work in lifetime low-wage jobs that give them the flexibility to move in and out of the workforce. In general, women make up the majority of the part-time and contingent jobs that rarely offer the benefits women need for a secure financial future, such as pensions. Twenty-five percent of all female wage and salary workers are part-time, compared to about 11 percent for men.

Caregiving doesn't just impinge on the course of a caregiver's career; it can often preclude her from working at all. Six percent of caregivers who were previously employed reported they stopped working because of caregiving, 11 percent took a temporary leave of absence, and another 4 percent took early retirement. All told, roughly a quarter of caregivers who were previously employed stopped working for an extended period of time because of their caregiving roles.

The sacrifices that informal caregivers routinely make during midlife — a peak earning period — reduce lifetime earnings and retirement savings. It is estimated that caregivers lose an average of $550,000 in total wage wealth, and their Social Security benefits decrease an average of $2,100 annually, as a result of caregiving. These figures would be even larger if losses associated with childcare responsibilities were also included.

These financial sacrifices can be particularly troubling for women: time out of the workforce diminishes their earning power, which is already reduced by the wage gap. As a result, women are more likely than men to face poverty in retirement: 12 percent vs. 7 percent.

As the number of women who provide informal caregiving increases — and if caregiving continues to negatively impact women's earning power — the number of poor older women will inevitably increase as well.

Caregiving's Impact on Women's Health

Women with caregiving responsibilities often face more than financial stresses; mental and physical challenges are also part and parcel of informal caregiving. Although the overwhelming majority of adults who provide informal care to a parent age 65 or older say they feel loved, appreciated, and proud of the care they provide, a substantial number feel worried, frustrated, sad, depressed, or overwhelmed.

These emotional stresses can be accompanied by physical impairments as well. One-third of informal caregivers describe their health status as fair or poor. In reality, the situation is far worse. One study found that two out of three informal caregivers were in ill health. Although most caregiving is short-term, prolonged responsibilities take a toll on the emotional and physical health of caregivers.

Approximately one-third of informal caregivers are "very" or "somewhat concerned" about juggling caregiving with other aspects of life. Caregivers worry about not having enough time to spend with their spouse, partner, or children, or by themselves. Concerns about maintaining personal health or missing work as a result of caregiving are also very common.

In some cases, this emotional stress leads to depression, which can impair a caregiver's ability to provide care and also endanger her own health. The incidence of depression is higher among informal caregivers than in society at large, and women are diagnosed with depression at twice the rate of men. Other common physical manifestations of caregiving stress include insomnia, indigestion, changes in appetite, and increased frequency or intensity of headaches. Informal caregivers can become so overwhelmed with caregiving that they neglect their personal health until a crisis arises, and such crises are often costly. An expectation that women will bear additional health-related costs due to increased informal caregiving could have a devastating impact on their retirement security.

Routine caregiver tasks such as heavy lifting and moving; changing of bedding; dressing; bathing; and helping with the toilet can cause acute and chronic physical strain, particularly when caregivers lack appropriate training. Forty-four percent of informal caregivers report physical strain as a result of their caregiving activities. Stress imposed by daily caregiver tasks may render informal caregivers more susceptible to illness. One study found that chronic stress in informal caregivers can weaken the caregiver's immune system. Because the majority of informal caregivers are over age 50, their risk of experiencing health problems is already relatively high.

Bearing the Burden

There are some in the long-term care community who in fact object to the use of the word "care," who prefer instead the phrase "long-term services and support." OWL supports that preference, but for us the reality is that women *do* care — emotionally, physically and financially. OWL just doesn't believe women — or anyone else — should be expected to willingly sacrifice their own retirement security or health as a consequence of caring.

So America depends upon women as caregivers, and in many ways expects them to assume this role — that's nothing new. The important question is why. OWL would submit that the answer is deceptively simple: America depends on women because it can. As long as words like love and commitment, duty, and family are used in relation to caregiving, society will always see it as "women's work."

Unfortunately, women's work is consistently devalued, and too often policy solutions reflect this bias. Caregiving is a perfect case in point. Current long-term care policy assumes women will continue in this role, and many of the "solutions" — while well-meaning and even helpful in the short term — revolve around encouraging women to continue to do this work. Changing the way we talk and think about the work of caregiving would also lead us to focus more on the person who needs the service and the service itself. OWL is convinced that changing the focus as such would produce better long-term care policy.

OWL also believes we need to build a new paradigm for long-term care policy that values caregiving and, moreover, is aimed at getting the best and most appropriate care to those who need it — without requiring women to sacrifice their economic security in retirement to achieve it. This repositioning would put caregiving on a whole new plane. Caregiving relationships are as varied as the faces of those who provide care, and the motivations for providing such are more

complicated than obligation or familial love.

Now, the challenge: There is no simple remedy in sight. Public policy and community services should be improved, but we also must confront difficult and pervasive social norms that expect women to care for others more than they care for themselves.

The aging population and increased longevity are two trends that could drain the nation's informal caregiving resources if a comprehensive long-term care and support system is not developed and implemented. Appropriate public policy responses are critical if we are to address the emotional, physical, and financial challenges facing caregivers today and to ensure that caregiving does not jeopardize their own health and retirement security tomorrow.

Public Policy Recommendations

OWL feels the following policy recommendations would help to lighten some of the load for caregivers, and provide retirement security protections that are particularly critical for women.

Expand the Family and Medical Leave Act (FMLA) to Make It More Inclusive and Effective
First, there should be a broader definition of immediate family member whose care qualifies as a covered event. Second, the law should be expanded to cover smaller workplaces. To the extent that small businesses express concern with such an expansion, consideration should be given to tax policies to help mitigate any adverse impact. Third, the FMLA should be amended to extend prorated benefits and protections to caregivers who work less than the current minimum of 1,250 hours a year, or who have worked for a particular employer for less than a year. Fourth, serious consideration should be given to wage supplementation during a period of leave to enhance use of the benefit.

Finally, federal policymakers should expand the worker benefits that are protected under the law. Like the mandatory continuation of health benefits under current law, the FMLA should also require employers to continue any employer contributions to qualified retirement plans during a covered leave period. This requirement would ensure that caregivers do not risk their own retirement as a result of their commitments to family and community. Given their higher rates of poverty in retirement, this is a particularly critical issue for women.

Modify the Medicare Program to Support Informal Caregiving
The Medicare program should become a reliable partner for informal caregivers. First, Medicare should be amended to allow informal caregivers who do not have access to employer-sponsored coverage, and who care for Medicare-eligible or enrolled spouses or relatives, to buy into Medicare. Women who leave the workplace early or shift from full-time to part-time jobs to be caregivers can lose access to affordable health insurance. Women without coverage will sometimes forgo preventive medical care, diagnosis, and treatment, which can result in more serious and costly illness down the road. In light of the numerous emotional, physical, and financial stresses caused by informal caregiving, access to affordable health insurance is crucial.

Second, the Medicare program should be amended to provide a comprehensive prescription drug benefit. Prescription drugs are a critical component of health care for older Americans and people

with chronic illness or disabilities. A Medicare prescription drug benefit is of vital importance to people in need of informal care as well as to those who care for them. Affordable prescription drugs help individuals maintain their health and functioning, which could reduce the need for informal care and perhaps prolong their ability to provide such care.

Any discussion of "modernizing" Medicare's benefit package should recognize that Medicare has a critical role to play in meeting the chronic health care needs of beneficiaries, which in turn will limit medical emergencies, prevent excess disability, and support informal caregivers. Medicare should provide a chronic care benefit and cover respite care, adult day care, and other community-based long-term care and support services.

Strengthen Social Security by Recognizing the Work of Informal Caregivers
Informal caregivers who work less than full-time or who take a leave of absence from work should be protected in retirement. There are several approaches to help ensure that benefits are not reduced in retirement due to caregiving during working years.

One approach is to disregard up to five years of lower income when calculating Social Security retirement benefits if income has been reduced due to unpaid caregiving. For example, a worker who moves from full-time to part-time work, or who leaves the workforce temporarily to provide care, should not have that period of lower income included in a Social Security base year computation. Alternatively, a worker could receive credits in the Social Security system for up to five years of work for unpaid caregiving. Either of these revisions would help reduce the extent to which women are penalized in retirement for fulfilling caregiving responsibilities during prime earning years.

Improve Pension Coverage for Caregivers in the Paid Workforce
Federal pension law should be revised to better protect the retirement security of caregivers. While pension reform will benefit all women, it particularly resonates with the needs of women who are informal caregivers. OWL was pleased that in 2001 Congress changed pension laws to reduce vesting requirements from five to three years, better reflecting women's work patterns.

However, we should take it one step further and count leave time under the Family and Medical Leave Act as service time, and it should accrue to help meet any pension vesting requirements. Such revisions would allow more women to qualify for pension coverage and would also help protect informal caregivers who move in and out of the paid workforce due to caregiving. Further, employers should not be allowed to exclude part-time and temporary workers from pension benefits or contributions as the law currently permits. Women who work part-time because of informal caregiving are particularly affected by this policy.

Create a Dependent Care Tax Credit Building on the Childcare Tax Credit
The existing childcare income tax credit is designed to compensate in a small way for the childcare costs of working parents, but it does not offset broader dependent care costs. In addition to the age restrictions for dependents, the tax credit has a number of other shortcomings. The definition of "dependence" is too restrictive to be an effective relief mechanism for most family caregivers. The test of "dependence" should be made less restrictive in terms of the dependent care reimbursement account and patterned more closely after the California informal

care tax credit law. The credit should also be refundable. Some dependent care tax credit proposals before Congress require a doctor certify that a care recipient needs assistance with three or more activities of daily living (ADLs), but OWL is concerned that this is overly restrictive.

Provide Greater Support for Public Caregiver Assistance Programs and Innovations
Funding for federal and state programs that assist informal caregivers by providing information, training, referrals, and respite care should be expanded. Policymakers took an important first step two years ago when Congress launched the National Family Caregiver Support Program (NFCSP) with the 2000 reauthorization of the Older Americans Act. Currently under a $141.5 million appropriation for FY 2002, the program is intended to provide informal caregivers with critical information, training, counseling, and respite services.

The direct services for caregivers that will be implemented through the NFCSP are clearly critical to older women. Information is power to anyone struggling with a long-term care situation, and the NFCSP will provide an important one-stop shop for caregivers. The training piece of the NFCSP is also important, not just in its positive affect on the care provided, but for the protections it could provide the caregiver. This can be physically demanding work, and proper training — lifting techniques, for example — can avoid debilitating injuries to caregivers. The support group and respite components of the NFCSP are also a significant step in the right direction towards minimizing the negative consequences for caregivers. The opportunity for caregivers to talk about these challenges with counselors and peers in similar situations can be an invaluable source of emotional support.

However, more can be done. The NFCSP was developed as an initial effort to meet the needs of only a segment of the caregiver population. NFCSP targets only the informal caregivers of older adults, as well as older individuals who are raising their grandchildren or caring for children with disabilities. As a result, many of America's caregivers cannot avail themselves of these important programs. For example, a spouse caring for a partner under the age of 60 is not eligible for these services. These eligibility restrictions represent a significant shortcoming of the program.

It is also worth mentioning that the program is woefully underfunded. In fact, the current funding level translates to just a few dollars for every caregiver in America. This lack of resources is already a problem today. As the baby boomers age, it could easily become a crisis tomorrow.

Create Incentives to Private Sector through Tax Policy
Tax policy should provide incentives to the private sector to develop programs that assist women in the paid workforce who provide informal care. While there should be tax incentives for the whole range of caregiver assistance services that employers might provide, the incentives should provide the greatest benefit for employer policies that promote the development of eldercare programs and services made available to the entire community.

Build a Larger Workforce of Formal Caregivers
Federal policy should be designed to improve the quality and quantity of the formal caregiving workforce, such as home health workers. Formal caregivers assist and supplement the work of informal caregivers and play an important role in providing comprehensive care to individuals

requiring long-term care and support. Public program reimbursement should be adequately targeted to formal caregivers. Additionally, public policies and programs should be designed to provide low-wage health care workers with access to affordable health insurance when their employers do not provide such benefits. Low wages and a lack of benefits create high turnover among portions of the health care workforce, adding to the work of informal caregivers.

Make Dependent Care Spending Accounts Applicable to Eldercare
Dependent care spending accounts offered by employers to employees have been successful in offsetting childcare expenses but have been less successful with expenses related to eldercare. They would be useful to workers with eldercare costs if federal tax policy were changed to allow more claims for eldercare. For example, the definition of "dependence" should be modified so that adult family members would not be required to spend eight hours a day in the home of the worker in order to qualify. Current rules also require that any unused portion of the spending account revert to the employer at the end of the year. Allowing unused funds to roll over at year's end would permit greater flexibility for eldercare costs, which, unlike childcare, can vary significantly from year to year. Additionally, employees should have at least two opportunities during the course of a year to establish and fund a dependent care spending account; current law permits only one opportunity per year.

Conclusion

America lacks an effective system to address caregiving. As a result, caregivers — the majority of whom are women — are often pushed beyond their means and suffer long-term consequences as they struggle to meet the needs of those who depend on them. The demographics are clear, and now is the time for Congress and the Administration to take the appropriate steps to head off a national caregiving crisis by instituting important reforms designed to benefit informal caregivers. Thank you for taking the lead by holding this hearing on women's role in caregiving and its consequences.

STATEMENT OF GAIL GIBSON HUNT, EXECUTIVE DIRECTOR, NATIONAL ALLIANCE FOR CAREGIVING, BETHESDA, MD

Ms. HUNT. Thank you for the opportunity to speak this morning on the role of women as participants in our nation's long-term care system. As we have heard over and over this morning, long-term care has a female face. Because we live longer, more of us will now and in the future will require long-term care at home, in community settings and in nursing homes.

We know who provides that care. Data from the Paraprofessional Healthcare Institute estimate that 86 percent of the paid caregivers are women. Those are the ones doing the hands-on care for the sick and frail in home health agencies and personal care workers in nursing homes and assisted living.

But I am here to talk as Director of the National Alliance for Caregiving in terms of long-term care. One thing that has not been said today, and we have heard a lot of statistics about family caregiving, is the value of the unpaid family care in this country is estimated by the United Hospital Fund at nearly $200 billion a year, and that is more than the cost of nursing home and home healthcare combined. So keep that in mind.

Make no mistake about it. Family caregivers are the unpaid extension of our country's healthcare system. Without them, the long-term care system would collapse, and we have heard a lot about who the family caregiver is, the 46-year-old baby boomer woman. One thing to keep in mind, though, when we are talking about caregiving: approximately a quarter of U.S. households contain someone, male or female, caring for an elderly relative or friend, and nearly three-quarters of them are our mothers, sisters, daughters or nieces.

We know that a third are caring for more than one person, and more than 40 percent have children at home under 18. We also know that half of these women are really providing at least one activity of daily living. That is really intensive hands-on personal care: bathing, dressing, feeding, toileting. Nearly a third of them are providing personal care for three or more of these activities.

We have heard about the impact on their lives, but first of all, I think it is important—nobody has really mentioned this—we need to remember that most people view family caregiving positively. As difficult and frustrating and isolating as it is, when asked for a single word that defines caregiving for them, most caregivers will pick a positive term, "loving," "rewarding," or "helpful."

The biggest reward is seeing that their loved one is getting good care. Nonetheless, as we have heard, caregiving often carries emotional, physical and financial burdens. One financial burden that has not been mentioned is the fact that on average caregivers spend $171 a month on out-of-pocket expenses or the equivalent of an IRA each year for many women who may not have a pension in the workplace.

We have heard about the impact on caregiving in work as well. So what can be done to help these women who are holding up the long-term care system with their unpaid labor? First of all, they need more recognition that their efforts are appreciated and meaningful. The National Family Caregiver Support Program was a step

in that direction, but it needs to be increased substantially and given more visibility.

Another form of recognition would be a White House Conference on Caregiving, a national public awareness campaign.

Second, caregivers need financial support, such as Senate 627 begins to offer in the form of a tax credit, the $3,000 tax credit Senator Breaux mentioned.

Third, they need information about resources, their loved one's illness, treatment, prognosis, and services for themselves as well as the family member. And training in the hands-on skills necessary to do the personal care they are doing.

Last, they need services whether in the form of respite, counseling, or support groups or in the form of assistance from paid or volunteer caregivers to help with those many personal care tasks.

This past July, the Alliance and the Partnership for Caring convened a Caregiver Empowerment Summit to develop a National Caregiving Agenda for empowering family caregivers. We had a three-point action plan: to strengthen the national coalition of groups engaged in addressing the problems of caregivers; develop a national public awareness campaign; and develop a grassroots campaign to promote activism among caregivers.

Each congressional office received a copy of the agenda, and we encourage you to take a look at it and join the Alliance and the other Summit participants in implementing these steps.

In closing, the Chinese have a saying that "women hold up half the sky." In the case of long-term care, women hold up most of the sky, and we need to continue to support them doing so. Thank you.

[The prepared statement of Ms. Hunt follows:]

National Alliance for Caregiving
A National Resource for Caregivers

Testimony for a Joint Hearing
of the

THE UNITED STATES SENATE
SPECIAL COMMITTEE ON AGING

and the

HEALTH, EDUCATION, LABOR, AND PENSIONS
SUBCOMMITTEE ON AGING

February 6, 2002

By

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Mr. Chairman and Members of the Committee:

Thank you for the opportunity to speak to you regarding women and long-term care. My name is Gail Gibson Hunt; I am Executive Director of the National Alliance for Caregiving, a nonprofit coalition of 30-some national organizations that have come together around the issues of family caregiving. We conduct research; develop national programs to support family caregivers, such as our Internet clearinghouse of consumer materials; analyze policy; and work to increase public awareness of caregiver needs and concerns.

In this hearing, we are looking at the role of women as participants in our nation's long-term care system. Long-term care has a female face. Women represent the vast majority of those being cared for as well as those, both paid and unpaid, providing the care. Women have higher levels of chronic illness and disability than men as we age. We have a higher incidence of Alzheimer's disease, for example. And because we live longer than men, more of us will now and in the future require long-term care at home, in community settings and in nursing homes.

And who provides that care? Again, the ranks of paid and unpaid caregivers are filled with women. Data from the Paraprofessional Health Care Institute estimate that 86 percent of paid caregivers are women--those providing hands-on care for the sick and frail--bathing, dressing, and feeding them--through home health agencies, as independent self-employed personal care workers, and in the whole array of nursing homes, assisted living facilities, and board and care homes.

But I would like to talk mostly about the family caregiver, who provides 80 percent of the long-term care in this country. The value of this unpaid family care is estimated by the United Hospital Fund at nearly $200 billion per year--more than the cost of nursing home and home health care combined. Make no mistake: family caregivers are the unpaid extension of our country's healthcare system. Without them, the long-term care system would collapse.

Who are these family caregivers? The national profile of the family caregiver from the national caregiver survey published in 1997 by the Alliance and AARP is a 46-year-old Baby Boomer woman, who works AND spends an average of 18 hours per week caring for her 77-year-old mother. Approximately one-quarter of US households contain someone caring for an elderly relative or friend, and nearly 73 percent of these caregivers are women--our mothers and sisters, daughters and granddaughters.

What else do we know about these women? Nearly one-third are caring for more than one person; more than 40 percent also have children under 18 living at home. They are married, working outside the home, and make considerable sacrifices to be caregivers.
We also know that half of these women are providing at least one Activity of Daily Living--bathing, dressing, feeding, toileting--and nearly a third are providing hands-on personal care for three or more of these activities. When we conducted a factor analysis of Caregiver Level of Burden (that is, hours spent caregiving by the more intense hands-on tasks), more than three-quarters of the Level 4 and 5 caregiving, the most intensive caregiving, is done by women.

What is the impact of caregiving on these women's lives? First of all, we need to remember that most people view caregiving positively--as difficult and frustrating and isolating as it can be. When asked for a single word that defines caregiving for them, most caregivers will pick a

positive term, such as "loving," "rewarding," or "helpful." The biggest reward is seeing that their loved one is getting good care. Nonetheless, caregiving often carries emotional, physical and financial burdens, especially if the caregiver is by herself without other family members to share the burden, if she lives with the older person, and/or if the care recipient is very ill or has dementia. One in four caregivers experience emotional stress and about 15 percent of women report physical strain or physical problems due to caregiving. Financial stress is another matter: on average, caregivers spend $171 per month on out-of-pocket expenses--or approximately $1.5 billion per month--for groceries, medications, home modifications, and the like, for their family member. This is the equivalent of an IRA each year for many women who may not have a pension through their workplace.

In terms of caregiving and work, we see another dramatic impact on women. Three-quarters of caregivers work full or part-time, and half of those who work are making some sort of work-related adjustment. Those workplace accommodations break out as follows:

Go in late, leave early, take time off from work	49%
Take leave of absence	11
Drop back to part-time, take less demanding job	7
Lost job benefits	4
Turned down promotion	3
Chose early retirement	4
Give up work entirely	6

In the MetLife study of the cost of caregiving to US employers, the estimate of annual cost in terms of lost productivity is between $11.4 and $29 billion per year. The MetLife Juggling Act study, which we conducted with Brandeis University, indicated that the cost to "intense" caregivers over a caregiving and working "career" was nearly $600,000 in lost pensions, wages and Social Security.

So, what can be done to help these women who are holding up the long-term care system with their unpaid labor? First of all, they need recognition that their efforts are appreciated and meaningful. The National Family Caregiver Support Program is a step in that direction, but needs to be increased substantially and be given much more visibility to allow the aging network to offer the volume and variety of caregiver support programs needed. Another form of recognition could be a White House Conference on Caregiving and a national public awareness campaign. Second, caregivers need financial support, such as S.627 begins to offer in the form of a tax credit. Third, they need information--about resources; their loved one's illness, treatment, and prognosis; and services for themselves as well as the family member--and training in the hands-on skills necessary to do personal care. Lastly, they need services, whether in the form of respite or counseling or support groups, or in the form of assistance from paid and volunteer caregivers to help with those numerous tasks of personal care.

This past July the Alliance and Partnership for Caring convened a Caregiver Empowerment Summit to develop a National Caregiving Agenda for empowering family caregivers. The Summit participants agreed on a three-point action plan:

1. Strengthen the national coalition of groups engaged in addressing the problems of caregivers.

2. Develop a national public awareness campaign.
3. Develop a grassroots plan to promote activism among caregivers.

Each Congressional office has received a copy of the agenda, and we encourage you to take a look at the agenda and join the Alliance and the other Summit participants in implementing these steps. Congress can play a vital role in accomplishing these goals, not only through legislation, but also by encouraging the administration to develop a White House Conference on Caregiving and calling for a Surgeon General's report on caregiving.

In closing, the Chinese have a saying that "women hold up half the sky." In the case of long-term care, women hold up most of the sky and we need them to continue doing so. Let's give them the support they need.

The CHAIRMAN. Thank you, Ms. Hunt and Dr. Young. Thank you very much. I think that you have made some good points, and as Senator Mikulski and I were talking, you really have sort of a smorgasbord of ideas about what we may be able to do, Dr. Young, that you listed, and you know, the thing that bothers me is we do not really have anything comprehensive. We got a lot of little ideas here, a little bit there, a little bit here, a little bit there. Hopefully, if you do a lot of little bits, you may add up to something good.

But I am really concerned that we do not really seem to have a comprehensive policy as a nation, again a nation that is as strong as the United States, which has such a huge growing senior population. I mean our obligation, again, is not to just get people to live longer, but also to live better lives, particularly in the last part of their lives, and we do not really have long-term health insurance available. It is extremely expensive. It is not covered by Medicare.

We have really bastardized Medicaid and humiliated people to having to become poor in order to qualify for some type of nursing home assistance, and that really is not enough. And I am just wondering, you know, the Federal Employees Health Benefit Plan, our Federal insurance, this year for the first time will offer long-term healthcare insurance.

I am a big believer in trying to help provide affordable insurance to the general population so that we at a young age can start buying health insurance that covers long-term care for when we need it. The bill that we have, as you are aware, has a up to $5,000 deduction, and it obviously has to be made refundable for lower income people to help them buy long-term care insurance.

It seems to me if we can get a large number of people in that pool buying insurance, helping those who do not have enough money to buy it themselves, that that would go a long ways to saying that we as a nation have some type of a comprehensive program to provide long-term care.

Can either of you just comment on that concept?

Dr. YOUNG. I think it is a good concept. I think it is a great beginning, and I think that you are right, there needs to be a comprehensive overhaul that will effect all different kinds of opportunities and programs and education and benefits for people who are primary caregivers.

That certainly is a great first step, but it is just a first step. It really is not going to address millions and millions of poor women who are involved in caregiving today, who even with that benefit are not going to be able to afford the insurance. The impact of having——

The CHAIRMAN. Well, they could if it is a refundable tax credit.

Dr. YOUNG. It is if it is refundable, but again we have to look at the wage basis that they are starting with and what the eventual cost of the insurance will be. Also, the devil will be in the details of what the insurance will really cover and what it will provide and for how long and what the benefits are. As we well know, there is a kind of social insurance covenant with our country around what Medicare and Medicaid would provide, and we have seen cutbacks and changes and shifts in those programs over the lifetime of what they will cover and what they will reimburse.

So I think that it is a great first step; it addresses the need. It brings it to the forefront in a very important way, but it is just a first step.

The CHAIRMAN. Well, I really look forward—and I recognize Senator Mikulski—but as a member of the Finance Committee, and I think that the tax code offers a great deal of potential to try and use the Federal Government in a direct manner of trying to provide a program that is comprehensive and that does provide long-term care coverage in a way that would allow everyone to have access to it. And we are going to be working on that hopefully this year.

Senator MIKULSKI.

Senator MIKULSKI. Senator Breaux, I think you are really right, and that is why I am so supportive of it and why I worked for the Federal employee benefit. First of all, people need to be able to afford the insurance. Second, we have to make sure the insurance is not a new racket or scheme, because we know where there is need, there is greed, and where there is greed, there are scams and scum.

This is why part of the Federal employee package has a lot of education in terms of even the checklist on what a good solid policy is. When I bought my own long-term care policy, I turned to the web site of the National Association of Insurance Commissioners that had a basic checklist to go down to see the questions you needed to ask yourself as you went forward.

This is all important. I think would be a very important tool to the middle class, knowing that the poor have other demands on them, but it would be a very important tool in the middle class.

I worry about the financing of long-term care, but I also worry about the human capital, and this takes me to my next point. There are really two groups of caregivers. One is the informal caregiving at home, and I was really stunned by hearing that if we factored out, I guess, at the minimum wage, there is $200 billion of family caregiving going on that no government, no insurance company, nobody could take care of. So we need to strengthen them, and I think you have given excellent testimony.

Then I want to go back to quote "paid caregivers," and I wonder what your thoughts are on this, because this is a human capital crisis, as well as a financing crisis. The human capital is the family and how we can strengthen the family, and I think you have given excellent recommendations, but could we talk about the workforce? Because when we look at the people who work at nursing homes, they are often underpaid, undertrained, in many instances particularly either nursing homes or in the invisible aspects at home, home health, there are people with language challenges I wonder what your thoughts on that are, which is how we can strengthen the human capital over in terms of the paid caregiving, because I think it is really a stretch here.

Am I right about this, and could you share your thoughts and insights on this? Because I think those of us involved in job training and workforce oversight would appreciate your input. I mean, you know, I spoke with such affection of my dad, but when we had to turn to a nursing home, it was the nurses and the nurse aides that were turning someone who was kind of a beefy grocer who looked like a lacrosse player. I mean really that was a big challenge.

Dr. YOUNG. I would speak to it actually by telling you about my own story. I lost my mother last year to progressive dementia and Alzheimer's disease, and she also experienced psychotic depression as a consequence of that, and had lived a number of years in assisted living, and even though finances in her case was not the overriding issue, when she required a level of care that could only be provided in a nursing home, the problem was because of the level of training, the poor wages, the lack of support, the number of staff that were available, the quality of care that she received was really abysmal.

And it was not because the people there did not want to give good quality care. I met wonderful, caring, trained people who really cared about our frail elderly and wanted to be supportive, but the lack of resources, the way we finance and support the wages that go, and the kind of reimbursement schedule that goes, to nursing homes so that they can actually provide the level of care necessary, so that people are well taken care of in a kind of a preventative way in terms of caring for them physically as well as mentally and emotionally, I think really needs to be challenged.

I think that you would like recommendations. We will get back to you with a set of them.

Ms. HUNT. I wanted to follow up on the long-term care insurance question that you raised, Senator Breaux. I am a supporter of long-term care insurance, and I think this program that they are offering to Federal employees and retirees in the military is really a good step in the direction, but you have to remember that that is not going to take care of today's caregiver.

We are the ones who are going to have to be concerned about Baby Boomers' long-term care in the future. For today's caregiver, the person they are caring for is not going to be eligible for long-term care insurance. So we need to be sure that we also keep in mind supports like the National Family Caregiver Support Program, lifespan respite programs, for example, and other kinds of programs, the tax credit, the $3,000 tax credit for today's caregiver.

Senator MIKULSKI. What about the human capital issue?

Ms. HUNT. Well, I think that there is no question that this is a concern. There have been briefings by the Paraprofessional Healthcare Institute, which is the group particularly focused on the aides, the people doing home health, and the fact that it is not just an issue of not having enough training and having language problems, as you mentioned, and not having a living wage, and not having a career ladder, but there are not enough of them. That is just an issue by itself, too.

Senator MIKULSKI. Why would there be?

Ms. HUNT. Why would there be when you can work at McDonald's and in some cases you can get benefits, and you cannot get them in these other circumstances, but I guess what I am saying is there are groups which are beginning to address the concerns of the paid caregiving, particularly the paraprofessional, workforce.

There is a bill that is looking at nursing, at the nursing shortage, but that does not really deal with the paraprofessional.

Senator MIKULSKI. No, that is my bill.

Ms. HUNT. The person that you are talking about?

Senator MIKULSKI. That is my bill with Tim Hutchinson and Ted Kennedy, John Kerry, Jim Jeffords and some others. I do not want to go into this in great detail at this hearing, but again, turning to experiences in Maryland, what we see, again, at the nursing home, there are the nurses, then there are the paraprofessionals that support the nurses, and some medical supervision on a daily and a weekly basis.

I am looking at a continuum of opportunity. My bill also focuses on the community college—for many women who would like to enter the career or men who want to enter the career of nursing, the whole idea of going to Johns Hopkins or University of Maryland is more of a reach than they could do with their family lives, but going to the community college, particularly where life experience is always factored in, can move along. You see in my mind the community college and the 2-year nursing degree offers an opportunity for long-term care.

The second thing is I would hope that if we look at the experiences of trained paraprofessionals, really trained, certificate programs, then those certificate programs could be parlayed into the community college, so if they took the 6-week program on "x" or "y" that constitutes an allied health program, that certificate could count toward courses in nursing—and we all know the innovation of this.

So you see where there would be the career ladder, they could move up, move up in income, where they begin to have new opportunities we have already attracted people. We just do not pay them, and there are these other issues. So I know that my time is up.

If I could, Senator Breaux, one of the other questions I worry about is fragmented services. Even if you have got the money, where in the dickens do you begin, where do you go, who do you know that is reliable? I mean really the whole idea of knowing about day care, geriatric evaluation. Now we hope that this has been addressed in the National Family Caregiver Support Program, and I must also acknowledge the role that Senator Jeffords and Senator Mike DeWine played. We could not have done the authorization without Senator DeWine and Senator Jeffords.

Senator Gregg had particular issues, and that is why we had a lot of wrinkles, but we worked again in a bipartisan way. What do you think about it? Has the Caregivers Program addressed the information issue or is it uneven, and the fragmented nature of the system?

Ms. HUNT. Well, I think that is a lot to lay at the feet of $125 million, but, yes, I think that is a beginning. I think the National Family Caregiver Support Program, which as you know sends the money down through the state units and then to the area agencies, has been helpful, particularly because the area agency is given the responsibility of being the sort of one-stop shopping place that caregivers and family members, the older person, is supposed to go to get information about what is available in the community.

That needs to be strengthened even more, no question about it, because you still hear about people who say I had no idea there was adult day care for my parent with Alzheimer's or I had no idea what range of services were available. So information and finding

integrated information or places where you can go and you can get information is really still a need, but it is getting better.

One thing that I think has been helpful, in a small way, is the Benefits Checkup, which is an Internet resource of the National Council on Aging. You can enter information about the older person's income, and where they live, and it tells you the public benefits that the person is eligible for, and I think that that is something that people would have had to seek out before in several places, and now they are able to go to this.

It is an Internet resource so you have to be a little bit Internet savvy to use it. But I think that it is helpful, and I think that there are other kinds of programs like that that are working to provide more integrated information for family caregivers.

Dr. YOUNG. I am hoping that in conjunction with that program that there, in fact, is the kind of outreach and education to people in communities that really let them know what is available to them. I think for a lot of people who are involved, the kind of caregivers, the informal caregivers we have been talking about, their lives are so challenged on a daily basis about all of the activities and things that they have to pull together and collaborate on and get done and accomplish in their lives, that their ability to do that kind of research takes them into yet another task, another challenge, and I would hope to see that ultimately we could even do a kind of public education outreach that is similar with what has been done with the CHIP program that would allow States to really speak to communities about what is available to them, how to get information in the same kind of aggressive way that we educate people about what is available in terms of insuring their children.

Senator MIKULSKI. I have no other questions.

The CHAIRMAN. Thank you very much, Senator Mikulski. I want to thank Senator Mikulski for joining with our committee and putting our two committees together on this issue. I think that as many people in Congress who get interested in this, the better chance we have of coming up with a comprehensive long-term health plan for the seniors and the caregivers in this country.

We will pay very dearly for not having a comprehensive long-term plan in place as the baby boomer generation begins to retire. It is already a huge problem. When we add 77 million more seniors to the program with life expectancy of women being around 80 years of age and growing, the fastest generation growing in terms of growth in population are people 85 years of age and older, and we all know that, and so this presents a huge problem and huge challenges to this country, but I am certainly of the opinion that we have the wherewithal, the determination to move toward solving it.

We are going to work very hard in this Congress to come up with something that begins that process. I believe very strongly in the concept of health insurance, long-term care, with the Federal Government helping to pay for a portion of it, or maybe all of it for people who do not have the wherewithal to do it themselves.

We heard some great stories from our colleagues, our Senate colleagues, about their personal experiences, which, you know, duplicate millions and millions of other Americans who do this everyday,

and we thank them and thank you, Dr. Young and Ms. Hunt, for your testimony as well.

And we also have a written statement from Kathleen Kelly, who is Executive Director of the Family Caregiver Alliance, which will be made a part of the record.

With that, we will have this committee adjourned.

Senator MIKULSKI. Edifying and challenging. Thank you.

[Whereupon, at 11:10 a.m., the committee was adjourned.]

APPENDIX

Statement of Kathleen Kelly
Executive Director, Family Caregiver Alliance
San Francisco, California
Testimony Before a Joint Session of the
Health, Education, Labor & Pensions Committee
and the
Special Committee on Aging
Hearing on Women and Aging: Bearing the Burden of Long-Term Care
February 6, 2002

Madame Chairwoman, Mr. Chairman and Members of the Committee:

First, I want to thank the members of both committees for holding this important hearing today. Over the years, both committees have done important work in creating the tools that family caregivers rely on to meet the complex needs of their spouses, families and communities. These needs will continue to expand as our aging population grows and the reliance on home and community-based solutions increases.

In my position as the Executive Director of Family Caregiver Alliance (FCA), I know intimately the challenges that family caregivers struggle with each and every day. Now celebrating our 25th year, FCA operates programs at the local, statewide and national levels to support and strengthen caregiving families. FCA's mission is to support and assist families and caregivers through education, services, research and advocacy. Our goals are to:

* Serve as a leader in health and long-term care services, education, research and advocacy.
* Develop, implement and evaluate leading edge programs, which respond to the ever-changing needs and characteristics of caregivers in the community.
* Advocate for inclusion of family caregivers and adults with cognitive impairments in health and long-term care policies.
* Uphold the quality and effectiveness of direct services, education and information.
* Generate a strong resource base that enables more caregivers to be served.

And now, with the recent launch of FCA's National Center on Caregiving, we can take our cutting edge research, programs and services and use them to help meet a growing national need.

Recently, Congress took a momentous step in reauthorizing the Older Americans Act (OAA). I applaud your commitment to modernize this program. I am particularly pleased that Congress recognized the growing demand for a federal investment in families and their caregivers and responded by creating the National Family Caregiver Support Program (NFCSP).

Why is the NFCSP so important? Well, when caregivers are provided with the services they need, like education, training, respite and other services, they can provide care to a family member, keep them out of an institution and reduce the reliance on other federal programs such as Medicaid and Medicare.

What do we know about caregivers? We know that most of them are women - about 75%. We know that women who are caregivers usually spend 50% more time providing care than male caregivers. We also know that 51.8% of caregivers are employed full-time and that the average age of a caregiver providing care for someone aged 50+ is 46. We also know that female caregivers are more likely than males to suffer from anxiety, depression, and other symptoms associated with emotional stress.

What does all this mean? It means that women are bearing the burdens of long-term care.

These burdens can include the financial and emotional toll that comes from being a member of the "sandwich generation" - those caring for an aging parent and a child simultaneously. It also means that many women must take time out of the workforce to care for family, friends, and members of the community. This can mean taking a part-time job instead of a full-time one. It can mean taking sick days or family and medical leave. It can also mean quitting a job to care full-time for a sick spouse or parent. Unfortunately, this time out of the workforce usually results in fewer contributions to Social Security and employer-sponsored pensions so women can expect lower retirement income just when they need it most.

Why is this a compelling human need? After the tragic events of September 11th, and considering the current downturn in the economy, we understand that long-term care, Alzheimer's disease, Parkinson's and other debilitating illnesses are not foremost on everyone's mind. However, when a family faces a devastating diagnosis, or the sudden stroke of a loved one, it becomes a very personal and immediate need; they desperately want information and help and frequently do not know where to turn. Yet we know that family caregivers are reluctant to use support services, particularly respite care, even though these services can reduce depression and delay institutionalization. Despite this hesitation, many respite programs having waiting lists that reach into the thousands.

What can Congress do? The creation of the NFCSP is an important first step. But, we know what the current fiscal constraints can mean to programs such as this. So we must fight to maintain funding and support for this program and for others that provide critical research and services to family caregivers. Programs like those under the Social Services Block Grant, groundbreaking research conducted at federal institutions like the National Institute on Aging, and safety net services, such as respite care, education and training, that states provide under federal Medicaid guidelines. And we must take incremental steps to expand services. Very small steps can mean very big things to family caregivers.

I'll leave you with this one example. I was talking to a Caregiver Resource Center (CRC) employee in California the other day and she was telling me about a client using respite services. The client, a woman who had been married for 52 years, was ready to institutionalize her husband. In her words, "[she] just couldn't take it anymore." Well, the woman who worked at the CRC probed a little to try and get more information. "Why can't you take it anymore," she asked. It turns out the woman missed playing golf twice a week. She missed seeing her friends, she missed being outdoors and she missed taking a small break. But she couldn't afford both the golf game and the respite care - she and her husband were living on a fixed income. The agency worker told her that the CRC would pay for the respite if the woman could pay for the golf game. And twice a week, for three hours each day, this woman was able to play golf. But more importantly, she was able to keep her husband home, to care for him, and to be happy. That's the difference that programs supporting family caregivers make. They don't just *change* lives; they allow people to *live* them. So the way I see it, we absolutely must not forget our commitment to support family caregivers - after all, we simply cannot afford to.

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Statement for the Record Submitted by the
American Association for Geriatric Psychiatry to the
Subcommittee on Aging of the
Committee on Health, Education, Labor, and Pensions
And the
Special Committee on Aging
United States Senate
Joint Hearing on
Women and Aging: Bearing the Burden of Long-Term Care
February 6, 2002

The American Association for Geriatric Psychiatry (AAGP) is pleased to have the opportunity to submit a statement for the record on women and caregiving. AAGP is a professional membership organization dedicated to promoting the mental health and well-being of older people and improving the care of those with late-life mental disorders. AAGP's membership consists of approximately 2,000 geriatric psychiatrists, as well as other health professionals who focus on the mental health problems faced by senior citizens.

AAGP members have a particular interest in this issue because of our work with patients with Alzheimer's disease and related dementias who require significant care in very difficult circumstances. The primary caregivers for these patients are often their wives, sisters, or daughters – and professional caregivers for these patients are generally women, as well. The work that geriatric psychiatrists do with these patients invariably involves work with their family and professional caregivers.

Below are some statistics on the scope of the problem:

- It is estimated that four million Americans currently suffer from Alzheimer's or a related form of dementia. Nearly 10 percent of all people over age 65 and up to half of those over age 85 are thought to have Alzheimer's or another form of dementia.
- Approximately 19 million Americans have a family member with Alzheimer's. Approximately 360,000 new cases occur each year. However, these numbers are increasing as the population of older adults increases. It is estimated that 14 million Americans will have Alzheimer's by the middle of this century.
- During the course of the illness, patients suffer progressive loss of cognitive function, and become unable to perform simple activities of daily living. They eventually lose the ability to care for themselves and become dependent on caregivers for such basic tasks as dressing, bathing, toileting, and feeding.
- A person with Alzheimer's lives an average of eight years after initial diagnosis and may live as many as 20 years after the onset of symptoms. The length of time people live with Alzheimer's disease and its associated disability has profound emotional and financial impact on their families and caregivers.
- People with Alzheimer's tend to live with their families until the most advanced stages of the disease – slightly more than half of them are at home at a given time. However, many families find that at some point in time, they need to place elderly relatives with advanced Alzheimer's in a nursing home. Today, it is estimated that half of all nursing home

patients suffer from Alzheimer's. The per patient cost for nursing home care averages $42,000 per year, but can exceed $70,000 per year.

AAGP's educational mission engendered its recent Initiative on Alzheimer's Disease and Related Disorders, designed to educate consumers, policymakers, physicians and other health care professionals about the diagnosis and treatment of late-life dementia and its associated caregiving and policy implications. Of the many demanding and important roles that caregivers undertake, caring for older adults with Alzheimer's disease and other dementing disorders is one of the most devastating and dreaded tasks in our society. As the "baby boom" population approaches old age, the numbers of Americans who need such care will increase substantially. And it is women who most often provide the care.

Alzheimer's disease is a shared condition affecting not only the patient but also the patient's family. Often, a close family member bears much of the responsibility for ensuring that the patient's treatment plan is implemented, and that the patient's basic needs are met. Such responsibility can take an enormous emotional and physical toll on the family member, especially when coupled with the psychological distress associated with watching a loved one deteriorate.

As the disease progresses, the person with Alzheimer's disease becomes increasingly dependent upon caregivers. In addition to the loss of cognitive ability, there is a loss of self experienced by the patient. Family members must cope with the associated personality changes, as well as disorders of mood and behavior, all of which can be profoundly disturbing. For this reason, the caregiver of the Alzheimer's disease patient often is referred to as the hidden, or second, patient who suffers from the disease.

One of the roles of a patient's physician is to help provide much needed support to family and caregivers by explaining the diagnosis and providing information about the expected course of the illness, available treatments, and prognosis. Physicians can also help ensure that problem behaviors and other associated psychiatric symptoms (that are common manifestations or complications of dementia) are being managed as well as possible and provide referral for psychiatric care and other psychosocial support when necessary. The physician must facilitate ongoing discussion about the changing needs of both the patient and caregiver, assessing whether and how these needs are being met, providing information about available resources in the health system and the community, and arranging appropriate referrals.

Alzheimer's disease can create a significant disruption in a family. Roles and responsibilities change, and people handle these major adjustments differently. Not surprisingly, conflicts may arise. Some family members will be eager to understand the patient's disease, and some may deny the problem.

Family caregivers of Alzheimer's disease patients experience a range of natural emotions in response to the disease. These feelings, which may include frustration, anger, fear and sadness, as well as concerns about their own memory lapses, can be managed by talking with their physician or by referral for counseling if necessary.

Beyond natural reactions to the disease, family and caregivers of Alzheimer's disease patients are at risk for developing serious physical, emotional and behavioral health problems. Therefore, it is important for caregivers and their family members to be aware of, and watch for, symptoms such as anxiety, depression, social withdrawal, sleeplessness, exhaustion, impaired concentration, irritability, anger, and even abusive behavior toward the Alzheimer patient. When these symptoms occur, the caregiver should discuss them with their physician, and should undergo evaluation to determine if treatment is needed.

Numerous studies have linked caregiving of patients with dementia to psychiatric problems and higher rates of psychotropic drug use. Diagnostic interviews also reveal a higher prevalence of anxiety and clinical depression among caregivers than in control groups and the general population. Studies indicate that a substantial percentage of caregivers – as many as fifty percent – experience depressive symptoms severe enough to warrant intervention and treatment.

Spouse caregivers often suffer most. Those with milder depressions may benefit significantly from long term social support. When social support mechanisms are insufficient to alleviate the depression, antidepressant medication may be helpful. In fact, treating even mild depression can make a remarkable difference to both the caregiver and the primary patient. For caregivers with major depression, antidepressant medication is often indicated. Caregivers who develop major depression or problems with alcohol or drug abuse may become so ill that they are unable to continue caring for the Alzheimer patient.

When these conditions occur, psychiatric treatment and other psychosocial interventions can improve the quality of life and well-being for family, caregivers and patients. It is important that appropriate treatment for caregivers be available – both for their own and the patients' benefit.

It is important to recognize that depression associated with, or brought on by caregiving, is not necessarily alleviated when the patient dies. Caregiver follow-up is often necessary, and referral for bereavement counseling or supportive therapy may be helpful. Some studies indicate that men tend to experience a worsening of depression after the death of a spouse with Alzheimer's disease, while women may improve.

Sustaining the health and stamina of caregivers should be part of Alzheimer's disease patient care. Studies have demonstrated that emotional support from family and friends, self-confidence, and help wit household chores all were found to positively influence caregivers and protect against stress. Use of community support services and other resources such as respite care can be extremely helpful, and formal caregiver support programs have been shown to significantly delay nursing home placement of Alzheimer patients. In addition, psychosocial and behavioral interventions for both patients and caregivers can help ease caregiver burden and optimize patient care – while failure to receive appropriate treatment can hasten caregiver burnout and lead to premature institutionalization of the patient. The relationship between Alzheimer's disease and the family system is reciprocal: the well-being of the family and caregivers depends on the well-being of the patient, and vice versa. Therefore, a coordinated, effective treatment program that successfully manages the patient's behavioral and mood disorders can have a substantial positive effect on the well-being of all of family members. Conversely, preserving

and promoting the health and well-being of family caregivers is essential to maintaining the patient's well-being.

The behavioral and emotional conditions commonly associated with Alzheimer's disease caregiving tend to respond robustly to a combination of traditional psychotherapies and supportive interventions. Over time, attention to the caregiver's mental and physical health can improve quality of life for the patient, the caregiver, and their extended family.

AAGP believes that it is crucial for all stakeholders in our health care system recognize the extraordinary demands made upon caregivers of patients with dementia. There are a variety of public policies that should be adopted, expanded, or strengthened to address the multiple issues at stake.

First, the ultimate relief for caregivers will come from the eradication of Alzheimer's disease. We know now enough to understand that such a remarkable feat may be attainable in the foreseeable future. We must assure continued research into the causes, treatment, and, ultimately, prevention of Alzheimer's disease and other dementias.

Second, until a cure is found, the treatment of these patients requires that their caregivers be supported and, when necessary, treated. Programs that provide community support services (e.g., Area Agencies on Aging and other sources of public funding for home health and respite care services) and those that provide coverage for health care services (e.g., Medicare reimbursement for health and mental health services), must recognize that Alzheimer patients cannot be treated adequately unless their families and caregivers also have access to the treatment and the support that they need. Unfortunately, in some situations, Medicare carriers deny coverage for mental health services for Alzheimer patients when those services focus on helping the caregiver to manage behavioral complications. Ideally, care of patients and caregivers should be integrated and comprehensive. An elderly wife caring for her husband with progressive dementia that makes him more and more helpless must have support for her own physical, emotional, and social needs. A younger woman caring for her mother may be physically more robust but may also have a job as well as caregiver responsibilities for her young family. These women, who care for their parents, and who, in turn, are parents caring for their own children, define the "sandwich generation." If appropriate support and services are not present, these women will be exposed to more health problems and suffering in an already agonizing situation, with the attendant risk of premature institutionalization of their beloved family members, adding further cost and distress.

Our society understandably has an aversion to taking a hard and honest look at these most difficult circumstances, but, in fact, more and more Americans will face these problems in the next few years, even as hundreds of thousands do today. AAGP commends the Special Committee on Aging and the HELP Subcommittee on Aging for focusing attention on the complex issues confronted by women who undertake this kind of care. These women are a vital resource within our families and communities, and we cannot afford to ignore the high risks they face. AAGP looks forward to working with Senators from both panels to develop initiatives – in both the private and public sectors of our health care system – to support these women, ease their burden, and preserve their health.

Statement
Women's Institute for a Secure Retirement
U.S. Senate Special Committee on Aging &
Aging Subcommittee of the Senate Health Education Labor and Pensions Committee
Joint Hearing on Women and Aging Issues
February 6, 2001

On behalf of the Women's Institute for a Secure Retirement (WISER) we appreciate the opportunity to submit comments to the U.S. Senate Special Committee on Aging & the Aging Subcommittee of the Senate Health Education Labor and Pensions Committee for the joint hearing on Women & Aging issues on the ways in which women's caregiving responsibilities result in lower pensions and Social Security benefits and how information and planning options can help to ensure that women do not end up living in poverty.

The Women's Institute for a Secure Retirement (WISER) is a non-profit organization whose primary mission is education – providing women with information and retirement planning skills so that they can surmount the overwhelming challenges to securing retirement income. Our overarching goal is to alleviate poverty among older women.

Working women today already face greater challenges than men. Women earn less, have less to save for retirement, are less likely to be covered by a pension plan, and are more likely to take time out of their careers – often the peak earning years – to care for children, for parents and other family members. To deal with these challenges, women need to pay attention to their finances early and throughout their lives. Education and awareness are the keys to improving women's chances of preventing their caregiving roles from stealing their chances for a secure retirement.

Women's Roles as Caregivers

As the Senators know, women are paying a huge price as the nation's caregivers – they not only work outside the home but they have not been relieved of their responsibilities in the home. They sacrifice their financial futures as well as their time to make sure that their families are cared for. According to a survey by the Social Security Administration, women beneficiaries have 29 years of earnings compared to 38 years of earnings for men – a difference of nine years.

As a result of a woman's dual burden of caring for her family and working outside of the home, the majority of working women are generally disadvantaged in their pensions and investments. Nearly 40 percent of women are dependent on Social Security for almost all of their income because they have had fewer opportunities to participate in the retirement

plans provided by employers. The combination of lower income and fewer pension

opportunities mean that women are less able to save.

The reality of women's working lives is that no matter how women's roles in society continue to change, women are still more likely to leave the workforce or to work part-time to accommodate caregiving responsibilities. In addition to maternity leave, they also bear the primary responsibility for sick relatives – resulting in shorter job tenures –women's average job tenure is 4.4 years lagging behind men's (5.0 years).

Other Reasons Why Women Need More Retirement Income

- Women live longer than men, nearly 4 years.
- Women are likely to be single – and not remarry. Unmarried women are more likely to live out their years in poverty.
- Women earn less than men so their Social Security and pension benefits are smaller.
- Women are more likely to need long-term institutional care.

The Effect of Women's Longer Lives

Popular financial advice suggests that Americans generally need to plan to replace anywhere from 70 to 85 percent of their income at retirement. Unfortunately, this advice doesn't work for women, who are likely to need more than 100 percent of their pre-retirement income in order to remain secure throughout their longer lives.

The longer life expectancy of women necessarily means that at some point during their retirement the vast majority will find themselves alone. In fact, about 80 percent of men die married and 80 percent of women die single.

Living alone is a predictor of elderly poverty and women are much more likely than men to live alone – in 1998, only 43 percent of older women lived with their spouses, compared to 73 percent of older men. A single elderly woman is twice as likely as an elderly man to be poor. In 1998, about 1 out of 5 single older white women were living in poverty, while almost half of all single older minority women were poor or near poor.

The implication of caregiving and inadequate savings and retirement benefits is far-reaching. But one of the major challenges facing the Committees today is to make sure that women realize what steps they will need to take today to ensure that they receive care for themselves in their old age. Today about one in five Americans older than age 65 needs assistance with everyday living activities. For those over age 85, nearly half need assistance.

Many people believe that Medicare and regular health insurance cover long-term care in a nursing home but most long-term care is actually paid for by family members. Yet, most families are not aware of how their elderly parents are planning for their future care.

Consider the Story of Alice Turner

Although Alice Turner was meticulous about her financial affairs, she never told either of her daughters who lived at the other end of the country that she had purchased a long-term care insurance policy.

When Alice became seriously ill, a long distance nightmare began – largely, because Alice's daughters were not aware that she had paid for insurance to cover a long-term stay in the nursing home. Since Medicare would only pay for 20 days in a nursing home, Alice's care began to look more like medical roulette than a medical recovery plan.

First, there would be a medical crisis. Alice would go into the hospital's Intensive Care Unit, get discharged to a nursing home for 20 days and then sent home. The next medical crisis would be handled in the same way – based on what looked like her limited Medicare coverage, instead of what she needed.

It was only after Alice's death that her daughters learned about the long-term care policy. If Alice's daughters had known . . . they would have avoided this agony and Alice would have gotten the medical care she needed without interruption.

Long-term care insurance covers a range of services that can help women live at home or receive care outside the home. While it is not for everyone, education is needed so that working Americans learn about the availability of private, long-term care insurance.

Study after study indicates that most Americans believe – incorrectly – that their Medicare benefits will cover long-term care costs. Most Americans are unaware that they can create their own, individual, private safety net with a long-term care insurance policy that will guarantee them a choice of services that existing government programs cannot.

Currently, long-term care insurance is a product aimed at the middle class. An above-the-line tax deduction for long-term care insurance – a proposal that has been passed several times by both houses of Congress and is now included in the President's budget outline – would make long-term care insurance affordable for an even larger number of people. Because they live longer than men, women are most at risk of needing long-term care. Because they typically have smaller retirement assets, they are most at risk of becoming impoverished because of their long-term care needs.

We need to address these issues now and ensure that women protect themselves so that they do not end up their lives in poverty after a lifetime of providing care for others. Again, we thank the Committee for your leadership in acknowledging these issues.

The Women's Institute for a Secure Retirement is a non-profit organization that was launched in 1996 by the Teresa & H. John Heinz III Foundation. WISER's overarching goal is to alleviate poverty among older women and to include increasing awareness among the general public, policymakers, and the business community of the structural barriers that prevent women's adequate participation in the nation's retirement systems.

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