PLANNING FOR LONG-TERM CARE

HEARING

BEFORE THE

SUBCOMMITTEE ON HEALTH

OF THE

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HOUSE OF REPRESENTATIVES

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PLANNING FOR LONG-TERM CARE

WEDNESDAY, MAY 17, 2006

HOUSE OF REPRESENTATIVES,
COMMITTEE ON ENERGY AND COMMERCE,
SUBCOMMITTEE ON HEALTH,
Washington, DC.

The subcommittee met, pursuant to notice, at 2:05 p.m., in Room 2123 of the Rayburn House Office Building, Hon. Nathan Deal (chairman) presiding.

Members present: Representatives Deal, Ferguson, Burgess, Brown, Pallone, Eshoo, Capps, and Allen.

Staff Present: David Rosenfeld, Chief Health Counsel; Ryan Long, Counsel; Brandon Clark, Policy Coordinator; Chad Grant, Legislative Clerk; John Ford, Minority Counsel; Jessica McNiece, Minority Research Assistant; and Jonathan Brater, Minority Staff Assistant.

MR. DEAL. The committee will come to order. The Chair recognizes himself for an opening statement.

We are here to address aspects of long-term care planning which, if we addressed it in totality, we would take a very long time to do so. There are certainly dozens, if not more, issues surrounding the provision of and the payment for long-term care, which certainly deserve our attention. I believe we can all agree, however, that the magnitude of the task must not dissuade us from taking on this important and timely subject in manageable increments.

Last year, this subcommittee's hearing on long-term care financing set in motion a process which resulted in significant reforms, the implementation of which we are monitoring closely to ensure adherence to Congressional intent. I hope this hearing today will set the stage for additional progress through a bipartisan effort this time around.

Long-term care is one of the most significant demographic and fiscal challenges of this century, and of particular importance because of rapidly aging populations. In 2000, there were an estimated 9.5 million people with long-term care needs in the United States, including 6 million elderly, and 3.5 million non-elderly. These numbers are projected to grow dramatically in the coming years, especially after 2030, when the Baby Boom generation begins to reach 85. The senior population, 12.4 percent in 2000, is predicted to rise to 20.6 percent by 2050, the fastest growing share being in the 80 plus. It is projected to rise from 3.3 percent in 2000 to 8 percent in 2050. This population,

which is most likely to need long-term care services, is projected to more than triple, from about 9.3 million to 33.7 million people nationally.

Today, we will examine how the private marketplace is addressing long-term care planning, often in partnership with the Government. One recent example is the Deficit Reduction Act's expansion of long-term care insurance partnerships, which states are eager to establish with Federal guidelines on implementation. I support even greater collaboration to promote long-term care insurance, as well as to explore new ways of bringing home equity into the financing equation on the front end, in order to expand care options, and to forestall, or at least minimize reliance on scarce public resources. To this end, I plan to introduce soon a bill to create demonstration projects for States to develop innovative programs for individuals who will utilize home equity on qualified long-term care services to retain a greater amount of the assets than otherwise permitted should they subsequently apply for Medicaid.

Today, we are also examining the critical role of caregiving and its challenges for both caregivers, as well as those who train caregivers. Most impaired persons who reside in the community rely largely on donated care from friends and family. In 2004, the Congressional Budget Office estimated that replacing donated long-term care services for seniors with professional care would cost $76.5 billion, and this number does not even account for the cost of replacing donated care provided to persons with long-term care needs under age 65. Another analysis in 1997 estimated that the value of donated care for people of all ages who had impairments, measuring it as the foregone wages of caregivers, to be at $218 billion.

We need to better address caregiving and caregiver challenges to ensure public dollars are used efficiently and effectively, and to support American families struggling to do right by their loved ones. To this end, I support the concepts behind the Lifespan Respite Care Act of 2005, sponsored by Mr. Ferguson of this subcommittee and several other members of the Energy and Commerce Committee. The bill seeks to address the physical, emotional, and financial problems that impede caregivers' ability to deliver care now, and to support their own care needs in the future, and to delay and possibly even obviate the need for costly institutionalization in both instances. Although easily and often mischaracterized, targeted and accountable respite care programs makes sense.

I am now pleased to recognize my friend, Mr. Brown, for his opening statement.

[The prepared statement of Hon. Nathan Deal follows:]

PREPARED STATEMENT OF THE HON. NATHAN DEAL, CHAIRMAN, SUBCOMMITTEE ON HEALTH

The Committee will come to order, and the Chair recognizes himself for an opening statement.

Addressing all aspects of long-term care planning could keep us here almost indefinitely. There are dozens if not more issues surrounding the provision of and payment for long-term care which deserve our attention. I believe we can all agree, however, the magnitude of the task must not dissuade us from taking on this important and timely subject in manageable increments. Last year, this Subcommittee's hearing on long-term care financing set in motion a process which resulted in significant reforms, the implementation of which we are monitoring closely to ensure adherence to Congressional intent. I hope this hearing today will set the stage for additional progress through a bipartisan effort this time around.

Long-term care is one of the most significant demographic and fiscal challenges of this century and of particular importance because of our rapidly aging population. In 2000, there were an estimated 9.5 million people with long-term care needs in the U.S., including six million elderly and 3.5 million non-elderly. These numbers are projected to grow dramatically in the coming years, especially after 2030 when the baby boom generation begins to reach 85. The senior population—12.4% in 2000—is predicted to rise to 20.6% by 2050; the fastest growing share, 80+ ("oldest old") is projected to rise from 3.3% in 2000 to 8% in 2050. This population, which is most likely to need long-term care services, is projected to more than triple from about 9.3 million to 33.7 million nationally.

Often overlooked by policy experts and media, approximately one-third of long-term care expenditures pay for services for non-elderly people. In 1994, about 3.4 million adults aged 18 to 64 and 400,000 children below the age of 18 used long-term care services. The majority of those people lived in community-based settings (homes or group residences). In general, people who are younger than 65 are likely to be impaired as a result of conditions such as developmental disabilities and mental illness (although they may also suffer the kinds of physical problems that older people experience). Common causes of impairment among children are respiratory problems and mental or neurological conditions such as autism.

Today, we will examine how the private marketplace is addressing long-term care planning often in partnership with government. One recent example is the Deficit Reduction Act's expansion of long-term care insurance partnerships which states are eager to establish with federal guidance on implementation. I support even greater collaboration to promote long-term care insurance as well as to explore new ways of bringing home equity into the financing equation on the front-end in order to expand care options and to forestall or at least minimize reliance on scarce public resources. To this end, I plan to introduce soon a bill to create demonstration projects for states to develop innovative programs for individuals who utilize home equity on qualified long-term care services to retain a greater amount of assets than otherwise permitted should they subsequently apply for Medicaid.

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At this time, I would also like to ask for Unanimous Consent that all Committee Members be able to submit statements and questions for the record.

I now recognize the Ranking Member of the Subcommittee, Mr. Brown from Ohio, for five minutes for his opening statement.

MR. BROWN. Thank you, Mr. Chairman.

I appreciate your having this hearing and your interest in long-term care planning, but with all due respect, the Republican leadership in Congress, pure and simple, lost their credibility on this issue last year, when they tried to cut $43 billion, and succeeded in cutting $26 billion from the Medicaid program. In my home State of Ohio, there is a waiting list of almost 1,400 people for home and community-based care. There are no minimum staffing requirements for nursing homes, because the nursing homes say they can't afford them. Nurses who serve disabled Medicaid beneficiaries are facing a cut in pay. There is a nursing shortage, and Medicaid is cutting nurses' pay. That is the fast track to a crisis.

Ohio is not alone. No State Medicaid program has been spared, yet there is no talk among Republican leadership of reinvesting the $43 billion back into the Medicaid program. There is no sign of remorse when the Congressional Budget Office estimated that one-third of the Medicaid savings would come from taking coverage and benefits away from Medicaid enrollees. There was, however, an inexplicable air of righteousness when these Republicans chose to get some savings by cracking down on asset transfers, never mind that some of those dollars would come by kicking some impoverished seniors out of nursing homes and denying others access. Never mind that many seniors knew nothing about Medicaid when they contributed to their grandchild's education, or helped a child pay catastrophic medical bills. They transferred assets, so tough luck.

A Congress who treats the elderly like guinea pigs when it comes to Medicare Part D, and treats them like criminals when it comes to Medicaid, is not a Congress you can trust when it comes to long-term care planning. The Bush Administration revealed its true colors when, earlier, it tried to block grant Medicaid. If you can't trust an Administration that tries to starve our Nation's insurer of last resort, then who can you trust?

More than 4.2 million Americans rely on Medicaid for long-term care services. In Ohio, the income cutoff for long-term care is $6,300 per year. Private long-term care insurance premiums are about $1,000 for healthy 65 year olds who purchased the coverage when they were 55. Premiums are twice that for healthy seniors who wait until they are 65 to purchase coverage, and 7 times that for seniors who wait until they are 75 to purchase coverage. Anyone who believes this country can do without a long-term care safety net needs a primer on U.S. poverty rates. Long-term care isn't discretionary. The Federal Government should fully fund Medicaid long-term care, which will stabilize our long-term care safety net.

Until we responsibly address current and near-term needs, planning for future long-term care coverage is an exercise void of any legitimacy.

Thank you, Mr. Chairman.

MR. DEAL. I recognize the Vice Chairman of this subcommittee, Mr. Ferguson, for his opening statement.

MR. FERGUSON. Thank you, Mr. Chairman, and thank you for holding this very important hearing, and thank you for your kind words about my bill, the Lifespan Respite Care Act.

The words "long-term care" first bring to mind nursing homes or chronic care facilities, or costly hospital stays and arduous medical treatment, but the conversation about long-term care doesn't begin until we mention the Nation's family caregivers. They are the first responders in taking care of our elderly and disabled of all ages. That is because most of our elderly or chronically ill family members are being cared for at home. Some estimates say that family caregivers provide 80 percent of all long-term care in the United States. If a monetary value were to be placed on this care, family caregivers are providing support and direct services to their family members a sum valued at $306 billion annually, more than twice of what is spent nationwide on nursing home and paid home care combined, and an amount comparable to Medicare spending in 2004.

In my home State of New Jersey alone, there are nearly a million caregivers who provide care valued at almost $8 billion annually. If we don't recognize this fact and consider the needs of family caregivers, their ability to continue to provide this level of support may well be jeopardized if, as a Nation, we don't rally on their behalf.

While most families take great joy in helping their family members to live at home, it has been well documented that family caregivers suffer from physical and emotional problems directly related to their caregiving responsibilities. Three-fifths of family caregivers recently surveyed reported fair or poor health themselves, and caregivers are 46 percent more likely than non-caregivers to report frequent mental distress.

Among some elderly caregivers, the mortality rate has been even reported to be 60 percent higher than non-caregiving populations. The simple things we take for granted, like getting enough rest or going shopping, become rare and precious events. Family caregivers often miss their own doctors' appointments, or fail to deal with other family crises, because of their overriding commitment to caregiving to their loved one.

Today, as a part of this discussion on long-term care, I want to continue our discussion about respite care with our panelists. Respite care is a modest, low-cost service that simply provides a temporary break for the enormity of constant caregiving, but the benefits reaped are enormous. Respite care, the most frequently requested family support service, has been shown to provide family caregivers with the relief necessary to maintain their own health, and bolster their family stability, keep marriages intact, and avoid or delay more costly nursing home or foster care placements.

The legislation that I have introduced, that Chairman Deal referenced, the Lifespan Respite Care Act, would help set up a network of respite care services to help caregivers and their families receive the help that they need.

Mr. Chairman, I want to thank you again for your leadership on this issue, and for holding this important hearing today, and I look forward to working with you to work on behalf of caregivers and families.

I yield back.

MR. DEAL. I thank the gentleman. Mr. Pallone is recognized for an opening statement.

MR. PALLONE. Thank you, Mr. Chairman.

I had originally prepared a different statement for today's hearing, but decided to change it, after a visit this morning from a couple of my constituents whose parents had suffered from ALS, more commonly referred to as Lou Gehrig's disease. I wasn't present at the meeting, because of a committee markup, but my staff asked me to share their concerns. Three young women came to share their stories in my office about their parents, who were inflicted with this terrible disease that left them completely debilitated. One woman described the effects of the disease as being "buried alive slowly over the course of a few years."

And the reason I bring this up is because during this meeting, one woman, who couldn't have been older than 25, sobbed in my office as she described how she had to quit her job as a teacher in order to take care of her father after he was diagnosed with ALS. She described the unfairness of the situation and the tremendous pressure placed on her as she became her father's primary caregiver. She also spoke of the

frustration her father experienced as he became helpless and had to rely on his daughter to have the most basic needs met.

The questions she raised in our meeting are questions this committee will need to consider when we talk about long-term caregiving. Who will need it, who will do it, and who will pay for it? These questions will become incredibly important over the next 30 years, as the number of persons aged 65 or older, those most likely to be in need of long-term care services, is projected to double, yet these questions are just as important, if not more, for those who are disabled as they are for the elderly.

And Mr. Chairman, the demand for long-term care in the future is expected to rise substantially, placing tremendous strains on Federal and State budgets that are already strapped for cash. While the budgetary impact of long-term care is concerning, I believe it has often been misused as a rallying cry to gut Medicaid, which explains some of the harmful changes my Republican friends enacted last year. I fear the new rules laid out in the Deficit Reduction Act could leave many innocent low-income families, who never intended to game the system, with too few options to access the long-term care they need, and end up costing the program even more.

Now, Mr. Chairman, as we discuss planning for our Nation's future long-term care needs, it is simply not enough to worry about how to finance such care. There are other serious problems that we face, such as the availability of caregivers. Until now, unpaid family caregivers, like the women in my office today, have supplied the bulk of long-term care. According to the Administration on Aging, an estimated 22 million Americans are providing uncompensated care at any one time. It has been estimated that replacing such informal long-term care services with professional caregivers would cost between \$50 billion and \$103 billion annually.

And Mr. Chairman, I think that we have a very serious problem on our hands that requires real solutions. That is why I thank you for calling today's hearing, and look forward to hearing the testimony from our witnesses.

Thank you.

MR. DEAL. I thank the gentleman.

At this time, I would like to ask unanimous consent that all Members be allowed to submit their opening statements for the record. Without objection, so ordered.

Ms. Eshoo, you are recognized for an opening statement.

MS. ESHOO. Thank you, Mr. Chairman, for holding this hearing today.

The issue of long-term care is something that will affect every American in some way, shape, or form. I know that there are members of this committee that have been involved in the care of family members, myself included, and you don't know what this is until you are faced with it yourself. Because at best, there really is a patchwork of things that are out there. There really isn't anything that is comprehensive, and very few Americans, perhaps the numbers are rising now, and we will get into that in the Q&A, but really very few Americans have long-term care insurance policies that can then step up to and meet what the needs are. As I became more involved in this, with the care of my father and then my mother, I inquired with friends of mine about the policies that they had bought for the region that we live in. They really didn't buy the kind of coverage they needed, and of course, it varies across the country what the costs are, but certainly in the Bay Area, it is an expensive place to do business.

And I was reminded by a very dear friend of mine, who is much younger than I am, that long-term care is not just about the elderly. She was in a river rafting accident, and had to be airlifted from a very remote place, because that is where you go river rafting, it is not in the middle of the city, and required quite extensive surgery on her leg, her ankle, and when she finally came home, she required five weeks of recovery care, and it cost her a bundle of money, 24 hours a day, so she went out and shopped hard for a long-term care policy, which reminded me of my own vulnerabilities at the age that I am at.

So, this is an issue that we not only need to explore, but to understand very well, not only what is out there, what is affordable, what isn't, are there public policy directions where we can move in order to make this more accessible for people, and also, in terms of the system that we already have, does it need to be updated? Are there parts of Medicare that need to be reshaped, so that in-home services can be enjoyed, in terms of reimbursement, where often the only reimbursements are now in a hospital setting.

I think that we have a lot of work to do on this, and I want to commend my colleagues for their opening statement, both Mr. Ferguson's and Mr. Pallone's, because I think they have touched on a lot of things. But this is very large, it is very broad, it is very deep, and for those of us that are sitting here talking about it, it is going to affect us, too. So, it is in all of our interests to have a system that is going to speak both publicly and privately to all Americans.

So, I look forward to the testimony that is going to be offered today, and thank you, Mr. Chairman, for holding the hearing.

MR. DEAL. I thank the gentlelady. Ms. Capps is recognized for an opening statement.

MS. CAPPS. Thank you, Mr. Chairman, and I, too, thank you for holding this hearing today, and thank our witnesses for being part of it.

And you know, we spend a lot of time in this body, but in our country as well, as more and more people are aging, thinking about retirements, later years. We have debated Social Security this year. We have had the Medicare Modernization Act, and we are trying to enroll people and so forth, but very seldom do we really sit down and talk about long-term healthcare, and I am glad for this hearing for that reason. I think it is the choir in here that we are all kind of speaking to. Whether we have individual differences, we are here because we agree that this is a topic that needs to be addressed, and that is the most significant part of today's hearing, in my opinion.

We should be really intensifying our efforts in this direction, but there is so much else on our plate. Yet that has been the problem. I think it was about a year ago, we had one other hearing on this. We have pieces of legislation here and there, but what we do need to acknowledge is what we all spend time thinking about as we grow older, as we live with loved ones and family members who are facing really tough decisions, because of certain lacks in our communities, in our society, both in programs and opportunities, resources, and the rest. But these have to do with the kind of life we envision having in our older age, having security for independent living, whatever that setting might be, having adequate housing and assistance. As a nurse, I have often worked with my colleagues in discussing a continuity of care as people become less able to care for their own needs in whatever that setting would be.

So I am looking forward to a serious discussion of ways in which we can empower people to plan for the long-term care that they and their loved ones know they are going to be needing, if not needing immediately. It is on everybody's mind. We should be encouraging young people to prepare for this, and there is long-term healthcare insurance, so that people can have greater freedom to choose, but unfortunately, so few people can take advantage of this, the only opportunity that I know of to really kind of look ahead, and do the kind of specific planning for long-term care needs.

That means that we have an obligation here in this body, and this subcommittee has an obligation, I believe, to work together to develop a greater safety net, call it whatever we want to call it, for seniors and others who really look to us to provide some of their needs for long-term healthcare.

We are way behind in this country, from countries in Europe and other places, in our care for elderly, and I think it is time we catch up, and as Frank Pallone and Anna Eshoo, my colleagues, have illustrated, it is not just about turning 65 and older. Those with severe impairments,

developmental disabilities from a very young age, will not have had time to sign up for long-term healthcare, or any kind of insurance. They probably do not have the assets for this. Who is looking out for their needs? They deserve to be cared for, too, and we can't simply turn this burden over to family members, who aren't really equipped always to provide for the best quality of care.

So we have a burden, we have a responsibility, we also have an opportunity. We have an opportunity to provide the right kind of leadership in this place, that calls upon the private sector, that calls forth the programs and agencies that do exist in our communities, that want to be partnering with us. None of us can do this alone, but the leadership really has to come from this place, and I call it a moral responsibility of society to care for those who are in situations where they cannot care for themselves.

Thank you. I went past my time. I am sorry.

[Additional statements submitted for the record follows:]

PREPARED STATEMENT OF THE HON. BARBARA CUBIN, A REPRESENTATIVE IN CONGRESS FROM THE STATE OF WYOMING

Thank you Mr. Chairman.

Today we have an opportunity to take a closer look at long-term care for individuals unable to manage for themselves even the most common daily activities many of us take for granted.

As Medicaid is the largest source of government payment for long-term care, the issue presents a tremendous fiscal challenge as our population ages. Often overshadowed by problems facing Social Security and Medicare, long-term care expenditures are projected to go up from $195 billion in 2004 to $540 billion by 2040. These numbers could be even larger if impairment prevalence increases.

This is disturbing considering that no more than 10 percent of seniors in our nation currently have long-term care insurance. The number of individuals annually enrolling in these plans tripled to 900,000 from 1988 to 2002, but more can be done. I hope our panelists today will help shed light on options at our disposal to encourage planning among our middle-income earners, helping them avoid Medicaid dependency.

From using reverse mortgages and home equity loans to help today's seniors deal with the cost of long-term care, or using targeted tax incentives to encourage enrollment among our future seniors, there are potential market-based solutions that may ultimately prove to be more efficient and cost-effective than relying solely on public funding.

Today we'll also have the opportunity to discuss issues relating to caregivers and caregiver training. As our population ages, the demand for these workers, and the hands on support they provide, will go up.

We have over 70,000 Medicare beneficiaries in Wyoming out of our population of half a million. Our total number of seniors is even higher. Wyoming is truly a frontier state when it comes to access to healthcare, and we are home to plenty of seniors who currently face challenges in receiving reliable care.

The last thing a Wyoming senior should have to worry about is whether there will be someone to take care of them when the time comes. I will look to our panelists today for guidance on what we can do on the federal level to foster a favorable climate for this profession, and the seniors it serves.

Thank you Mr. Chairman.

PREPARED STATEMENT OF THE HON. JOHN D. DINGELL, A REPRESENTATIVE IN CONGRESS FROM THE STATE OF MICHIGAN

Currently, more than ten million Americans need long-term care services, and this number will only grow larger as our population ages. Planning for long-term care is an important and complex issue that should be carefully examined by the Committee. I thank the Chairman for calling this hearing, and thank all of the witnesses who are here to today to share their knowledge.

Much of today's hearing will focus on long-term care planning for the elderly, and several questions need to be addressed. First, where do the disabled fit in? Private market solutions advanced by some of the witnesses will offer little aid for those living with disabilities. These individuals are unlikely to even qualify for a long term care insurance policy. And few of those living with disabilities have home equity that would enable them to tap reverse mortgages as an option. I hope that as we move forward on this matter we do not forget the millions of younger Americans with disabilities who have long-term care needs.

Second, what about those with limited financial means? While private market solutions have a role to play in helping meet the growing need for long term care, those solutions are most accessible to those with higher incomes. I believe we should also look at building a strong public foundation for long-term care for those who cannot afford private options.

Third, how accountable will private market solutions be? Health and welfare security is too important to be left solely to private industry with a profit motive. As we examine private options, it is critical that we have standards in place to ensure that consumers can obtain quality products, at affordable prices, that they can depend upon when needed. There will need to be a strong public role in overseeing the operations of the private market.

Fourth, what is the real cost of the private market solutions? Today we will hear about how barriers can be eliminated so that more people will be encouraged to purchase long term care insurance and reverse mortgage products through changes in the tax code. Unfortunately the tax code is often an inefficient way to encourage these kinds of actions. It accrues benefits to primarily wealthier individuals, and inefficiently targets those resources with benefits often going to those who have already purchased such coverage. Public programs can be more efficient at targeting our scarce resources where they are needed.

Fifth, does planning for long term care at a national level include ensuring there are enough care-givers to meet the growing demand? As we will hear in today's testimony, there is already a shortage today, and it will only grow worse as the baby boomers age. A majority of long-term care is provided informally, which means care is provided for free through family or friends. It is important that we take time to understand what options might be used to expand the use of trained and interested informal caregivers. But informal care is not the answer to a workforce shortage that is already reported by a majority of States. A paid care-giver workforce is important to supplement informal care or provide respite for informal caregivers. We need to ensure that these caregivers receive adequate wages and benefits if we hope to fill this shortage.

Finally, how can we as a Nation plan for long-term care without having a strong safety net in place? Medicaid is an essential component to any realistic discussion of long-term care, and we should be talking about strengthening it. The Deficit Reduction Act took us in the wrong direction.

This country needs to have a coherent long term care policy. I thank the Chairman again for holding this hearing and thank the witnesses for being here to educate us about this important issue.

MR. DEAL. It is all right.

I am pleased to introduce our first panel today, on the topic that is the issue of discussion, that is, planning for long-term care: Dr. Barbara Stucki, who is Project Manager of the National Council on Aging; Dr. Joshua M. Wiener, Senior Fellow and Program Director, Aging, Disability, and Long-Term Care, RTI International; Ms. Karen Ignagni, who is the President and CEO of American Health Insurance Plans; Mr. Greg Jenner, Executive Vice President, American Council of Life Insurers; and Dr. Byron Thames, Board Member, AARP.

Ladies and gentlemen, we are pleased to have you here. We have your statements that are made a part of the record, and I would ask you in the 5 minutes that we allot to each of you to try to summarize those issues, and hit the high points for us, and with that, Dr. Stucki, we will recognize you first. Pull that a little closer, and probably press the button to make it work.

DR. STUCKI. There. Is that working? Yes.

MR. DEAL. Pull it a little closer.

STATEMENTS OF DR. BARBARA R. STUCKI, PROJECT MANAGER, NATIONAL COUNCIL ON AGING; DR. JOSHUA M. WIENER, SENIOR FELLOW AND PROGRAM DIRECTOR, AGING, DISABILITY AND LONG-TERM CARE, RTI INTERNATIONAL; KAREN IGNAGNI, PRESIDENT AND CEO, AMERICAN HEALTH INSURANCE PLANS; GREG JENNER, EXECUTIVE VICE PRESIDENT, AMERICAN COUNCIL OF LIFE INSURERS; AND DR. BYRON THAMES, BOARD MEMBER, AARP

DR. STUCKI. Okay. Here we go. Good afternoon, Mr. Chairman and members of the subcommittee. My name is Barbara Stucki.

Over the past 13 years, I have been conducting research on private-sector financing for long-term care. I currently manage the Use Your Home to Stay at Home Initiative for the National Council on Aging. I would like to thank you for providing the NCOA the opportunity to testify about the need to include home equity as an essential element of long-term care planning.

The recent passage of the Deficit Reduction Act, which includes limits on home equity for Medicaid eligibility, sends a strong message to Americans that housing wealth will now be part of the long-term care financing mix. Americans want to continue to live at home as they grow

older, even if they need help with everyday activities, but many impaired, older homeowners are unprepared for the financial challenges that can come with a chronic health condition.

This is true not only for cash-poor seniors, but also for middle income families who often struggle to pay for the extra cost of help at home. Today, there are two main planning tools to deal with these challenges. One option is to buy long-term care insurance, which often occurs before retirement. The more common approach is to rely on income and savings, and hope for the best. When seniors rely on this pay-as-you-go strategy, they often need to turn to Medicaid. Tapping home equity offers a third alternative that fills an important gap.

By taking out a reverse mortgage, impaired older homeowners can convert a portion of their home equity into cash, while they continue to live at home for as long as they want. Reverse mortgages have many unique features and strong consumer protections that make these loans an important option for impaired elders. In addition, reverse mortgages do not require the borrower to make monthly payments, so borrowers are not at risk for losing the house, as they could be with a conventional mortgage loan.

What is the potential of reverses mortgages for long-term care as a planning tool? In 2003, the median home value among seniors was over $122,000. Over 80 percent of people aged 65 and older are homeowners. We estimate that over 13 million older homeowners are candidates for using a reverse mortgage to pay for long-term care. Of these, about 5 million either receive Medicaid benefits, or face the financial risk for needing government to help with long-term care.

Encouraging the use of home equity can help to rapidly reduce the need for government assistance by strengthening an elder's ability to age in place. The proceeds of a reverse mortgage are tax free, and can be used to pay for a wide array of unmet needs, including help with daily activities, home repairs and modifications, and transportation. This flexibility offers an important new way to supplement and strengthen Medicaid and private insurance, by first providing resources sooner to keep small problems from becoming a major catastrophe. Second, by increasing flexibility in the household budget, to help seniors cope with the financial ups and downs that often come with declining health and ability, and third, by strengthening the ties of reciprocity that underlie the networks of informal support for elders.

Despite the potential of reverse mortgages, older Americans have not been using their substantial housing assets to pay for aging in place. Instead, home equity is usually liquidated by selling the house, often in a crisis situation, to pay for nursing home care. We believe that there can be a better way.

To encourage more effective use of home equity, it would help to create a new public/private partnership demonstration program for reverse mortgages. Under this partnership, homeowners with moderate incomes who use a certain portion of their home equity to pay for home and community services could be allowed to protect some or all of their assets from Medicaid spend-down requirements. There are similar initiatives already underway to create such incentives for aging in place, such as the Reverse Mortgage Incentive Program that is being considered in Minnesota. Efforts such as these indicate State interest in this type of approach, and can provide guidance for the development of a partnership program.

Another important resource is the new National Clearinghouse for Long-Term Care Information. NCOA would like to thank the committee for creating the Clearinghouse to educate Americans about long-term care. It will be important that the Clearinghouse include information and decision support tools to help elders and their families make wise decisions on the use of home equity and reverse mortgages.

In conclusion, NCOA believes that reverse mortgages have the potential to be a powerful force for systems change. With over $2 trillion tied up in the homes of older Americans, home equity can help to rebalance our Nation's long-term care delivery system, integrate financing for housing and supportive services for seniors, and create new opportunities for public/private partnerships.

With supportive public policies, appropriate incentives, and careful protections, the voluntary use of reverse mortgages offers an additional option for impaired older Americans to take action today, and to use their existing resources more effectively.

Thank you.

[The prepared statement of Dr. Barbara R. Stucki follows:]

PREPARED STATEMENT OF DR. BARBARA R. STUCKI, PROJECT MANAGER, NATIONAL COUNCIL ON AGING

Good afternoon, Mr. Chairman and Members of the Subcommittee. My name is Barbara Stucki. Over the past 13 years, I have been conducting research on private sector financing for long-term care. I currently manage the Use Your Home to Stay at Home Initiative for the National Council on Aging (NCOA). I would like to thank you for providing the NCOA the opportunity to testify about the need to include home equity as an essential element of long-term care planning.

Americans want to continue to live at home as they grow older, even if they need help with everyday tasks (termed "age in place"). Many impaired older homeowners, however, are unprepared for the financial challenges that can come with a chronic health condition. This is true not only for cash-poor seniors, but also for middle-income families who often struggle to pay the extra cost of help at home. When family budgets become strained due to unexpected long-term care expenses, impaired elders often turn to

Medicaid for support. Due to the high cost of nursing homes, elders who get help in institutional settings are especially vulnerable to spending-down to Medicaid.

We believe that reverse mortgages offer important opportunities to rapidly reduce the need for government assistance by strengthening an elder's ability to age in place. Over 80 percent of people age 65 and older are homeowners.[1] For many older Americans, home equity is the most important financial resource to increase their resilience to the financial shocks that can come with declining health and ability. These added resources can help impaired elders to both avoid a costly crisis, and to plan ahead for these needs. Greater use of home equity among older homeowners has the potential to reduce their risk of needing Medicaid by:

- Providing resources sooner to keep small problems from becoming major catastrophes.
- Increasing flexibility in the household budget to help seniors to pay a wide array of expenses associated with aging in place, and to reduce the financial shocks that often come with declining health and ability.
- Strengthening ties of reciprocity that underlie the networks of informal support for elders.

Encouraging older Americans to use reverse mortgages to "age in place" also can offer a more effective and equitable approach to reducing taxpayer burdens for long-term care than limiting Medicaid eligibility or benefits. With over **$2 trillion** tied up in their homes, home equity has the potential to help to rebalance our nation's long-term care delivery system, integrate financing for housing and supportive services for seniors, and create new opportunities for public-private partnerships.

Home Equity – A New Resource for Long-Term Care Planning

Americans of all ages value their ability to live independently. But without careful planning, living at home with an impairment may be difficult. A serious fall or chronic illness can quickly drain hard-earned retirement dollars. Maintaining adequate cash flow can also become problematic when the need for supportive services fluctuates from month to month. Families who are assisting elders with a progressive chronic condition, such as Alzheimer's disease, face considerable uncertainty in trying to budget funds to provide help for many years.

Currently, there are two main financial strategies to deal with these challenges. One option is to purchase long-term care insurance before retirement, when a person is healthy and premiums are affordable. The more common approach is to rely on income and savings, and hope for the best. Most seniors today rely on this "pay as you go" approach, and often to turn to Medicaid and other public programs for assistance when they come up short.

Tapping home equity offers a third alternative for homeowners who could not prepare for this need with private long-term care insurance or savings (Figure 1). By taking out a reverse mortgage, older homeowners can convert a portion of their home equity into cash while they continue to live at home for as long as they want. To qualify, all owners of the property must age 62 or older. Borrowers do not need to make any loan payments for as long as they (or in the case of spouses, the last remaining borrower) continue to live in the home as their main residence. When the last borrower moves out of the home or dies, the loan becomes due.

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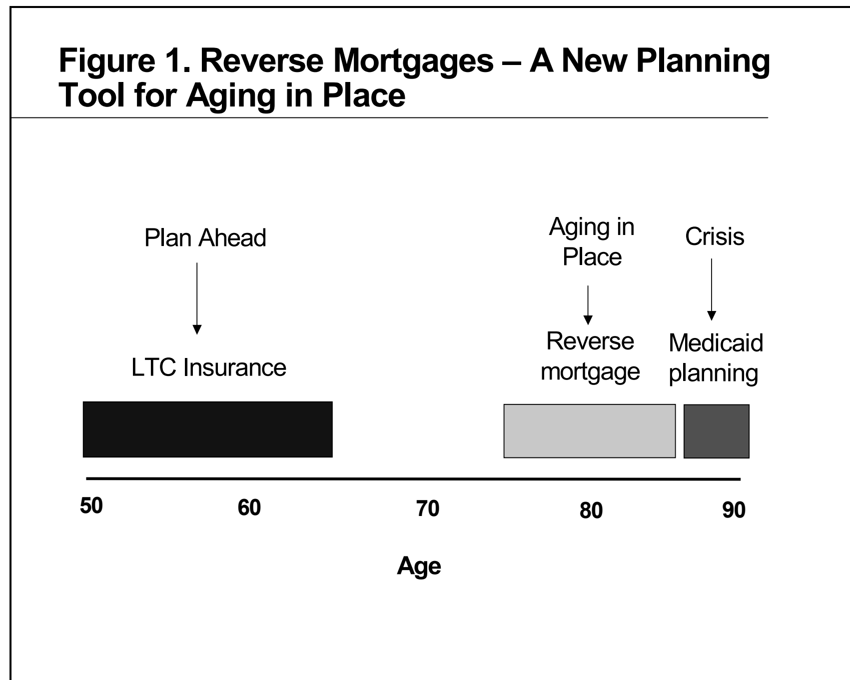
[1] Callis, Robert R. and Cavanaugh, Linda B. (2004). Census Bureau Reports on Residential Vacancies and Homeownership. Washington, DC: United States Department of Commerce News, CB04-179.



If used wisely, reverse mortgages can pay for preventive measures and day-to-day support so that impaired elders can continue to live at home safely and comfortably for many years. As an immediate long-term care financing tool, these loans also have the potential to reduce the risk that impaired elders and their families will to turn to Medicaid in times of crisis. The following example highlights the potential benefits if a homeowner with $150,000 in home equity took out this loan:

> Scenario #1: Janet Zibley (age 85) has arthritis, which makes it difficult for her to manage on her own. She pays a neighbor $1,000 per month to help around the house. But when she needs more assistance from a home health aide, her monthly bill for services can be over $3,000. At her age, Janet could receive $102,378 from a reverse mortgage. Her line of credit could cover monthly expenses of $1,000 for over 13 years, or $3,000 each month for over 3 years, at the current interest rate.

When an unstable health condition disrupts the family budget, it can be easy to come up short when it is time to pay the bills. A reverse mortgage credit line can help manage cash flow since the money is available when needed. Borrowers only pay interest on the amount that they use.

Strengthening the Safety Net

Shifting the focus of long-term care from the facility to the home has profound implications for the amount, timing, and sources of funding that will be needed. When a person develops a chronic health condition such as diabetes, arthritis, or Alzheimer's disease, aging in place means more that just staying put. They will need a place to live that is safe and fits with their abilities. As driving becomes difficult, it is important to have reliable and affordable transportation. Extra funds for family caregivers or for home modifications (such as a ramp or lift) can extend the time that an impaired elder can live at home.

One of the challenges of our current long-term care financing system is that it is based primarily on insurance approaches. Insurance works best to protect against catastrophic costs, such as nursing home care. However, this financing mechanism is not appropriate to deal with everyday expenses, such as weekly transportation to the doctor or help with household chores. These expenses can still be a big burden on the family budget, and can increase the risk for spend-down among impaired elders on a fixed income.

Reverse mortgages can supplement and strengthen insurance-based long-term care financing strategies by offering older homeowners more flexibility to fill unmet needs and critical gaps in services. Proceeds from a reverse mortgage are tax-free, and borrowers can use these funds for any purpose. Borrowers can select to receive payments as a lump sum, line of credit, fixed monthly payments (for up to life in the home) or in a combination of payment options.

Home equity can be the "glue" that holds an elder's financial plans together when they have a chronic health condition. Consider the potential value of a reverse mortgage if a family that lives in a house that is in good repair and worth $150,000 took out this loan. They own their home free and clear of any debt:

> Scenario #2: Tom and Jill Smith (ages 69 and 65) bought long-term care insurance that will pay for services when they need help with personal care (such as bathing, dressing, or eating) or supervision due to Alzheimer's disease. For now they can still manage on their own, but want to add a bathroom downstairs to reduce the strain of climbing the stairs. Based on Jill's age, the Andersons would receive $66,104 from their reverse mortgage. They could take $20,000 of the loan to install a new bathroom. They could keep the rest ($46,104) in a line of credit. These funds could be used to meet any additional expenses before they become eligible for services under their long-term care insurance policies.

This story highlights how people with a chronic condition can have a variety of unmet needs, even with good financial planning.

Another limitation of Medicaid and private long-term care insurance is that they are designed to help seniors cope with a severe mental or physical impairment after it has occurred. In contrast, reverse mortgages can reduce long-term care risks by paying for a wide array of early interventions that help impaired elders avoid a crisis. A high proportion (46 percent) of older homeowners have a functional limitation, such as difficulty with climbing stairs or carrying groceries, that may make it hard for them to continue to live at home safely.[2] While these impairments are modest, they can have serious consequences if they lead to bigger problems such as malnutrition or debilitating injuries.

Potential of Reverse Mortgages

In the past few years, there has been a dramatic increase in the volume of reverse mortgages made nationwide, reaching over 195,000 loans originated in total.[3] Low mortgage rates, combined with growing awareness of this loan, have significantly increased the popularity of reverse mortgages.

Older homeowners can select from several different types of reverse mortgages. These include:

- Home Equity Conversion Mortgage (HECM) – This program is offered by the Department of Housing and Urban Development (HUD) and is insured by the FHA. HECMs are the most popular reverse mortgages, representing about 90% of the market.

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[2] Stucki, B. (2005). Use Your Home to Stay at Home. Washington, DC: National Council on Aging.

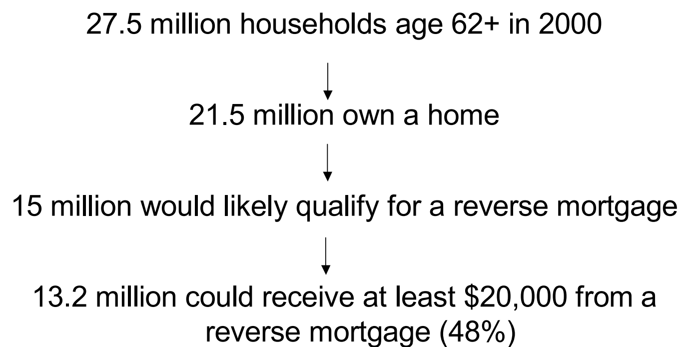
[3] National Reverse Mortgage Lenders Association Year-By-Year HECM Production (1990-Present). From www.nrmalonline.org, retrieved 5/15/06.

- Fannie Mae Home Keeper loan - Borrowers can receive more cash from these loans than with a HECM since the loan limit for this product is higher.
- Financial Freedom Cash Account loans – This product is beneficial for seniors who own homes that are worth more than $400,000 since there is almost no maximum loan limit.

As private residences continue to appreciate in value, their equity grows as a financial resource. The median home value among people age 65 and older in 2003 was $122,789. The amount that reverse mortgage borrowers can receive is based primarily on the value of the home, the type of loan, and the current interest rate. A HECM loan at today's interest rate for a house worth $122,789 could range from $52,950 for a borrower age 65, to $67,261 for a borrower age 75, to $82,884 for a borrower age 85.

When the last borrower dies or moves out of the home, the reverse mortgage becomes due and needs to be paid. How much equity will be left at this point depends on the amount of money used from the loan, how long the loan was kept, interest rates, and any home appreciation. If, at the end of the loan, the loan balance is less than the value of the home, then the borrower or heirs get to keep the difference. An important protection offered by reverse mortgages is that the borrower (or heirs) will never owe more than value of the home at the time they sell the home or repay the loan. This is true even if the value of the home declines.

Figure 2. Candidate households to use a reverse mortgage for aging in place



Source: NCOA (2005). *Use Your Home to Stay at Home*. Analysis based on data from the 2000 Health and Retirement Study.

Based on our analysis of data from the 2000 Health and Retirement Study, we estimate that a total of **13.2 million** (48 percent of the 27.5 million elder households) are candidates for using a reverse mortgage to pay for long-term care (Figure 2). These households would likely meet the requirements to qualify for this type of loan. In addition, they would likely receive a loan worth at least $20,000 based on their age and the value of their home.

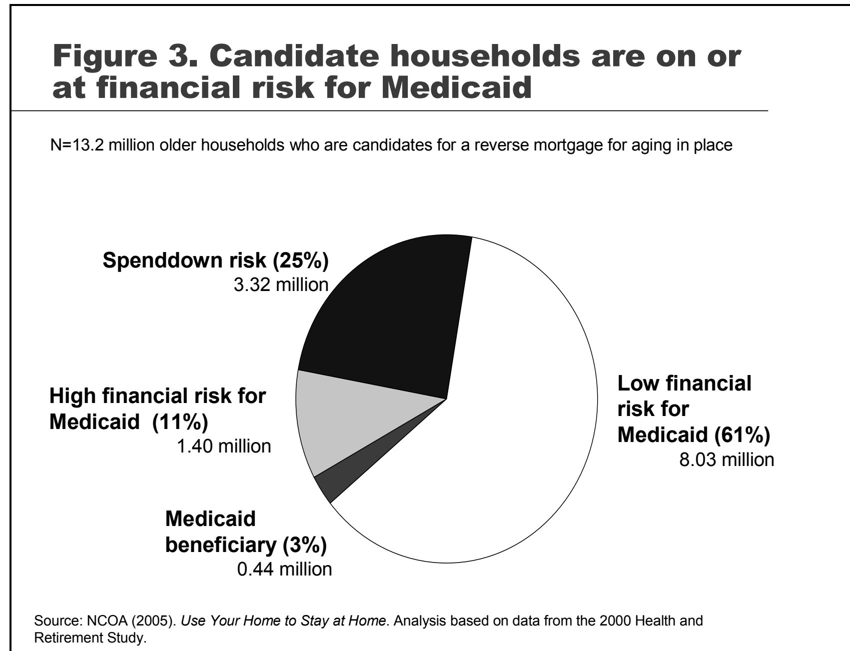
Medicaid and Reverse Mortgages

Until recently, policymakers have largely favored preserving the home of impaired elders. The passage of the Deficit Reduction Act of 2006, which includes limits on home equity for Medicaid eligibility ($500,000 or less, up to $750,000 at state discretion), now sends a strong message to Americans that housing wealth will be part of the long-term care financing mix. As a result, impaired elders who have a large amount of equity in their home will be more likely to consider using a reverse mortgage. The law explicitly allows elders to use this financing tool to reduce home equity to meet Medicaid eligibility levels.

We believe that Medicaid could also benefit from voluntary initiatives to encourage impaired elders with modest housing assets to tap their home equity. An important target for these efforts are older homeowners who are most likely to turn to public programs for assistance. We estimate that among the 13.2 million households that are likely candidates for a reverse mortgage, about 5.2 million (39 percent) either receive Medicaid benefits or are at financial risk for needing government assistance (Figure 3). This vulnerable population includes distinct subgroups, each of which will likely respond differently to incentives for reverse mortgages.

Pre-Medicaid population – These elder households are important from a policy standpoint because their limited financial resources place them at greatest risk for turning to public programs should they need long-term care. The group that may benefit most from incentives for reverse mortgages may be spend-down risk households. These households are primarily composed of "tweeners," elders whose financial resources are sufficient to pay for everyday expenses but not to handle substantial out-of-pocket payments for services and supports at home. These elders may be able to qualify for Medicaid by depleting their income and assets to pay for long-term care (termed "spend-down") in the community.

For many tweeners, home equity is their main financial buffer against substantial medical and long-term care expenses. For these elders, uncertainty about future health expenses can make getting a reverse mortgage seem like a risky proposition. Borrowers who spend their equity at an earlier stage will have fewer financial resources when they become more severely impaired. Tweeners might be encouraged to tap home equity by a public-private partnership program that would provide additional protections and help them to leverage their limited assets so they can stay home longer.



Medicaid long-term care beneficiaries – Though Medicaid beneficiaries may be receiving home and community services, additional cash from reverse mortgages can help cover unmet needs while providing greater choice and control over services. A significant challenge for these elders who live at home is the strict financial eligibility requirements for Medicaid Home and Community Based Services (HCBS). States that restrict the income available to HCBS beneficiaries, and limit spousal protections, often place these older homeowners at risk for moving to the nursing home since they are left with few resources to pay everyday expenses or to deal with financial emergencies such as a leaky roof.

To increase the financial resilience of these elders, Medicaid could allow HCBS beneficiaries to supplement their benefits with the proceeds of a reverse mortgage. These additional funds could make a critical difference in their ability to pay for the expenses associated with living in the community. This approach could also provide additional support to family caregivers.

Implementing this strategy will require changes to limitations on supplementation under Medicaid. Currently, beneficiaries are not allowed to receive additional financial assistance from other sources, since Medicaid is seen as a payer of last resort. One option would be to develop a plan of care for beneficiaries that would include everyday expenses that could be covered by the loan. This approach to using home equity would need to be evaluated carefully, to take into consideration such factors as the presence of a spouse.

Our research indicates that only about 3 percent of older homeowners are Medicaid beneficiaries. This may reflect the fact that these elders have few financial resources, including housing wealth. However, recent research suggests that other factors may also be at work. In particular, older homeowners who face nursing home stays of 100 days or longer are more likely to sell the home than those who do not need such lengthy care in a facility.

Reverse mortgages could make it easier for Medicaid nursing home beneficiaries who still own a home to transition from the facility to the community, if this is their wish. Loan funds could pay transition expenses and cover care management costs that facilitate a move from the institution to community living. These funds could also help impaired elders to pay for substantial home modifications and other assistance not covered by Medicaid, that can help them to stay at home.

Expanding the Use of Home Equity Through Public-Private Partnerships

Despite the potential of reverse mortgages, older Americans have not been encouraged to tap into their substantial housing assets to pay for home and community long-term care services. Instead, home equity is usually liquidated by selling the house, often in emergency situations, to pay for nursing home expenses.

Getting people to adopt new behaviors is never easy. This is especially true for reverse mortgages, since the idea of tapping home equity for aging in place is a relatively new concept. A new public-private partnership demonstration program for reverse mortgages would play an important role to identify the right kind of incentives and messages that will get older homeowners to take action. Such a program could expand the options for impaired older homeowners, and encourage them to tap the equity in their homes sooner to avoid a crisis.

Elements of a partnership program for reverse mortgages. The model for this new public-private partnership program for reverse mortgages could be the existing Long-Term Care Partnership Program (LTC Partnership). The goal of the LTC Partnership is reduce Medicaid expenditures by encouraging the purchase of private long-term care insurance as a way to delay or eliminate the need for policyholders to rely on Medicaid. Individuals who buy designated partnership policies are allowed to protect some or all of their assets from Medicaid spend-down requirements, should they exhaust their insurance benefits and need public assistance for long-term care. Under this program, policyholders must still meet Medicaid income requirements.

A similar approach could be used to encourage older homeowners with moderate incomes to take out a reverse mortgage to fund their long-term care needs rather than relying on Medicaid. Under this type of partnership, borrowers who use a certain portion of the equity in their homes to pay for home and community services could receive more favorable treatment under Medicaid's asset rules. One issue would be whether borrowers would still need to meet Medicaid income requirement. Impaired older homeowners who participate in a reverse mortgage partnership program would likely need these funds to help them to continue to live at home once they qualified for Medicaid.

In developing this type of public-private initiative for reverse mortgages, there will be many issues that go beyond the framework of the LTC Partnership. These include:

- Determining which types of expenditures, including paying for such items as a new furnace or support for family caregivers, qualify as "long-term care services" to meet Medicaid requirements under the partnership program.
- Monitoring the use of reverse mortgage funds, to ensure that they are being used appropriately.
- Determining the amount of home equity that would meet the program criteria to receive more favorable treatment of assets under Medicaid.
- Identifying the loan payment options (lump sum, line of credit, monthly payment) that will be allowed under the reverse mortgage partnership program.
- Prioritizing access to services and supports under a state HCBS program for participants in the reverse mortgage partnership program who want to continue to live at home.

One of the benefits of a reverse mortgage is that they can currently be used for any purpose, including to pay for a wide array of services and supports, as needed. This

flexibility will also create additional challenges to ensure that the loan funds are being used as intended under the partnership program.

Example from Minnesota. Many of these issues were recently tackled by policymakers, along with aging and housing experts, in the State of Minnesota, who developed a model reverse mortgage incentive program targeting older homeowners at risk of needing nursing home care. This effort was conducted as part of an ongoing study that is being funded by the Assistant Secretary for Planning and Evaluation (ASPE) and the Administration on Aging (AoA), and directed by NCOA and the Lewin Group.

The proposed program, which is being considered by the Minnesota Legislature, would combine education and counseling, with reduced reverse mortgage closing costs and assistance in the home through the state's Alternate Care program. Older people with modest value homes (worth up to $150,000) who need supportive services that are not paid by government programs would qualify for reverse mortgage incentives. These would include up to $1,500 to pay the upfront mortgage insurance premium for a HECM loan, and reduced servicing fees. To qualify for help at home under the Alternate Care program, program participants would need to use up the proceeds of their reverse mortgage loan, or spend substantially all of the payments from a reverse mortgage to pay for services for a period of at least 24 months or in an amount of at least $15,000. Besides help at home, these services and supports could include basic shelter needs, home maintenance, and modifications or adaptations, necessary to allow the person to remain in the home as an alternative to a nursing facility placement. Participants would be required to spend the proceeds of their loan according to their individual spending plan. Those who used home equity to qualify for Alternate Care program would not be required to pay a monthly participation fee for the program, nor would they be subject to an estate claim by the state for the services they received.

Minnesota believes that the program would add another layer of access to services and supports for this vulnerable population. In addition, the program could free up some public resources and may influence when and where these elders access public assistance in the future.

Reducing Loan Costs

Many seniors are deterred by the substantial upfront costs of reverse mortgages. Today, a 75-year-old HECM borrower with a home valued at $150,000 would have to pay $6,000 in closing costs on a loan worth $83,490. These closing costs (the origination fee paid to the lender and the upfront mortgage insurance premium required by HUD) represent a significant amount of the money that could be available to pay for long-term care. Additional costs include other loan-related fees (such as title search and inspections) and any repairs that the house may need to meet minimum HUD requirements.

To help reduce their long-term care expenditures, state Medicaid programs could be allowed to subsidize mortgage insurance, origination fees, and other closing costs for long-term care beneficiaries. Such incentives could make this financing option more attractive to elders with limited liquid resources, including Medicaid beneficiaries who live in the community, and increase the amount of funds available to them.

The costs associated with taking out a reverse mortgage become even more critical for impaired elders. These seniors are likely to be older and poorer than typical reverse mortgage borrowers. It will be important for the Department of Health and Human Services to work with HUD and the mortgage industry to identify ways to reduce the cost of HECM loans for this vulnerable population.

Strengthening Consumer Protections

The market for reverse mortgages will continue evolve rapidly over the next few years in response to growing consumer interest in these loans. How these changes unfold will hold significant policy implications for our aging society. With so much wealth tied

up in the home, the decisions that older homeowners make about this financial asset can significantly impact our nation's ability to balance public and private funding for long-term care and to respond to consumer preferences for aging in place. The public sector will need to play an active role to ensure that these developments include strong consumer protections and appropriately serve the needs of older Americans.

Despite the promise of reverse mortgages, few older homeowners are interested in tapping home equity for long-term care, often due to a lack of understanding about how these loans work. An important new resource to help address this barrier is the establishment of the National Clearinghouse for Long-Term Care Information, as part of the Deficit Reduction Act of 2006. NCOA would like to thank the Committee for creating this resource to educate Americans about long-term care. It will be important that the Clearinghouse include information and decision-support tools to help elders and their families make wise decisions on the use of home equity and reverse mortgages as a planning tool for aging in place.

A unique feature of reverse mortgages is that all borrowers must first meet with a HUD-approved reverse mortgage counselor before their loan application can be processed or they incur any costs. The main objective of this counseling is to educate potential borrowers about the appropriateness of these loans to address their financial needs and situation. We commend HUD for its recent efforts to expand counseling to address the unique needs of older homeowners who are considering a reverse mortgage so they can continue to live at home. The AoA is also playing a key role in providing the infrastructure for more in-depth counseling on reverse mortgages for aging in place through its Aging and Disability Resource Centers.

Ongoing discussions and joint actions by government, industry, and the private nonprofit sectors will be critical to overcome a wide array of barriers to the use of reverse mortgages, and to create a substantial "win-win" for government and consumers in the near future. Close collaboration between CMS, AoA and HUD should be encouraged as part of Federal policy, to achieve this goal.

Conclusions

As the population ages and the pressure on state Medicaid budgets rises, it becomes increasingly important to find effective ways to improve our long-term care financing system. Funding the growing demand for long-term care is a major national challenge that will require increased spending by both the public and private sectors.

Reverse mortgages have the potential to be a powerful force for system change, and to expand the boundaries of what is possible in using private funds to finance home and community services. Using this asset as a planning tool for aging in place could significantly enhance the resilience of older Americans to the financial risks of long-term care. If used wisely, a reverse mortgage can help borrowers to live with independence and dignity for many years. With supportive public policies, appropriate incentives, careful protections, and innovative products, the voluntary use of reverse mortgages may offer additional options for impaired older Americans to take action today, and use their existing resources more effectively.

MR. DEAL. Thank you. I mispronounced it. It is Stucki.

DR. STUCKI. Stucki.

MR. DEAL. I am accustomed to the Stuckeys from Georgia. You will have to excuse my pronunciation.

Dr. Wiener.

DR. WIENER. Mr. Chairman and members of the committee, thank you for this opportunity to discuss one of America's greatest challenges, the financing and organization of long-term care.

My name is Joshua M. Wiener. I am a Senior Fellow and Program Director for Aging, Disability, and Long-Term Care at RTI International, a nonprofit, nonpartisan research organization. I have conducted research and policy analysis on long-term care since 1975. In my testimony today, I would like to make six points.

First, the aging of the Baby Boom generation will dramatically increase demand for long-term care, but it will not be unaffordable. The likely increase in demand for long-term care has led some observers to forecast an apocalyptic situation, where the financial burdens become so great that they will be unbearable for our society. But, though nobody knows the future for sure, this doomsday scenario seems unlikely. According to the Congressional Budget Office, total long-term care expenditures for older people are projected to increase from 1.3 percent of the gross domestic product in 2000 to 1.5 to 2 percent of the GDP in 2040. My own, earlier projections are in this range, although I would put them slightly higher today. Within a healthcare system that is already 18 percent of GDP, these changes are relatively modest.

Second, the United States faces a serious problem recruiting and retaining high quality long-term care caregivers. This will be discussed in detail by the second panel, but the key point is that, although there is some possibility for technological fixes, long-term care is fundamentally a hands-on service provided by people, not machines. Over the long run, there is a major demographic imbalance between the number of people likely to need long-term care services and the number of people available to provide those services. The ratio of people aged 20 to 64, the working age population, to the number of people aged 85 and older, the population most likely to need long-term care services, is projected to decline from 37.8 in 2000 to 11.4 in 2050.

Third, private long-term care insurance can play more of a role than it does today, but most older people cannot afford the policies. Over the last 20 years, a small but growing market for private long-term care insurance has developed. At the same time, a substantial body of research suggests that the affordability of private long-term care insurance is a major barrier to its growth. That affordability is a problem should not be a surprise. According to a study by America's Health Insurance Plans, the average premium for a good quality policy with inflation protection and non-forfeiture benefits, for persons who purchase at age 65, was $2,862 in 2002. The premiums for a married couple are well over $5,000 per year for a good policy. At the same time, the median income for households headed by persons aged 65 to 74 was only

$34,243 in 2004, and declined sharply with increasing age. Thus, even with generous assumptions about the willingness of people to pay, private long-term care insurance is very expensive for most older people.

One possible strategy to make long-term care insurance more affordable is to make it a tax deductible expense, a strategy which President Bush and the insurance industry has endorsed. The problem, at least for the elderly population, is that the effective Federal tax rate is so low that for that $2,862 premium, for the median person in the elderly population, that would decrease the premium by $43, not enough to make a difference.

Fourth, private long-term care insurance requires tougher regulation, especially related to inflation protection. A major gap in existing regulation of private long-term care insurance concerns how inflation is addressed. Most policies in force today do not automatically adjust for inflation over time. Instead, they provide a fixed dollar maximum benefit per day in a nursing home, or a visit by a home care provider. Inflation can have a devastating impact on the purchasing power of the policies. For example, at 5 percent annual inflation, a $100 per day benefit in a nursing home at age 65 would need to pay $265 per day at age 85 to maintain the same purchasing power.

Fifth, tapping into home equity can help, but most people with disabilities do not have much home equity. In 2002, median home equity among older persons with any disability was $56,956, and only $35,640 for persons with severe disabilities.

Sixth, and finally, while the private sector can play a larger role, long-term care is predominantly a public responsibility in the developed world, and unless we consider proposals that are far more radical than what has been put on the table so far, the public sector is likely to continue to pay for the large majority of costs for people who need long-term care services.

Thank you.

[The prepared statement of Dr. Joshua M. Wiener follows:]

PREPARED STATEMENT OF DR. JOSHUA M. WIENER, SENIOR FELLOW AND PROGRAM DIRECTOR, AGING, DISABILITY AND LONG-TERM CARE, RTI INTERNATIONAL

The financing and organization of long-term care for older people and younger persons with disabilities needs reform. Although long-term disability is a normal life risk and nearly half of all older persons will spend some time in a nursing home, the need for long-term care comes as a surprise to most Americans and their families who have to cope with it (Spillman and Lubitz, 2002). With very little public or private insurance against the high costs of nursing home and home care available, users of long-term care incur very high out-of-pocket costs. As a result, Medicaid is the principal source of financing for long-term care, even though many of the users were not initially poor. Although most persons prefer home and community-based services, the vast bulk of long-term care expenditures are for institutional care. Finally, with the aging of the

population, demand for long-term care will increase in the future, placing financial pressure on public programs and private resources.

Despite these problems and the fact that long-term care is the third leg of retirement security, public policymakers have not given it the attention it deserves. We have had substantial debates about how to assure income security (Social Security) and health care (Medicare), but not how to make sure that people receive high quality long-term care in a way that is affordable to them and to society.

In my testimony today, I would like to make six points:

- The financial burden of long-term care will increase as the population ages, but, by itself, it will be manageable.
- The U.S. faces serious labor force problems regarding how to recruit and retain high quality workers to provide this care.
- Private long-term care insurance can play more of a role, but older people cannot afford it.
- Long-term care insurance needs stronger regulation, particularly related to inflation protection.
- Home equity conversions can help, but most people with significant disabilities do not have much home equity.
- Long-term care is predominantly a public responsibility throughout the developed world and is likely to remain so.

The aging of the baby boom generation will increase demand for long-term care, but it will not be unaffordable by itself.

The need for long-term care services affects persons of all ages, but the prevalence of disability increases sharply with age. The Census Bureau projects that the population age 85 and older, the population most likely to need long-term care services, will increase from 4.3 million in 2000 to 20.9 million in 2050. About half of all persons age 85 and older had a disability in the community or are in a nursing home (Johnson and Wiener, 2006). Although there appears to have been a decline in disability rates among the older population over the last 20 years (Freedman, Martin and Schoeni, 2002), the large increase in the number of older people due to the aging of the baby boom generation ensures that the demand for long-term care services will rise. Some analysts estimate that the obesity epidemic and the resulting diabetes will offset past declines in disability rates and that disability rates will increase again in the future (Lakdawalla, Battacharya and Goldman, 2004).

The likely increase in demand for long-term care has led some observers to forecast an apocalyptic situation where the financial burdens become so great that they are unbearable for our society. Although nobody knows the future, this doomsday scenario is unlikely. According to the Congressional Budget Office (2004), total (public and private) long-term care expenditures are older people are projected to increase from 1.3 percent of the Gross Domestic Product (GDP) in 2000 to 1.5 to 2.0 percent of GDP in 2040. These projections are in line with my own earlier projections (Wiener, Illston and Hanley, 1994), although they probably should be somewhat higher because of the workforce issues discussed below. Ultimately, we will have to pay long-term care workers more to induce them to provide services. Within a health care system that is already 18 percent of GDP, these changes are relatively modest. Moreover, many other countries, such as Sweden, Japan, Germany, and England, already have populations that are much older than ours without unduly dire results (Organization for Economic Co-operation and Development, 2005).

In sum, long-term care is sure to be a larger financial burden on public and private burden in the future. However, the increase, by itself, should not be so large as to immobilize public initiatives to make the system better. The question is more one of political will than economics. The issue is complicated, however, by the fact that long-

term care mostly affects the same populations that uses Medicare and Social Security, both of which have substantial long-run financial problems.

The United States faces a serious problem recruiting and retaining high quality long-term care caregivers.

Although some technological improvements are possible, long-term care is fundamentally a hands-on service provided by people, not machines. The United States faces serious problems in recruiting and retaining long-term care workers, a situation that will only grow worse over time. Nationally, turnover rates for certified nurse assistants in nursing homes were estimated to be approximately 78 percent per year in 2001, which is likely to adversely affect quality of care (American Health Care Association, 2002). As a result of high turnover and vacancy rates, providers incur substantial recruitment and training costs (Leon, Marainen and Marcott, 2001; Pillemer, 1996). Major reasons for the shortages include low wages and benefits, a lack of career ladder, inadequate training and poor work culture.

Over the long run, there is a major demographic imbalance between the number of people likely to need long-term care services and the number of people likely to be available to provide it. The ratio of persons ages 20-64 (the working age population) to the number of persons age 85 and older (the population most likely to need long-term care services) is projected to decline from 37.8 in 2000 to 11.4 in 2050 (Lewin Group, 2002). While this data are often used to illustrate the potential economic burden of Medicare, Medicaid and Social Security, they also have profound implications for the availability of personnel to provide long-term care services. It will be far more difficult to recruit and retain workers in the future, and they probably will be more costly.

Private long-term care insurance can play more of a role, but most older people cannot afford it.

Over the last 20 years, a small but growing market for private long-term care insurance has developed. As of 2001, approximately 8 percent of older people and far less than one percent of the nonelderly population had some form of private long-term care insurance (Johnson and Uccello, 2005). Public policymakers have been interested in promoting private long-term care insurance as a way of increasing choices available to individuals and reducing Medicaid expenditures by middle-class beneficiaries.

A substantial body of research suggests that the affordability of private long-term care insurance is a major barrier to its purchase. Most studies found that only a relatively small minority of the elderly population (generally 10 to 20 percent) can afford good quality private long-term care insurance (see, for example, Wiener, Illston and Hanley, 1994; Rivlin and Wiener, 1988; Rubin, Wiener and Meiners, 1989; and Wiener and Rubin, 1989). Projections suggest that these percentages will increase, but that the bulk of older people will still not be able to afford policies in the future. Other research has found higher percentages of older people to be able to afford private long-term care insurance by assuming purchase of policies with more limited coverage, by assuming that older people would use assets as well as income to pay premiums, or by excluding a large proportion of older people from the pool of people considered interested in purchasing insurance.

That affordability is a problem should not be a surprise. According to a study by America's Health Insurance Plans, the average premium for a good quality policy with inflation protection purchased at age 65 was $2,346 in 2002; the average premium for a good quality policy with inflation protection and nonforfeiture benefits was $2,862 in 2002 (America's Health Insurance Plans, 2004). Thus, premiums for a married couple approximate $5,000 per year for a good policy. Premiums at age 79 are approximately three times as much. However, the median income for households headed by persons aged 65-74 was only $34,243 in 2004, and declines sharply with increasing age (U.S.

Census Bureau, 2006). Thus, even with generous assumptions about the willingness of people to pay, private long-term care insurance is very expensive for most older people.

A number of policy strategies have been proposed to make long-term care insurance more affordable. One possible strategy is to encourage purchase at younger ages, when premiums are lower. Premiums for a good quality policy with inflation protection and nonforfeiture benefits purchased at age 50 are half what they are at age 65. While some employers do offer these policies, they rarely contribute towards the cost of the premiums. In addition, people in their 40s and 50s are concerned about their mortgage payments, child care costs, college education expenses for their children, and general retirement; they are rarely interested in long-term care. The marketing dilemma is that people are interested in long-term care when they are older and cannot afford the policies; at the age when they could afford the policies, they are not very interested.

Another possible strategy is to make long-term care insurance a tax deductible expense, a strategy which President Bush and the insurance industry have endorsed. This approach, especially for the elderly population, is likely to be ineffective because it would not substantially reduce the price of the insurance. According to the Urban Institute-Brookings Institute Tax Policy Center, the median effective federal individual income tax rate for elderly childless households was 1.5 percent in 2003; for the older population as a whole, it was only 7.3 percent. Thus, for the median elderly household, it would reduce the $2,862 premium cited above by $43. Since tax deductions benefit upper-income households more than lower- and moderate-income households, this strategy would also be regressive in terms of tax policy. An earlier analysis of proposed tax incentives (Wiener, Illston and Hanley, 1994) found that these policies were expensive in terms of lost revenue, but mostly benefited persons who would have purchased policies without the increased tax benefits.

Long-term care insurance requires tougher regulation, especially regarding inflation protection.

The quality of long-term care insurance policies has improved dramatically over the last 20 years and there are many good products currently available. Regulation by the states, encouraged by the tax provisions in the Health Insurance Portability and Accountability Act (HIPAA), deserves some of the credit for pushing policies to improve.

A major gap in existing regulation of private long-term care insurance concerns how inflation is addressed. It is critical to solve this issue because health care inflation, including long-term care, is substantial and policies are typically sold years in advance of when benefits are used. Most states only require that insurers offer a product where the indemnity value increases by 5 percent per year. Most policies in force today do not automatically adjust for inflation over time; instead they provide fixed dollar maximum benefits per day in a nursing home or visit by a home care provider.

Failure to have automatic inflation adjustments can have a devastating impact on the purchasing power of the policies. For example, at 5 percent annual inflation, a $100 per day benefit in a nursing home at age 65 would need to pay $265 per day at age 85 to maintain the same purchasing power. The longer the period of time between the initial purchase of the power and its use, the more important it is to have compound inflation protection. For example, a $100 per day indemnity benefit purchased at age 50 would need to pay $551 at age 85 to maintain the same purchasing power.

Insurance companies often offer the insured the option of purchasing additional coverage over time at the new attained age instead of automatic inflation adjustments. Since disability rates are exponential by age, premiums quickly become unaffordable. To retain purchasing power, the premiums at age 82 would be approximately ten times, in nominal dollars, what they were at age 62. The premiums will skyrocket over time, but the incomes of the elderly will not.

It is not hard to understand why insurers resist regulations requiring inflation adjusted policies—policies with inflation protection cost are roughly twice the price of policies without inflation adjustments. Higher premiums mean lower sales. Nonetheless, policies without inflation protection may not provide substantial protection against the costs of long-term care.

Tapping into home equity can help, but most people with disabilities do not have a lot of home equity.

Inspired in part by the recent increase in home prices, policymakers are increasingly interested in finding ways to use home equity conversions to finance long-term care. Typically, these mechanisms are home equity loans that do not have to be paid off until the borrower dies or moves from the house. While there is little doubt that home equity accounts for the vast majority of the wealth of the older population, policymakers need to be cautious in how much home equity can be used to pay for long-term care (Merlis, 2005). In 2002, median home equity among older persons with disabilities was $56,956 and $35,640 for persons with severe disabilities (Johnson and Wiener, 2006). Restrictions on the amount of home equity that can be used, closing costs for home equity conversions, including mortgage insurance, and interest costs substantially erode the amount of money available to pay for long-term care directly. Merlis (2005) estimated that for a 70-year old borrower, these costs could account for about a third of the cost of the loan over 15 years.

Some analysts have suggested using home equity conversions to purchase private long-term care insurance, which provides more coverage than may be available though direct use of home equity to purchase long-term care services. While the use of home equity would marginally increase the proportion of older people who can afford private long-term care insurance, it seems unreasonable to expect that people will partly deplete their major asset to purchase a product, one of whose major purposes is to protect their major asset. Moreover, individually sold private long-term care insurance has very high overhead, due to substantial marketing, commission, and profit costs. Most private long-term care insurance policies have long-term loss ratios of 60 percent, which roughly means that 60 percent of the premiums are used for benefits. Thus, the use of home equity (with a "loss ratio" of 66 percent) to purchase a private long-term care insurance policy (with a loss ratio of 60 percent) would result in only about one in three home equity dollars providing benefits, which is an inefficient use of funds.

Conclusion: While the private sector plays a role, long-term care is predominantly a public responsibility in the developed world.

The major focus of federal policymakers in long-term care financing over the last decade has been to find ways to increase the role of the private sector and to decrease the role of the public sector. Public sector financing currently dominates long-term care, accounting for about two thirds of long-term care expenditures for older people (U.S. Congressional Budget Office, 2004).[1] Moreover, approximately 78 percent of nursing home residents have their care financed by either Medicare or Medicaid (American Health Care Association, 2006). The United States is not alone in this large role played by the public sector. In Ireland, New Zealand, Japan, Australia, Canada, Germany, the United Kingdom, the Netherlands, Norway and Sweden, long-term care is financed primarily through public programs. Only in Germany does private long-term care insurance play a significant role, and that is as an alternative for upper-income individuals to the social insurance provided by the quasi-public "sickness funds."

[1] If mandatory out-of-pocket contributions towards the cost of care by Medicaid beneficiaries in nursing homes were counted, the public role would be substantially higher.

While there is little doubt that private sector financing can play a bigger role than it plays now, it seems unlikely that private financing can become the dominant source of funding for long-term care without more radical and costly initiatives than are currently contemplated. Research suggests, for example, that the people who can afford private long-term care insurance are not the people who spend down to Medicaid (Rivlin and Wiener, 1988; Wiener, Illston and Hanley, 1994; and Rubin and Wiener, 1989). As a result, expansion of private long-term care insurance is unlikely to affect Medicaid costs more than marginally. Thus, federal policymakers bear a special responsibility to improve Medicare and Medicaid for the majority of the people who need and use long-term care services.

MR. DEAL. Thank you. Ms. Ignagni.

MS. IGNAGNI. Thank you, Mr. Chairman, and members of the committee. It is a pleasure to be here.

We took your challenge seriously to approach this issue in a rather broad way, and with that in mind, we have tried to cover four topics in our testimony.

First, we provided data about the problem. I think my colleagues have done a very good job of highlighting that. I am only going to touch on a couple of things that haven't already been said.

Second, we discussed what our health plans have brought to the Medicaid program, and the accomplishments there. Third, we have given you comprehensive information about the private market. I am delighted to talk about that, and I would like to point out a couple of things. And finally, we have ended with making seven recommendations, which I will highlight.

First, in terms of data, I think what puts the problem in perspective, and the challenge, probably more properly stated, is that over the next 25 years, the population over 65 will double. That is not the end of the story, however, because also in the same period, the population over 85, most likely to need long-term care will also double. These individuals will have multiple chronic conditions. We already know that currently 20 percent of Medicare beneficiaries have at least five medical conditions, accounting for approximately two-thirds of Medicare expenditures. So the challenge of dealing with co-morbidities and various kinds of healthcare problems occurring together in people who are aging will be even more significant over time. This is clearly going to, as Mr. Chairman, you observed, and your colleagues have observed, the members of the subcommittee, put a strain on public programs, individual families, and the healthcare system.

Now, the policy question that you have articulated is how do we find the balance between what the public sector role is, and what is the private sector sole. First, I think is a window into uncovering the answer to that question. We have taken a look, and provided details now, in terms of the distribution of expenditures for long-term care.

Medicaid is covering 45 percent. Out-of-pocket costs amount to 23 percent. Medicare is covering 14 percent. Private insurance is covering 11 percent, but we have seen gains in that area. I will highlight them in a moment. The balance is from other resources, individuals, et cetera.

How much does it cost? This is a very important part of the conversation. It hasn't yet been highlighted, but it is roughly $71,000, on average, for a one year stay in a nursing home. That would be a private room, a little less for a semi-private room. That is an average, higher or lower, depending upon the area of the country that you are from. It is $32,000 for a private room in an alternative living facility, and that gives you a sense of the relative distribution of the dollars. It is $25 per hour, roughly, for home healthcare services. For aides, it is roughly half of that, but that gives you a sense of the burden, potentially, on families.

We noted in the Kaiser Family Foundation research, there are two widely held misconceptions. One is that a third of the population think nursing home care is approximately $40,000 per year, so there is a major gap there, and also, most of the population think that there is a public safety net that will take care of them when they need care, notwithstanding their income, and that is clearly not the case.

So, as you think about policy approaches, we first wanted to congratulate you, Mr. Chairman, and the members of this subcommittee in moving forward on the first step, which is to pass a partnership program. We now know that 25 states are in the process of developing partnership programs, and that is very good progress since the enactment of the Deficit Reduction Act, in a very short period of time. The next step is for HHS to develop regulations, a template, basically, to guide the States in how they might submit planned amendments, so that they can move very quickly.

Before I turn to the private sector, I would like to just highlight a couple of lessons that we have learned in the Medicaid arena. Our health plans are working very well for the dual eligibles, who qualify for SSI, and others who need long-term care needs. We have described in our testimony innovative programs that offer continuity of care, care coordination, individually targeted, and customized care. We have described programs addressing fragmentation in various programs, and how we put them together, in bringing services to the public programs. We have talked about the importance of the special needs program, and we have made a specific policy proposal about a potential adjustment under Medicaid, which I will highlight as we wrap up our recommendations.

In terms of the long-term care market, consumers with long-term care now are seeing a very broad protection offered in the market. It used to be primarily focused on nursing home care. It is much broader

today, in terms of home care, assisted living facilities, et cetera. They are receiving more personal care support, which is important for families. Particularly, Mr. Ferguson observed the issue of respite care. It is enabling individuals to remain at home, which we know is so important, and it is generating savings for Medicare and Medicaid.

Also encouraging, Mr. Chairman, is that there is a growth in the employer market. I will highlight a specific recommendation there. We have discussed in our testimony affirmative support for the NAIC guidelines with respect to long-term care. I want to highlight one. We are often asked the question about post-claims underwriting. The guidelines developed by the NAIC, which 30 States have adopted now, prohibits post-claims underwriting. We support that, and believe it is not justifiable. We are required under these regulations to disclose any prior rate increases. I might note that 80 percent of the insurers that are operating in the long-term care market have never had a premium increase.

Lastly, there are very specific regulatory requirements with respect to guidelines for suitability, to whom you might sell long-term care insurance, who should not be offered long-term care insurance. I wanted to assure the subcommittee that we are very comfortable with that, and very much supportive of that. We have provided a great deal of additional information, Mr. Chairman, about how private healthcare, long-term care insurance works, what we can bring to the healthcare system.

I would like to summarize by making seven recommendations. First, we have had comments already about the above-the-line deduction. This is important, because it would put long-term care on an equal playing field with acute care, and level the playing field there, and not penalize individuals who purchase long-term care.

Second, I would highlight that three quarters of individuals now who are purchasing long-term care in 2005 are purchasing inflation protection, versus only 40 percent back in 2000. We have talked about flexible benefits programs, Mr. Chairman, and the opportunity that should be accorded to individuals who want to purchase long-term care insurance with flexible benefit dollars. If they do not use those resources in the FSAs, they lose them now. That is a very important place. It can expand the employer offerings, and that could be a very fruitful way to expand long-term care.

We have talked about removing barriers to Medicaid managed care. We have talked about potential demonstrations. We have advocated for a Commission on Long-Term Care, to focus very specifically on the issues that all of you have raised today.

Finally, we have talked about a specific office to address the unique resource issues with respect to workforce training. Those are major issues that we need to get our hands around, and finally, in long-term care, we need to talk about quality performance measurement. We have offered some observations there, and we would be delighted, Mr. Chairman, to talk about them in the Q&A session.

Thank you.

[The prepared statement of Karen Ignagni follows:]

PREPARED STATEMENT OF KAREN IGNAGNI, PRESIDENT AND CEO, AMERICAN HEALTH INSURANCE PLANS

I. INTRODUCTION

Good afternoon, Mr. Chairman and members of the subcommittee. I am Karen Ignagni, President and CEO of America's Health Insurance Plans (AHIP), which is the national association representing nearly 1,300 private sector companies providing health insurance coverage to more than 200 million Americans. Our members offer a broad range of health insurance products in the commercial marketplace and also have a strong track record of participation in public programs.

AHIP's members, who represent about 90 percent of the current long-term care insurance marketplace, share your commitment to meeting the long-term care needs of our nation's aging population and we appreciate the opportunity to testify on this important issue. We applaud Congress for enacting legislation earlier this year to expand long-term care partnerships. We particularly want to thank members of this committee for your leadership on this critically important legislation.

My testimony today will focus on five areas:

(1) Broadening the conversation on long-term care to recognize the continuum of health care services Americans will need throughout their lives;
(2) The importance of moving forward to implement the newly expanded long-term care partnerships in a timely manner;
(3) The innovative strategies AHIP members are using to contain costs and improve quality in Medicaid;
(4) An overview of private long-term care insurance, including the financial protection it offers consumers and the cost savings it provides to Medicaid and Medicare; and
(5) Recommendations for additional policy changes that should be pursued to help more Americans secure protection against long-term care costs.

II. BROADENING THE CONVERSATION

Our members urge the subcommittee to take an approach to long-term care that broadens the health care discussion to focus on the continuum of health care services that people need throughout their lives. Our current health care system focuses primarily on treating episodes of acute illness, rather than managing chronic conditions. This is true despite the fact that 20 percent of all Medicare beneficiaries – chronically ill patients with five or more medical conditions – accounted for more than two-thirds of the Medicare program's costs in 2004. Likewise, long-term chronic care management is a key cost and quality issue for Medicaid. Our tax system also takes a narrow view of our nation's health care needs by orienting incentives toward the coverage of acute care benefits.

The aging of the baby-boom generation – the 77 million Americans born between 1946 and 1964 – poses multiple challenges for policymakers. More men and women are approaching retirement than ever before and they will live longer into old age than any

previous generation. The U.S. Census Bureau estimates that between 2003 and 2030, the population age 65 and older will increase from 36 million to 72 million, reaching twenty percent of the total population. Meanwhile, the population of those aged 85 or older – the population most likely to need long-term care – is projected to increase from 4.7 million in 2003 to 9.6 million in 2030, and then double again to 20.9 million by 2050.

In the next 30 years, more than half the U.S. population will be living with at least one chronic condition. When narrowing this profile to seniors, Census Bureau data suggest that approximately 80 percent of seniors have at least one chronic condition, and 50 percent of those have two or more chronic conditions. Chronic illnesses such as cancer, diabetes, Alzheimer's disease and hypertension exacerbate age-related health problems and increase the likelihood of needing long-term care. Currently, nearly half of all nursing home residents have Alzheimer's disease. By 2050, the Alzheimer's Association estimates that 14 million baby boomers, nearly one in five, will find themselves living with the disease. We need to make major adjustments to address 21st-century realities and our aging population. At the same time, we need to explore a range of public-private partnerships that could make long-term care costs more predictable and expand service options for consumers.

While Medicare and Medicaid already are burdened by high costs, public programs designed to meet the needs of the elderly will become increasingly strained in the years ahead. One of the crucial questions facing policymakers, therefore, is how to create an appropriate balance between public and private responsibilities – between the obligation of government to provide a safety net for those who need it and the obligation of citizens to provide for themselves to the extent they are able to do so.

The Costs of Long-Term Care

According to the Government Accountability Office (GAO), Medicaid currently pays for about 45 percent of all long-term care expenditures, followed by out-of-pocket payments (23 percent), Medicare (14 percent), and private insurance (11 percent). Other public and private sources account for the remaining 7 percent.[1] The Congressional Budget Office (CBO) has projected that the cost of providing long-term care services nationwide to the growing elderly population will nearly triple in real terms over the next 40 years.[2]

The scope of the long-term care funding problem is particularly clear when costs are examined on an individual level. Genworth Financial, an AHIP member, has been commissioning annual cost of care studies since 2001. The most recent study[3], based on information gathered in January and February 2006, includes the following findings:

- Nationally, the average annual cost for a private nursing home room (single occupant) is $70,912 ($194.28/day), reflecting a 2.2 percent increase over 2005 rates ($190.20/day). The average cost of care for a private room in urban areas is 17 percent greater than in non-urban areas. Louisiana has the lowest average annual cost for a private room ($42,304), while Alaska has the highest average annual cost ($191,140).
- Nationally, the average annual cost for a semi-private room (double occupancy) is $62,532 ($171.32/day), a 2.3 percent increase over 2005 rates ($167.44/day).
- Nationally, the average monthly cost for a private one-bedroom unit in an assisted living facility (ALF) is $2,691.20 (a daily rate of $88.48), reflecting a 6.7 percent increase over 2005 survey rates ($2,522/month). These rates do not include any

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[1] David Walker, Comptroller General, Government Accountability Office (GAO), Testimony, March 21, 2002

[2] Congressional Budget Office, *The Cost and Financing of Long-Term Care Services*, Testimony, April 27, 2005

[3] Genworth Financial, *2006 Cost of Care Survey*, March 2006

one-time community or entrance fees. Approximately 33 percent of the ALFs surveyed charge a one-time fee, commonly referred to as a community or entrance fee, ranging from $50 to $8,490, with a national average one-time fee of $1,369.68.

- Across all home health care provider types, the average hourly rate for home health aides is $25.32, a 13 percent increase over 2005 survey results. The average hourly rate for homemaker services is $17.09, a 3 percent increase over 2005 survey results.

These figures translate into financial obligations that few families have the resources to meet.

Common Misconceptions

At the same time, public attitudes about long-term care are skewed by three widespread misconceptions: (1) that the risk of needing long-term care is relatively remote; (2) that the costs of such care are considerably lower than is actually the case; and (3) that Medicare and Medicaid can fully provide care should the need arise.

On each of these three points, the realities are dramatically different than the perception:

- The risk of eventually needing long-term care, far from being remote, is quite high. Today, 44 percent of people reaching age 65 eventually will spend some part of their lives in a nursing home.[4] It will take time and public education to make Americans more aware of the risks associated with needing long-term care in old age.
- A recent public opinion poll found that one-third of those surveyed believe nursing home care currently costs less than $40,000 a year – less than 60 percent of actual costs.[5]
- Perhaps the most serious misconception, however, is that there is an adequate public safety net in place to protect those who need long-term care. The belief appears to be widespread that Medicare and Medicaid will somehow meet these needs. The reality is that neither program offers adequate protection.

The Role of Medicare and Medicaid

Medicare, the federal health insurance program for the elderly and disabled, is designed primarily to pay for acute care services provided by hospitals and physicians. While Medicare does cover some nursing home care for patients following a hospital stay, its coverage is limited to 100 days, which by definition, excludes those who need ongoing assistance.

Medicaid, the joint federal-state program for low-income individuals, does pay for long-term care – but only for those who have exhausted nearly all of their own resources. Because Medicaid is a means-tested program, qualifying for assistance requires proving that one is impoverished, or nearly so.

Another harsh reality is that becoming eligible for Medicaid can mean losing control over how and in what setting long-term care will be delivered. Covered services vary substantially from state to state, as does the quality of care. Some states that have been relatively generous about authorizing long-term care services at home have experienced runaway costs and have been forced to scale back such arrangements. For many who rely on Medicaid, their only option is to enter a nursing home, even if they would prefer home care.

The recent expansion of long-term care partnerships, discussed in the following section, was an important step toward creating opportunities for individuals to purchase long-term care coverage and reduce the burden on public programs.

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[4] Congressional Budget Office, *Financing Long-Term Care for the Elderly*, April 2004

[5] Kaiser Family Foundation Public Opinion Spotlight, http://www.kff.org/spotlight/longterm/10.cfm

III. IMPLEMENTATION OF EXPANDED LONG-TERM CARE PARTNERSHIPS

AHIP applauds Congress for expanding public-private long-term care "partnerships" under the Deficit Reduction Act of 2005 (DRA). The Energy and Commerce Committee deserves special recognition for its work on this legislation. The partnerships authorized by the DRA will allow many Americans to receive the financial protection provided by long-term care insurance while also ensuring that Medicaid will play a role in meeting the needs of those who require extended long-term care stays.

Building upon the innovative partnerships that already have been implemented in New York, California, Connecticut, and Indiana, this legislation creates powerful new incentives for more Americans living in all states to prepare for the future by purchasing long-term care insurance. Individuals who purchase partnership policies will have the added peace of mind of knowing that if their policy benefits are exhausted, the government will cover the costs of their continuing care through Medicaid without first requiring them to "spend down" their life savings and become impoverished.

In recent years, sales of partnership plans in the four states that have operated them have steadily increased. Between 1996 and 2004, partnership enrollment increased from 28,000 to 172,000.[6] Independent research indicates that partnership plans are attracting enrollees who generally would not buy non-partnership long-term care insurance. Further, research indicates that the partnership enrollees have lower incomes and fewer assets than other long-term care insurance purchasers.[7]

Next Steps

While the passage of this legislation is a major accomplishment, the next step is for the Department of Health and Human Services (HHS) to move forward to develop the regulatory structures that will facilitate the implementation of partnerships in the states. The expansion of the partnership program has the full support of the states and they are ready to launch once the regulatory requirements are established for approval of their plans. To date, more than 20 states have enacted or introduced legislation that would enable their state to establish a partnership program. We are working with our members, state officials, and others to develop a template for a fast-track process and streamlined application that states can use to amend their Medicaid plans to include partnership programs.

IV. THE SUCCESS OF PRIVATE SECTOR STRATEGIES IN MEDICAID

While examining the private sector's role in meeting long-term care needs, it is important to recognize that health insurance plans have made an important contribution toward helping Medicaid programs use their limited resources to expand access, improve quality, provide transportation services, and take other steps to better serve beneficiaries. More than 20 years of experience demonstrates that Medicaid health plans increase beneficiary access to care and improve outcomes, while ensuring that the federal government and state Medicaid programs receive the highest possible value for the dollars they spend on health care.

Increasingly, health plans are proving that integrated systems of care work well for beneficiaries who are dually eligible for Medicaid and Medicare, who qualify for Medicaid through eligibility in the federal Supplemental Security Income (SSI) program,

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[6] Letter to the Honorable Charles E. Grassley re: Overview of the Long-Term Care Partnership Program, Government Accountability Office (GAO), September 9, 2005, p. 4 of the enclosure and "Partnership Insurance: An Innovation to Meet Long-Term Care Financing Needs in an Era of Federal Minimalism," Mark R. Meiners, Hunter L. McKay, and Kevin J. Mahoney, Journal of Aging and Social Policy, Vol. 14, No. 3/4, 2002, p. 87

[7] Meiners, McKay, and Mahoney, 2002, p. 87

and other beneficiaries with long-term health care needs. Innovative programs in Minnesota and Texas demonstrate that Medicaid health plans effectively coordinate care for beneficiaries with long-term care needs. Health plans operating in these states have shown that private plan techniques including care coordination, the design of individualized treatment regimens, and encouraging more community-based care improve health outcomes, reduce costs, and deliver high levels of patient satisfaction while maintaining high quality of care. For example:

- Health plans participating in the Texas STAR+PLUS program (includes dual eligibles and beneficiaries eligible for the federal SSI program) reduced emergency room visits by 40 percent and reduced inpatient admissions by 28 percent while promoting quality care. The STAR+PLUS program saved the state $17 million dollars – in just one county – in the first two years.
- A CMS evaluation of the Minnesota Senior Health Options (MSHO) program found dually eligible beneficiaries had fewer preventable emergency room visits and were more likely to receive preventive services after enrolling in a Medicaid health plan. MSHO enrollees report a 94 percent satisfaction rate with their care coordinators.

UnitedHealth Group, through its affiliate, Evercare, has worked with six states, including early efforts in Florida, Arizona and Minnesota, to develop a model that addresses the problems of fragmentation in our health and long-term care systems for people with chronic illness and disabilities. These programs pair a personal care manager with comprehensive services, including acute, nursing home, home- and community-based, behavioral health, and pharmacy care. These programs have had documented success in reducing acute events, such as emergency room visits and hospitalizations, and allowing individuals to remain in their communities and avoid costly nursing home placement.

Another AHIP member, UCare Minnesota, is improving the health and well-being of beneficiaries through its participation in the MSHO program mentioned earlier. To understand the value of this program, consider the circumstances of a 75-year-old resident of Ramsey County – “Mr. O” – who had diabetes and heart disease when he joined MSHO. Before joining UCare, Mr. O’s health began declining further because he wasn’t able to manage his own care and the basic activities of daily living. He was hospitalized four times in the year before he joined UCare.

Once Mr. O joined UCare, his health and life began to improve. His care coordinator made sure that Mr. O had regular appointments with his primary care clinic. She arranged for Meals on Wheels to bring healthy meals each day. She also arranged for a skilled nurse to visit every other week. The coordinator also had a home health aid come in three times a week to help him with personal care, such as bathing, grooming, and dressing. In addition, the coordinator arranged for a service to help with homemaking and weekly chores. Once Mr. O’s health and home life improved, so did his outlook on life. He told the care coordinator that she is his “ray of sunshine” because of the help she has given him.

As we see the benefits of this coordination, AHIP members are playing leading roles in many states in the effort to coordinate the Medicare and Medicaid programs for dually eligible beneficiaries. This type of integration has been discussed for many years and practiced successfully in a few areas. Now, through the Medicare Special Needs Plans that were authorized by the Medicare Modernization Act of 2003 (MMA), a growing number of plans are coordinating both acute care and long-term care services for dual eligible beneficiaries. The addition of a prescription drug benefit to Medicare and the growth of Medicare Advantage availability across the nation have created new incentives for states to align care for dually eligible beneficiaries.

States now have an opportunity to facilitate coordination and higher quality care for these beneficiaries, and AHIP members are uniquely positioned to bring their health care

delivery competencies to this partnership. By tailoring benefits, delivery systems, and provider networks to meet the specific needs of these vulnerable beneficiaries, Special Needs Plans can provide access to high quality care without the disruptions that these seniors would otherwise encounter in accessing benefits from two separate programs. The early experience with Special Needs Plans indicates that this integration of benefits can succeed in providing beneficiaries with better health care across the entire continuum of services they need.

While this success is encouraging, we see certain challenges – for beneficiaries, states, and the Medicare program – arising from the differences in the benefits covered and the providers participating in the Medicare and Medicaid programs. To ensure that Medicare and Medicaid integration continues to grow, it will be important to align incentives. Later in this testimony, we discuss steps that can be taken to remove barriers and improve our nation's long-term care policy. One critical step for further integration of care for dually eligible long-term care beneficiaries will be to readjust the calculation of the federal upper payment limit (UPL) for supplemental payments made by states to publicly owned hospitals and facilities.

V. THE ROLE OF PRIVATE LONG-TERM CARE INSURANCE

Approximately 10 million Americans have purchased long-term care insurance.

According to an AHIP study, consumers with long-term care insurance are 66 percent less likely to become impoverished to pay the costs of long-term care, and long-term care insurance reduces the out-of-pocket expenses of disabled elders. Those with private long-term care insurance receive an average of 14 more hours of personal care per week than similarly disabled non-privately insured elders. Another benefit of long-term care insurance is that it allows those with chronic illnesses and the disabled to remain in their homes. Approximately half of patients and family caregivers interviewed by trained nurses and social workers said that in the absence of their long-term care insurance benefits, the patients would not be able to remain in their homes and would have to seek institutional alternatives.[8]

Long-term care insurance also can reduce state and federal Medicaid expenditures and federal Medicare home health expenditures. According to the AHIP study mentioned above, Medicaid savings are projected to total about $5,000 for each policyholder with long-term care insurance and Medicare savings are estimated to exceed $1,600 per policyholder. Aggregate savings to Medicare and Medicaid for the current number of policyholders are estimated at about $30 billion. These savings will grow as more people acquire policies and the average age of purchasers continues to decline.

Types of Long-Term Care Insurance and Benefits

Several types of long-term care insurance policies are available to consumers. Most are known as either "indemnity" or "expense incurred" policies. An indemnity or "per diem" policy pays up to a fixed benefit amount. With an expense-incurred policy, consumers choose the benefit amount when they buy the policy and they are reimbursed for actual expenses for services received up to a fixed dollar amount per day, week, or month.

Many companies also offer "integrated policies" or policies with "pooled benefits." This type of policy provides a total dollar amount that may be used for different types of long-term care services. There is usually a daily, weekly, or monthly dollar limit for covered long-term care expenses. For example, under a policy with a maximum benefit amount of $150,000 of pooled benefits, the consumer would receive a daily benefit of

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[8] AHIP, *Benefits of Long-Term Care Insurance: Enhanced Care for Disabled Elders, Improved Quality of Life for Caregivers and Savings to Medicare & Medicaid*, September 2002

$150 that would last for 1,000 days if he or she spent the maximum daily amount on care. However, if their care costs less, they would receive benefits for more than 1,000 days.

A number of companies offer "hybrid" products that combine long-term care benefits with another insurance product. For example, one type of hybrid that links long-term care insurance to life insurance provides protection against long-term care expenses while at the same time paying a death benefit if the policyholder dies without ever requiring long-term care services.

Consumers generally have a choice of daily benefit amounts ranging from $50 to more than $300 per day for nursing home coverage. Because the per-day benefit purchased today may not be sufficient to cover higher costs years from now, most policies offer inflation adjustments. In many policies, for example, the initial benefit amount will increase automatically each year at a specified rate (such as 5 percent) compounded over the life of the policy.

Long-term care insurance policies contain a wide range of benefit options at moderately priced premiums. For example:

- Long-term care insurance plans offer coverage of nursing home, assisted living facility, home health care, and hospice care. On a case-by-case basis, plans also provide certain alternate care services not listed in the policy (e.g., covering a stay in a special Alzheimer's facility or building a wheelchair ramp to allow the individual to remain in his or her home), subject to the policy's benefit limits.
- Other common benefits include care coordination or case management services, support with activities of daily living, medical equipment coverage, home-delivered meals, spousal discounts, and survivorship benefits. Plans also commonly cover caregiver training to ensure that caregivers learn basic techniques for safely caring for patients in their homes (e.g., transferring patients from their bed to a chair). In addition, virtually all plans cover respite care, designed to pay for brief periods of formal care to provide relief to caregivers.
- Plans contain provisions that guarantee their renewability, have a 30-day "free look" period, cover Alzheimer's disease, provide for a waiver of premiums once a claim is processed, and give policyholders the option of covering nursing home stays without limits or caps.
- Age limits for purchasing coverage also are expanding. Our members now offer individual policies to people as young as 18 and as old as 99. In addition, recognizing that consumers want to plan ahead for their long-term care needs, plans offer inflation protection for the dollar value of a purchased benefit at an annual 5 percent compounded rate, funded with a level premium that stays the same from one year to the next. Companies also offer plans that have a non-forfeiture benefit that allows beneficiaries to retain some benefits if they lapse their policy.

The growth in employer-sponsored plans is especially encouraging. The average age of the employee electing this coverage is 45 – compared to an average age of 60 for persons who buy long-term care insurance outside of the employer-sponsored market. To date, over 2 million policies have been sold through more than 6,000 employers, and accounts for about one-fourth of the long-term care insurance marketplace.

Premiums for long-term care insurance policies depend on multiple factors, including the entry-age of the policyholder and comprehensiveness of the benefit package selected. At the same time, the subcommittee should be aware that average premiums have remained stable over time. AHIP estimates that a vast majority of long-term care policies currently in effect today have never experienced a rate increase. In addition, within the past few years there have been significant enhancements to long-term care

insurance. For example, prior hospitalization requirements have been eliminated and benefits have been expanded to include coverage in assisted living facilities, adult day care and home health care, in addition to nursing home care, thus giving buyers more benefits for their premium dollars.

Examining Who Buys Long-Term Care Insurance

AHIP recently commissioned a study[9], conducted by LifePlans, Inc., to identify who buys long-term care insurance in the individual market and understand what motivates them to do so. Ten insurance companies participated in this study, representing more than 80 percent of total sales of long-term care insurance policies in 2005. These companies contributed a sample of 1,274 buyers, 214 nonbuyers, and design information on 8,208 policies. In addition, 500 individuals age 50 and over were surveyed from the general population. This study builds upon similar work completed in 1990, 1995, and 2000.

The study's key findings include the following:

- The average age of individual purchasers of long-term care insurance declined from 67 years to 61 years between 2000 and 2005. Two-thirds of all individual long-term care policies sold are now purchased by people younger than 65. The major demographic differences between buyers and nonbuyers are that the latter tend to be somewhat older, less likely to be employed, and have lower incomes than buyers of long-term care insurance. In 2005, 71 percent of buyers had incomes exceeding $50,000, 13 percent had incomes between $35,000 and $50,000, and another 13 percent had incomes between $20,000 and $35,000.
- Buyers are almost twice as likely as nonbuyers to strongly agree that "it is important to plan now for the possibility of needing long-term care services." On another key statement, nonbuyers are more than twice as likely as buyers to agree that "the government will pay for most of the costs of long-term care if services are ever needed." Nonbuyers also were much more likely than buyers – 70 percent versus 14 percent – to underestimate the cost of a nursing home in their area.
- In examining the coverage offered by long-term care insurance policies, the study found a trend toward the purchase of comprehensive coverage. In 2005, 90 percent of policies sold were comprehensive (i.e., covering both institutional care and home care) – compared to 77 percent in 2000 and 37 percent in 1990. Over the past five years, the average daily nursing home benefit has increased by 30 percent. In addition, more than three-quarters of buyers chose some form of inflation protection in 2005, up from 41 percent in 2000.
- A highly significant finding from the 2005 study is that more than 80 percent of current nonbuyers would be more interested in buying a policy if they could deduct premiums from their taxes. Approximately three-fourths of nonbuyers said they would be more interested in buying long-term care insurance if they thought the government would provide stop-loss coverage once their private insurance benefits ran out or if they felt premiums would remain stable over time.

Consumer Protections – Strengthening the Market

The adoption of robust standards for consumer protection has been vital in strengthening the market for long-term care insurance, and our members are committed to providing quality products, transparency in their products, and consumer choice. We

[9] LifePlans, Inc., *Who Buys Long-Term Care Insurance in 2005? A Fifteen Year Study of Buyers and Nonbuyers*, April 2006

view these protections as key to giving consumers confidence, expanding the market, and providing viable solutions to work hand-in-hand with Medicaid coverage for the poor.

In the past, there have been questions about post-claims underwriting. Our position is that this is never justifiable. On the other hand, efforts to detect and prevent fraud should not be viewed as post-claims underwriting. AHIP supports the strong stand taken on this issue by the National Association of Insurance Commissioners (NAIC). We also support the NAIC's most recent Long-Term Care Insurance Model Act and Regulations.

To give the committee a broad picture of the value of the NAIC provisions, below are some of the key requirements:

- policies must be guaranteed renewable or noncancellable;
- limitations apply to the use of pre-existing conditions and prior hospitalization requirements;
- policies cannot limit or exclude coverage by type of illness, treatment, medical condition or accident;
- policies must contain continuation or conversion of coverage provisions;
- policies must provide numerous disclosures, including an outline of coverage and safeguards to prevent unintended lapses of policies;
- post-claims underwriting is prohibited;
- minimum standards are established for home health benefits;
- policies must contain suitability provisions that provide standards for appropriate long-term care insurance purchases;
- policies must offer inflation protection;
- policies must offer non-forfeiture of benefits and, if declined, the provision of contingent benefits upon lapse; and
- requirements address premium rate stability, including disclosure to consumers relating to rate stability.

VI. RECOMMENDATIONS FOR NEXT STEPS

Above-the-Line Federal Income Tax Deduction for LTC Insurance Premiums

AHIP supports federal legislation to enact an above-the-line tax deduction for long-term care insurance premiums. This legislation has been introduced in every legislative cycle since 1999-2000 and the current level of support reflects growing congressional interest in this issue.

The proposal for an above-the-line tax deduction would allow taxpayers to claim a tax deduction regardless of whether they itemize their deductions and regardless of whether they have other medical expenses. For example, a person who pays $1,500 in premiums for long-term care insurance could reduce his or her taxable income by the full $1,500 under this proposal.

By contrast, current law allows taxpayers to deduct premiums for long-care term insurance only if they itemize deductions and only to the extent that their medical expenses exceed 7.5 percent of their adjusted gross income. In other words, a person with an adjusted gross income of $40,000 must have $3,000 in medical expenses before he or she can claim any tax deduction for long-term care insurance premiums or any other medical expenses. Because this threshold is so high under current law, fewer than five percent of all tax returns report medical expenses as itemized deductions. An above-the-line tax deduction would eliminate this 7.5 percent threshold and allow all long-term care insurance policyholders to claim a tax deduction.

AHIP estimates that an above-the-line tax deduction for long-term care insurance premiums would reduce premiums by about 19 percent and, additionally, increase the

number of individuals purchasing long-term care insurance by 14 percent to 24 percent.[10] A strong educational campaign would further increase these projected growth rates.

As Congress considers federal tax incentives, we urge lawmakers to recognize that more than 20 states have enacted enhanced tax incentives for the purchase of long-term care insurance. These states are: Alabama, California, Colorado, Hawaii, Idaho, Indiana, Iowa, Kansas, Kentucky, Maine, Maryland, Minnesota, Missouri, Montana, New York, North Carolina, North Dakota, Ohio, Oregon, Utah, Virginia, West Virginia, and Wisconsin. These state laws have taken an important first step to enhance the affordability of long-term care insurance. By enacting an above-the-line tax deduction at the federal level, Congress can create a more powerful incentive – with the states working in partnership – for all Americans to protect themselves against the financial risk of long-term care needs.

Offering LTC Insurance Under Cafeteria/FSA Options

AHIP also strongly supports legislative provisions that would enable employers to offer long-term care insurance as an option under cafeteria plans and flexible spending arrangements (FSAs). We urge subcommittee members to support inclusion of these provisions in the conference report for H.R. 2830, the "Pension Protection Act." While we recognize that budgetary constraints may prevent Congress from taking action this year on other more ambitious proposals, we are confident that enactment of this legislation – despite its relatively modest price tag – would yield significant progress in increasing the number of Americans who protect themselves against the high cost of long-term care.

Enactment of the cafeteria/FSA proposal goes hand-in-hand with the expansion of long-term care partnerships. This legislation would make long-term care insurance more affordable to more Americans and, in doing so, help to ease some of the financial pressure that long-term care costs are imposing on Medicaid and Medicare. At a time when state and federal budgets are severely strained by health-related costs, this provision offers a common sense solution for reducing this burden on taxpayers and helping more Americans prepare for their future long-term care needs.

It is also important to recognize that employers are uniquely positioned to increase awareness about the value of long-term care insurance. This provision would allow employers to include information about long-term care options in their employee benefit packages and help employees make sound decisions.

Cafeteria plans, which allow employees to customize their benefits packages, and flexible spending arrangements, which allow employees to use pre-tax dollars to pay for medical expenses not covered by health insurance, are valuable employee benefit tools that can be made even more effective for American workers with enactment of this legislation. Allowing employees to purchase long-term care insurance on a pre-tax basis through these popular employee benefit arrangements would allow more families to purchase coverage. Moreover, this would put long-term care insurance on a level playing field with other employer-sponsored benefits – such as 401(k) contributions – that are not taxed.

To date, more than 50 House members – 29 Republicans and 25 Democrats – have cosponsored bills that would allow long-term care insurance to be offered under cafeteria plans and FSAs. We thank members of the subcommittee who support these bills. We stand ready to assist you in promoting final passage of this new option for expanding access to long-term care insurance.

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[10] AHIP, *Tax Deductibility of Long-Term Care Insurance Premiums*, March 2000

Removing Barriers to Medicaid Managed Care

The federal upper payment limit (UPL) program has proven to be a barrier to expanding Medicaid managed care to beneficiaries. UPL programs provide federal matching funds for supplemental payments made by states to publicly owned hospitals and facilities. UPL payments are based on the amount of inpatient services the public facility provides to Medicaid beneficiaries who are covered under the Medicaid fee-for-service program. Health plan payments to these facilities are not counted in determining the UPL payment, which creates a financial disincentive for states to meet beneficiary needs through Medicaid health plan programs – despite their proven ability to improve health care for the most vulnerable members of the Medicaid population.

AHIP supports a solution that would allow states to continue to expand beneficiary access to effective managed care programs while continuing to support safety net providers and maintain funding levels for their Medicaid programs. Medicaid health plan payments to public facilities should be included for purposes of determining the UPL payment. This proposal is consistent with the manner other supplemental payments – for example, disproportionate share hospital payments and payments for graduate medical education – are currently made. This proposal would remove the barrier that currently exists to expanding beneficiary access to systems of care that improve their well-being in a cost-effective manner.

Exploring Best Practices and Demonstrations

To better meet the needs of the long-term care population, policymakers should explore opportunities to address the following priorities through Medicaid:

- maximizing consumer self-direction, independence and health in homes and communities;
- promoting models of coordinated, multi-disciplinary, continuous care and support across all settings and throughout the life spans (in contrast to a model of intermittent, episodic care); and
- emphasizing prevention for patients (risk assessment, early identification and intervention).

Creating a Presidential Commission to Address the Nation's Long-Term Care Needs

This commission would make recommendations to Congress and the Administration for accomplishing a wide range of goals including:

- exploring how to create a seamless long-term care continuum from acute to chronic care;
- exploring tax incentives to encourage individuals to take planning responsibility for their own long-term care needs;
- exploring how to redesign Medicaid to allow dollars to follow the person across all settings, ensuring that access to quality long-term care and services can be received in the settings of choice; and
- exploring the potential to increase utilization of technology (telehealth, monitoring devices, electronic medical records, etc.) in all care settings – particularly in rural settings.

Establishing a Federal Office to Address Long-Term Care Workforce Issues

A federal office should be established to address professional and paraprofessional long-term care workforce issues and provide recommendations to improve the recruitment, training, retention and practice of a strong long-term care workforce.

Establishing a Quality Agenda for Long-Term Care

Congress and the Administration, in collaboration with consumers, providers and other stakeholders, should establish a uniform quality agenda for long-term care and supportive services, including measurement and reporting across the continuum of services and settings, and performance-based payment, taking into account consumer satisfaction, health literacy, and progress in addressing disparities. Recognizing the efforts underway by the Ambulatory Care Quality Alliance (AQA), the Hospital Quality Alliance (HQA), and the Pharmacy Quality Alliance (PQA), a similar public-private collaboration is needed to address quality challenges in long-term care settings.

VII. CONCLUSION

We appreciate this opportunity to testify about these important issues and look forward to continuing to work with the subcommittee to advance policy solutions to help all Americans prepare for their future long-term care needs.

MR. DEAL. Thank you. We are about to have a vote. If we are really lucky, we might get through with this panel's presentations before we have to go vote.

Mr. Jenner, you are next.

MR. JENNER. Thank you very much, Mr. Chairman. I will do my best. My name is Greg Jenner, and I am the Executive Vice President for Taxes and Retirement Security for the ACLI, American Council of Life Insurers. On behalf to the organization and its 350 members, I would like to express my appreciation for the invitation to appear before you today, and to applaud you for drawing attention to this very, very important issue.

Much of what I am going to discuss today will relate to tax issues. I hope you will forgive me for that. Tax is the world that I functioned in most often. Before joining ACLI, I was Acting Assistant Secretary of the Treasury for Tax Policy. I also realize that taxes aren't within this committee's jurisdiction, but most concerns about long-term care insurance relate to cost and accessibility, and as you have heard earlier--darn it--those issues are, to a great extent, determined by the tax laws, particularly at the Federal level. Okay.

The need and cost of long-term care is ever increasing, and the burden will become unsustainable over time. Life expectancy continues to increase. It is compounded markedly by the graying of the Baby Boom generation, of which I am a proud member. Combine this with the rapidly increasing cost of health and long-term care, and you have a fairly toxic mixture. Recent surveys show that about 65 percent of Americans have made no plans whatsoever for their long-term care needs, even though we know that a majority of the care is provided by

family members in the home. One of the important features of long-term care insurance is to pay for training of those family caregivers.

Although the market is evolving for long-term care, most Americans don't own such insurance. There are impediments. Those impediments include greater demands for competing discretionary income, impediments to streamlined products that lower costs, and lack of awareness of the need for long-term care expenses.

You in Congress will continue to play an important role. Earlier this year, for example, you passed the Deficit Reduction Act of 2005, that enabled all the states to enter into long-term care partnerships. That will ultimately ease the burden on their Medicaid budgets, and on individual consumers, who must now spend down their assets. We thank you very much for your help and support on this issue.

Equally important is a provision that I would like to point to today. It is contained in the House version of the pension bill now in conference. It would eliminate an impediment in the tax code that prevents companies from offering policies that combine features of an annuity with long-term care insurance. Now, you may wonder why that is important. The reason has to do with consumer attitudes towards insurance. Most Americans recognize the need to insure against risk--health insurance, fire insurance, traffic accidents--but most people have limited resources, and many aren't willing to purchase insurance where the policy offers no accumulation feature, where they can't save within the policy. There is no good reason that they can't, but the tax law right now prohibits it, so we worked closely on this issue with the members and staff of the Ways and Means Committee, and thanks to Chairman Thomas and others, it is now included in the pension bill, at least the House version of the pension bill. We would urge you to assist Chairman Thomas in getting that included in the final conference report.

The change would allow people to accumulate assets during their working years. When they retired, they would have an annuity. They could use the annuity to pay lifetime income, or if they needed it, long-term care services. They would have flexibility. It is an example of a win/win situation for consumers, and an excellent example of how Congress and the private sector can work together to facilitate innovation.

As has been noted earlier, cost is a major reason people don't buy long-term care insurance. It has been called to your attention about the proposal for the above, the line tax deduction for long-term care premiums, and the proposal to permit the use of employer-sponsored cafeteria plans, and flexible spending accounts for that purpose. These changes would go far to help control rising costs and strains on the Medicaid budget. Individuals would have the ability to pay privately,

and have the ability to choose among various features and care settings best suited to their needs.

In conclusion, we believe that protection and coverage for long-term care is critical to the economic security and peace of mind of all American families, and that private long-term care insurance is an important part of that solution. ACLI looks forward to working with this subcommittee to help all Americans protect themselves against the high cost of long-term care.

Thank you very much, Mr. Chairman.

[The prepared statement of Greg Jenner follows:]

PREPARED STATEMENT OF GREG JENNER, EXECUTIVE VICE PRESIDENT, AMERICAN COUNCIL OF LIFE INSURERS

My name is Gregory F. Jenner, and I am Executive Vice President, Taxes and Retirement Security, for the American Council of Life Insurers (ACLI). The ACLI is a Washington D.C.-based national trade association representing more than 350 member companies that offer life insurance, annuities, pensions, long-term care insurance, disability income insurance and other retirement and financial protection products. I am responsible for policy development, formulation and implementation with respect to all tax, pension and retirement security issues, and serve as the senior tax expert for and principal liaison on those issues between member companies and Congress, the IRS, and the Treasury Department. Prior to joining ACLI, I served as Acting Assistant Secretary of the Treasury for Tax Policy.

We are delighted that this Subcommittee is addressing an important issue facing this nation – long-term care. We applaud Chairman Nathan Deal (R-Georgia) and Ranking Member Sherrod Brown (D-Ohio) for drawing attention to this matter, and we are pleased to discuss with the Subcommittee the important role that private long-term care insurance plays in helping to provide the retirement security of millions of middle-income families, and what Congress can do to help those families prepare for their retirement.

The Need for Long-Term Care and the Role of Long-Term Care Insurance

ACLI's recently-updated study on long-term care in the "Baby Boom" generation notes that about 55 percent of those 85 and older require some form of long-term care, and about 19 percent of all seniors suffer from some degree of chronic impairment. By 2050, it is estimated that up to 5.4 million seniors will need the services of a nursing home – the most costly form of long-term care – and another 2.4 million will require home health care[1].

The cost of long-term care is high and increasing, averaging $70,912 annually for a private room or $62,532 annually for a semi-private room in a nursing home; $25.32 per hour for a visit by a home health aide; and an average annual *base* rate of $32,294 for the services of an assisted living facility.[2] Since 1990, the price of nursing home care has increased at an average annual rate of 5.8 percent – almost double the overall inflation rate.

Total annual expenditure on long-term care for the elderly is estimated to be $135 billion, which accounts for over 9.7 percent of total spending on health care for persons

[1] ACLI 2005 Study: "Long-Term Care Insurance or Medicaid: Who Will Pay for Baby Boomers' Long-Term Care?"

[2] Genworth Financial 2006 Cost of Care Study

of *all* ages. This is roughly 1.2 percent of the U.S. GDP. Of greater significance is that the elderly account for a disproportionately large percentage of total health care expenditures -- 36.3 percent of expenditures -- while accounting for only 12.4 percent of the population.[3] Because baby boomers are aging and the cost of care is increasing, total spending on nursing home care is expected to more than triple over the next 25 years and to increase more than five-fold in the next 45 years. These increases will place a crushing burden on Medicaid and ultimately on taxpayers, most of whom are working-age adults. Currently, there are about five working-age adults per senior, but by 2030, there will only be 2.9 – a 40 percent decline. This decline will occur while both the need for and cost of long-term care increase.

At the same time, life expectancy has increased dramatically. Unfortunately, increased longevity comes at a price: the likelihood that more seniors will require long-term care. Given this increasing possibility that the typical senior will require long-term care, and given the escalating costs of that care, whether elderly boomers enjoy a comfortable retirement or suffer economic hardship may depend largely on their ability to afford such long-term care. Most boomers have not planned for this reality and face the prospect of paying large sums out-of-pocket or relying on Medicaid. A February 2006 survey conducted by Public Opinion Strategies found that 65% of Americans have made no plans for their own or for family members' long-term care needs.[4] Moreover, Medicaid currently only covers the cost of long-term care after a senior has spent down virtually all assets and retirement income. Neither option is very appealing and may leave seniors and their spouses impoverished, with few long-term care choices.

Private insurance currently pays for 8 percent of total nursing home expenditures but 36 percent of overall health expenditures. There is clearly a large gap in the financing of long-term care services that private insurance can fill. Our goal, as well as the goal of Congress, should be to find ways for the average consumer to plan for the ever-increasing need for long-term care through the private sector instead of through government programs.

If three-quarters of individuals between the ages of 40 and 65 who can afford long-term care insurance were to purchase and maintain a policy throughout their senior years, then by 2030, annual savings in Medicaid nursing home expenses would total $19 billion, and annual savings in out-of-pocket expenses would total $41 billion. Given this, it is clear more needs to be done to convince the Baby Boom generation of the need for this type of investment NOW.

The Evolving Long-Term Care Insurance Market

Both the individual and group (employer-sponsored) segments of the long-term care insurance market are evolving and growing. The American Council of Life Insurers, with the assistance of America's Health Insurance Plans, recently surveyed long-term care insurance providers and found that:

- The market has grown to nearly $7 billion in premiums, and now covers over 5 million people.
- Between 2003 and 2004, the individual long-term care insurance market grew 7.5 percent and the group market grew 25 percent.
- The amount paid out in claims has also increased, with carriers paying $2.1 billion in benefits in 2004, about 20 percent more than in the previous year.[5]

Because private long-term care insurance is priced on the assumption that an individual will hold the same policy and pay the same premium until he or she needs

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[3] U.S. Department of Health and Human Services; U.S. Census Bureau.
[4] Public Opinion Strategies 2006 Survey
[5] ACLI (2005)

long-term care, premium rates vary depending on the age of the policyholder at policy issue and the specific benefits and coverage chosen. Additionally, younger candidates for policies are much more likely to pass underwriting screens than are older candidates. For these reasons, consumers are encouraged to purchase insurance while they are in their 40s and 50s, when premiums are lower and more affordable. The typical buyer of long-term care insurance is aged 55-60 (although the average age of those who enroll in group plans is in the forties), married, college educated, with an annual income in excess of $50,000. Women are more likely to buy coverage than men.

Although the market for long-term care insurance is growing, most Americans have not yet purchased this insurance protection. Impediments to even greater market growth include competing demands for discretionary income, limited incentives to purchase long-term care insurance, impediments to streamlined products that will lower costs to consumers, and the lack of awareness of the need to plan for potential long-term care expenses.

Long-term care insurance products continue to evolve to give policyholders more choices and flexibility at the time they need care. When long-term care insurance was first offered, over 30 years ago, most plans only covered stays in skilled nursing facilities. Since the mid 1990s, more flexible care options and consumer protections have become available. Today, most policies provide coverage for care received at home, in an adult day care facility, in an assisted living facility, or in a nursing home. Additionally, plans are now guaranteed to be renewable, have a 30- day "free look" period, offer inflation protection, cover Alzheimer's disease, have a waiver of premium provision, and offer unlimited benefit periods. Benefits are paid when a person needs help with two or more activities of daily living (such as eating, dressing, or bathing) or is cognitively impaired.

Some of the innovative benefits and financing arrangements that companies now provide include:

- Caregiver training benefits that cover the cost of training a person (friend or family member) who will then care for the insured in the insured's home on an unpaid basis. The benefit is usually equivalent to five times the daily benefit and not subject to an elimination period.
- "Per diem" or cash benefits that pay without regard to cost of services or pay benefits in cash. These benefits make it easier to understand and file claims and allow the claimant greater flexibility to utilize informal caregivers.
- Shared lifetime maximum benefit pools that allow a policyholder who uses up all of his or her benefits to tap into a spouse's lifetime maximum, or to leave any unutilized benefits at death to a surviving spouse.
- Independence support benefits that pay for home modifications and personal emergency alert systems that would enable a policyholder to remain in the home for a longer period of time.
- Death benefits that will return all or a portion of past premium payments in the event the policyholder dies before utilizing long-term care insurance benefits.
- International benefits that pay for services received in a foreign country.

Congressional Involvement in Long-Term Care Insurance Product Innovation

The United States Congress will continue to play an important role encouraging the evolution of the long-term care insurance marketplace. Significant changes were enacted earlier this year and others are pending as we speak. We look forward to continuing our excellent relationship with the House Energy and Commerce Committee and other committees of the House to encourage greater flexibility and innovation in the long-term care marketplace.

- **Long-Term Care Partnerships**

Earlier this year, Congress passed and the President signed into law the Deficit Reduction Act of 2006. That bill expanded the ability of the states to enter into the Long-Term Care Partnership program, which will ultimately ease the burden on state Medicaid budgets and on individual consumers. We thank and congratulate the members of this Committee for their help and support.

These public-private Partnerships, currently operational in four states, allow consumers to purchase long-term care policies whose benefits must be fully utilized prior to qualifying for Medicaid. Many states are now looking to utilize this new public policy opportunity by seeking approval from the Department of Health and Human Services for an amendment to their State Medicaid plan in order to implement a Partnership program. Insurers anticipate that Partnership programs will provide a greater incentive to purchase long-term care insurance in those states that choose to participate.

ACLI is currently working to implement these partnerships in all 50 states and the District of Columbia. This is an excellent example of an innovative program that offers a "win-win" opportunity for the states and consumers.

- **Flexible Retirement Security Proposal**

I have been asked to focus primarily on innovations in long-term care insurance products. It is my pleasure to call to the Committee's attention a proposal pending before the Congress that we believe would have significant beneficial effects on the marketplace. That provision is contained in the House version of the pension bill now in conference.

It comes as a surprise to no one that the tax code has considerable effect on the pricing of insurance products and the ability of companies to create innovative solutions that address the needs of consumers. Provisions of the tax code prevent companies from offering policies that combined the features of an annuity with the benefits of long-term care insurance.

Removing this impediment would likely result in increased utilization of long-term care insurance. The reason had to do with consumer attitudes toward insurance. Most Americans recognize the need to insure against risk, whether it is the risk of an early demise, a traffic accident, or the risk that a person will need long-term care. But most people have only limited resources, and many are unwilling to purchase insurance where the policy offers no accumulation feature; i.e., where the premiums paid are lost to the policyholder if the insurance is not used. Without some sort of "savings" feature, consumers with limited resources often were not willing to purchase insurance, including long-term care insurance, even though they recognize its importance.

So why did the tax law prohibit long-term care insurance from offering an accumulation feature, such as an annuity? Quite frankly, there was no good reason. Therefore, we worked with members and staff of the Committee on Ways and Means to develop a provision that would permit the combination of an annuity and long-term care insurance in one policy (and clarify that life insurance and long-term care could also be combined). That provision is in the House version of the pension bill now pending in conference. We would like to thank Chairman Thomas for including it in the bill, and also thank Mrs. Johnson of Connecticut, Mr. English of Pennsylvania, and Mrs. Tubbs Jones of Ohio for their hard work and support. We would also encourage the members of this Committee to actively support inclusion of this provision in the final pension conference report.

This proposal would create more flexibility and choice for American consumers. During working years, individuals could accumulate assets in an annuity; at retirement, depending on the needs of the individual, that annuity could be used to provide lifetime income. A long-term care insurance benefit within the annuity would pay for long-term care services. For the long-term care/life insurance combination, the life insurance would

serve its critical function of death protection, while also being available to provide funds for payment of long-term care costs.

Although life insurance, endowment and annuity contracts can be exchanged without tax if certain conditions are met, currently, long-term care contracts and riders are not included in the tax-deferred exchange provisions. The law should be updated to include long-term care contracts and riders among the permitted tax-deferred exchangeable insurance products.

This is an excellent example of the law unintentionally standing in the way of innovation in the marketplace. We will continue to work with you in the Congress to remove such unnecessary barriers to innovation. We believe that, with your help, our industry can adapt and accommodate the changing needs of the American consumer.

- **Tax Incentives**

Cost is a major reason why more Americans have not yet purchased long-term care insurance. Although product combinations may prove to be an attractive alternative to stand alone long-term care insurance for some individuals, an even more broadly appealing and effective solution to the financing of long-term care would be the passage of measures that reduce the cost of long-term care insurance, particularly for moderate-income individuals, the persons who need the protection of long-term care insurance the most. Partnerships and combination products can only go so far to accomplish this. If Congress determines it is important that individuals of moderate means are protected in this fashion, there are steps that can be taken.

Although not strictly a product innovation, we would encourage Congress to provide individuals with a phased-in above-the-line federal income tax deduction for the eligible portion of the premiums they pay to purchase long-term care insurance. This would create a more even playing field between long-term care insurance and health insurance (which we all agree is crucial). In addition, Congress should permit long-term care insurance policies to be offered under employer-sponsored cafeteria plans and flexible spending accounts. This benefit is allowable for similar accident and health coverage and there is no strong policy consideration to justify the exclusion of long-term care insurance. Finally, we would urge that individuals be permitted to exchange tax free one qualified long-term care policy for another long-term care policy better suited to the insured's needs.

Allowing individuals to pay for their long-term care insurance premiums through cafeteria plans and flexible spending accounts, as well as through flexible retirement security combination products, will provide a range of options both inside and outside the employment context. Such measures could go far to help control rising long-term care costs, rising long-term care needs, and rising strains on the Medicaid budget. Individuals will have the ability to pay privately and have the ability to choose a variety of services and care settings best suited to their needs.

- **Other Related Legislation**

In this spirit, other members of Congress have been likewise engaged in the discussion of how to encourage individuals to plan for their long-term care costs. For example, Rep. Terry (R-NE), who serves on this Committee, has introduced a bill that would allow individuals to exclude from gross income distributions made from their individual retirement accounts, 401(k), or 403(b) plans that are used to pay for long-term care insurance premiums for themselves or their spouses.

An optional federal charter for life insurers, including long-term care insurers, would also help long-term care insurance innovations reach consumers in a more timely and cost-effective manner. Senators Sununu and Johnson recently introduced S. 2509, which would create an optional federal charter. Today, it can take up to two years for an innovative long-term care insurance product to be approved in all 50 states and the

District of Columbia and be sold nationally. Consumers should have the benefit of a timely array of long-term care product choices that best meet their needs.

- **Federal Government Long-Term Care Insurance Program**

The federal government and the states have also recognized the need to educate individuals in the workplace about planning for their future long-term care needs. The federal government, by Act of Congress, has taken the lead and set the example for other employers by offering federal employees and their families the protection of long-term care insurance. Through this program, federal employees are able to help protect their retirement savings from a long-term care event and will have the choice of providing care for themselves or a family member in the home, through assisted living or in a nursing home.

- **Other Innovative Solutions**

Although we are focused today on innovations in long-term care insurance, the nature of governance is that you (and we) will likely be focused elsewhere tomorrow. But solutions to the pressing problems of financing retirement and longevity should not be viewed as a snapshot. Our industry is committed to examining these issues on an ongoing basis. As important, we need to know that, if we develop an innovative idea, we can come back to this Committee and win your support. We, as an industry, look forward to a constructive partnership with the Congress in developing and implementing creative solutions to this country's retirement needs.

Private Long-Term Care Insurance: An Important Part of the Answer

In conclusion, we believe that protection and coverage for long-term care is critical to the economic security and peace of mind of all American families. Private long-term care insurance is an important part of the solution for tomorrow's uncertain future. As Americans enter the 21st century, living longer than ever before, their lives can be made more secure knowing that long-term care insurance can provide choices, help assure quality care, and protect their hard-earned savings when they need assistance in the future. We also believe that the costs to Medicaid – and therefore to tomorrow's taxpayers – will be extraordinary as the baby boom generation moves into retirement, unless middle-income workers are encouraged to purchase private insurance now to provide for their own eventual long-term care needs.

Congress has encouraged the American public to insure themselves against the need to pay for long-term care by adopting the Deficit Reduction Act of 2006 and allowing for the expansion of LTC Partnerships. Congress should build on that momentum by encouraging the development of innovative products such as combination annuity/long-term care insurance products and life/long-term care insurance products. Further, Congress should include long-term care insurance products in cafeteria plans and flexible spending accounts, and consider other tax incentives to encourage the sale of these products.

Again, ACLI looks forward to working with this Subcommittee to help Americans protect themselves against the risk and high cost of long-term care.

MR. DEAL. Thank you. We have six votes coming up, and it will take at least an hour to do that. Dr. Thames, I am going to go ahead and recognize you, and I think if we run from here to the floor, we will probably all make it.

So, I recognize you, Dr. Thames, at this time.

MR. THAMES. Thank you very much, Mr. Chairman. I will stay well within the limits.

It is important, our members feel, to remain independent in later years. It is an often overlooked component of retirement planning, is financing those future long-term needs. As our population continues to age, we will increasingly rely on long-term care services to remain independent. Therefore, we need to do a better job of one, educating consumers about the importance of planning for long-term care needs, two, ensuring there is a range of long-term care options to choose from, and three, providing better means of financing long-term services and supports.

Long-term care should be a critical part of retirement planning. AARP educates our members through publications and other tools, but the challenge is great. Denial of costs, immediate financial needs, and other factors keep many Americans from focusing on long-term care planning. We have to do better in the future to help Americans focus on this.

Once individuals begin to plan, they discover their options for paying for long-term care are limited. There is no comprehensive public system of long-term care, and very few private options. Insurance is costly, and not always accessible. Public programs are limited. Caregivers are strained, and costs of care can quickly outstrip personal savings. We need better options.

Long-term care insurance has a limited role in financing long-term care, but it needs to be more affordable and accessible. The Long-Term Care Partnership Program may offer a new financing option to some, but strong consumer education and other improvements to this program are important. Increased attention is being paid to the role that home equity could play in financing long-term care. Reverse mortgages could be an option for some individuals, but the costs are still very high.

I will skip some of the examples we gave of up to $25,000. We need to remove the high cost barrier to the use of reverse mortgages for long-term care, and given the limited experiences most consumers have with reverse mortgages, a logical way to test them is through a limited demonstration program. Demos could be designed to reduce borrower costs, a key reason that people do not take out reverse mortgages. Congress must begin to look for options that allow Americans to pay for the care they need in the setting of their choice.

AARP is ready, willing, and able to work with members on both sides of the aisle, the Administration, and all stakeholders, to address the long-term care our country is facing. Thank you.

[The prepared statement of Dr. Byron Thames follows:]

PREPARED STATEMENT OF DR. BYRON THAMES, BOARD MEMBER, AARP

Mr. Chairman and members of the Subcommittee, I am Dr. Byron Thames, a physician and a member of AARP's Board of Directors. Thank you for the opportunity to testify today. Remaining independent in later years is a priority for AARP members. Yet, if you ask the average person about retirement planning, one of the most critical components is often overlooked – how to finance future long-term care needs.

Most of us don't want to think that we will ever need long-term care, but the reality is that as our population continues to age we will increasingly rely on long-term care services to remain independent. Therefore, we need to do a better job of educating consumers about the likelihood for needing long-term care, the cost, options, and the importance of planning prior to a crisis.

We must also ensure that there are a range of long-term care options from which to choose. Based on recent reports, sales of private long-term care insurance policies have slowed and Long-Term Care Partnership programs in the original four states have sold relatively few policies. Reverse mortgages have high costs and are more expensive than home equity loans.

Americans also need a better means of financing long-term services and supports. Current financing options are often too expensive and too complex. In some cases, they are also tied to institutional care rather than a system that gives consumers what they want, such as self-directed care with cash payments to purchase services.

We commend the Subcommittee for taking the first step by holding this hearing. We urge members to look for positive ways to encourage and enable more persons to plan for long-term care.

Our testimony today will focus on the need for broader education efforts and three financing options -- long-term care insurance, the Long-Term Care Partnership Program, and reverse mortgages -- and improvements that should be made to each to enhance their ability to be viable financing options for Americans.

Consumer Education: A Critical and Ongoing Step

The first big challenge to planning for long-term care is public education. It is difficult to get many people to prepare for something so far in the future. Yet the goal should be that we think of long-term care as a critical part of retirement planning. We all should understand the likelihood of needing long-term services and supports at some time in the future; the types, costs, and availability of such services and supports; the options available to help plan and pay for such services; why it is in our interest to plan; and where we can go for further information and assistance about how to plan. The recently enacted Long-Term Care Information Clearinghouse will be a new resource to help Americans plan for long-term care.

AARP is working to educate our members about long-term care. For example, our publications include articles on topics such as long-term care insurance, reverse mortgages, long-term care costs, assisted living, nursing homes, and innovative ways to receive services at home. We also use other tools to educate our members such as AARP's consumer guide to reverse mortgages, Home Made Money, and tip sheets on topics ranging from hiring a home care worker to purchasing long-term care insurance to choosing an assisted living facility.

There are several obstacles that must be overcome in order for significant numbers of Americans to plan for long-term care. First, from what we've heard from our members, there is a great deal of resistance to thinking about long-term care. For example, persons associate long-term care with nursing homes and/or insurance, and they believe that talking about the issue signifies sickness and/or a loss of personal control or independence. Our members do not want to become a burden to their families. They

also want to have choice, and for the vast majority of individuals, this choice is staying in their homes.

It is also not unusual to find individuals under the mistaken impression that Medicare covers long-term care, so they believe that further long-term care planning is unnecessary. Since individuals frequently have negative perceptions or misimpressions about long-term care, they are often discouraged from seeking out information, and in denial about their likely need for future services. As a result, they will often wait until a crisis to act.

On top of this, there are day-to-day realities that families across this country face. Most families are focused on immediate needs -- making mortgage payments, saving for their children's college education, and paying for rapidly increasing health care costs. Many in the sandwich generation are saving for their children's college education while also helping to pay for their parents' long-term care needs. That's all before individuals save for their own retirement. Under these circumstances, planning and saving for long-term care often falls to the bottom of the priority list.

When the day-to-day financial demands on many Americans are coupled with the negative perceptions about long-term care, there are significant challenges to engaging individuals in planning for their futures. That is why it is important that long-term care be considered as a part of overall retirement planning.

Current Options are Limited: Americans Need More Financing Options

Even once individuals get past their day-to-day demands and begin to look into planning for long-term care, they discover that their options to pay for long-term care are quite limited. There is no comprehensive public system of long-term care available to most Americans and very few other long-term care financing options exist. Long-term care insurance is limited and generally expensive. According to America's Health Insurance Plans, in 2002, the average cost of a long-term care insurance policy with automatic inflation protection was $1,134 per year when purchased at age 50 and $2,346 per year if purchased at age 65.

The Long-Term Care Partnership Program allows individuals who buy long-term care insurance policies under the program to protect a certain amount of their assets and become eligible for Medicaid if they meet all of Medicaid's other eligibility criteria. The expansion of this program may provide a new option for some Americans to finance their long-term care, but public education is critical around this option and additional improvements should be made to the program.

Public programs are also limited. Medicare covers some home health and skilled care, but does not cover nursing home stays. Medicaid – while a critical safety net for those with no other options – has income and asset limits that require impoverishment.

For individuals who pay out-of-pocket for care, they often find that costs associated with years of care outstrip personal savings. The average annual nursing home costs were over $64,000 for a semi-private room and over $74,000 for a private room in 2005. The average hourly rate for a home health aide in 2005 was $19, so as little as 10 hours a week of home health care would average close to $10,000 a year.

Many Americans rely on informal caregivers, such as family and friends, for the bulk of long-term care services. According to an analysis of data from the National Long-Term Care Survey for AARP, over 90 percent of persons age 65 and older with disabilities who receive help with daily activities are helped by unpaid informal caregivers. Two-thirds of those 65 years of age and older with disabilities who receive help with daily activities only receive informal unpaid help, up from 57 percent in 1994. But caregivers face many physical, emotional, and financial demands that often take a serious toll. If caregivers do not take care of themselves or get the support that they need, they may no longer be able to care for their loved ones and may need someone to care for them.

AARP believes that Americans need more options to plan and pay for their care. Due to the limited options available today, Medicaid has become the default payer of long-term care. One of the reasons that we strongly opposed the Medicaid changes in the Deficit Reduction Act was that the legislation took a punitive approach without providing alternative long-term care financing options for individuals. We hope this hearing will be part of ongoing work in Congress to give Americans incentives and positive options to plan and pay for future long term services and supports that they may need.

Long-Term Care Insurance

Relatively few older persons have private insurance that covers the significant cost of long-term care. Many common long-term care needs (e.g. bathing, dressing, and household chores) are not medical in nature, do not require highly skilled help and therefore, are not generally covered by private health insurance policies or Medicare.

The market for private long-term care insurance has grown in recent years, but its overall role is still limited. Long-term care insurance pays for only about 9 percent of all long-term care costs. By the end of 2002, over 9.1 million long-term care insurance policies had been sold in the United States, with about 6.4 million of these policies still remaining in force. Most policies sold today cover services in nursing homes, assisted living facilities, and in the home. Typically, policies reimburse the insured for long-term care expenses up to a fixed amount, such as $100 or $150 per day. To receive benefits, the insured must meet the policy's disability criteria. Nearly all policies define disability as either severe cognitive impairment or the need for help in performing at least two activities of daily living (such as bathing and dressing). Most policies sold are in the individual market.

The cost of long-term care policies varies dramatically depending on a number of factors: the consumer's age at the time of purchase, the amount of coverage, and other policy features. Insurance companies can increase premiums for entire classes of individuals, such as all policyholders age 75 and older, based on their claims experience in paying benefits. Older adults are more likely to have more long-term care needs and higher costs, thus higher premiums. Other factors that affect the policy's premium include the duration of benefits, the length of any waiting period before benefits are paid, the stringency of benefit triggers, whether policyholders can retain a partial benefit if they let their policy lapse for any reason, (including inability to pay -- nonforfeiture benefit), and whether the policy's benefits are adjusted for inflation. Individuals with federally qualified long-term care insurance policies can deduct their premiums from their taxes, up to a maximum limit, provided that the taxpayer itemizes deductions and has medical costs in excess of 7.5 percent of adjusted gross income.

Many of the reasons already outlined that cause individuals to not plan for long-term care also are reasons that individuals have not bought long-term care insurance policies -- denial, believing Medicare pays for long-term care, and cost. Some individuals are wary of long-term care insurance due to large premium increases and market instability, for example when insurance carriers decide to leave the market. Further, some individuals are not able to qualify for long-term care insurance due to underwriting. For them and others, long-term care insurance is not a viable option.

Consumer protections are a critical part of long-term care insurance policies. Standards and protections for long-term care insurance policies could make them better products that consumers are more likely to buy. For example, an individual who buys a policy in his or her 60s may not need long-term care for over 20 years. Without inflation protection, the value of the insurance benefits can erode over time. A daily benefit of $100 in coverage will not buy as much care in 2025 as it does today. Nonforfeiture protection allows a consumer who has paid premiums for a policy, but can no longer afford to pay premiums, to still receive some benefits from the policy. Another important protection is premium stability to help protect consumers whose premiums

increase above a certain threshold. Long-term premium affordability is an important reason why persons may drop long-term care policies or not buy policies in the first place.

The National Association of Insurance Commissioners (NAIC) has developed a Long-Term Care Insurance Model Act and Regulations that states can adopt to provide standards for long-term care insurance policies sold in a state. NAIC standards include: inflation protection, nonforfeiture, required disclosures to consumers, minimum standards for home health and community care benefits, premium rate stabilization, and standards for what triggers benefits. While all states have adopted some of the NAIC provisions, only about 21 states have adopted a critical provision on premium stability that protects consumers from unreasonable rate increases that could make their policies unaffordable.

Legislation (H.R. 2682) introduced by Representatives Nancy Johnson (R-CT) and Earl Pomeroy (D-ND) updates consumer protections mandated by the Health Insurance Portability and Accountability Act of 1996 and incorporates some of the consumer protections in the NAIC Model Act and Regulations. AARP supports the standards for long-term care insurance included in this legislation.

Education is also critical for individuals to decide whether or not to purchase a long-term care policy, and if so, which policy best suits their needs. To make an informed decision, consumers need to understand many things, including: the terms that are used in policies, what the benefits are and when they start, what is not covered, what the consumer pays, and how they can compare one policy to another. Different policies may use different definitions and make it hard for consumers to make an apples-to-apples comparison of long-term care policies. Consumers who are considering purchasing long-term care insurance need better tools to help them compare different policies to find which one is best for them.

Finally, there has been some discussion of establishing a mandatory long-term care insurance program. AARP urges caution about moving in this direction. As cited above, long-term care insurance is not affordable to many Americans without some kind of subsidy. Further, long-term care insurance is not available to many individuals with pre-existing conditions. Therefore, insurance market reforms would be necessary.

Long-Term Care Partnerships

Prior to the enactment of the Deficit Reduction Act, the Long-Term Care Partnership Program was only operating in California, Connecticut, Indiana, and New York. The Deficit Reduction Act (DRA) allows all states the option to enact partnership policies. The new partnership programs do include some important consumer protections. Long-term care insurance policies in these new programs must meet specific criteria including federal tax qualification, specific provisions of the 2000 NAIC Model Act and Regulations, and inflation protection provisions. Compound annual inflation protections will be required for purchasers below age 61 (states can determine the level of protection, such as 3 percent or 5 percent). Some level of inflation protection will be required for purchasers between the ages of 61 and 75. The DRA also requires the development of a reciprocity agreement by the Department of Health and Human Services to enable purchasers to use their benefits in other partnership states; however, states may opt out of this reciprocity.

The expansion of the partnership program could mean that a significant number of individuals will have a new financing option available to them. However, consumer education is absolutely critical. In order to make an informed decision about whether or not to purchase a partnership policy, it is important for individuals to understand that Medicaid eligibility is not automatic. Even though a partnership policy allows purchasers to protect a certain level of assets if they deplete their insurance benefits, individuals must first meet the state's income and functional eligibility criteria in order to quality for

Medicaid. These criteria may change by the time individuals apply for Medicaid. If individuals do not meet these criteria, they will not be eligible for Medicaid.

If a long-term care policy's functional eligibility criteria are different than a state Medicaid program's functional eligibility criteria, individuals may have a gap in coverage after they use up their long-term care policy and before they qualify for Medicaid.

In addition, once individuals qualify for Medicaid after depleting their insurance benefits, there is no entitlement to home-and community-based services. Thus, individuals may not be able to receive the home-and community-based services that they were receiving under their policy under Medicaid.

As the federal government and states implement the partnership program, they should include strong consumer education, so that consumers understand what they get and what they do not get with a partnership policy. There should be clear disclosure of current income requirements for Medicaid benefits and the state's right to change those requirements. Guaranteeing the types of services (particularly home-and community-based services) that the state would provide to eligible partnership policyholders under Medicaid would be a good improvement in the program. States and the federal government should consider adding additional consumer protection standards, such as premium stability, to partnership policies. Strengthening the reciprocity agreement would also benefit consumers and give them peace of mind if they anticipate moving in the future to another state that does not participate in the reciprocity agreement. Further, states should monitor nursing home admissions to ensure that equal access is available to everyone on the waiting list, regardless of source of payments.

Over time, it will be important to evaluate the results of the partnership program to determine its impact on individuals and the Medicaid program. According to a Government Accountability Office review of the program, in the four original partnership states, about 172,500 policies are in force and about 1,200 individuals are receiving partnership benefits. Since the program began, about 250 policyholders in all four states have exhausted their long-term care insurance benefits, and of those, about 120 have accessed Medicaid. It is unclear whether these persons using Medicaid would have likely spent down to Medicaid absent their participation in the program. It is not clear whether the policies were purchased by people who otherwise would not have bought insurance, whether the partnership policies are a substitute for other long-term care insurance policies, and whether participants would have used Medicaid regardless. Because partnership policyholders tend to be younger than other long-term care policyholders, it may be hard to assess the full impact of the partnership program on Medicaid for now. It is possible that not enough time has passed for many partnership policyholders to have exhausted their long-term care insurance policies and become eligible for Medicaid.

Reverse Mortgages

Because of the large and growing amount of home equity held by some older Americans, increased attention is being paid to the role that home equity could play in financing long term care. Over the past decade, more homeowners have begun using their home equity as a means of paying for long-term care services. In some cases, they have done so by selling their homes and using the proceeds to pay for services in assisted living and continuing care retirement communities (CCRCs). Others have used home equity to retrofit their houses or to pay directly for home and community-based services.

One of the tools increasingly used by people who want to tap into their home equity is a reverse mortgage, which is a loan against a home that requires no repayment until the borrower dies, sells the home, or permanently moves out of the home. There are two basic types of these mortgages: public sector reverse mortgages that must be used for a single purpose, and private sector reverse mortgages that can be used for any purpose. Public programs are offered by some state and local governments, generally at a low cost, and with income requirements. Most of these programs are limited to paying for home

repairs or property taxes, although Connecticut developed a program specifically for long-term care financing.

Private sector reverse mortgages can be used for any purpose and have no income requirements. They are offered by private lenders and have high costs. They include the Home Equity Conversion Mortgage Program (HECM) that is insured by the Federal Housing Administration (FHA) of the Department of Housing and Urban Development (HUD), as well as two smaller private programs. Federally insured HECMs make up about 90 percent of the private sector reverse mortgage market.

To qualify for a HECM, an individual must: be age 62 or over; occupy the home as a primary residence; have paid off the mortgage or have a mortgage balance that could be paid off with proceeds from the reverse mortgage at closing; undergo required counseling; and live in a home that meets minimum HUD property standards. According to a HUD study, HECM borrowers tend to be older, female, from a variety of racial and ethnic groups, live alone, and have lower incomes.

The amount of money available from a private sector reverse mortgage depends upon: the age of the youngest borrower; the value of the home; the median home value in the county; current interest rates and other loan costs; and the type of private sector loan. Money from the reverse mortgage can be paid to the borrower as a lump sum payment at closing, monthly payments, a line of credit, or a combination of these methods. Borrowers make no loan payments as long as they live in the house – an advantage for an older person who wants to remain at home rather than enter a nursing home. The loans are paid back when the last living borrower dies, sells the house, or permanently moves away.

Despite their advantages, reverse mortgages are not suited for everyone. The high costs associated with the loans are a real disadvantage – particularly to a lower income person with a modest amount of home equity. The private reverse mortgage market is relatively new, and although still growing, consumers do not yet have tremendous choice. And current private sector reverse mortgages are not available to anyone under the age of 62, which excludes their use as a source of long-term care financing for younger persons with disabilities.

Using Reverse Mortgages as a Long-Term Care Financing Tool

Reverse mortgages could be an option for some individuals to pay for long-term services and supports, such as home health care, chore services, respite care, and home modification. Home-and community-based services help enable an individual to live at home, where most older adults want to be. As the Subcommittee examines reverse mortgages, it is important to note in what ways they would be useful as a long-term care financing tool and in what ways they would not be helpful.

High Costs of Reverse Mortgages are a Barrier to their Use

The high costs of reverse mortgages are a significant barrier to their use, including as a long-term care financing option. During the past year, the average value of a home in the HECM program was about $255,000. The fees and other non-interest costs of a HECM on such a home in many urban areas can be over $25,000 over the life of the loan. The upfront costs would include $5,100 for the initial mortgage insurance premium, up to another $5,100 for the lender's origination fee, and about $2,200 in third-party closing costs. The average borrower in the program is a 74-year-old single female. If she lives to her remaining life expectancy (until age 86) and uses only half of her initial loan amount, she could also owe about $5,000 in monthly servicing fees and about $8,000 in periodic mortgage insurance premiums.

So the total cost of the loan -- excluding interest -- could be about $25,400 over the life of the loan, which is greater than the average annual income of HECM borrowers. Most Americans would be highly reluctant to take out a loan in which the fees alone

exceed their annual incomes. But many older homeowners are faced with exactly this dilemma -- an attractive loan that meets their needs and is insured by the federal government -- but costs significantly more than they believe is reasonable or are willing to pay.

The substantial costs faced by an individual who chooses to use her home equity for long-term care can be illustrated in the following examples. A 75-year-old HECM borrower in a $150,000 home who uses her HECM to pay for $3,000 a month in home care would pay a 53.2 percent total annual percentage rate if her loan were to end after one year. Because of the higher origination fees and mortgage insurance premiums, the same borrower in a $250,000 home would accrue costs at an effective rate of 72.3 percent at the end of the first year even though she borrowed the same amount of money for home care. (See attached appendix for a more detailed analysis of the costs associated with reverse mortgages.)

While the effective rates on HECMs go down over time, homeowners with disabilities are more likely to borrow for shorter periods with higher effective costs. Moreover, the usage patterns that borrowers are likely to follow if they are using HECMs for long-term care are not reflected in current disclosure requirements. As a result, required disclosures are likely to significantly understate the effective short-term costs for borrowers who need money to pay for monthly service costs.

Reverse Mortgages and Long-Term Care Insurance – Critique of Existing Provision

In 2000, Congress included a provision in the American Homeownership and Economic Opportunity Act that waives the upfront mortgage insurance premium for individuals who get a reverse mortgage through HECM if all the available equity is used to buy long-term care insurance. Consumer organizations – including AARP – have objected to the required tie to an insurance purchase and, to date, HUD has not implemented the program.

Tying the purchase of long-term care insurance to a reverse mortgage is expensive for the consumer and not necessarily the best way to finance needed services for a number of reasons. The homeowner pays all the costs associated with the reverse mortgage plus the premiums and cost-sharing associated with the long-term care insurance policy. Current disclosure requirements do not adequately ensure that consumers are fully informed of the total, combined cost of the loan and the insurance policy. Over time, reverse mortgage costs can double or triple the total cost of purchasing long-term care insurance due to high upfront loan costs and the growing amount of interest charged on the loan. (See attached appendix for examples of the costs associated with purchasing long-term care insurance with a reverse mortgage.)

Another concern with tying a reverse mortgages to the purchase of long-term care insurance is the lack of a requirement to disclose the risks related to long-term care insurance policy cancellation or lapses. If an individual exhausts all available reverse mortgage funds for the long-term care insurance premiums and is no longer able to pay the premiums, the policy could be cancelled or lapse due to nonpayment. The insurance coverage would be lost; the borrower would owe substantial and growing debt on the home; and would no longer be able to pay for the cost of long-term care.

Finally, borrowers could only use the loan money to pay for insurance policies and not to directly purchase home-and community-based services or for home modifications that may better meet their needs. Most older Americans want to remain in their homes and receive needed services there rather than be institutionalized. Use of reverse mortgages may be one means of financing long-term care, but consumers should not be required to use their equity to purchase an insurance policy. Rather, they should have the choice to use the equity for the appropriate services in their homes. We are urging Congress and the industry to look for ways to reduce the high costs of reverse mortgages

for all homeowners, and especially for older homeowners with disabilities, to enable them to remain independent in their homes.

A More Promising Approach

As the Subcommittee examines reverse mortgages, we believe that several principles are important to guide the consideration of reverse mortgages as a long-term care financing option:

- Reverse mortgages should be a voluntary option and not a requirement.
- The high costs of reverse mortgages should be reduced, especially for those with long-term care needs.
- Reverse mortgages should have strong consumer protections, including required counseling and protections against those who might take advantage of reverse mortgage borrowers.
- Consumers should be informed of the range of available long-term care financing options and their pros and cons (including costs), as well as the potential financial impact on a spouse, so that consumers can make an informed decision about the best option for them.

We encourage the Subcommittee to examine ways to reduce the costs of reverse mortgages for individuals with long-term care needs. The high costs of reverse mortgages are the greatest barrier to their use for long-term care. Specifically, we encourage consideration of a public-private approach to reducing reverse mortgage costs for individuals with long-term care needs. Congress could consider pursuing such an approach in place of the incentives to use reverse mortgages to purchase long-term care insurance that were included in the 2000 housing legislation.

One approach might be to provide lower cost reverse mortgages to individuals with long-term care needs through a competitive demonstration program in selected states. Such a demonstration might be done as part of the HECM program, and states would compete to participate based on their willingness to take steps to lower the costs to consumers. States could choose to originate and service these lower cost HECMs and/or provide other subsidies and services to qualified homeowners. HUD could have the flexibility to reduce some of the loan costs for eligible borrowers, especially the up front mortgage insurance premium. Lenders and services could compete to participate in the program based on fees charged to consumers. Such a program could be tried on a smaller scale and should include an evaluation of its effectiveness in reducing reverse mortgages costs, the use of reverse mortgages as a long-term care financing option, which segments of the population might be best served by using reverse mortgages to pay for long-term care, how reverse mortgages could help expand access to home-and community-based services, and how to give people more choice and control in how they receive long-term care services.

Borrowers would be able to access their own home equity to pay for the lower-cost services they want that are tailored to meet their needs instead of waiting for estate recovery and liens to reimburse Medicaid for the institutional care they want to avoid. Borrowers would also not be as limited in their choice of providers or services as they would be under Medicaid.

The public sector has experimented with reverse mortgages relating to long-term care. The HECM program also provides valuable experience that could be drawn on to establish such a program to allow older homeowners with long-term care needs to remain in their homes longer by using reverse mortgages to pay for services that they need to remain independent. Such a program would create opportunities for the federal and state governments, the private sector, and consumer groups to work together to explore the potential of reverse mortgages to pay for long-term care.

Conclusion

Just as Americans need to plan for long-term care, Congress must look for options that would allow Americans to pay for the care they need in the setting of their choice. We urge you to move beyond all the long-term care jargon and acronyms to focus on the individuals and families, such as the husband and wife who have lived in their home most of their lives and want to stay there, but need services and supports to help them remain at home or the widow who is suddenly on her own and needs help after caring for her husband for years.

AARP looks forward to working with this Subcommittee, Congress, the Administration, and all stakeholders to help Americans plan for their future long-term care needs and give them more tools to do so. We stand ready to work with members on both sides of the aisle to begin to tackle this important challenge.

Appendix
Analyzing the Cost of Home Equity Conversion Mortgages (HECMs)

The non-interest costs of a HECM loan for a borrower of average age (74) living in a home of average value ($255,000) can be about $25,000, assuming the borrower lives to the remaining life expectancy (12 years) prescribed by federal Truth-in-Lending disclosures for HECM loans. Table 1 itemizes the fees, all of which are charged to the loan at closing except for the monthly servicing fee and monthly mortgage insurance premium.

Table 1: Total HECM Fees until Life Expectancy for a 74-year-old Borrower in a $255,000 Home*

Loan Fee	HUD Limit or Specification	Amount
Origination Fee	Limited to 2% of home value or HUD's county equity limit, whichever is less	$5,100
Upfront Mortgage Insurance Premium (MIP)	Equals 2% of home value or HUD's county equity limit, whichever is less	$5,100
Third-Party Closing Costs	Limited to "customary & reasonable"	$2,200**
Monthly Servicing Fees	Limited to $35 per month	$5,040***
Monthly MIP	Equals 0.04167% of loan balance each month	$8,014***
TOTAL FEES =		**$25,454**

Source: AARP calculations based on:
* The average HECM borrower in FY 2005 was 73.8 years old and lived in a home worth $254,900.
** Hypothetical national average; actual figures range from less than $2,000 to more than $6,000.
*** Assuming borrower lives to the remaining median life expectancy (12 years) for a 74-year-old and withdraws 50% of the available loan amount at closing, which is the credit line usage pattern prescribed by Truth-in-Lending law for HECM disclosures. In this loan, the amount withdrawn from the HECM credit line at closing is $71,115, which is 50% of the available credit line amount. The assumed interest rate is the one that was in effect on 5/10/06, which was 6.48%. For additional information see the Methodological Note on page 2.

Table 2 shows all the costs on the HECM loan from Table 1. The "Loan Fees" column shows that the fees of $25,454 from Table 1, when added to the loan balance,

generate $20,552 in interest charges over the 12 years of the 74-year-old borrower's remaining life expectancy. The "Loan Advances" column shows that a credit line cash advance of $71,115 to the borrower at closing generates another $83,325 in interest charges. So at the end of the loan, the homeowner has borrowed $71,115, but now also owes $25,454 in loan fees plus $103,877 in total interest charges for a total cost of $129,331 – which is 182% of the loan amount ($71,115). The loan balance (amount owed) at this time is $200,446.

Table 2: Total HECM Fees, Interest, and Loan Advances until Life Expectancy for a 74-year-old Borrower in a $255,000 Home*

	Loan Fees	Loan Advances	TOTAL
Principal	$25,454	$71,115	$96,569
Interest	$20,552	$83,325	$103,877
TOTAL =	$46,006	$154,440	$200,446

* See table 1 for details about this loan.

Methodological Note: The total of ongoing costs actually paid on the loan presented in Tables 1-2 would differ from the amounts estimated for the following reasons:

- The tables assume that the initial interest rate never changes over the life of the loan. But the interest on HECM loans is adjustable. So if the actual rate decreases, then ongoing interest and mortgage insurance premium (MIP) costs would be less, and if the actual rate increases, then ongoing interest and MIP costs would be more.
- The tables assume that the loan ends when the borrower reaches her remaining median life expectancy. But some borrowers will remain in their homes longer than that, and others will leave or die sooner. The total costs for longer-lived borrowers would be greater than the estimated amounts, and the total costs for those who leave or die sooner would be less.
- The tables assume that creditline borrowers withdraw 50% of their available loan funds at closing and none thereafter, which is the withdrawal pattern prescribed for HECM disclosures by federal Truth-in-Lending law (as explained in the footnotes to Table 1). In reality, HUD research has found that creditline borrowers have withdrawn their available funds at a substantially earlier and greater rate. Since the amount of funds remaining available in a HECM creditline grows larger every month, this more aggressive actual withdrawal pattern would result in larger loan balances and, therefore, greater charges for interest and monthly mortgage insurance premiums.

The Cost of Purchasing Home Care & Long-Term Care Insurance Using a Home Equity Conversion Mortgage

The short-term cost of a federally-insured Home Equity Conversion Mortgage used to purchase home care is substantial. The table below shows the total annual average percentage rate on a HECM used to purchase home care at $3,000 per month for a 75-year-old borrower assuming three different initial home values.

Total Annual Percentage Rate of a HECM*
Used by a 75-Year-Old Borrower to Purchase Home Care
for $3,000 Per Month at Three Initial Home Values

At End of Year:	**Total Annual Percentage Rate when Home Value =**		
	$150,000	**$250,000**	**$550,000**
1	53.2%	72.3%	91.7%
2	19.4%	24.7%	30.3%
3	Funds Exhausted in 7th Month	15.4%	18.1%
4		12.0%	13.6%
5		Funds Exhausted in 8th Month	11.4%

*Source: AARP calculations based on an origination fee equaling 2% of home value or HUD limit ($362,790), whichever is less, monthly servicing fee of $35, interest as of 5/15/06 (6.48%), and typical third-party closing costs for each home value.

The cost of long term care insurance (LTCI) purchased with a HECM includes the cost of the LTCI policy plus the cost of the HECM, which includes upfront fees plus monthly servicing, interest, and mortgage insurance costs.

The table below assumes that a 62-year-old couple living in a $250,000 home is using a HECM to purchase a LTCI policy that costs $508 per month in May of 2006. It also assumes an interest rate of 6.48%, a monthly servicing fee of $35, an origination fee equaling 2% of the home value ($5,000), $2,201 in 3rd-party closing costs, and -- to simulate a provision in current law that forgives the upfront mortgage insurance premiums if all of the HECM proceeds are used to buy LTCI -- no upfront mortgage insurance premium.

The table demonstrates how the average total monthly cost of this loan would rise over time in 2-year increments. In particular, it shows how much the monthly cost of this HECM would add to the cost of the monthly LTCI premium being paid by this couple:

- Over the first two years, the loan adds 82 percent to the cost of LTCI.
- By the time the couple reaches age 70, the monthly cost of its HECM loan ($518) would exceed the cost of its monthly LTCI premium, adding 102 percent to the cost of the LTCI premium.
- At this couple's approximate life expectancy (age 82), the monthly loan cost ($1,714) would add 337 percent to the cost of the LTCI premium, for a total monthly cost of $2,222.

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	Increases in Monthly Costs for Using a HECM to Buy LTCI (as outlined above under current law provision)			
In Years	**Monthly LTCI Cost***	**+ Monthly HECM Costs****	**= Combined Monthly Cost of LTCI and HECM**	**Monthly Cost Increase*****
1-2	$508	$418	$926	82%
3-4	$508	$361	$869	71%
5-6	$508	$419	$927	82%
7-8	$508	$518	$1,026	102%
9-10	$508	$645	$1,153	127%
11-12	$508	$798	$1,306	157%
13-14	$508	$978	$1,486	193%
15-16	$508	$1,189	$1,697	234%
17-18	$508	$1,432	$1,940	282%
19-20	$508	$1,714	$2,222	337%
21-22	$508	$2,038	$2,546	401%
23-24	$508	$2,412	$2,920	475%
25-26	$508	$2,843	$3,351	560%
27-28	$508	$3,338	$3,846	657%
29-30	$508	$3,908	$4,416	769%

Source: AARP calculation based on the following data:
* $508 is the monthly premium for the prepackaged "Comprehensive 150+" plan offered by the U. S.
Office of Personnel Management through its Federal Long Term Care Insurance Program at www.opm.gov.
**Includes servicing, interest, and periodic mortgage insurance premium plus $7201 in upfront costs divided by number of months since closing.
*** Monthly HECM costs divided by monthly LTCI costs. These percentage increases would be less if LTCI premiums rise, but that would increase the total cost to the consumer.

MR. DEAL. Thank you. Excellent job from everybody.

We are going to stand in recess, pending these votes. We will be back probably in about an hour.

[Recess.]

MR. DEAL. First of all, thank you all for your testimony, and those bells will go away in a few minutes. We did have a series of six votes, and we are, I think, now going into recess, to await further action of the Rules Committee. But I will get started.

First of all, very interesting points of view have been expressed here. Obviously, the overall purpose of this hearing today is to hopefully put aside political rhetoric and put aside all the things that sometimes make judgments around here difficult, and try to come to some real solutions. I truly am of the opinion that one of the solutions has to be a greater penetration in the insurance market of long-term care insurance, and I certainly agree with the two insurance company type representatives who

are on the panel, that some of the incentives that are one, in the pension reform bill, that hopefully the Senate will agree to that language, are steps in the right direction. I think the deductibility of premiums would be a huge step in the right direction of encouraging people to go ahead and make that determination.

Some of you heard me say at one time that I think there are phases of your life, and in the early stages, we buy life insurance because we are afraid we won't live long enough, and then, once we cross the top of that mountain and on the other side, we realize that we really need long-term care insurance, in case we live too long. So, I think hopefully, we will give some incentives and some legislative encouragement to have a blending of those products, whether it be an annuity that Mr. Jenner talked about, an annuity that becomes transferable to a long-term care situation. Those, I think, are the innovative type answers that we ought to be looking for.

With that general comment, and I don't mean to overlook the reverse mortgages, because I do think those are appropriate. I think we have a long way to go in terms of educating the American public about what that product is, and I believe Dr. Thames is the one who mentioned it, we have to be concerned about front end costs that might be an impediment to that.

Are there other things that are available, or should be available, that we haven't touched on, to begin to make people more personally responsible, because I quite frankly think we are at a time where we can no longer continue to look to the Government to be the only and exclusive source. We have taken some steps in the Deficit Reduction Act that would encourage more self-sufficiency and private initiative, but what are some other things that maybe we haven't talked about, and anybody can jump in. Yes.

MS. IGNAGNI. Mr. Chairman, I think that the point that we touched briefly, but didn't spend a great deal of time on, in addition to the strategies that you just put on the table, the flexible spending accounts, that has a modest cost associated with it, relative to other strategies, and it would be the second piece, I think, of a strategy, the first being the partnership. We are hoping that HHS now will proceed to develop regulations that set the expectations with respect to what the States need to do. The states are ready, which is very exciting, but I do think looking at strategies that could be affordable, in the context of the current budgetary discussion, so we won't have to wait another year to lay down another pylon.

So, I think that should be given a great deal of consideration. It is also the most affordable opportunity for individuals, because you are pooling risk broadly in the employer context, so it is a very good start

from that perspective. The above-the-line deduction levels the playing field, as you said, and it provides an opportunity for everyone to purchase, in the same way they purchase acute care. So, I think that those are three basic pylons that can be looked at very productively.

MR. DEAL. Okay. Anyone else? Dr. Wiener, you were a little skeptical in your testimony about whether people would actually buy long-term care insurance, even if it were a deductible, above-the-line deduction. And I heard your oral testimony in the context of senior citizens who, because their incomes have come down, and are not really paying a lot of taxes, that might not be an incentive for them, but wouldn't it be an incentive on the front end at early ages, where people are in their prime years, and their tax rates are going to be higher? Wouldn't it be an incentive?

DR. WIENER. It clearly would be more of an incentive at younger ages, for exactly the reason that you said, that their tax rates are higher. The marketing problem for long-term care insurance at that age group is what are 40 year olds and 50 year olds concerned about? Well, their mortgage payments, because they haven't yet paid off their house, child care, saving for college education for their children, saving for general retirement, and so, in general, when policies have been offered to employees, something in the range of 7 to 8 or 9 percent of people have picked it up, so it has not been a very high percentage.

Clearly, if you made it cheaper, that would increase the affordability, but I am not sure, I mean at age 50, for a really good policy, you are still talking about $1,500 a year, so even if you were to reduce that by a third, you would be talking about $1,000 a person, $2,000 roughly for a married couple. That is not an insignificant amount of money.

So, the other problem, of course, is that the vast majority of the tax laws will go to people who have already purchased policies, rather than for people who are buying them new. That is almost always an inherent problem with tax incentives. You give money to people who have already done, or will already do, what you are trying to induce them to do.

MR. DEAL. But we shouldn't penalize them for having made the right decisions early on, I wouldn't think, either. Yes, Mr. Jenner.

MR. JENNER. I am sorry, Mr. Deal. Thank you very much. You could actually tailor a proposal, if you wanted to, to limit it to newly acquired policies. So, I mean, if that were the only thing that were holding you back, you could say for new policies only.

MR. DEAL. But I think that would penalize folks who made the right choice on their own.

MR. JENNER. You are absolutely right. So, it is a balance that you would have to strike, but--

MR. DEAL. I think Dr. Thames is right, though. There has got to be a lot of education, even on this issue. Yes, Dr. Thames.

MR. THAMES. Well, I think we ought to just take a minute to say something about the CLASS Act. You know, where you would take, and understand that I am not endorsing it entirely, I am not even completely knowledgeable, except to say that anything we do, I am sure the panel is aware, that this would have everybody that is 18 years of age and older, who is working, pay into a long-term care type product. They could opt out, but it would be automatically enrolled unless they did opt out.

Now, what we liked about it, from the AARP standpoint, is it creates a large pool, and the large pool, of course, allows you to get more stable rates and more affordable rates and competition. The problem is, we are not sure that enough people would stay into it, to have it be a fund that would be stable, and there for enough funds for people to draw from. But it is an idea to look at, at least where people are funding it when they are younger and in their working years, and get enough insurance on the insurance people to have to work on that thing to help us, and to educate them to the fact, this is another program like Social Security, where you are going to pay money in, but you expect to get a value out of it at the end.

And of course, we feel, in general, that both public funds and private funds ought to be in there together. There will always be people who can't work enough, or who are low enough income, that we are going to have some kind of a safety net for them, but there are a lot of other folks that if we get them in the program young enough, like at 18, how much would they have to put in there, if they are going to work until they are 62 or 65 or maybe longer, like many of our people do, maybe that kind of an idea with insurance people is something that we ought to be looking at.

MR. DEAL. Well, I know I have talked with some of you privately about what I think insurance products of the future might look like, and I think we are going to see, hopefully, a hybridization of what insurance products look like, too, to deal with that needing a life insurance policy the early part of your life, and then moving to a point where you need long-term care insurance in the latter part of your life. The problem, of course, even with life insurance policies, many people, like myself, buy full life policies, whole life policies. I will get the terminology right in a minute. And paying those premiums for a life insurance policy past the point that you really believe you need that life insurance policy any longer, there is a great disincentive to do that. If you could convert that premium you are paying for the life insurance policy over to something you do need, such as a long-term care policy, and have a blending of that

product, I think those are hopefully the kind of things we might see in the future.

I know we need to take some legislative steps to make that a little more possible. What else do we need to do beyond what is in the pension reform bill?

MS. IGNAGNI. I think, Mr. Chairman, you said something very important. If you build it, they will come. You need not worry about the private sector's interest or ability to respond to the challenge. But there is a major barrier there, as you have just stated, with respect to the incentives. We favor acute care. We disproportionately penalize people who want to invest in long-term care for their future, and we don't, now, if you think about just the flexible benefit side of things, people lose money at the end of the year, or they buy four pairs of eyeglasses. We should be able to let people make their own decisions. Same with the above-the-line deduction. We will have products throughout the market that will do a number of things that you have suggested, and some other things we haven't already thought of. The private sector has had a very positive track record.

The partnership program is an excellent start along those lines. You can already see 25 States in five months passing legislation to get ready to proceed on partnership, when in fact, once HHS acts, I don't think you even really need legislation. So, they are ready to go, and you are going to see a number of very exciting products. So, I don't think you have to worry about that, but I think you have got your finger on exactly what the problems are, the lack of clear signals that this is on an equal playing field, and as we expand and enlarge this conversation, it is no longer about acute care in this silo, it is about breaking down those barriers, and I think it is important.

MR. DEAL. Dr. Stucki, I think, to get you in on our discussion here, our conversation, the steps we took, and we got criticized for it, we were criticized in opening statements from this subcommittee earlier today about some of the things we did on asset transfers, because it is part of an education process, and a reorientation of the role of the Government in this whole issue.

You know, quite honestly, I suppose if you took a poll of most people, they would probably tell you that they think the Government, under Medicare, provides long-term care coverage. I think they really would. In my constituency, I think that would be very true. We took a step, in the Deficit Reduction Act, dealing with asset transfers, to begin to draw some clear lines, say, you know, that is not the case, and we are going to enforce it to make sure people are not taking advantage of the system in that regard.

And I do think one of the products that will get more attention is the reverse mortgage. What do you see the industry doing to address some of the stated concerns, such as high front end costs, high expenses associated with it? What do you see happening there?

DR. STUCKI. Well, I think there is a great deal going on, both at the industry level, and with HUD, as well as some of the initiatives that are being taken by States to address costs. So, I think it is an across the board effort that is just going on right now. One of the major developments is that the industry and HUD have developed a Reverse Mortgage Working Group, which is really working hard to re-engineer the HECM program, the Home Equity Conversion Mortgage, which now represents about 90 percent of the reverse mortgage market. I think as part of that effort, they are beginning to see ways in which they can restructure the room, in order to reduce the mortgage insurance premium, and to reduce the servicing fees set aside, so I think that is very much under discussion right now.

We also have to realize that as more people are getting into considering a reverse mortgage and taking it out, that there is a growing competition among various lenders, and in many of the hotspots throughout the country, we are seeing that the origination fee is dropping significantly. So, already consumers are benefiting from lower costs at that end.

The program that I am working with right now, which is a study that is being funded by ASPI and the Administration on Aging, is working with selected States and communities to see what they can do. I touched on it in my testimony, that Minnesota has actually crafted legislation that would create a reverse mortgage incentive program, where the State would pay up to $1,500 of the mortgage insurance premium, the up front costs. They would help reduce the servicing fee set-aside, and they would also provide some lower cost back-end protection for those people once they use up their home equity.

So, I think there is a great deal going on right now. I think we are going to be seeing a lot more lenders in the market, who are coming in, who are offering new products. We are going to have more investors in the market, and all of that is going to work, I think, within a real short time, to help reduce some of those costs.

MR. DEAL. Ms. Capps, you are recognized for questions.

MS. CAPPS. Thank you. Sorry to come running in after our voting session. Dr. Wiener, I was hoping to address this query to you. Today, there have been points raised about a number of tax-related provisions to enhance purchase of long-term care insurance. Changing the rules about the combination of life insurance and long-term care insurance, which is a provision in the pension bill, costs $8.6 billion over 10 years,

apparently. The deduction for long-term care insurance, as proposed by the Administration in 2004, was estimated to cost $21 billion over 10 years. Now, I don't have an estimate on the cost of changing the rules for flexible spending accounts, but I would imagine that anything we do in the area of this sort of remedy is going to have quite a cost attached to it.

And my basic question to you, and then maybe some other members of the panel would like to chime in, is if we focus on the Tax Code, Dr. Wiener, is this really the best way to ensure that we meet our citizens' long-term healthcare needs in the future? We could do that, but are there more efficient and more equitable ways, perhaps, that we should be addressing today?

DR. WIENER. Well, prior to your coming in, we were discussing some of the efficiencies of the tax deductions and other things. In my view, and based on the research that I have done, tax incentives tend to be inefficient ways of trying to motivate people to change behavior. They mostly reward people for doing what they would have done otherwise, and one can argue that there is a social value in recognizing them, but if you are trying to change behavior or meet people's needs, it may not be the best possible way.

The clear alternative is to do something of a more direct funding, either by increasing funding for something like the Administration on Aging, or trying to provide incentives through the Medicaid program, or through the Medicare program, to provide more home and community-based services, or to upgrade services in nursing homes, or provide some of the care coordination that is needed.

So, I think that is kind of the choice that Congress has before it.

MS. CAPPS. I know. We are skirting the edges, if you want, from me, and I understand the motivation to encourage individual incentives by making tax incentives, then, the individuals can respond, and maybe the private sector can respond, as well.

I am not opposed to that idea at all. I am wondering if you could push this a little further for me, and pardon me if I am going over ground that has been covered, but are there ways to use that idea of the reasons for people getting into tax incentives, to leverage, to have a more service oriented program, really to take on something new. As Medicare was a brand new idea when it first came forward, how could we do that without making it sound like a real heavy, in terms of expensive, but also, in terms of federally involved? Is there a way to do that which also could leverage the private sector and individuals to respond in the same way?

Let me start, again, with you, Dr. Wiener, because I think you may have some ideas in this area.

DR. WIENER. Well, actually, I--

MS. CAPPS. You probably proposed them.

DR. WIENER. Well, actually, I, as I think has sort of become clear, I am not a fan of using the Tax Code to--

MS. CAPPS. That is why I am thinking what is an alternative that--

DR. WIENER. Well, I mean--

MS. CAPPS. --would not be too unappealing to a lot of my colleagues.

DR. WIENER. Well, let me suggest an alternative, that on a grander scale, might work quite well, and that is the Administration has proposed, as part of the reauthorization for the Older Americans Act, the so called, what they are calling the Choice Program, which among its other components, would provide for coverage for home and community-based services for a more moderate income group, that are in need of nursing home level care, but have more in the way of income than the current Medicaid standards.

Karen talked about trying to get a balance between acute care and long-term care, but it seems to me that the principal imbalance we have is that if you are lucky enough, and I use the word advisedly, if you have something like a heart condition, Medicare will sort of pay an unlimited amount of money, but if you are unlucky enough to get Alzheimer's disease, then you have to impoverish yourself before the Government will come in, and that is, I think, the kind of dilemma that we face. And clearly, for me, the question for society as a whole, which the Chairman kind of alluded to, is long-term care going to be fundamentally a private responsibility, as it is largely here in the United States, with only government help available if you are poor, or become poor, or is it going to be a kind of broader social responsibility, as it is in Germany and Japan, and some of the other European countries.

MS. CAPPS. That is a fundamental--I know I am treading on a next series of time, but if--since it is just you and me, Chairman, could I push this thought--

MR. DEAL. Go right ahead.

MS. CAPPS. Thank you.

MR. DEAL. I am going to ask--

MS. CAPPS. And I know other hands went up, but could I state a real bias of mine, and it comes from being a nurse, but I am just going to use my staff person, not the one sitting with me, but in our office, who came back from being with her grandmother for a few days, because she became ill. She is in her 90s, and the illness was quickly treated in the hospital. It was maybe flu, maybe pneumonia, whatever, but then came the big challenge to the family of confronting the fact that she couldn't--she had been living alone independently. This is so universally experienced. Why can't we do some things together as a society? But

let us not leave ourselves out, in the Federal government, of providing the kind of assistance--no one wants to go to a nursing home--why is that the only choice, when with some assistance, so much cheaper, so much more respectful, for dignity, so much more life enhancing, because I, at my age, I want this comfort. I know where everything is in my house--and it is so disruptive to all of a sudden have to move to a very expensive facility, just because one of the Federal programs will--and you have to spend down all of your assets to do all the things that we don't like.

When can we come, in this place, Mr. Chairman--because I don't think the panelists are the problem--I think the responsibility is in the Congress, to initiate an attempt to bring us all together, we all want the best thing for our family members and eventually, for ourselves, we are talking about ourselves, to do the right thing in the community? It is so clear that we are not--it isn't there now. And it is so--we are spending so much money to do other things that are not in the best interest. Am I way off base?

MR. DEAL. Would you yield?

MS. CAPPS. I will yield back. Well--

MR. DEAL. Will you yield to me, and we will have some more discussion here. Well, thank you for yielding.

I think we are sort of like that, I think it was the car repair mechanic, says pay me now or pay me later, I think the question, though, is who is going to do the paying? Now, I like the idea of incentivizing people to do it on their own, and the reason being is we have two great examples of how we have used the Tax Code to incentivize people's conduct, and that is, we allow them to deduct their mortgage interest as an incentive to own their own home. It has been a huge success. We incentivize people to be charitable, by allowing them to deduct their charitable contributions. Most charitable organizations, churches, and others, would say they like that pretty good.

Now, I am told, and I was looking at the statistics I have here, that if you add all public contributions for the cost of long-term care together, it is somewhere in the neighborhood of 71 percent public contribution. That is, the taxpayer is paying for about 71 percent of the cost of long-term care, and that other, what, 29 percent is being paid by the individuals. Now, I don't know that we can sustain that over the long haul. I think we need to begin to tap into that private resources as early as possible.

MS. CAPPS. With all due respect, Mr. Chairman, doesn't that indicate we are not doing it the right way, or very well? Because I don't think reverse mortgages is going to be the answer for everybody.

MR. DEAL. I don't either.

MS. CAPPS. And I support your underlying premise, but I am wondering if our panelists could jump in here, maybe--since there are so few, you and me here, we can make the rules a little more flexible.

MS. IGNAGNI. Sure. I would love to give you a quick response. Oh, I am sorry. Ms. Capps, I think you have made an important point, which is that it is not a zero-sum game. Let me give you some recommendations, some of which we were talking about earlier.

One, the partnership program that was passed, what is very, very clear, people who are not purchasers of long-term care insurance, who have the resources to do so, have indicated loud and clear, we have provided some information in our testimony, that were there tax preferred incentives, they would do so. So, that is point number one.

Point number two is, back on the partnership. That is going to, I believe, create a great deal of excitement out in the States, and really appeal to folks, because you have that public/private, you have the back end Medicaid protection. Consider this. We haven't talked about this, Mr. Chairman, in the discussion so far. A number of our members wanted very much to have their existing long-term policies, care policies, considered partnership program policies with that back end. That would provide more opportunity, more expansion, that is another very realistic way to begin to combine the two. The flexible benefits accounts, you asked how much it would be, it is 2.5 to 2.6, depending upon whom you ask, so that is the score on that particular strategy, letting people purchase long-term care insurance through flexible benefit plans.

We have made a number of recommendations on the Medicaid side that could be drawn out, the special needs population, the upper payment limit. This is now a disincentive for health plans to participate on the SSI side, because states get penalized if they--because our resources don't count for the upper payment limit. So, you could put together all these strategies, get to the above-the-line deduction. That would make a big difference. But Mr. Chairman, I think drawing this out, you could have a very specific series of public and private strategies that could work together. You could dial it back, depending upon how much by way of resources.

MS. CAPPS. With all respect, could I say from my years of being a public health nurse, and I have been a visiting nurse as well, talking about reverse mortgages and tax incentives, it is fine for the people it will work for. They probably could have managed some other way, even without that. But there is a huge number of people, many with disabilities. Don't forget the people who need long-term care for--

MS. IGNAGNI. That is why I made the point about the--

MS. CAPPS. I understand that.

MS. IGNAGNI. –public-sector strategies, too.

MS. CAPPS. But some people never have had a mortgage, could never buy any kind of long-term care insurance, and whatever happened to the concept of providing, and much of it is not highly skilled care, into the home, that for at least part of it, we will have to have some public incentive, because the private sector is going to need to make some kind of profit on this, and if that even only works for a certain population. I think we have to broaden our partnership, if we are going to get past a certain set of our community.

MS. IGNAGNI. And I think we can do that.

MS. CAPPS. I think so, too.

MR. DEAL. May I, Mr. Chairman?

MS. CAPPS. It is--you are the Chairman.

MR. DEAL. Why don't we--

MS. CAPPS. Now that we have another member here--

MR. DEAL. Why don't we let the ones that would like to respond to your question respond, and then, we will go to Mr. Pallone for his questions.

MR. JENNER. Ms. Capps, I want to correct a fairly serious misconception about the long-term care combination proposal that is in the pension bill. It doesn't create a new tax incentive. It eliminates a tax hurdle that prevents this combination, and therefore, all of the revenue loss associated with that proposal is new take-up. It is new policies being written, people who are not buying long-term care now. So, we are not throwing money after people who would otherwise be taking these policies up anyway. We are creating the ability for people who aren't buying the policies now to buy them. So, that revenue loss is good stuff.

MS. CAPPS. Broadening that circle is a great thing. To me, it is here, but somehow, we have got to get out here, too.

DR. WIENER. Couldn't agree with you more.

MS. CAPPS. So, yeah, sure. Okay.

DR. WIENER. I would like to just comment a little bit about the long-term care partnerships. Years ago, I learned a term from Karen's husband, which was "that dog don't hunt." And it seems to me--

MR. DEAL. That is a good Georgia expression.

MR. JENNER. Yes, I know it is. You know, if you look at the history for the last 15 years of the partnerships in the four States that have had them, they have been flogging this idea consistently for the last 15 years, and have put in a substantial amount of resources from the Robert Wood Johnson Foundation and others, much more than is going to be available for most of the States that are talking about doing the program, And the end result is that in the four States that have a combined elderly

population of 6.1 million, they have sold about 175,000 policies in force. So, it is a little less--

MS. CAPPS. Drop in the bucket. But a drop.

DR. WIENER. It is a drop in the bucket, and so, I think it has basically not succeeded very well in the marketplace, and clearly, if you extend it to 46 states plus the District of Columbia, you will get more than 175,000, but I guess we will get to see, because legislation has been passed, and we will have a good social experiment, but it is hard to see what is going to be so dramatically different in this new environment that will allow it to take off when it hasn't attracted people, or agents very much, in the past.

And I think part of the problem is that long-term care insurance is principally sold by trying to convince people that Medicaid is a terrible program, and if you buy the product, you will stay off, and what the partnership program requires is kind of an 180 degree turnaround, and say you know, Medicaid, not so bad, buy it, and you will get on earlier than you would otherwise. So, I don't think many agents are willing to kind of change their line of attack, and I think that has had a major impact, in terms of the number of sales. And I think the other part is, as Karen kind of alluded to in part of her testimony, people who buy private long-term care insurance do so for a variety of quite fuzzy and soft reasons, to increase their level of choice, to be more independent, and so on. The partnership has been so straightforwardly an asset protection program that it kind of hasn't computed. So, you know, we will get to see, but I think there is reason, based on past history, to be skeptical on how far the partnership is going to take us.

MS. CAPPS. Mr. Chairman, could I make one comment, because I have overused my time so far already, but I appreciate this interchange, and I want to put myself on the record as being very interested in us taking on this issue, as difficult as it is going to be, because I think we have, well, I don't want to use the word train wreck, but we have a combination of aging population and an overloaded Medicaid--I mean, we can't afford it, even without the Baby Boomers coming on. I don't think we have a very long window, this is not a luxury conversation we are having today, and I would hope that there would be a sense of urgency in our subcommittee, and I will be right there with you.

We have avoided this topic, all of us, here in this place for a long time, and I would like to be on the record as expressing the urgency that it be something we do. It is not going to be easy, and maybe, we will just make some steps, and we started some steps, but I think we have to push and push, because it is before us.

And now, I will yield back. Thank you.

MR. DEAL. Okay. Mr. Pallone, it is your turn. We are not going to give you as much time as Ms. Capps and I got.

MR. PALLONE. I apologize, Mr. Chairman. I had another markup that I had to vote on just for the last half hour, and I guess I only missed the last couple. I was here earlier when the panel testified.

I wanted to ask two questions of Dr. Wiener. It is Wiener or Wiener, I don't know, Dr. Wiener.

DR. WIENER. Wiener.

MR. PALLONE. Wiener. One is about reverse mortgages, and then, the second one is just about long-term care insurance and young people. With regard to reverse mortgages, there are millions of Americans who are under 65 with disabilities, who are in need of long-term care services, but many of these individuals have little home equity, because of their disability, and many of these individuals with disabilities may not be able to obtain or afford private insurance. Could you please comment on how well you think reverse mortgages and private long-term care insurance will work for Americans living with disabilities?

DR. WIENER. Well, for younger people with disabilities, they will be almost always medically underwritten out of being able to buy private long-term care insurance. If they are lucky enough to work for a company that offers private long-term care insurance through a group plan, they may or may not have to go through medical underwriting, but in general, they will not be able to buy policies, and--

MR. PALLONE. And that is because, on the one hand, they don't build up equity, and on the other hand, because they are young, or on the other hand, they can't get insurance, right, because of disability?

DR. WIENER. That is correct. And I think it is also worth noting, as I certainly put forward in my written testimony, that while there is a lot of home equity out there, if you actually look at people with disabilities, they have much less. For the elderly population, for which I have figures with me, in 2002, the median home equity for people with any disability was $56,000, and for people with severe disabilities, people who need a lot of services, it was about $36,000. So, that is certainly better than nothing, but it doesn't necessarily take you terribly far, especially after you deal with the up front costs and rising interest rates.

In preparation for this hearing, I reviewed a very good paper on home equity conversion by Mark Merlis, and he was talking about interest rates of 5.5 percent. If I could get my home equity loan back to 5.5 percent, I would be a very happy man.

MR. PALLONE. Now, what about long-term care insurance for younger individuals in general? You know, you said, I think, that it can be more affordable for younger people, because they have more time to pay into their policy, but one of the concerns I have is that with 46

million Americans without any health insurance, and with families struggling to save for retirement and higher education, is that really the best use of people's money? In other words, are they likely to invest in that kind of a policy, when they are struggling to save for retirement in general, and higher education courses. Is it really a best use of their money to buy long-term care insurance, if they have these competing concerns?

DR. WIENER. Well, I don't know that there is anyone on this panel, including the representatives of the industry, that would say that people should buy private long-term care insurance over acute insurance, or save for their children's college education. I think you put your finger on an important issue, though, and people have to make tradeoffs, and to the extent that they are dealing with more fundamental issues, and I would certainly put coverage for acute care insurance as part of that, they are not going to be purchasing private long-term care insurance.

MR. PALLONE. And the other thing I wanted to mention. I don't know if anybody--again, I missed the questioning, so in terms of consumer protections, what kinds of consumer protections would be necessary if someone was serious about buying a policy? In other words, should policies contain consumer protection, inflation protection, protection from total forfeiture if you miss a couple payments, a minimum daily benefit, and flexibility to change, as new innovations in care occur? I mean, should those kinds of things be considered?

DR. WIENER. Well, I think by far, the biggest gap in the regulation of private long-term care insurance has to do with inflation protection. Long-term care costs have been going up. Over the last 15 years, the price of nursing home care has gone up on an average of 6 to 9 percent a year. So, I don't think, personally, that insurance companies should be allowed to sell policies that don't increase with inflation.

It is in the nature of that kind of product, that you are buying it years in advance of using the services, and that even modest inflation rates, the purchasing power of policies erode tremendously, and that is especially true for employer sponsored plans, where it could be 30 or 40 years between initial purchase and use of the policies. It seems to me that that sort of portends that people have protection when the purchasing power just evaporates over time.

MR. PALLONE. My time is out. It is up to the Chairman if he wants the other panel members to comment.

MR. DEAL. I think in light of the fact that you have raised the issue, I think the others should be allowed to comment.

MR. PALLONE. Absolutely.

MS. IGNAGNI. Mr. Pallone, I think you have raised a very important issue about consumer protections. In our testimony, we noted some of

the NAIC model protections. They have been adopted by 30 States. We fully support them, and we are in the process of trying to get the other 20 to adopt them as well.

A number of issues, virtually all of them on your list, are included in the model. So, I think that is a very important step forward. Also, the data show that 70 percent of the policies purchased in 2005 have inflation protection, versus 40 in 2000, and the reason that a person wouldn't want to purchase inflation protection, there are some individuals that do purchase this very late in life, and inflation protection doesn't make as much sense as it would, quite rightly, as you suggest, for the 40 or even 50 year old, 55 year old.

A final point, Mr. Chairman. Dr. Wiener made some points about the partnership programs. If it would be acceptable to you, we would like to provide data to show what have been the constraints existing in the four States in the partnership programs, and why a number of the States now are trying to change that regimen, and we have some very productive data to report on that. So, I didn't want to take anybody's time, but if that would be acceptable, we would like to do that.

MR. DEAL. Yes, without objection.

[The information follows:]

Financing Long-Term Care: Exploring the Benefits of the Expanded Public-Private Partnership

Policy Brief
January 26, 2006

I. Introduction: New Legislation Will Greatly Improve Climate for Long-Term Care Insurance

Congress is soon expected to give final approval to legislation which will clear the way for expanded public-private long-term care (LTC) insurance partnerships.

An expanded partnership will allow many Americans to secure the financial protection provided by private LTC insurance, while ensuring their investment will carry over into the Medicaid program should they require public assistance for an extended LTC stay. Establishing this partnership between Medicaid and private LTC insurance will greatly enhance the attractiveness of LTC insurance products, boosting projected enrollment in the years ahead, as well as relieving Medicaid of some of the costs of financing LTC for the elderly.

This policy brief explores the possible impact of the expanded partnership on the current LTC insurance marketplace. It then describes a model that has been developed to project the potential long-term budget impact of this legislation, and suggests an approach that may further enhance the market, while producing sustained savings for public programs.

II. Most Americans Are Not Prepared for Long-Term Care Costs

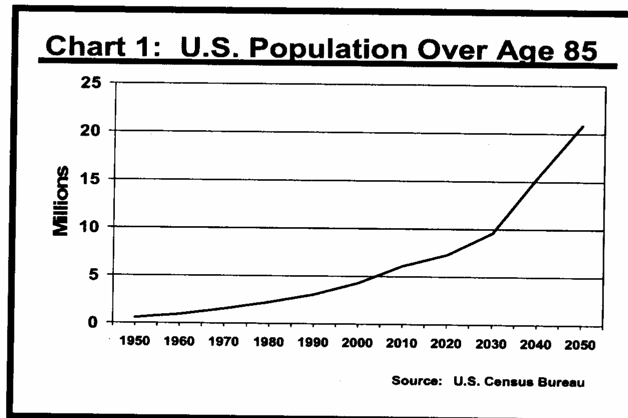
The aging of the baby-boom generation -- the 77 million Americans born between 1946 and 1964 -- poses multiple challenges for policymakers. More men and women are approaching retirement than ever before -- a baby-boomer turns 50 every eight seconds -- and they will live longer into old age than any previous generation.[1]

Public programs designed to meet the needs of the elderly and infirm will become increasingly strained in the years ahead -- a daunting prospect with Medicare and Medicaid already burdened by high costs. One of the crucial questions facing policymakers, therefore, is how to create an appropriate balance between public and private responsibilities -- between the obligation of government to provide a safety

net for those who need it and the obligation of citizens to provide for themselves to the extent they are able to do so.

There are clear signs that more attention needs to be paid to the nation's long-term care needs in the future. Consider the changing demographics, driven by the powerful twin engines of population size and longevity. The U.S. Census Bureau estimates that between 2000 and 2040, the population age 65 and older will increase from 35 to 80 million and will constitute over twenty percent of the total population.[2] Meanwhile, as shown in Chart 1, the population of those aged 85 or older -- the population most likely to need long-term care -- will more than triple, increasing from about 4.2 million in 2000 to 15.4 million in 2040.[3]

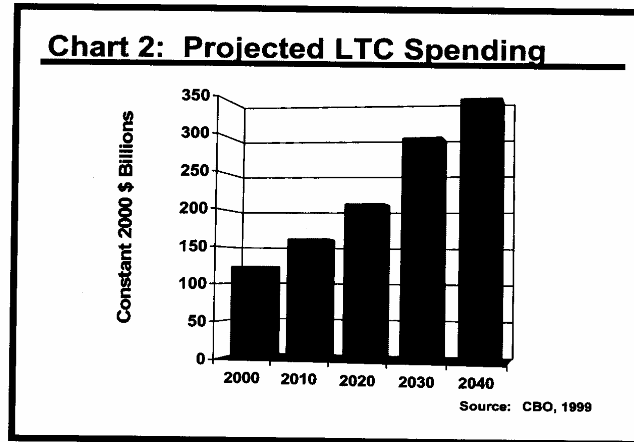
As the population lives longer and grows older, more and more Americans will need assistance with daily living or life-long care. Long-term care most often takes the form of assistance in performing a range of basic activities, including eating, bathing, dressing, preparing food, keeping house, handling finances, and remembering to take medicines.



The impact of these converging demographic trends is compounded by chronic illness. In the next thirty years, 157 million Americans, over half the population, will be living with at least one chronic condition.[4] Chronic illnesses such as cancer, diabetes, Alzheimer's disease and hypertension complicate age-related health problems and increase the likelihood of needing long-term care. Currently, nearly half of all nursing home residents have Alzheimer's disease.[5] By 2050, the Alzheimer's Association estimates that 13.4 million persons age 65 and older, or 15 percent, will find themselves living with the disease.[6]

The Congressional Budget Office (CBO) has projected the costs of providing LTC services nationwide to this growing elderly population. According to these

projections, as shown in Chart 2, national LTC spending on the elderly is expected to nearly triple in real terms over the next 40 years.[7]



How will Americans pay for the growing cost of long-term care? In 2005 the average daily cost of a private room is $203, or $74,000 annually.[8] Rates in many places are, of course, much higher than the average; in New York City, for example, the average daily cost of a private room in 2005 is $320, or nearly $117,000 annually.[9] The average length of stay in a nursing home is about 2.4 years, so the bill for a typical stay can easily exceed $175,000 -- and much more in high-cost urban areas.[10] It has been conservatively estimated that the average cost of a semi-private room will exceed $190,000 a year by 2030 -- when the oldest of the baby-boomers will reach age 85 -- and, depending on health care inflation, that estimate may prove to be low.[11] The stark reality is that few people are wealthy enough to finance prolonged long-term care services. And, as a result, people must choose between purchasing long-term care insurance for protection, or counting on public programs -- principally Medicaid -- to pay for their care, if and when they need it.

Public attitudes about long-term care, however, are skewed by three widespread misconceptions: that the risk of needing long-term care is relatively remote; that the costs of such care are considerably lower than is actually the case; and, finally, that Medicare and Medicaid can fully provide care should the need arise. Policymakers must address these misconceptions as part of any effort to elevate the national discussion about long-term care and to educate the public about the need to protect themselves with insurance.

- The risk of eventually needing long-term care, far from being remote, is quite high. Today, 44 percent of people reaching age 65 will eventually spend some part of their lives in a nursing home.[12] It will take time and

public education to make Americans more aware of the risks associated with needing long-term care in old age.

- A recent public opinion poll found that one-third of those surveyed believe nursing home care currently costs less than $40,000 a year -- less than 60 percent of actual costs.[13]

- Perhaps the most serious misconception, however, is that there is an adequate public safety net in place to protect us in the event that we need long-term care. The belief appears to be widespread that Medicare and Medicaid, between them, will somehow do the job. The reality -- widely understood by policymakers but not yet by the broader public -- is that neither program offers what any reasonable person would regard as adequate or acceptable protection.

Medicare, the federal health insurance program for the elderly and disabled, is designed primarily to pay for acute care services provided by hospitals and physicians. While Medicare does cover some nursing home care for patients following a hospital stay, its coverage is limited to 100 days, which by definition, excludes those who need ongoing assistance.

Medicaid, the joint federal-state health-financing program for low-income individuals, does pay for long-term care -- but only for those who have exhausted nearly all of their own resources first. Because Medicaid is a means-tested program, qualifying for assistance requires proving that one is impoverished, or nearly so. To receive coverage, individuals must "spend down" their assets to very stringent eligibility levels and demonstrate that virtually all of their income is going towards meeting the cost of care.

One predictable result is that many middle-class elderly Americans, facing the prospect of high long-term care costs, "spend down" their assets by transferring them to family members. Clearly that was never the intent of Congress or the states, but this dynamic is one of the many factors that have combined to drive up Medicaid costs -- 63 percent in the past five years alone.[14]

The harsh reality is that becoming eligible for Medicaid means losing all control over how and in what setting such care will be delivered. Covered services vary substantially from state to state, as does the quality of care. Some states that have been relatively generous about authorizing long-term care services at home, for example, have experienced runaway costs and have been forced to scale back such arrangements. For many who rely on Medicaid, their only option is to enter a nursing home, even if they would prefer home care.

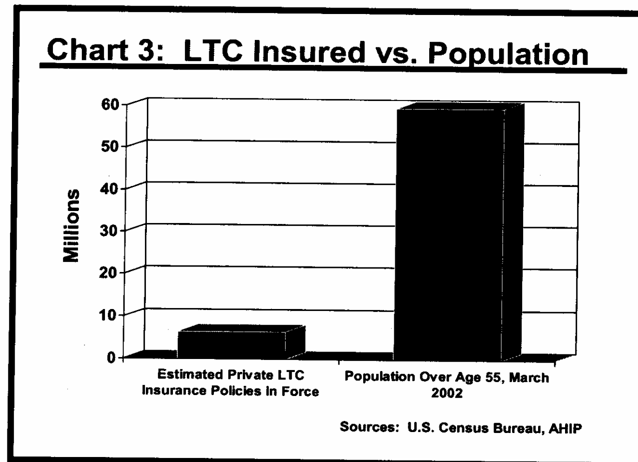
Nevertheless, despite its many shortcomings Medicaid has essentially become the default payer of the nation's long-term care costs. According to the Government Accountability Office (GAO), Medicaid currently pays for about 45 percent of all

long-term care expenditures, followed by out-of-pocket payments (23 percent), Medicare (14 percent), and private insurance (11 percent). Other public and private sources account for the remaining 7 percent.[15]

In the face of the increasingly obvious need for better alternatives to Medicaid and Medicare, relatively few people -- about 10 percent of the elderly and even fewer of the non-elderly -- have thus far purchased private long-term care insurance. A sound public policy would seek to relieve pressure on public programs -- especially Medicaid -- by creating opportunities for private long-term care insurance to take on more of the burden of financing such care.

III. Understanding the Current Public-Private Interaction

The private market for LTC insurance has been growing, with effective policies being sold to many Americans. Sales of private LTC insurance increased from 380,000 policies sold in 1990 to over 900,000 policies sold in 2002.[16] And, yet, as shown in Chart 3, it remains true that only about 10 percent of Americans over the age of 55 have private insurance protection for LTC costs. It is important for policymakers to understand the reasons many Americans leave themselves exposed to the large potential costs of an extend LTC episode -- costs that can wipe out savings that a retiree worked a lifetime to accumulate.



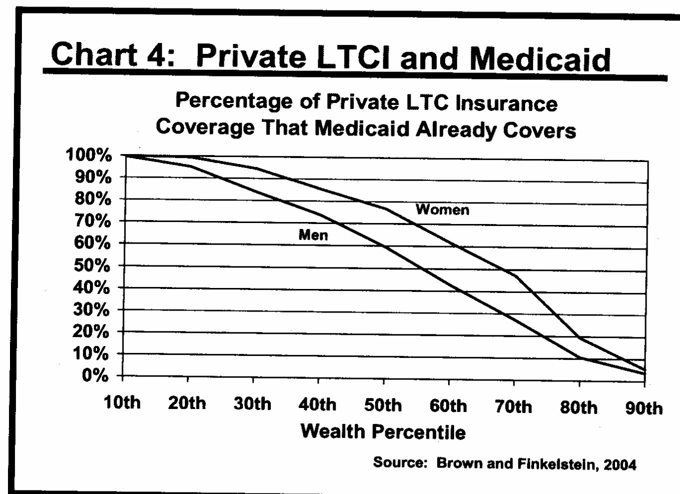
To better understand the private LTC insurance market, Jeffrey Brown and Amy Finkelstein, economists at the University of Illinois at Urbana-Champaign and the National Bureau of Economic Research, respectively, built a model of the financial consequences for consumers who buy or forego LTC insurance.

The model assesses consumer financial conditions based on income and asset data, probabilities of long-term care episodes used by the insurance industry, and premium and coverage assumptions derived from prevailing standards in the marketplace.

Based on output from this modeling effort, Brown and Finkelstein conclude that the primary hindrance to further expansion of private long-term care insurance is the presence of last resort public insurance -- namely the Medicaid program -- that is not coordinated with private insurance coverage.

The disincentive for private insurance is tied, in part, to the fact that when a consumer buys private LTC insurance, the assets protected under that policy are not, in general, protected under Medicaid. So having spent resources on private insurance premiums, many elderly and nearly elderly with moderate to low levels of financial assets could still lose their savings if the costs of the LTC episode exceeds the coverage they can afford to purchase.

The Brown-Finkelstein model was able to quantify the disincentive effect of the lack of coordination between private coverage and Medicaid, as shown in Chart 4. This chart demonstrates that, for large portions of the wealth distribution, the amount of asset protection secured by purchasing a private policy is redundant of the protection provided through the Medicaid program. This redundancy substantially reduces the willingness of these consumers to pay premiums for private insurance coverage.



IV. The Long-Term Care "Partnership"

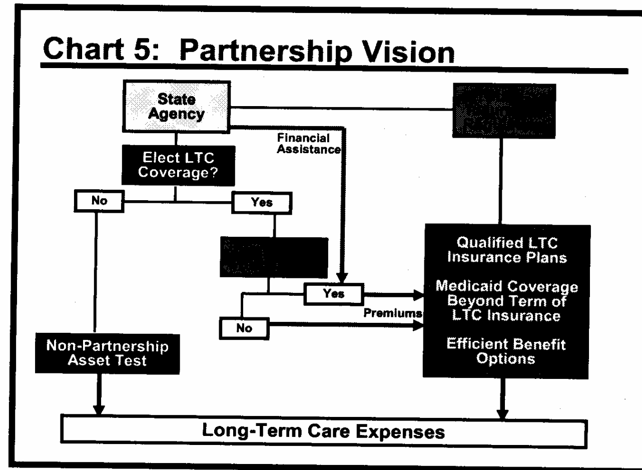
In the 1980's, as states began experiencing rapid LTC spending increases in their Medicaid programs, they began experimenting with the use of private insurance options. The Robert Wood Johnson Foundation joined the effort by funding a demonstration program, starting in 1988, called the "LTC Partnership Program." The Partnership was initiated to test how private insurance and Medicaid could work together to provide better insurance protection, at lower public cost, to the elderly population. In general, the state Partnerships encouraged the purchase of private LTC insurance for a given level of asset protection and LTC duration. The critical innovation of the Partnership program was that, beyond the term of the private coverage, Medicaid would cover the LTC costs, with the assets protected by the private insurance also exempt from the Medicaid asset test.

In 1993, as states neared implementation of the Partnership concept, some in Congress expressed the concern that this demonstration program could lead to higher income purchasers of private LTC insurance qualifying more easily for Medicaid coverage. These Members of Congress successfully imposed a moratorium on new states entering the demonstration project -- a moratorium that remains in effect today. As a consequence, for more than a decade, only four states have been allowed to run Partnership demonstrations -- California, Connecticut, Indiana and New York.

After a slow start up period as insurers and state agencies worked through the regulatory structure, Partnership plan sales have increased steadily in recent years. Between 1996 and 2004, Partnership enrollment increased from 28,000 to 172,000.[17] Moreover, independent research indicates that Partnership plans are attracting enrollees who generally would not buy non-Partnership LTC insurance. Further, research indicates that the Partnership enrollees have lower incomes and fewer assets than other LTC insurance purchasers.[18] This data support the contention that establishing a Partnership between private and public insurance can attract insurance purchasers who are likely to end up on Medicaid if they ever need extended LTC services.

V. Congress Poised to Enact Key Partnership Legislation

The vision for a more a more robust private insurance component in LTC financing begins with removing the cap on the number of states allowed to participate in the Partnership program. The overall vision -- illustrated in Chart 5 -- is for an integrated approach that increases awareness and provides the proper incentives for an effective LTC financing system.



Congress is about to take a large and important step toward this vision in legislation that will be soon enacted. This legislation allows all states to participate in the Partnership, eventually achieving portability of insurance across states, establishes a framework for ensuring regulatory stability, and funds a small education initiative to make consumers aware of LTC costs and insurance options.

VI. Modeling the Federal Budgetary Impact of the Partnership Legislation

The Partnership approach to LTC financing will be an important part of lowering long-term government cost projections.

Chart 6 describes a simplified estimating approach for determining how the legislation will alter federal budgetary costs. This estimating approach is based on examining Medicaid savings and costs for two different groups of people:

- First, there are those older Americans who, in the absence of the Partnership, would forego insurance and depend entirely on Medicaid if they need LTC. For this group, increased sales of LTC insurance should reduce Medicaid costs because, with insurance, they will, on average, get Medicaid much later in a LTC episode. For instance, many Americans have enough financial assets to cover LTC for just one year, but, as of 1997, the average length of a nursing home stay was well over two years.[19] If private LTC insurance typically covers two years worth of care, then encouraging more insurance purchases could reduce Medicaid's expenses by one year for those beneficiaries who end up needing extended LTC.

- Second, there are those persons who would get insurance even if the Partnership did not pass. For these people, extending to them the

Partnership concept is likely to speed up Medicaid coverage and increase federal costs, as they will not be required to spend down all of their assets to qualify for Medicaid.

Chart 6: Estimating Approach

	Length of LTC Stay Before Medicaid Coverage Begins:
Non-Partnership LTCI	3 years
Partnership LTCI	2 years
No Insurance	1 year

- **Model is built to estimate how much Medicaid must cover of an average person's LTC costs.**
- **Private assets are assumed to cover, on average, one year's worth of LTC costs.**
- **Giving Partnership status to policies that would have been Non-Partnership plans increases costs.**
- **Selling Partnership plans to persons who otherwise would not get insurance at all decreases costs.**

Over time and using reasonable assumptions, allowing all states to establish Partnership programs, thus removing a barrier to more demand for insurance coverage, will produce growing savings for the federal government and the states. The reason is simple: the market for private LTC insurance remains largely untapped, and enrollment among those who otherwise would rely exclusively on Medicaid should reduce public sector costs.

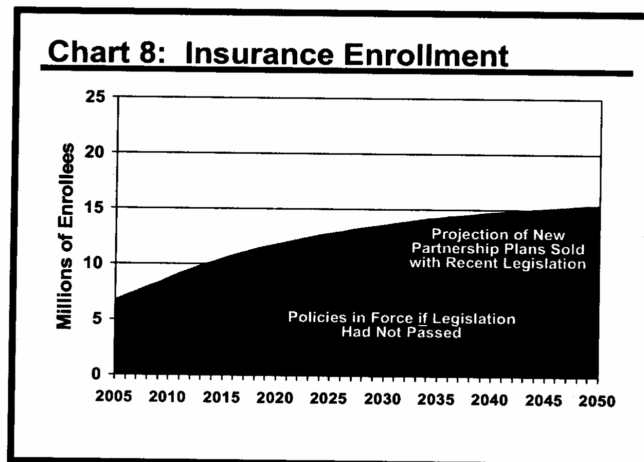
Chart 7 provides a set of assumptions that were used to estimate the net budgetary impact due to passage of the Partnership legislation. As shown, it is assumed that new purchases of Partnership plans will increase to about 400,000 in the first year after reform passes and remain steady over time. Persons are assumed to purchase this insurance at age 60 and begin to access LTC services in larger numbers beginning at age 80.

With Partnership insurance, Medicaid's responsibility for LTC costs should not begin for about two years, which means a lower percentage of LTC users than those who need Medicaid after one year, with a shorter expected duration at that point. On the cost side, those who get Medicaid coverage under the Partnership after two years instead of after three years, as would be the case for non-Partnership insurance, increases Medicaid costs but by less than the savings from expanded Partnership demand because there are fewer people and the estimated average LTC duration that is picked up by Medicaid is shorter.

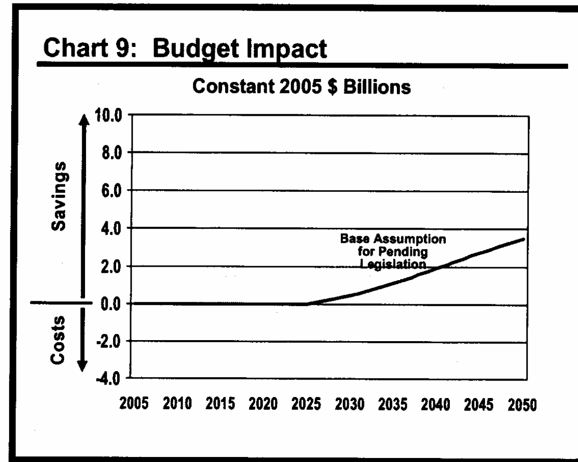
Chart 7: Key Assumptions

Some Key Parameters:	Assumptions
Insurance Sales	400,000 per year with new legislation; 250,000 per year and declining if legislation had not passed
Age of New Policy Purchasers	60
Probability of LTC Use in a Year for Anyone Age 80 and Older	5%
For Persons Experiencing a LTC Episode, Probability of the Duration Exceeding...	1 Year: 45% 2 Years: 20% 3 Years: 10%
Average Additional Length of Stay for Persons Experiencing a LTC Episode Exceeding...	1 Year: 1.5 Years 2 Years: 1.0 Years 3 Years: 0.8 Years
Covered LTC Costs	$70k in 2005, +1.5% real growth

As shown in Chart 8, this set of assumptions represents an increase in demand for Partnership plans, with more than 15 million people enrolled in LTC insurance in 2050 with the legislation as opposed to well below 10 million without passage of the legislation.



As shown in Chart 9, with these assumptions, greater private LTC insurance coverage will reduce government costs by growing amounts, in real terms, after about 2025, reaching nearly $4 billion annually in 2050.



The estimating model allows adjustments to test different policies or assumptions regarding how the program will evolve over time.

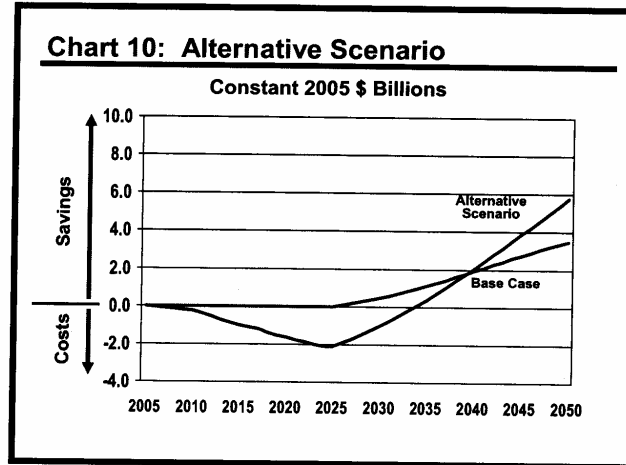
For instance, to further invigorate demand for Partnership insurance, policymakers could consider providing additional financial incentives for persons who purchase Partnership coverage, either in the form of tax assistance or perhaps direct premium assistance. Adding premium subsidies to the model increases short term costs but also increases long term savings because it will induce higher demand among persons who otherwise would rely entirely on Medicaid.

New provisions could also be explored to encourage widespread care management and more efficient benefit options, including cash and counseling, which will slow the projected rising cost of care. Cash and counseling has been shown in successful demonstrations to foster beneficiary independence and reduce government costs by empowering consumers with the financial control to make choices among competing care options. Although the program has been directed at younger, disabled populations, the concept of beneficiary financial control and choice should be able to produce better financial performance among the elderly LTC population as well.

The estimating model can be further adjusted to assume the existing stock of non-Partnership policies is fully converted into Partnership plans, which would increase costs relative to the pending legislation.

Chart 10 shows the results from incorporating all three of these alternative assumptions -- subsidies, slower growth in LTC costs, and "grandfathering" of existing policies -- into a new projection. As shown, the alternative scenario would increase costs through about 2040, at which point the additional savings from

higher Partnership enrollment would exceed the premium subsidies and costs of "grandfathering" current plans.



VII. Conclusion

The aging of the U.S. population is likely to require adjustments throughout society and in particular in government spending and tax policy. It is important for the government to begin now to plan for the added fiscal burden an aging society represents.

A critical component of that preparation is a renewed effort to promote private insurance for LTC costs. It is clear that LTC is an event that needs insurance: it is an expensive and unpredictable event in one's life, and yet it is also an event that will occur in a high percentage of elderly households.

Congress should be commended for the foresight it is showing in enacting the Partnership legislation. It is a common sense approach to LTC. Americans who protect their financial assets with private LTC insurance should not be forced to spend down their resources if their LTC needs exceed what can reasonably be purchased in the private market. Widespread use of the Partnership concept, together with effective education and clear financial incentives, will invigorate a much more robust private insurance marketplace. Using reasonable estimating assumptions, such a marketplace will be good both for enrollees and long-term fiscal policy.

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[18] Meiners, McKay, and Mahoney, 2002, p. 87.

[19] CBO, 2004, p. 34.

DR. STUCKI. Yes, if I could make a clarification with regard to reverse mortgages and younger people.

We have to keep in mind that currently, only people aged 62 and older qualify for a reverse mortgage. So, as a possibility for the younger

population, that simply isn't an option. So, that is one of the limitations that--

MR. PALLONE. Is that--I am sorry, with your permission, Mr. Chairman. Is that a legal prohibition, or just that is what they sell?

DR. STUCKI. Well, we have to keep in mind that the most popular reverse mortgage is the HECM, the home equity conversion mortgage, which is a HUD program, so under the HUD program right now, it is age 62, and all the other products have adopted that same standard, at age 62.

MR. PALLONE. Theoretically, the ones that are private could sell to younger people, but they just follow the model, the HUD model.

DR. STUCKI. Well, again, one of the unique, I am sorry, one of the unique features of a reverse mortgage is that it is a non-recourse loan, which means that a person never owes more than the value of the home at the time of the sale, even if the value of the loan is higher than the value of the home.

Now, what that means is, the way that works out is that to provide that kind of protection, the amount of the loan that is available at younger ages is going to be smaller than at older ages, so the further down the line you push the age, the lower the loan is going to be. These loans, the reason that we are talking about them for aging in place is because when people are most likely to need long-term care, in their eighties, is the time when they are going to get the most benefit from a reverse mortgage.

MR. PALLONE. Thank you.

MR. JENNER. May I just add, Mr. Chairman, that with respect to inflation protection, Karen mentioned the NAIC model. The NAIC model mandates that the purchaser of insurance be offered the option of inflation protection. They need not take it, but they must be offered it. So, it is a question of whether you mandate that, or whether you offer the consumer the choice.

MR. THAMES. Mr. Chairman. May I please respond briefly to Mr. Pallone's question with, and meld that with one of the things that the chair has already demonstrated that he is interested in, and that is the demonstration project.

One of the things our testimony would show is that we are interested in a demonstration project, in people with severe disabilities, and those who do, indeed, have some equity. We would believe that you could do a demonstration project with those people who have equity and are disabled, and that HUD could, for instance, forgive some of the up front mortgage insurance premium for those people, and lower the allowable origination and servicing fees, and the lenders could compete to participate in the program, again, lowering the origination and the servicing fees they would charge, and loan investors could also compete

with the interest rate, in decreasing it. The State governments could be into the program, because they could target supportive services to the bars, paying the loan fees, providing information, referral services, home modification grants or loans, care assessment, and coordination services.

What all of these do, then, is give what all of our surveys show these older people with or without disabilities want. They can stay in their homes as long as possible, and they have choice about how they spend their money, and they would have more of their money to spend on home and community services, and in changing their home environment to make it where they could stay longer there.

MR. DEAL. Well, thank you all. I think this discussion that we have had, and it has fortunately been a discussion, I wish we could have more hearings that were more on this model. It is that we are facing great challenges. The demographics of an aging population present challenges. It does require us to think in new ways. It does require us to be resourceful. It does require us to use the resources both that are available in the private hands of individuals, as well as the resources of the Federal government, in a more responsible manner. We may be late in the game of deciding what direction to take, but we are in the game now.

We did make some significant changes in the Deficit Reduction Act, whether it be the partnerships that have been referred to, or the incentives that we have provided now, that States can do more community, home and community-based services without having to get a Federal waiver to do so. I think we are moving in the right direction. I appreciate very much the contributions of this panel, and with that, we will let the first panel go, and we will get to the second panel, if they would come forward.

Well, thank you all for your patience in waiting around for us. This is one of those days when votes do interfere, but we are pleased to have you here. This is a panel that is made up, and I will introduce the people at this time: Mr. Scott Conner, who is Vice President of Products and Health and Safety Services of the American Red Cross; Dr. Larry Wright, Director of the Schmieding--is that close enough--

DR. WRIGHT. Yes. That is perfect.

MR. DEAL. --Schmieding Center for Senior Health and Education in Springdale, Arkansas; and Ms. Candace Inagi.

MS. INAGI. Inagi.

MR. DEAL. That is good. I did good. Good for a Southern accent, isn't it? Who is Assistant to the President for Government and Community Relations of the Service Employees International Union Local 775 in Washington.

Lady and gentlemen, we are pleased to have you, and we will have your testimony made a part of the record, as the previous panel's testimony was, and we would recognize each of you for 5 minutes, and starting with Mr. Conner.

STATEMENTS OF SCOTT CONNER, VICE PRESIDENT, PRODUCTS AND HEALTH AND SAFETY SERVICES, AMERICAN RED CROSS; DR. LARRY WRIGHT, DIRECTOR, SCHMIEDING CENTER FOR SENIOR HEALTH AND EDUCATION; AND CANDACE INAGI, ASSISTANT TO THE PRESIDENT FOR GOVERNMENT AND COMMUNITY RELATIONS, SERVICE EMPLOYEES INTERNATIONAL UNION LOCAL 775

MR. CONNER. Thank you. Chairman Deal and members of the subcommittee, thank you for providing us the opportunity to testify today on such an important issue. We at the American Red Cross commend you for your leadership in addressing the needs of the elderly in our Nation, and specifically addressing the needs that caregivers face.

Recognizing that caring for a loved one is a very personal experience, I am proud that the American Red Cross plays a role in helping caregivers provide support to their loved ones. For 125 years, as of last week, actually, the American Red Cross has been America's partner in preventing, preparing for, and responding to disasters. Annually, the Red Cross responds to over 70,000 disasters.

In addition, we train more than 17 million Americans each year in lifesaving skills. From first aid and CPR to babysitting courses, the American Red Cross is committed to preparing our neighbors for any disaster. To that end, we have established a program to prepare individuals on caring for the elderly. In 2004, the American Red Cross began offering a family caregiving course that covers the skills needed in caregiving. There are nine 1 hour modules that cover subjects ranging from general caregiving skills to assisting with personal care, eating healthy, and home safety. Additionally, and importantly, we offer a course to the caregiver themselves on caring for the caregiver. Anyone that has taken care of a loved one knows how taxing these services can be.

We are expanding this program by developing new ways to make the skills available to more people. The Family Caregiving Reference Guide, to be sold in retail outlets, will come out later this year. Furthermore, we are working on developing an enhanced website and offering online education. We also offer, for professional caregivers, a nurse assistant training program, and together, we prepare a program for

seniors that includes disaster and health and safety emergency preparedness.

We have a variety of other programs offered to benefit caregivers. These include Lifeline, which is a personal response system, transportation services, where volunteers help seniors get to appointments, volunteer shopping programs for those who are disabled or shut in, community feeding support, and in certain chapters, we have adult day care centers.

Our family caregiving skills training program is still fairly small by our standards. While we have more than 800 chapters, we only delivered about 18,000 family caregiving modules last year, and the reasons for this are several. Many caregivers simply do not self-identify, and they have very limited time to attend presentations. There is also, sometimes, a financial issue. New ways need to be found to help support this. We believe that the expansion of family caregiving skills knowledge within the American public will help to ameliorate the long-term care problem that we have been talking about all afternoon, but families simply cannot do it alone.

To that end, we encourage the committee to consider three critical areas. First, awareness. Large-scale health communications programs to raise awareness of rewards of caregiving, and encourage people to self-identify. Members of Congress can help promote caregiving programs in their local communities, and we encourage each of you to do so.

Second, resources and time. Congress could consider public policy that encourages insurance companies, again, what we have been talking about this afternoon, and Medicare and Medicaid to help pay for family caregiving education, as well as requiring the healthcare industry to provide the training. Doctors in hospitals should prescribe caregiver education. However, many healthcare providers will not recommend education, unless it is covered by insurance. Diabetes education is reimbursed, as is childbirth education. It is time that we reimburse for caregiving education as well.

And last, how to lessen the hardships of caregiving. Continuing to provide for growth of all manner of nationally supported services and programs for caregivers, such as the National Family Caregiver Support Program, FMLA, and so many others. Congress should also consider economic support to families, be it through tax credits or allowing education costs to be deducted on Federal taxes.

I thank you again for the opportunity to be here today.

[The prepared statement of Scott Conner follows:]

PREPARED STATEMENT OF SCOTT CONNER, VICE PRESIDENT, PRODUCTS AND HEALTH AND SAFETY SERVICES, AMERICAN RED CROSS

Chairman Deal, Congressman Brown, and Members of the Committee, thank you for providing me the opportunity to testify today before you on such an important issue. I commend you for your leadership in addressing the needs of the elderly in our nation, and specifically addressing the needs that caregivers face. I know that for many of us in this room, caregiving is an especially personal issue. And I know that I am very proud that the Red Cross plays a role in helping caregivers provide support and comfort to their loved ones.

I am also pleased to be here today because this hearing sheds light on an important program that the American Red Cross launched in 2004 to help better prepare individuals to provide caregiving services to their loved ones, as well as to train individuals to provide caregiving services.

For 125 years, the American Red Cross has been America's partner in preventing, preparing for, and responding to disasters. The American Red Cross is known from coast to coast for our response to more than 70,000 disasters annually, the vast majority being single family home fires. We have more than 800 chapters spread throughout the United States and the territories, and we provide the nation with nearly one half of the blood supply.

As important, the American Red Cross trains nearly 15 million Americans each year in lifesavings skills. From first aid and CPR, to AED training and babysitting courses, the American Red Cross is committed to preparing our neighbors for any disaster that comes their way. To that end, we established a program to prepare individuals on caring for the elderly.

Services to Seniors

Seniors are critical to the mission of the American Red Cross. In fact, seniors comprise a large percentage of our volunteers. But when seniors fall ill, 78% rely on their own family members to take care of them.

A 2005 study showed that 36% of Americans mentioned the American Red Cross first when asked what organization should be involved in teaching home nursing in case of a pandemic. This was 5 times as many people as the second most often selected organization.

For family members who are confronted with an unforeseen combination of circumstances that requires them to step in and provide care, the American Red Cross Family Caregiving program prepares them to respond. It is indeed a family emergency when a grown son or daughter finds themselves totally unprepared the day an elderly relative becomes sick. A busy and full life one day is taken over with caregiving responsibilities the next. For many days thereafter they may find themselves cleaning up hazardous environments, helping with personal care, and managing medications. Recent research has brought to light that caregivers endure personal and financial hardships – trouble in their jobs and the decline of their own health and relationships. These are some of the same kinds of things the American Red Cross volunteers face in disaster situations. Training makes a difference.

Our Family Caregiving program prepares families to respond in a manner to prevent hardship and further injury, keep basic needs met, and keep their loved ones health stable under the guidance of the family doctor.

Lay caregivers need training to deal with life-threatening emergencies – infection control, administering medications, moving a sick person without doing further injury. In Family Caregiving we teach the emergency action steps (Check, Call, Care), responding to sudden illness, safe disposal of syringes, oxygen, medications, food safety, disposal of

hazardous waste, and many other skills needed to keep people alive till the situation stabilizes.

History of the Family Caregiving Program

The program was developed with funds from a private donor – Josephine A. Osterhout – whose estate provided money to Red Cross National Headquarters to "help the elderly in America." In 2001, before embarking on the Family Caregiving program, National Headquarters, in partnership with the National Caregivers Alliance and AARP, commissioned a national telephone survey of caregivers. We learned that 22 million households are caring for a sick or elderly loved one. We found that Josephine Osterhout was not alone in thinking that America's elderly could be helped by the American Red Cross.

Our study also revealed that Americans see the American Red Cross as a logical source of information on Caregiving. It was generally felt that the American Red Cross had a good deal of experience, either directly or indirectly, with caregiving –

- Experience with Bloodmobiles transferred to developing transportation service for the elderly and disabled
- Disaster relief efforts transferred to developing a respite care program
- Experience as a trainer in first aid and CPR, the American Red Cross was seen as having the expertise to produce caregiver training materials.
- A reputation as being reliable and caring in an emergency would be a value in obtaining the trust necessary to have caregivers and their loved ones accept the services that the American Red Cross might provide.

Most adults receiving long-term care at home – 78% rely exclusively on family and friends to provide assistance. (Thomson, 2004, Georgetown University). Research has shown that providing care to elderly family members is a serious health risk for caregivers. Studies consistently find high levels of depressive symptoms and mental health problems among family caregivers as compared to their non-caregiving peers (Family Caregiver Alliance, 2003, L. Gray). The caregivers that provide the greatest level of care often experience the greatest financial burden, including lost wages and missed work.

Red Cross Programs that Train Caregivers

Family Caregiving

The American Red Cross Family Caregiving program offers nine modules that help participants provide better care and gain an understanding of safety, nutrition, general care, and legal and financial issues. Since each session is just one hour, the presentations can accommodate even the busiest schedules.

Our modular program design lets participants choose any presentation, in any order, and pay a nominal fee for only those they attend. No matter which presentations are selected, participants enhance skills, reduce stress and build confidence.

Topics include:

- Home Safety
- General Caregiving Skills
- Positioning and Helping Your Loved One Move
- Assisting with Personal Care
- Healthy Eating
- Caring for the Caregiver
- Legal and Financial Issues
- Alzheimer's disease or Dementia

- HIV/AIDS

In 2005 the American Red Cross delivered 18,000 Family Caregiving modules. The program may be delivered by any American Red Cross Chapter, by Authorized Providers, or by any senior serving organization or community based organization.

The Family Caregiving program is currently being expanded to reach more caregivers by developing new ways to reach out to them such as:

- New products: Our new Family Caregiving Reference Guide to be released later In 2006 – a skills reference book with a DVD that will be distributed in retail outlets in addition to the American Red Cross Chapters.
- Online programs to help train caregivers.

Nurse Assistant Training Program

American Red Cross had 12,000 nurse assistants enrolled in the Nurse Assistant Training program in 2005. The program meets all federal requirements and complies with state regulations for training nurse assistants. Additionally, it provides the participant with the knowledge and skills needed to appropriately care for individuals in the extended care setting as a nurse assistant.

The purpose of the program is to provide information and skills enabling nurse assistants to provide quality care for residents in nursing homes, as well as supplemental information and skills that will enable them to provide quality health care for clients at home.

Together We Prepare For Seniors

Together We Prepare is a program that includes presentations and materials provided by chapters to help seniors take key steps toward preparing for natural disasters and man-made emergencies. These steps include 1. Make a plan; 2. Build a kit; 3. Get trained; 4. Volunteer; and 5. Give Blood. For seniors, making a plan and building a kit are two key actions to prepare for all hazards.

Additionally, the Red Cross developed a targeted resource for seniors entitled the "Disaster Preparedness for Seniors by Seniors Guide." Chapters often combine the Together We Prepare program with the Family Care Giving Program to provide basic preparedness information as well as skills for caregiving for seniors.

Other Senior Serving Programs:

Local American Red Cross chapters throughout the US offer a wide variety of services to seniors in their own communities such as:

- Lifeline – Lifeline® is a personal response and support services system for seniors and the physically challenged. It promotes independence, peace of mind and early intervention to those in need and for loved ones. This Personal Emergency Response Service (PERS) is available 24-hours-a-day, 365-days-a-year.
- Transportation – Volunteers, many of which are seniors themselves, transport other seniors in need to medical appointments and other important trips.
- Shoppers Programs – volunteers helping those who are shut in by going to the store for them.
- Community Feeding Support and Meals on Wheels
- Friendly Visitor and Tele-Care programs – Volunteers who call each morning or pay a visit regularly to home bound, elderly and disabled seniors.
- Adult Day Care

Challenges and Growth Opportunities for Family Caregiving Program

Although 18,000 Family Caregiving presentations have been done in 2005, the American Red Cross has encountered challenges in implementing our Family Caregiving program. Some of the challenges include:

- Caregivers do not attend chapter delivered training.
- Initial low turnout
- Sizeable initial resource requirements
- Lack of grant funding to support initiatives
- Caregiver issues
    - Self-identification by Caregivers
    - Time constraints

Overview of Challenges

In general we have found that there is a reluctant market for Family Caregiving Skills. Caregivers do not self-identify, and do not have time to learn the skills of caregiving. Yet the "work" of training Family Caregivers is likely to become an important concern in the near future because 78% of long term care is done by the family caregiver. There are roles the Federal government can play to address these challenges, and that will help to create an environment that expands family caregiving. Families providing a greater percentage of the care their loved ones need offers a humane solution to the long term care issue and goes a long way to helping solve the nation's long term care problems. But families cannot do it alone.

I encourage this Committee to consider three critical issues: first, a lack of awareness in communities across the country; second, the strains faced by caregivers with both limited resources and time; and third, the tremendous hardships of caregiving. We offer three promising steps that will lead to an environment where family caregiving can grow:

1. **Awareness**: Large scale health communications programs to raise awareness of rewards of caregiving and to encourage people to self-identify so they can get the help they need. Members of Congress can help promote caregiving programs in their local communities, and I encourage each of you to do so.
2. **Resources and Time**: Congress could consider public policy that encourages insurance companies and Medicare and Medicaid to help pay for family caregiving education for individuals, as well as requiring the healthcare industry to provide the training. Studies show that people prefer to get health information from their own doctors. Doctors and hospitals should prescribe caregiver education, however many health care providers will not recommend education unless it is covered by insurance. Diabetes education is reimbursed; as is childbirth education. It is time that we reimburse for caregiving education as well. Caregivers are an important component of the patient care team, and we ought to help insure that programs are available to meet the growing demand for caregivers in the United States.
3. **Lessening the Hardships of Caregiving:** Continuing to provide for growth of all manner of nationally supported services and programs for Caregivers such as the National Family Caregiver Support Program, FMLA and so many others. Congress should also consider economic support to families, be it through tax credits or allowing unreimburseable education costs to be deducted on federal taxes.

Mr. Chairman, Congressman Brown, I thank you again for the opportunity to be here before you today. On behalf of the entire Red Cross, I thank you for your leadership in addressing this difficult issue, and I can assure you that the American Red Cross stands ready to support any efforts to promote and expand family caregiving services and support. At this time, I am happy to answer any questions you may have.

MR. DEAL. Thank you. Dr. Wright, you are recognized.

DR. WRIGHT. Mr. Chairman. I would like to thank you, Mr. Chairman, and other members of the committee for convening this hearing, and for the opportunity to address you on this important issue. My name is Dr. Larry Wright. I am a medical doctor and a geriatrician. I have been in community-based geriatric medical practice for about 26 years, and the last 7 years, I have been the Director of a Regional Center on Aging affiliated with the Reynolds Institute on Aging, and the University of Arkansas for Medical Sciences. I am also the Medical Director of a community-based hospital senior health system in northwest Arkansas with the Northwest Health System.

My testimony today is based on my many years of medical practice in geriatrics, and working with older adults and with their families around caregiving issues, and my last 7 years as the director of a nonprofit education program that has been dedicated to developing an outstanding curriculum for training home caregivers. And we have now trained, at last count, over 500 caregivers to give the kind of care that I am going to describe in my testimony.

We believe that professionally trained in-home caregivers are a key to keeping older adults at home for life, and helping resolve America's long-term care crisis. To create an open environment in which a new generation of well-trained in-home caregivers can flourish and help older adults stay at home for life will require the removal of regulatory restrictions, the development of a delivery system that matches caregivers to those who need them, and a system for training professional caregivers that is linked to a certification process that assures qualified in-home caregivers.

I would like to clarify that the in-home caregivers I am referring to in my all remarks are the workers who give basic care to older adults in order to stay in their home. We are really not talking about healthcare and medical care in this regard. We are talking about those, much like family caregivers, but these hired caregivers who can give all sorts of assistance, including hands-on assistance for people who don't so much have skilled nursing needs at all, but have dependency in some activities of daily living, and therefore, need assistance with these basic needs. This is not really medical care, but what is often treated in the regulations as if it is.

Variously, these workers are termed direct care workers, care professionals, and personal care workers. Demographics demand a shift from institution-centered long-term care to a new, home-centered system. We need both, an improved Medicare/Medicaid funded system of long-term care for the most chronically ill, frail, and low-income seniors, and we need a new alternative, a new home-centered system of long-term

elder care for seniors, both those of low-income, and those who can pay privately.

Keeping more older adults at home is the only way, we believe, we can afford to care for twice as many elders living decades longer, with more chronic diseases. It may be America's best solution to the long-term care problem, if we do three things. Number one, we must improve the quality and availability of in-home caregiving by developing professionally trained and certified home caregivers, including family members, and a new corps of volunteer caregivers, as well as these hired direct care workers that I have referred to. Currently, there are no training requirements for independently contracted workers that do in-home paid caregiving. We must develop and implement national standards for the education and training of in-home paid caregivers, including a national certification organization, and tie payment to successful training.

Number two, we also need to review Federal and all State home health regulations, and deregulate the in-home caregiving. Again, caregiving, or personal care, as I am referring to, has been made in the regulations too often synonymous with home health, and has been tied to, therefore, the need for skilled nursing, and the resulting regulations represent a barrier to delivery of personal in-home caregiving to most Americans, whether they qualify for Medicaid or they are private pay, by any organization other than a home health agency. Caregiving is not healthcare, and should not be regulated like home health.

And number three, we should develop a comprehensive public/private delivery system of personal in-home caregiving that applies all available resources, family, volunteer, private, and public sectors, to integrated, home-centered, long-term care delivery.

In April, we at the Schmieding Center announced a partnership between the Schmieding Center for Senior Health Education and the International Longevity Center in New York, that organization, headed by Dr. Robert Butler, widely regarded as the father of geriatric medicine in this country, and the first Director of the National Institute on Aging. In this partnership, we are launching a project, a national project, for caregiving, in-home caregiving, and this project will intend to include national research and consensus-building among caregiving stakeholders, including organizations such as the National Alliance for Caregivers, headed by Gail Hunt, and other national caregiver organizations, as well as those involved in policy and academics interested in the subject of caregiving; and along with them, come to a consensus about this issue. Improving public awareness also, and developing a national model caregiver curriculum for in-home caregiving, along with pointing to the

development of a caregiving delivery model that can be replicated across America.

So, we will continue to work toward these important goals, and Mr. Chairman, I want to thank you for the opportunity to present our vision of an achievable approach to home-centered long-term care.

Thank you.

[The prepared statement of Dr. Larry Wright follows:]

PREPARED STATEMENT OF DR. LARRY WRIGHT, DIRECTOR, SCHMIEDING CENTER FOR SENIOR HEALTH AND EDUCATION

Improve and Refine Current Long-Term Care System

We all agree we must continue to improve and refine the Medicare/Medicaid-based long-term care system we have in place. Many improvements still remain to be made that will be beneficial to older adults, particularly those older adults burdened with the kind of serious chronic conditions that truly require skilled nursing home care and, most particularly, those without the ability to pay.

But we can never "improve" or expand nursing homes enough to make them the preferred choice for most older Americans. Even if we could make nursing homes desirable enough, we can't build enough new facilities to care for *double* or *triple* the number of seniors who will need long-term care over the next 20-30 years.

Develop a Home-Based Long-term Care Alternative

Baby Boomers increasingly demand that we *change* our system of long-term eldercare from an **institution-centered** method of long-term eldercare to a new **home-centered** system. We will need both:

1. An improved Medicare/Medicaid system of long-term care system for the most chronically-ill, low-income seniors
2. *and* a new alternative, a new home-centered system of long-term eldercare for all Baby Boomers—both those of low-income and those who will be private pay.

The demographics before us demand an alternative long-term care system that helps keep most elders at "home." Staying at home is what most elders and their families want. Keeping them at home is the only way we can afford to care for twice as many elders living decades longer than ever before. And it *can* be done—it may be America's best solution to the Age Boom of long-lived elders—if we do three things:

1. **Review federal (and all state) home health regulations and de-regulate in-home caregiving; i.e., remove Personal Caregiving from home health regulations.**
2. **Improve the quality and availability of in-home caregiving by developing professionally-trained and certified home caregivers, family members, and a new corps of volunteer caregivers**.
3. **Develop a comprehensive public/private delivery system of personal in-home caregiving that applies all available resources—family, volunteer, private and public—to integrated long-term care delivery.**

Separate Caregiving (Personal Care) from Home Health (Skilled Nursing)

I am *not* suggesting that we *change* home health regulations. Simply remove in-home caregiving (personal care) from the home health regulations—except when in-home care is prescribed by a physician as a medical necessity (skilled nursing). Right

now the home health regulations are unintentionally blocking access to in-home caregivers trained and provided through any reputable agency. How can that be? Current regulations do not differentiate between skilled nursing and personal caregiving under Medicare/Medicaid Home Health regulations--*even when the older adult does not need, qualify for, or receive Medicaid benefits.*

Because we have intermingled in-home personal **Caregiving** with **Home Healthcare (skilled nursing**) nearly all Americans, including the **70** percent of older adults who do *not* qualify for Medicaid benefits, are *excluded* from access to trained home caregivers from any reputable agency even when they are private pay.

Just remove in-home PERSONAL caregiving from Home Health regulations—except when prescribed by a physician. Removing the regulatory barriers to in-home caregiving may be the single most important action you can take
to provide better access to better caregivers for most Americans, including the 70% who pay for their own homecare. With this barrier removed, we ***can*** keep more elders at home for life, at lower costs, with more competition to provide professional in-home caregiving through professional caregiving agencies—both private and non-profit—and alleviate a colossal need.

Create A New Group of Professionally-Trained In-home Caregivers

There is an urgent need for the professional training of family, volunteer, and in-home paid caregivers, usually independent contractors, as well as the need for geriatric management services for families who are overseeing the care of a loved one in the home.

A large, new cadre of independent contract, in-home direct care providers is required to meet this growing need**.** However, almost none of these care providers have received professional training on how to care for an older adult in the home. Elders are thus very vulnerable to improper care and the family has no way to judge the competence of caregivers in the home setting.

Therefore, there is an urgent need for creating the standards and structure for support of a professionally-trained community of paid in-home caregivers who provide personal care and other non-medical services to older adults in the home and who understand the behavioral problems that may be present when caring for an older adults with a dementing or other chronic disease.

There are many barriers to the professional in-home caregiving many families need:

- **Currently, there are no caregiver training requirements for independent contractors working as in-home paid caregivers.** There are no standards for training and no structure in place today to support independent contractors working as in-home paid caregivers. There is no well-organized national organization or association that supports this evolving cadre of direct care providers to help establish caregiving as a career.
- **There *are* caregiver training requirements set by Medicare/Medicaid regulations for personal care and home health aides working for home health agencies.** However, only elders who require skilled nursing care can qualify for personal care provided by a home health agency. Such personal care must be prescribed by a physician and is available on a limited basis--not 24/7 for extended periods of time--as some families need. This is *not* long-term care. Families cannot simply request personal care services provided by a home health agency.
- **Nearly all families must contract privately with individual caregivers--and they must find them on their own. Most of the caregivers they find are untrained**. Families sometimes receive lists of potential in-home caregivers from hospitals or health care agencies. Sometimes they learn about potential caregivers by referral or through advertising. Many of the caregivers found

through these means have a heart-to-serve, but they have no formal training and limited knowledge about caring for older adults in the home.

- **In-home caregiving is not considered a career path**. Caregiving is generally viewed as minimum wage work. Currently there is no way for them to receive benefits, be bonded, receive further training and continuing education, etc. They are typically among the medically uninsured, a real problem in our health care system today.
- **As an independent contractor, the case load for an in-home caregiver varies and may not provide regular work;** therefore, many in-home caregivers leave the field and seek other employment that is often more stable, better-paid, and may even include benefits. This environment results in families often finding it very difficult to find and keep in-home paid caregivers when needed.
- **For-profit companies do exist that provide non-medical caregiving to older adults in the home, but few such companies exist that also can and do provide the physical and behavioral care that is often needed to care for older adults with dementia or other chronic, debilitating conditions**. Many of the private companies require little or no training for the caregivers they hire. When physical care is needed, most states have outdated regulations prohibiting any organization except a home health agency from providing that care. But if the older adult doesn't require skilled nursing care, they can't get the caregiving help they need to stay at home from *any* organization.

We must break with the past and find new ways to create a community of professionally-trained home caregivers--a community with the shared standards and structure needed to grow a large cadre of competent, compassionate, professionally-trained in-home caregivers. We suggest that we

- **Develop and implement national standards for the education and training of in-home paid caregivers.**
- **Create a national organization/association for the new generation of professionally-trained in-home caregivers, most of whom are independent contractors.** The organization will oversee the accreditation process of curricula used to train this cadre of caregivers, the certification/licensing process, the continuing education requirements to maintain certification, provide opportunities for group rates on medical and dental insurance, bonding, etc. Family members needing in-home paid caregivers will then be assured that a caregiver certified by the organization has been professionally-trained in home caregiving skills, tested for competency, and is continuing to add new caregiving knowledge.
- **Establish new in-home caregiving quality standards so that all third party payers, including CMS, require that all in-home caregivers must be members in good standing in the national professional home caregiver certification organization to qualify for reimbursement.** All agencies or companies providing in-home caregiver services for a fee to families must meet the same membership, training, continuing education, and quality standards for their employees.
- **Allow, encourage, and incentivize a new type of in-home caregiver staffing agency to provide families with caregivers who are professionally-trained in the physical care and non-medical care of an older adult and who understand the behavioral issues that might arise.** Keeping the cost of caregivers placed through these agencies at an affordable level, while paying the caregivers a reasonable wage and benefits, would provide professional

caregivers with career stability and provide families that need paid caregiving for a loved one with a reliable source for trained caregivers.

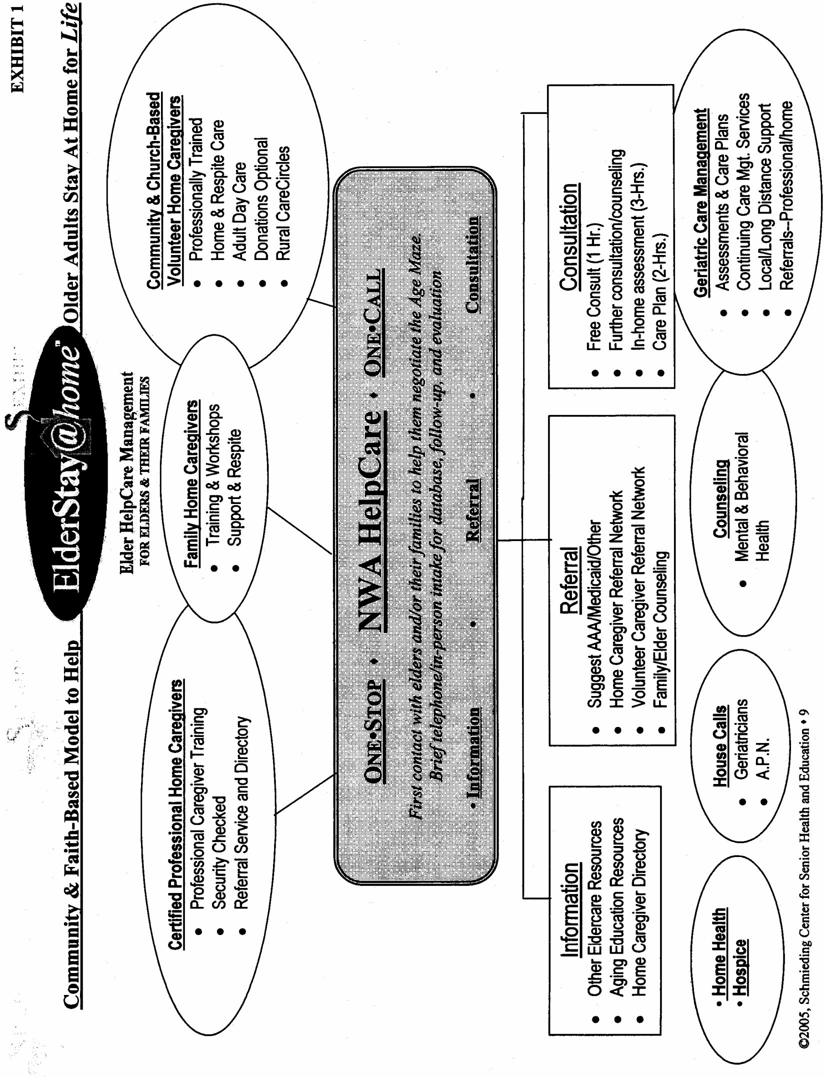
Again, all in-home caregiving recommendations depend on the removal of federal and state regulatory roadblocks to professional in-home caregiving and geriatric care management. In-home caregiving must be re-defined to separate it from "home health" care (skilled nursing) and its restrictions. Caregiving is *not* "health care" and should not be regulated as is medical care.

Develop a Comprehensive Public/Private Delivery System for Home-based Long-term Care.

With regulatory barriers removed and with a program for providing professionally-trained and certified home caregivers (including family, volunteer, and paid) is operational, there will still be a major issue of connecting older adults and their families with the resources they need to stay at home for life.

A model has been developed for a comprehensive, integrative delivery system combining public and private resources. It provides one-stop, one-call access to a community-based system of eldercare that provides information, referrals, and consultation to older adults and their families. The tool kit can be adapted as a private business, a non-profit service, a community-based service, a faith-based initiative and more.

It requires only the freedom from regulation so that the needed services can be delivered. There is great interest in pursuing this model at the community level and I believe this is the direction elder caregiving will develop over the next decade. It is flexible, fundable, affordable, and compassionate. (See Exhibit 1: "Community & Faith-based Model to Help Older Adults Stay at Home For Life")



MR. DEAL. Thank you. Ms. Inagi.

MS. INAGI. Thank you. Good afternoon, Chairman Deal, Mr. Pallone, and Mr. Allen. My name is Candace Inagi. I am Assistant to the President for Community Relations for SEIU 775, based in Washington State.

We have about 28,000 caregivers who are family caregivers, agency caregivers, and nursing home workers. SEIU represents 1.8 million workers nationally, and is the Nation's largest healthcare union. 775, which is, again, based in Washington State, includes many family

caregivers who are caring for Medicaid beneficiaries participating in the State's program of consumer-directed care.

We face a national shortage of direct care workers. At least 35 States currently report serious shortages of caregivers, and for individuals with chronic needs, often the biggest barrier is finding an available home care worker. It would be a mistake to think that the shortage of long-term care workers is a temporary phenomenon, a function of the current business cycle. It is important to see the labor shortage for what it really is, a rational response of people to a labor market that often pays lousy wages and has no benefits. The national average for a direct care worker is only $8.18, but average annual income for homecare workers range from $7,000 to $12,000 per year, since few can find full-time work.

We can expect the current shortage to get worse. The traditional long-term care worker, women between the ages of 25 and 45, have more economic alternatives these day. BLS estimates that we will need an estimated 5 million additional care workers to fill current vacancies, and meet the demand for additional services.

So, who will care for those with long-term care needs? We must support informal caregivers, and make it easier for friends and family to help with household activities, transportation, and chores that make it possible for those with disabilities to stay out of institutions. Homecare and other kinds of non-medical assistance often require more patience, strength, and sensitivity than technical skill. Because long-term care is often the most intimate of hands-on care, many people are more comfortable having, and actually prefer having, family members provide those services.

But informal caregiving is not the silver bullet to the workforce shortage. Trends like smaller families and greater economic mobility among families impact the supply of informal care.

We cannot meet the demand for long-term care solely through informal care. Our dysfunctional healthcare system already puts too much responsibility for long-term care services on the family. Medicaid and Medicare are enormously successful at helping low-income and disabled individuals access healthcare, but neither program is designed to address the long-term care needs of millions of middle class Americans. Medicare provides health insurance for seniors, as you know, and the disabled, but benefits are time limited, and the program excludes social supports. Medicaid addresses the long-term care needs of low-income Americans, but the income eligibility requirements make it a program of last resort. Many States have used Federal waivers to create home and community-based services that substantially improve the spectrum of long-term care choices available, but in most States, the program has yet

to shake the institutional bias completely. Washington State has done a very good job of rebalancing, so that we offer more home and community-based services in place of nursing homes, but many States do not have those choices.

Unpaid or informal care complements paid or formal care, since most consumers receive a mix of both over time. Paid care is an important source of respite for family members. Paid care can also supplement the efforts of family members during work hours. Paid care can substitute for unpaid care when individuals with multiple disabilities are physically and emotionally too much for family members to handle, or when family members simply burn out.

I would like to shift gears for a moment and mention the effort by several States to address the workforce shortage through the creation of Medicaid consumer-directed care. This arrangement, in which individual beneficiaries are allowed to select, manage, and if necessary, dismiss workers, offers beneficiaries greater autonomy and more choice. Beneficiaries that take advantage of consumer-directed care often have greater consumer satisfaction, because they get the type of care they want when they want it, and no longer are they stuck in bed waiting until an agency can provide assistance.

So consumer-directed programs can be problematic, too, however. Because the Medicaid beneficiary is the employer, not the State that actually pays for services, workers are in a very difficult position. They are unable to increase their wages or benefits, because their employer is indigent and lacks the resources to make caregiving a sustainable job.

SEIU has worked with Governors and policymakers in States like Washington to develop a solution that allows for an expansion of consumer-directed care. We have created a public agency--it is often called a public authority, or a home care commission--that can serve as a co-employer for the purposes of determining wages and benefits. Consumers retain the right to hire, fire, train, and supervise the care provider, and the care is provided when, and in the manner determined by the beneficiary. But workers have a co-employer, the State, with the resources to provide an adequate wage and health insurance. SEIU, representing the workers, is then able to negotiate with States, acting as the co-employer, for adequate wages and decent healthcare coverage. In California, Oregon, and Washington, the result has been a significant expansion of the labor market for direct care workers.

And I want to say that really, when we are talking about training and improving the workforce and meeting the needs that we have before us, with Baby Boomers entering the system, we have to look at wages and benefits and training as a means to stabilize and professionalize the workforce.

On the note of training, in Washington State, we have problems with accessibility. We are currently working with the State to make sure that there is a program of training that allows for portability of certification, so that you can take that training certificate across various parts of the long-term care continuum. We are working with the State to make sure that there are mentorship and apprenticeship programs.

But I think that I will close with the idea that in Washington State, and this sort of puts an exclamation point on the issue for the importance of training standards across the States, is that a hairdresser is required by the State to have 1,000 hours of training, a manicurist, something over 600 hours, and a caregiver, just 32 hours. So, on behalf of SEIU, I leave you with that thought.

We appreciate the opportunity to express the concerns of caregivers struggling to improve the care and quality of life for their clients.

[The prepared statement of Candace Inagi follows:]

PREPARED STATEMENT OF CANDACE INAGI, ASSISTANT TO THE PRESIDENT FOR GOVERNMENT AND COMMUNITY RELATIONS, SERVICES EMPLOYEES INTERNATIONAL UNION LOCAL 775

Good morning Chairman Deal, Ranking Member Brown and other Members of the House Energy and Commerce Subcommittee on Health. My name is Candace Inagi. I am Assistant to the President for Government and Community Relations for Local 775 of the Service Employees International Union. SEIU represents 1.8 million workers nationally and is the nation's largest health care union.

Local 775, based in Washington State, represents 28,000 home care and nursing home workers, including many family caregivers who are caring for Medicaid beneficiaries participating in the state's program of consumer-directed care.

We face a national shortage of direct care workers; at least 35 states currently report serious shortages of caregivers. For individuals with chronic care needs, often the biggest barrier is finding an available home care worker.

It would be a mistake to think the shortage of long term care workers is a temporary phenomenon — a function of the current business cycle. It is important to see the labor shortage for what it really is: a rational response of people to a labor market that often pays lousy wages and no benefits. The national average wage for a direct care worker is $8.18, but average annual income for home care workers ranges from $7,000 to $12,000 per year since few can find full-time work.

We can expect the current shortage to get worse. The traditional long term care worker — women between the ages of 25 and 45 — have more economic alternatives. BLS estimates that we will need an estimated 5 million additional direct care workers to fill current vacancies and meet the demand for additional services.

Who will care for those with long term care needs? We must support informal caregivers and make it easier for friends and family to help with household activities, transportation and other chores that make it possible for those with disabilities to stay out of institutions. Home care and other kinds of non-medical assistance often require more patience, strength and sensitivity than technical skill. Because long term care is often the most intimate of hands-on care, many people are more comfortable having family members provide those services.

But informal caregiving is not the silver bullet to the workforce shortage. Trends like smaller families and greater economic mobility among families impact the supply of informal care.

We cannot meet the demand for long term care solely through informal care. Our dysfunctional health care system already puts too much responsibility for long term care services on the family. Medicaid and Medicare are enormously successful at helping low-income and disabled individuals access health care but neither program is designed to address the long term care needs of millions of middle-class Americans. Medicare provides health insurance for seniors and the disabled but benefits are time-limited and the program excludes social supports. Medicaid addresses the long term care needs of low-income Americans, but the income eligibility requirements make it a program of last resort. Many states have used federal waivers to create home and community based programs that substantially improve the spectrum of long term care choices available, but in most states, the program has yet to shake the institutional bias completely.

Unpaid or "informal" care complements paid or "formal" care since most consumers receive a mix of both over time. Paid care is an important source of respite for family members; paid care can also supplement the efforts of family members during work hours. Paid care can substitute for unpaid care when individuals with multiple disabilities are physically and emotionally too much for family members to handle or when families burn-out.

I would like to shift gears for a moment and mention the effort by several states to address the workforce shortage through the creation of Medicaid consumer-directed care. This arrangement, in which individual beneficiaries are allowed to select, manage and if necessary dismiss workers, offers beneficiaries greater autonomy and more choice. Beneficiaries that take advantage of consumer-directed care often have greater consumer satisfaction because they get the type of care they want, when they want it. No longer are they stuck in bed until an agency decides to provide assistance.

Consumer-directed programs can be problematic too. Because the Medicaid beneficiary is the employer — not the state that actually pays for services — workers are in an impossible position, unable to increase wages or improve benefits because their "employer" is indigent and lacks the resources to make caregiving a sustainable job.

SEIU has worked with governors and policymakers in states like Washington to develop a solution that allows for expansion of consumer-directed care: creating a public agency (often called a public authority or a home care commission) that can serve as a co-employer for the purposes of determining wages and benefits. Consumers retain the right to hire, train, and terminate a personal care provider. Care is provided when and in the manner determined by the beneficiary. But workers have a co-employer -- the state -- with resources to provide an adequate wage and health insurance. SEIU, representing the workers, is able to negotiate with the state acting as the co-employer for adequate wages and decent health care coverage. In California, Oregon, and Washington, the result has been a significant expansion of the labor market for direct care workers.

On behalf of SEIU, we appreciate this opportunity to express the concerns of caregivers struggling to improve the care and the quality of life for their disabled clients.

MR. DEAL. Well, thank you all. I will get started.

For the last about 8 and a half years, my wife and I have been caregivers to our parents. I am probably the only one on this panel who had the pleasure and opportunity last night to put my mother to bed, to take off her prosthesis, to put her teeth in the right container and her hearing aid in the right place, pull the covers up, and kiss her goodnight.

I would have repeated that process this morning, had I not gotten up, left at 5:30 to catch an airplane, so I could be here with you. Eight and a half years of caregiving takes its toll. But, since my mother will be 100 years old in six months, I feel like that is the least that I could do for her. My wife's father, who also lives in the same house with us, will be 93 in about less than 2 months.

So, I know firsthand from whence I speak. Caregiving is a difficult job. It is even more difficult to find someone who can assist a family in doing that job. Dr. Wright, I am very intrigued with your testimony from the standpoint of the project that you are working on for a model. One of the most difficult things that we have encountered is finding people who can come into our home and do the day-to-day 9:00 to 5:00. I have a joke saying that my wife and I work the nightshift at the nursing home, because everything in our life revolves around being there at 5:00, because that is when the people that we have been able to hire go home, and on weekends, it is up to us.

It is very difficult to find people who will work, and we can't get that national average of $8. Ours is in the $10 range, plus we don't provide benefits, obviously, but just finding somebody who is available. The irony of it is that of the three ladies that we have had work for us in the last year, two of them have themselves been Medicare eligible. They are over 65, and it is very difficult to find anybody at any age who is willing to do this.

Now, I am intrigued also by your statement that we need to get regulations out of the way, and I am totally in agreement that what we are talking about, in most of these in-home situations, is not medical care. It is not medical care in the context of what we think of as home healthcare, either. How do we go about that, and what regulations are there, and whose regulations are they that we need to deal with?

DR. WRIGHT. Well, I think it is primarily Federal regulations about the home healthcare agencies, and that it basically, in most jurisdictions in this country, most States for certain, there has been no effort to get around this. It results in the fact that any agency that is not a certified home health agency under Medicare, they may be a home care agency, or they may a Center on Aging, like us. We cannot send our trained caregivers into the home to do anything but just helper, chore sort of things. In fact, for most, the specific limitation is characterized by the admonition that you cannot touch the individual. So, we are talking about people who, even when they have been through our training, 100 hours by the way, if they are not working for a home health agency, if they are working for anybody but themselves, if that individual they are working for falls on the floor, they are not allowed to pick them up.

Now, you know, honestly, you know, if the family, this individual, if you are contracting with an individual contractor, of course, they can do anything, but then, if that is the way much of the care is being delivered, this kind of care is being delivered, there is no way to get, you know, we do need this regulation, that is, we need standards to certify these people, which in itself could incentivize people to come in, but right now, even these organizations who, by the way, then kind of double what it costs to the family, the organizations that might hire these individuals, and provide service to the family, or providing replacement if someone is sick, and bond them, and that kind of thing, typically, they will charge $18 an hour. So, you haven't really helped the worker or the family very much by doing that, but again, under those regulations, those organizations can't let their workers actually touch the patient and do anything.

And they presumably claim to give some training, but in most cases, what we have found is they hire these people. They give them a book, say if you can't find an answer in the book, call the nurse who is on call for you, and they will try to help out, and so, we are neither giving quality nor are we giving access, and yet, a major, major part of the kind of care is just what your family needed, and it usually happens in a trigger event, like a hospitalization, where at the end of that hospitalization, the doctor says either you will have to be able to provide this care at home, or she is going to have to go to a nursing home. And then, the social worker comes in, and says well, we have got a short list of people that have done this kind of work in the past, and we will see if we can get them in the next 24 hours. And the family, under that scenario, is happy just to have a warm body that will show up. They don't ask about training, and unless it just happens coincidentally, that would be someone who is a retired nurse, or used to be a CNA in a nursing home, they won't get any training. And if someone has done this work long enough, they think they are trained, even if they are doing all the wrong things.

So, to create this workforce, going forward for the long-term care needs in home that we have, we have got to set some standards, and in doing so, we also could develop a national organization that might actually create some benefits for these workers as well.

MR. DEAL. My time has expired, even though my questions have not. Mr. Pallone, you are next.

MR. PALLONE. Thank you, Mr. Chairman. I wanted to ask Ms. Inagi. Inagi?

MS. INAGI. Yes.

MR. PALLONE. Okay. But again, I guess if anybody else wants to comment, please feel free.

First of all, today, we heard about a number of problems with direct care workers: low wages, lack of benefits, coupled with demanding work that is not always dependable, leads to high turnover. Basically, I just wanted you to tell me what is the effect of such a high turnover rate on the quality of care received by beneficiaries, and then, what recommendations do you have to increase worker retention in these areas, and reduce the high turnover rate?

MS. INAGI. Well, I spoke a little bit to this issue earlier. High turnover rates have every impact on quality care. If you think about Chairman Deal and his situation, or my own situation, with my sister in providing her care, if I can't rely on the person who I have hired to come in, and come in consistently, that is a strain on not only the family, but the client, who needs that stress the least in their lives.

I think that when you are talking about improving turnover, it comes back to the issue of what are we doing to improve the workforce as a whole, with regard to wages and benefits and access to training and mobility within the training program, so that people aren't coming into a job where, perhaps, they are making a little bit more than they can make at a hamburger stand, or maybe making a little bit more, but they are coming into an opportunity to be trained and move up through, perhaps coming from a caregiver to a certified nursing assistant, and then onward, and taking their training through the continuum of care in other services.

MR. PALLONE. I had--I wanted--did you want to say something? No. Okay. I just wanted to mention two possible, you know, programs or changes that, you know, might be of benefit, so if I could.

One is from my district. In my district, there is the Visiting Nurse's Association of Central Jersey, the VNA as it is called, recently implemented a Tele-Health program that nurses can use to monitor patients, and this helps reduce the demand on the VNA to provide care, and keeps the patients actively involved in their care.

Would any of you know about a similar model being adopted, and the pros and cons of such a model? I mean, the idea, from what I understand, is that the patient gets a computer, and they basically can interact with their caregiver, and it is like a videoconference, essentially.

MR. CONNER. The one program that we have at the Red Cross, we are affiliated with Lifeline.

MR. PALLONE. Yeah, I wanted to mention, you talked in the beginning about your babysitting course, and my eldest daughter took that course, and now she goes around and, well, she was 11 at the time getting babysitting jobs, because she is certified by you guys.

MR. CONNER. She should be able to command a higher wage, too, with that. That is a real plus.

MR. PALLONE. At any rate--

MR. CONNER. And Chairman Deal, you are exactly the kind of person, you and your wife, that we would encourage to take our family caregiving program. It is excellent, and teaches you all the skills you need. One program that we are very involved in, and very proud of, is with an organization called Lifeline, and it is somewhat similar to what you are talking about. You may have seen these services where you wear around your neck, or around your wrist, a button, and it is connected to a call center, this one happens to be in Massachusetts, and it is a fantastic system. If you fall, or something happens, you hit that button, you are immediately connected. They have, in their computer, all the neighbors. They have all the family members, et cetera. They can access 911 for you, so it is not exactly the visiting nurses, but it is one way to be very connected, and we really like that program.

DR. WRIGHT. I think these programs are being developed pretty quickly. I hear every time I go to a professional meeting, I hear of a few others, and they are particularly addressed at those healthcare needs of specific types of, especially monitoring diabetes, or monitoring certain diseases. At this point in development, it doesn't address the basic caregiving that we are talking about, but in terms of monitoring the health status of, I think, they are very promising programs.

MR. PALLONE. I was just going to ask Ms. Inagi again, the Washington State, there is this, in your home State, there is this Washington State public authority with caregiver workers. They have developed, under the State Medicaid program, an innovative partnership with caregivers for the consumer-directed care, under Medicaid, that has this public authority that acts as a co-employer with the beneficiary and helps them manage. Could you just talk about that a little bit? I know I am out of time, but maybe just quickly.

MS. INAGI. Thank you for that question. The public authority acts as a co-employer, so that caregivers across the State have the ability to negotiate for higher wages and benefits, and other training standards, and other standards in caregiving, like training. It gives the opportunity for consumers themselves to have a voice at the table. It has served to improve the standards of care, by making sure that caregivers go through background checks, that certain standards are met, that it has served to improve the quality of care for consumers by developing a referral system that previously did not exist, and is intended to be online and statewide.

And I think that the most important contribution that we have been able to see through this development is the beginning of this professionalized caregiver workforce. Again, caregivers started off at just about $8.62 an hour, just a few years ago, with absolutely no benefits

whatsoever, no vacation time, no sick time, so if they were sick themselves, they had to go to work anyway, and put the client at risk. And now, through the public authority, workers have been able to, in the service of improving care for their clients, negotiate for wages and benefits. They now have healthcare. They even have dental and vision, and are working towards better standards and training as we speak.

MR. PALLONE. Thank you.

MR. DEAL. Mr. Allen, you are recognized for questions.

MR. ALLEN. Thank you, Mr. Chairman.

This doesn't want to come over toward me. You have trained it, Frank.

Thank you all for being here today. I just wanted to make a couple of comments, and then ask a question. I think that you people may have covered this before, but when you look at people, I think, too many people think Medicare is going to take care of their long-term care, but in this country, that is clearly not true. About half of the revenues from nursing homes comes from Medicaid, and then about a quarter was paid out of pocket, 12 percent only by Medicare, and only about 10 percent was covered by private insurance. So, I think the issues, the broad issues that we are trying to figure out here are where the burden of long-term care and planning should fall, and whether Medicaid, which was designed to be a long-term safety net for the poor, should really assume so much of the cost.

We have a new House Long-Term Care Caucus dedicated to working in this area, and that is going to be chaired by Representative Shelley Moore Capito, Earl Pomeroy, Nancy Johnson, and me. And we are going to be working in this area as much as we can to try to develop some ideas. I appreciate all that you have been, that you said today. I thought, Ms. Inagi, I would like a couple of questions.

My experience goes back to my father, who spent the last 2 years of his life, or most of the last 2 years of his life, were in a nursing home, so it wasn't a care at home situation that you have been talking about in Washington, but it was a nursing home, and I was struck by the staffing issues they had. They wound up, for reasons I am not quite sure, basically hiring people from agencies, to whom they had to pay a great deal of money, or at least they had to pay a great deal of money to the agency. Those workers were better paid than they could afford to pay their own ongoing staff.

And I don't know, it seems to me you have talked at some length about this whole issue of improving wages and benefits for the staff in nursing homes, and I think you have dealt with this before, but the biggest barriers, one of them is funding. Do you have any suggestions, Ms. Inagi, or anyone else, for how to structure the funding, so that

ordinary staff for the nursing homes actually get compensated at a level at which the nursing homes can keep them?

MS. INAGI. Thank you for asking that question. We are doing a lot of work this year, and hopefully in the years to come, with good, responsible nursing home owners who are grappling with just those questions. Some private pay nursing homes can afford to pay their workers better wages and better benefits, just because of the fact that they are better resourced, while the nursing homes who provide the lion's share of Medicaid services really can't afford those same wages and benefits, and at the same time, they are struggling with buildings that are in disrepair, or that need improvement and modernization.

Funding is the key. We are working in the States to improve funding, and make the case in our State that we need to look at our vendor rates, and think more smartly about how we do our Medicaid reimbursement systems. Those are all incredibly challenging situations that we are involved with, and I would love to continue to work with your caucus, the Long-Term Care Caucus, as we delve through some of these very issues. We are working very closely with the Governor, as well as, as we like to call them, the techies at the different nursing homes, to try and grapple with those questions.

MR. ALLEN. If I could just add this. Part of this is a State problem. Part of this is a Federal problem, but at both the State and Federal level, the same thing is happening. As Medicaid costs go up at a rapid rate, and the feeling is we can't deal with them, we here in the Congress are considering ways to cut providers, to cut the reimbursement to providers, and it is almost as if we treat hospitals and nursing homes and every other provider the same way, and that leads to some overpayments and underpayments in the system. But also, at the State level, when it comes budget time, the urge is to cut payments to providers. It is certainly what has happened in my State of Maine.

And you are working for the State of Washington, or in Washington. I mean, can you sort of describe for us how much of this is a Federal issue, how much is a State issue, and give us some guidance on that, and I would ask the same question of the others who are here.

MS. INAGI. It is all about the Federal issues. We are all looking to you, and are, at this point, very fearful about those potential cuts. We don't know how we will manage, but it is driving some innovation, in terms of our looking at programs like worker's compensation and Social Security, in the sense that workers and employers both pay into a system that would meet the needs of long-term care for the long term, to put more money in where there is seemingly less money every day.

These are long-term solutions, not short-term solutions, unfortunately. But we want more money from you. That is what it comes down to.

MR. ALLEN. Thank you. Thank you all.

MR. DEAL. I am going to make a further observation and a question, and I will extend the same time to both of you, if you would like to participate in discussing this further.

We are really talking about something that is two different levels of what we are talking about here. My situation is with a mother and a father-in-law who are both retired public schoolteachers, who are not, at 93 and 99, not asking the Federal government or the State government for a penny. They have done it on their own, with the help of their family, and we work at counter purposes here sometimes. If we ratchet up the reimbursement levels, as Ms. Inagi would like for us to do, and that is certainly a laudable and understandable position for the worker, if we ratchet it up from the Government side, of requiring training and certification, we ratchet up at the same time the reimbursements that people are having to pay for those services.

If we do that, we create a disincentive for families like ours, and many, many others across the country, to try to do it themselves, and not make their parents a burden on the State or the Federal government. But because there are limited resources, they can only do so much, and they can only pay so much, and then, they are forced into the choice of saying okay, well, we will just go ahead and make sure that we make mom or dad Medicaid eligible, and we won't worry about the cost, because the Government is going to have to pick it up anyway. That is the dilemma that many families across this country are in. They want to keep their families at home, in a home setting. They want to be able to do it, and yet, they are caught in this conflict.

Now, my question is this. As we in the previous panel talked about trying to incentivize private systems, whether it be primarily long-term care insurance, and some other alternatives to funding for this kind of care, are most long-term care insurance policies keyed to the same regulatory scheme that State and Federal programs are, in terms of certification for the individual? I have looked at some policies, and they all say you can pick your caregiver, et cetera, et cetera, but I have a feeling that most of them, if you really would look at the fine print, are keyed to being employees that are going to be paid through the insurance policy, that are keyed to the level of control that the Federal or State policies do. Is that right, Dr. Wright?

DR. WRIGHT. Mr. Deal, my understanding is that that is the way it started out years ago, with the first long-term care insurance policies.

My information is that most of the better policies now do cover these in-home care workers without the qualifying skilled nursing.

MR. DEAL. Which has a dangerous side to it as well, obviously. And that is what all of you, I think, have expressed concern about.

One of the things I recently learned that my State is doing through some programs in their State vocational technical schools is they are beginning to offer, in some of these, a limited training program for home healthcare workers, for this kind of environment. I think it is a 10 week course, they told me, and they do get a certification of a sort. I don't know the extent of what that is. Is that similar to what you have been looking at?

DR. WRIGHT. That is similar to what we are doing, and I do think the community colleges around this country are a great resource for the kind of training, you know, the dissemination of this kind of training.

MR. DEAL. Well, I do, too, and what we are also dealing with is difficult to categorize sometimes. There are individuals who would like to do this kind of work, who would be willing to accept this kind of work. Many of them are in that retirement stage of their life, but want to come back, and need additional income, and are physically able to do so, and I think we are going to have a continuing number of those individuals past 65, who are going to be physically able to do a lot of things, and this is one area where I think they can be encouraged to participate.

So, my concluding comment is, I want to thank all of you for what you are doing. I think you are on the cutting edge of an issue that is going to mushroom substantially, and I thank you all, and would urge you to share with this committee any further developments, especially Dr. Wright, as you begin to model this program that you are talking about, I think it would be the kind of information that we would all like to have.

And I will stop, and Frank, I will let you, Mr. Pallone, I will give you time to do it.

MR. PALLONE. I don't have any questions.

MR. DEAL. Okay.

MR. PALLONE. Thank you.

MR. DEAL. Well, thank you. I appreciate your being here, too, Frank. Thank you for being here. This has been a long day, I know, for you, longer than you probably anticipated, because of our votes, but we do appreciate your input, and urge you to continue to supply us with information in the future.

And with that, the hearing is adjourned. Thank you.

[Whereupon, at 5:45 p.m., the subcommittee was adjourned.]

SUBMISSION FOR THE RECORD BY THE OLDER WOMEN'S LEAGUE

Women and Long-Term Care: *Where Will I Live, and Who Will Take Care of Me?*

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A Message from OWL's President

Happy Mother's Day!

EVERY YEAR, OWL WELCOMES Mother's Day as an opportunity to direct attention to issues of great concern to midlife and older women. Few issues fit this description better than long-term care, which shapes the lives of women in so many ways.

The U.S. long-term care system brings together three of OWL's core constituencies: long-term care recipients; their family members and friends, who provide informal caregiving services; and direct-care workers, who provide paid services in communities and long-term care facilities. A majority of each of these groups is women. Clearly, despite increasing participation by men in the work of providing care, long-term care remains a women's issue.

Recent research on the state of long-term care in the United States tells a startling story about a crisis that must not be allowed to worsen over the coming decades. According to a report on frail older adults by the Urban Institute's Retirement Project:

- "Only 53.1 percent of frail older people living alone received regular care in 2002. On average, older women with serious disabilities received 63 hours less care per month than their male counterparts...."
- "About 7 out of every 10 adult children who help their frail older parents are female. Daughters represent an even larger share of children serving as primary [activities of daily living] caregivers. Only about one in six primary caregivers are sons. Even among primary helpers with household chores and errands, daughters outnumber sons by nearly two-to-one."
- "[F]rail older women are less likely than frail older men to receive care from spouses because women are much more likely to be widowed."

The plight of direct-care workers in the long-term care system is equally serious. According to the National Clearinghouse on the Direct Care Workforce, direct-care workers are far more likely than than the average American worker to live in poverty.

For this year's report, OWL brings together a panel of friends and allies—national organizations that, like OWL, represent key stakeholders in the panorama of long-term care. The report serves as a written plenary session on the barriers to successful, high-quality care for recipients and their care providers. OWL, in the role of moderator, will respond to these issue briefs with an overview of how each area affects the lives of midlife and older women. Policy recommendations are included as a path to enhancing the long-term care experience for all women involved.

As always, we also present the stories of real women and their experiences with long-term care. These women represent the millions of midlife and older women across the country who deserve our utmost respect this Mother's Day. OWL is honored to dedicate this report to them.

Marilyn Z. Robinson
President, OWL
May 2006

Executive Summary

LONG-TERM CARE IS A WOMEN'S issue. The long-term care system—encompassing a range of services, settings, and programs—could not function without the contributions of millions of women who serve as primary formal and informal caregivers. It is also a family issue, with many families paying a high price—in money, time, and sometimes careers—to ensure their loved one's needs are met.

Research reveals that the need for long-term care is reaching crisis proportions. By 2030, one out of five people in the United States will be 65 or older. Those 85 or older are the fastest-growing segment of the population. As more and more elderly people become disabled and need long-term care, consumers, providers, and policymakers must confront the challenge of financing such care and ensuring its quality.

This report brings together five organizations that represent key stakeholders in the realm of long-term care. Through their voices, we learn about the dimensions of long-term care and about forward-looking policy recommendations that address the needs of our aging population. The report examines these issues across the landscape of service settings—home and community-based care, assisted living, and nursing homes—and through the personal stories of women whose lives have been shaped by the experience of long-term care.

Informal Caregiving—Tradition Is the Norm

- Informal caregiving by family and friends is the primary source of long-term care, providing 80 percent of the help needed. An estimated 44.4 million family caregivers over the age of 18 are providing care.
- While the older adult and society at large benefit from informal care, the caregiver is more than twice as likely to live in poverty and five times more likely to rely on Supplemental Security Income (SSI).
- Data on family caregiving between 1984 and 1999 indicates a drop in the use of formal services and an increased reliance on informal care. During that same time period, the proportion of elders with a disability who received only informal care increased from 57 percent to 66 percent.
- Older caregivers are most likely to be providing care for a spouse. Most are women, and most are over 75. Research shows that these older spousal caregivers are at increased risk of developing health problems themselves.
- Younger informal caregivers often face significant challenges related to their employment. Most report having to make work accommodations to manage their caregiving responsibilities, and as many as nine percent report having to leave their jobs completely.

Aging in Place—At Home and in the Community

The overwhelming preference of older and disabled adults is to remain in their homes and communities, maintaining independence, and aging with dignity without having to enter a long-term care institution.

- Thanks to the Aging Network, funded under the Older Americans Act, a well-established, cost-effective, and responsive system of home and community-based services is in place to provide supports for independent living.
- The Aging Network assists more than 8 million older adults and more than 660,000 caregivers every year in the U.S.; eighty percent of adults 65 and older with long-term care needs receive care and assistance at home and in the community.
- Despite these achievements, funding for institutional care far outweighs resources available for home and community-based services. Funding levels have generallyfailed to keep pace with inflation and the growing elder population.

- Medicaid offers nursing home care as a basic service, but states face a burdensome waiver process to fund home and community-based care.
- Housing security and safe, reliable, and convenient transportation are critical factors in ensuring that the home and community-based services system can guarantee readily available services.

Assisted Living—Meeting Individual Needs

- Assisted living has emerged over the last 20 years as an important and popular residential care option, allowing individuals to receive care in a manner that—ideally—promotes dignity, autonomy, independence, and quality of life.
- About two-thirds of the 80,000 people living in assisted care residences nationwide are women.
- However, rising costs and lack of public subsidies make this alternative unaffordable for most people with low or moderate incomes. Costs have increased 15 percent in the past year; the average base price of an assisted living unit is now $2,905 monthly.
- Unlike nursing homes, assisted living facilities are not subject to federal regulation or uniform standards. States vary in regulatory requirements, enforcement, oversight, and inspections. As a result, quality-of-care issues have arisen relating to inadequately trained or insufficient staff, medication errors, and resident abuse.
- High turnover—resulting in unmanageable workload demands on existing staff—is associated with poor resident outcomes. Compounding this problem is the concern that many assisted living workers are midlife and older women who will be hard to replace in the future.
- Care management is another critical component of quality care in assisted living. Coordination among health professionals, consumer understanding of services, and effective management of medication are major concerns.

Nursing Homes—When Institutional Care Is Unavoidable

- A 65-year-old woman alive today can expect to live another 19.5 years, with the increasing chance that she develop a chronic condition and a physical or cognitive disability.
- The reality is that 40 percent of women will need facility-provided care at least once in their lifetime. Often that care can be provided only in a facility with appropriate medical and social services.
- Nursing home care costs at least $192 a day (in 2006 dollars) with an average length of stay of two and a half years.
- Nursing homes account for three-fourths of all long-term care spending—more than $111 billion a year—with Medicaid funding 45 percent and Medicare 12 percent. Twenty-eight percent comes out of the pockets of individual residents and care takers.
- Lack of quality care is a major barrier. Nursing home care is inconsistent and, in some cases, unsafe. More than 90 percent of nursing home facilities lack nursing staff necesary to provide 4.1 hours of basic nursing care per resident each day.
- Workers are paid an average of $9.96 an hour, contributing to turnover rates ranging from 40 to 300 percent. As a result, residents often do not know from day to day who will be providing their care.
- Public policies are needed to protect nursing home residents from harm and ensure that their rights are upheld, including access to an adequately-funded ombudsman program and reliable information to help them make important decisions about long-term care.
- Also needed is a long-term care financing system that honors the caregiving roles of women and benefits to unqualified providers.

- National policies should be developed to compensate informal caregivers financially —through paid family and medical leave, tax credits, and Social Security credits, for example— and identify and provide support services for both the caregiver and the recipient.

Who Are the Long-Term Care Workers?

- Women make up the overwhelming majority of long-term care workers. About half of long-term care workers are people of color and most are in their early forties.
- Individuals often receive a mix of paid and unpaid care over time. The direct-care worker is generally the lowest paid of all health service support workers. A personal care worker employed by a home health agency earns an average of $8.18 per hour (though few can find full-time work) and a certified nurse assistant earns about $10 per hour.
- Direct-care workers leave their positions in droves and the ones who stay often live in poverty. More than one-quarter live below the federal poverty line and are more likely than other workers to lack health insurance and rely on public benefits to supplement their wages.
- The direct-care workforce is characterized by chronic shortages and high turnover rates. Serious shortages have been reported in 35 states.
- At the same time, demand is soaring for personal care providers. An estimated 5 million direct-care workers will be needed by the year 2030. However, the shrinking number of women between the ages of 25 and 40, their higher levels of educational achievement, and economic opportunities available elsewhere are creating a serious "care gap."

Informal Caregiving

Gail G. Hunt, Executive Director
National Alliance for Caregiving
Donna L. Wagner, Ph.D.
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IN THE UNITED STATES TODAY, informal caregivers—family and friends—are the primary source of long-term care, providing 80 percent of the help needed. According to the NAC/AARP report "Caregiving in the US: Findings of the National Caregiver Survey" (2005)[1], there are an estimated 44.4 million family caregivers over the age of 18. The majority of these caregivers are helping someone over the age of 50, and many are older women.

Women have traditionally made up the majority of the caregiving population; however, an increasing number of men are also providing informal care to a family member. In the 2005 survey, 39 percent of the caregivers were men. Although caregiving has been thought of as a "women's issue" in the past, it is more accurate to describe it as a "family issue." Women and men of all ages are care providers or care recipients, or provide support for caregivers and care recipients. This ubiquitous "family issue" is the foundation of our nation's long-term care system, and many families are paying a high price to make sure that their family member's needs are met.

In this issue brief, we describe the importance of the informal caregiver to the long-term care "system" in the United States—the issues and obstacles they face in their caregiving activities, their own needs, and recommendations for policy changes.

Family caregiving involves providing and arranging such services as transportation, meal preparation, and, often, personal care. The value of the informal care provided by family caregivers has been estimated at $257 billion a year.[2] In addition to the direct contribution of time, almost half the family caregivers surveyed in the 2005 NAC/AARP study reported that they were helping the care recipient financially, with an average of $200 per month. This investment of time and money benefits the older adult; however, it is also an investment that benefits society in long-term care cost savings.

> *Caregiving for an older parent increases the risk of living in poverty and relying on Supplemental Security Income (SSI) for income.*

For women, the cost of caregiving over time can be a serious issue. For example, Wakabayashi & Donato (2004)[3] found that caregiving for an older parent increases the risk of living in poverty and relying on Supplemental Security Income (SSI) for income; their data showed that women who were caregivers were more than twice as likely to live in poverty and five times more likely to receive SSI than were non-caregivers.

In a recent analysis of National Long-Term Care Survey data, Spillman & Black (2005)[4] identified some troubling family caregiving trends. In looking at the data on family caregiving between 1984 and 1999, the researchers found a drop in the use of formal service, compensated for by an increased reliance on informal care and the use of assistive devices. Between 1994 and 1999, the proportion of community-residing elders with a disability who used any formal services fell from 43 percent to 34 percent. During this same time period, the proportion of elders who were receiving *only*

informal care increased from 57 percent to 66 percent. Family caregivers were also more likely to be caring for someone over the age of 85, and more than half of spousal caregivers were age 75 or older.

Older caregivers are most likely to be providing care to a spouse, and most of the spousal caregivers are women. Research has consistently shown that older spousal caregivers are at risk of health problems themselves. Although many adult children who care for parents report high stress levels and increased incidence of illness as a result of their caregiving responsibilities, the older spouse who is caring for a husband or wife is at the greatest risk of adverse outcomes. Caring for a spouse is related to increased risk of depression, illness, and even death, as illustrated by a recent study that found the hospitalization of a spouse increased the risk of death for the older caregiver (Christakis & Allison, 2006)[5].

Younger caregivers often face a significant challenge related to their employment. The 2005 NAC/AARP survey found that 59 percent of caregivers were employed. Most of these reported having to make job accomodations to manage their caregiving responsibilities, including modifying work schedules, taking unplanned days off, and coming to work late or leaving early. As many as nine percent of employed caregivers said they have left work completely as a result of caregiving. Another 17 reported having to take a leave of absence to manage care. For women, caregiving can have a profound effect on lifelong earnings. Lost wages lead to lower levels of savings and Social Security benefits, creating a cost for caregivers that can extend for decades beyond the caregiving event.

The average age of an employed caregiver is 47; however, it is just as common to find young employees with care responsibilities for an older family member as it is to find older employees. Employees in their thirties may be caring for a grandparent or other older family member and, in some cases, putting their own career and family plans on hold while doing so.

Research has consistently shown that older spousal caregivers are at risk of health problems themselves.

Despite the personal, professional, and financial adjustments required of caregivers, many report that the experience was emotionally rewarding.

There are many changes, however, that would make caregivers' lives better. One is more help and recognition from formal health care providers. Family caregivers are not trained health care professionals, yet they are often called upon to provide tasks that, according to Susan Reinhart of Rutgers Center for State Health Policy, would make a student nurse tremble."

Caregivers tell us that they need more information about diseases, the aging process, and sources of help and support. They need a supportive boss who doesn't begrudge their caregiving role. They need a respite from caregiving. (This is especially true for the older caregiver who is caring for a spouse or sibling and managing their care 24 hours a day.) And they need a responsive long-term care system that doesn't impoverish the users or their families.

Policy Recommendations

Provide paid family and medical leave benefits on a national level.

To date, only the State of California offers a paid family and medical leave benefit, though several other states are considering adopting one. Leave provided under the federal Family and Medical Leave Act (FMLA) is unpaid and does not cover all workers.

Offer a caregiver tax credit.

Family caregivers are important to the "health" of our long- term care system and should receive at least a tax credit to cover some caregiving expenses.

Institute a national assessment program for informal caregivers.
Supporting the family and informal caregiver is important to the well-being of American families and the long-term care system generally. Such a program would identify those caregivers who need support and help locate services needed by both the caregiver and the care recipient.

Expand respite care services and increase funding for the National Family Caregivers Support Program (NFCSP).

Grant credit for years missed from work as a result of family caregiving.
Women should not have to choose between retirement security and their family responsibilities. We recommend, as has been suggested in the past, that a specified amount be credited to a worker's Social Security record for each year that worker was unable to work due to caregiving responsibilities.

NOTES

[1] National Alliance for Caregiving & AARP, *Caregiving in the U.S.: Findings of the National Caregiver Survey* (2005), Bethesda, MD.
[2] Arno, P., "The informal value of informal caregivers," presented at the American Association for Geriatric Psychiatry (2002) , Orlando, FL.
[3] Wakabayashi, C. & Donato, K., "The consequences of caregiving for economic well-being in women's later life," (2004), Department of Sociology, Rice University, Houston, TX.
[4] Spillman, B. & Black, K., *Staying the Course: Trends in Family Caregiving* (2005), Washington, DC: AARP.
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Informal Caregiving
Personal Story: Bev

CALL IT TRADITION OR EVEN FAMILY values—it has always been an expectation in Bev's family that you do what it takes to take care of your parents as they get older. Bev fit into that role very easily. After her step-father died, she moved back to the town where she grew up to help her mother, Kate.

Kate was in her seventies and could no longer take care of the family home alone, physically or financially. Bev and her husband built on an apartment where Kate was able to be independent and enjoy daily visits from her family and friends. Bev's husband, an RN with long-term care experience, was able to attend to Kate's health issues. She managed her own finances, did her own laundry, cooked her meals and drove her own car. Each week she would prepare one meal for the entire family.

Then, after more than ten years, everything changed. Kate, at age 89, had a stroke while visiting her sister out of town. As Bev and her family rushed 50 miles to the hospital, she knew their lives would change forever. The doctor came out and told Bev that the stroke was severe. Kate's mind would not realize that her entire left side was paralyzed. While intensive rehabilitation and physical and occupational therapy would help, the prognosis was not good. It was unlikely that Kate would be able to come home to live independently again. As the only surviving child, the entire responsibility for her mother's well-being fell on Bev. She quickly became Kate's advocate as well as her caregiver.

For six months, Kate was a skilled nursing/rehab patient at the top-ranked nursing home in Vermont, but her left side did not progress. She could no longer read or do crossword puzzles, and couldn't see the food on the left side of her meal tray. The care Kate received at the nursing home's skilled nursing ward was, to say the least, dismal. She tried to be continent, but time after time she would ring the bell for help only to be told by an aide, "I will be right back." Repeatedly she was "parked" in hallways with nothing to do but stare. Eyeglasses were left on the nightstand and not put on. Staff called her Katie rather than Kate.

Bev's patience ran thin. With rehab costing $30,000 a month and skilled nursing requiring $11,000 a month, she thought the level of care would be much better. Said Bev, "If this was the best nursing home in the state, what was the worst like?"

Kate was moved from skilled nursing to the regular part of the nursing home where she remains at 92. Despite Bev's vigilance, severe problems with her care continue. She has suffered a broken leg twice, and Bev routinely finds her with bruises and skin blisters. Bev constantly advocates for better treatment from the staff, but frequent staffing changes force her to start from the beginning to inform new employees of her expectations for her mother's care.

> *Bev explained that she wanted to be able to enjoy the time she has with her mother, and she doesn't know how much longer that will be.*

It has now been two years since the stroke. Bev feels that her mother's dignity has been stripped. Kate, who was always neat, clean, and organized

before her stroke, now avoids the dining room because she cannot rely on nursing home staff to tend to help her with soiled pads. Her room, at times, is a mess, with powder in her drinking water, dirty pads exposed in the trash, wipes next to her food tray, and dust on the floors. "My mother wouldn't live like that!" said Bev.

Every day, Bev works ten hours at her job as a vice president of human resources. She visits her mother at least three days a week. At first, she went every day, but soon became totally exhausted. She started a notebook in which she filled in all care plans, her questions and concerns. She attends care plan meetings every six weeks, taking vacation time to go. The nursing home claims they will follow up with Bev's concerns, but, with the exception of one wonderful social worker, little has been done.

Then there was Medicare Part D. One week Bev spent over 30 hours on the phone trying to get Kate's prescription drug coverage arranged.

This past winter, Bev hit bottom. She realized that she had lost balance in her life, that she simply could not be at her mother's nursing home every day, every hour, and that she needed to take time for herself. At the last care plan meeting, Bev was blunt, telling the nursing home staff that she didn't like coming in and finding things wrong with each visit. She explained that she wants to be able to enjoy the time she has with her mother, and she doesn't know how much longer that will be.

Bev continues to wonder—what happens to those who don't have an advocate for their care? Unfortunately, Bev said, "I think I know by looking up and down the halls and seeing their faces," Bev said. In her heart, Bev knows "that there is one woman who deserves dignity, respect and the very best advocate—and that is my Mom. She was always there for me when I needed her and now it is my turn to be there for her."

Home and Community-Based Services

Sandy Markwood, CEO
National Association of Area Agencies on Aging

LONG-TERM CARE IS OFTEN mistakenly thought of as end-of-life care. For many older women, it evokes images of nursing homes or persistent medical conditions that prevent them from caring for themselves or living on their own.

But our vision of long-term care should not be that bleak. The reality for older women is that they will attempt to "age in place"—remaining in their homes and communities for as long as they are able. This is, in fact, what most Americans want.

As older women age, their ability to take care of themselves can decrease. Some need a little bit of help to manage day to day; others need a great deal of help to continue to live independently. Such assistance may consist of a daily or weekly "visit" from a volunteer just to check in and ensure that everything is all right. Or it could be a regularly scheduled ride to medical appointments, a daily home-delivered meal, or assistance with finances, insurance, or legal services. It may also take the form of in-home personal care or home repairs.

Many older women turn to informal or family caregivers to provide assistance with one task or another. While those who are financially able may rely on private providers for support, those who do not have family or friends nearby, or who are without financial means, face major challenges.

The risks of lacking needed support are serious. If an older woman doesn't have the assistance or services she needs, her health and independence are endangered. If she stops cooking, for example, or can no longer get to the doctor's office regularly, her health may decline. If she cannot navigate the stairs in her home, she may be one step closer to institutional care.

The Philosophy

Luckily, help isn't far away. In communities across America, there is a system of home and community-based services that can offer older women who need a range of supports to continue living independently and avoid entering a long-term care institution.

> *Home and community-based care, which allows individuals to maintain their independence and to age with dignity in the comfort of their own homes, in familiar neighborhoods and communities, is overwhelmingly the preferred choice of older adults, as well as individuals with disabilities.*

For the past 40 years, the Aging Network (see below) has provided a broad range of support services to older Americans. Funded through the Older Americans Act, these services (1) promote the health, well-being, and independence of older citizens, and (2) support and complement the work of caregivers through the provision of home health, personal care, homemaker chore services, adult day care, respite care, senior center programs, telephone reassurance, friendly visiting, home repair, and such alternative community living arrangements as adult foster care and assisted living.

However, funding for institutional care in the United States far outweighs the resources directed to home and community-based services, even though studies have shown that older adults prefer to receive care in their homes and that home and community-based services can be provided at about one-fourth the cost of institutional care.

The Infrastructure for Home and Community-Based Services

Older Americans Act (OAA)

Since its inception in 1965, the Older Americans Act has been the foundation of services for older adults in the United States, The OAA forms the nucleus of our national system of home and community-based services for older Americans. It provides funding to states for a range of community planning and service programs for older Americans at risk of losing their independence. Since its enactment, the OAA has been amended 14 times to expand the scope of services, increase local control and responsibility, and add more protections for the elderly.[2]

Aging Network

To develop and implement a wide array of home and community-based services, a system of federal, state, and local agencies—known as the Aging Network—was established under the OAA. The core of the Aging Network is the U.S. Administration on Aging (AoA), 56 state and territorial agencies on aging, 650 Area Agencies on Aging (AAAs), 240 Title VI (of the OAA) Native American aging programs, and more than 30,000 service provider organizations. This critical aging infrastructure is the backbone of the U.S. home and community-based long-term care system, offering support to older persons and persons with disabilities.

Each year through the Aging Network, more than 8 million older Americans receive support services and 500,000 families receive assistance vital to their role as caregivers. While most home and community-based services are available to anyone over age 60, service providers try to target those who are most vulnerable, whether because of isolation, poverty, frailty, or cultural barriers.

Community Access Point: AAAs

Area Agencies on Aging serve as a single point of entry for the complex and fragmented range of home and community-based services for older adults and their caregivers. These include congregate and home-delivered meals, other in-home services for the vulnerable seniors (such as personal care and chore services), elder abuse prevention and protection, the nursing home ombudsman program, senior centers, transportation, consumer information, education and counseling, and senior employment. The local AAA either directly manages or coordinates with service providers to offer this wide range of services.

Many AAAs manage or receive funding from a variety of sources in addition to the OAA, including Medicaid waivers for home and community-based care, social service block grants, transportation funds, and state-funded, in-home service programs. AAAs have an extraordinary record of achievement in stretching limited federal resources to help hundreds of thousands of older people avoid costly nursing home placement and remain independent. OAA funds make it possible for AAAs to leverage millions of non-federal dollars from local governments, foundations, the private sector, and participant and volunteer contributions.

The Results

The home and community-based services system is well-established, flexible, responsive, and cost-effective, and meets the needs of more than eight million older adults and more than 660,000 caregivers every year in the United States.[3]

Take, for example, a 75-year-old widow who can no longer drive because of physical limitations. Public transportation in her community is scarce or inaccessible. If she can no longer get to the grocery store or her doctor's office, her independence and health are at risk. A senior transportation van to get her to the grocery store or to doctor's appointments could make a significant difference in her quality of life.

Another older woman may find it impossible to cook the nutritious meals for herself that she used to provide for her family, and her health may

deteriorate as a result. Connecting her to a senior center where lunch is served daily, or, if she is homebound, arranging for her to receive Meals-on-Wheels, could make a difference in her health and quality of life.

Recent AoA data show how successful Older Americans Act programs and services are in assisting older adults and their caregivers. AoA reports that 86 percent of family caregivers of OAA clients said the services "allowed them to care longer for the elderly than they could have without the services."[4] In addition, OAA-provided meals and services have allowed the nearly one-third of elderly clients who have health conditions that make them nursing home-eligible to remain in the community.

The Challenges

Much more needs to be done to meet the home and community-based service needs of all older adults. The Aging Network provides a proven infrastructure and workforce, OAA programs and services offer a tested and true policy foundation, and consumers and government agree that successful aging in place is the ideal.

Yet we face several major challenges that currently prevent the home and community-based long-term care model from serving all older adults who need it now or in the future: inadequate funding, misdirected federal policies, and a lack of attention to other systems (such as housing and transportation) that affect the provision of home and community-based care.

Until the following policy changes are put in place, older adults' ability to access the home and community-based care they need is in jeopardy.

Policy Recommendations

Funding Levels for Home and Community-Based Services Must Be Increased Significantly.

Federal funding for OAA programs and services has not kept pace with inflation or the growing population of eligible elders. Add increasing costs for wages, fuel, and food to the equation, and providers are struggling to offer services to all in need. Waiting lists for transportation services or meals delivery or caregiver respite are common in some areas of the country.

Every seven seconds, another baby boomer turns 60, the age of eligibility for most OAA programs and services. As a new generation of older adults seeks to age in place, communities and the Aging Network must have adequate resources to be able to respond.

Help communities prepare to meet demographic challenges.

The challenge in 2006 and beyond is largely one of demographics. By 2030, one out of every five people in the United States will be 65 or older. Those 85 and older are currently the fastest growing segment of the population, with their numbers increasing at a rate four times faster than that of any other age group.[5]

The OAA should be amended to authorize State Units on Aging, AAAs, and Title VI Native American aging programs to help communities prepare for aging baby boomers. Professional planners might offer the Aging Network's expertise to help state agencies, city and county elected officials, local government agencies, tribal councils, and private and nonprofit organizations develop policies, programs, and services to foster livable communities for all ages.

Eliminate the institutional bias in Medicaid long-term care policy.

Many federal policies do not recognize that the most cost-effective form of long-term care is provided through home and community-based services. These services are currently available through a fragmented and inconsistent array of federal, state, local, and private support services paid for through public and private financing.

Medicaid, the largest public program financing long-term care, has an inherent bias toward institutionalization. Congress established the home and community-based service waiver in 1981 to attempt to reduce this bias. The Medicaid waiver program gives states the option to apply for waivers to fund home and community-based services for people who meet Medicaid eligibility requirements for nursing home care. A 2000

study by the Assistant Secretary for Planning and Evaluation with the U.S. Department of Health and Human Services found that average spending on the aged and disabled under the Medicaid home and community-based waiver saved money—providing for an individual under the waiver program costs $485 a month compared to $2,426 for nursing home care.[6] Even so, nursing home care remains a basic service under Medicaid, while states still face a burdensome waiver process to offer home and community-based services.

Link affordable housing with needed support services.

Housing security is critical to the health and well-being of older adults. The home and community-based system will not succeed without the provision of affordable and accessible housing for older adults. Greater coordination needs to occur between housing and service providers to guarantee that such support services as meals, personal assistance, and housekeeping, as well as health services, are readily available and easily obtainable. While policy initiatives are underway to increase assisted living facilities stock, convert existing public housing into accessible housing, and provide increased coordination of support and housing services, progress has been slow and more commitment to these efforts by policy-makers is needed.

Develop systems to help older adults retain mobility.

Mobility is essential for an individual to live at home and in the community. Transportation provides necessary access to medical care, shopping for daily essentials, and the ability to participate in cultural, recreational, and religious activities. Feelings of isolation and loss have been reported among older adults who can no longer use personal automobiles. Public policy must focus on the provision of safe, reliable, and convenient alternative means of transportation for those for whom driving is no longer an option, as well as on efforts to help older adults retain their licenses and cars for as long as it is safe for them to do so.

Notes

[1] U.S. General Accounting Office, "Long-Term Care Insurance: Better Information Critical to Prospective Purchasers." Statement of William Scanlon, Director, Health Financing and Public Health Issues, Health, Education, and Human Services Division. Testimony Before the U.S. Senate Special Committee on Aging (September 13, 2000), page 4.

[2] For more information on the history and current implementation of the Older Americans Act, see the U.S. Administration on Aging's web site: http://www.aoa.gov/about/legbudg/oaa/legbudg_oaa.asp.

[3] U.S. Administration on Aging. *2004 Annual Report*, page 7. http://www.aoa.gov/about/annual_report/2004_ar.pdf.

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Assisted Living

Kathy Cameron, RPh MPH, Chair
Consumer Consortium on Assisted Living

ASSISTED LIVING HAS EMERGED over the past 20 years as an important and popular segment of the long-term care continuum for older adults. As an alternative to nursing home care, assisted living is a residential care option for people who typically can no longer live independently in their own homes. It provides or coordinates services to meet residents' individualized needs in ways that are intended to promote their independence and reflect their personal choices. This long-term care option is significant for midlife and older women because more than two-thirds of assisted living residents are women and are cared for by women.

As a result of an April 2001 hearing held by the U.S. Senate Special Committee on Aging on quality of care in assisted living, committee staff members asked assisted living stakeholders to develop recommendations designed to ensure more consistent quality in assisted living services nationwide. Shortly thereafter, a core group of assisted living stakeholders extended invitations to numerous national organizations, and the Assisted Living Workgroup (ALW) was formed with nearly 50 organizations representing providers, consumers, long-term care and health care professionals, regulators, and accrediting bodies. One of the first tasks of the ALW was to develop a uniform definition of assisted living that would provide consumers with a clear understanding of what kinds of assisted living services they should expect.

Developing a definition is particularly important because states use more than 26 designations to refer to what is commonly known as "assisted living."

The ALW agreed on the following definition:

Assisted living is a state regulated and monitored residential long-term care option. Assisted living provides or coordinates oversight and services to meet the residents' individualized scheduled needs, based on the residents' assessment and service plans and their unscheduled needs as they arise.

The philosophy underlying most assisted living communities is that a resident has the right to make choices and receive services in a manner that promotes dignity, autonomy, independence, and quality of life. These services are disclosed and should be agreed to in the contract between the provider and resident.

Assisted living is designed to respond to the needs of individuals who require assistance with such daily activities as bathing, dressing, and grooming, but who do not need 24-hour skilled nursing care. Some state regulations require a nurse in an assisted living facility, some require round-the-clock nurse availability and some require no nursing staff at all. Service provisions, as agreed to by the majority of ALW participants, must include but are not limited to:

- 24-hour awake staff
- Provision and oversight of personal and supportive services
- Health-related services (e.g., medication management services)
- Social services
- Recreational activities
- Meals
- Housekeeping and laundry
- Transportation

There is no one type of assisted living model or design. The setting could be a high-rise building housing several hundred individuals, or it could be a small group home for just a few. Living accommodations can include a full-size apartment or a single room. In some facilities, services are limited to meal preparation, housekeeping, medication reminders, and minimal assistance. In others, more intensive services, including help with administering medications, on-site nurses, and regular assistance with such daily activities as bathing and dressing are available. This variability makes it difficult for consumers and/or their caregivers to compare facilities and choose the one that best meets their current and future needs.

Several issues of concern related to assisted living have arisen in recent years. This issue brief will address four key issues that are of utmost importance to two groups of women: residents of assisted living services and/or their caregivers, and the direct care workers in assisted living facilities. These issues are:

- Affordability
- Quality, Accountability, and Oversight
- Staffing Retention and Training
- Resident Care and Care Management

Affordability

A recent MetLife Mature Market survey found that assisted living costs increased 15 percent in the past year. Now, the average base price of an assisted living unit is $2,905 monthly, or $34,860 annually. Boston, Massachusetts, had the highest average monthly cost, at $4,629. The lowest cost was $1,642, in Jackson, Mississippi. Researchers attributed the rising costs to the increasing popularity of assisted living among older adults.[1] Monthly rates vary significantly depending on the location of the residence, the type of accommodations (such as a private or shared room), and the services a resident needs, including medication management, assistance with activities of daily living, and specialized dementia care. In addition to these monthly costs, some assisted living residences also charge an admission fee.

The Assisted Living Resident

Gender

Over two-thirds of assisted living residents are female.

Age

The average age of residents in assisted living facilities in 2000 was 80. The average age of the oldest residents was 94, and the average age of the youngest resident was 66.

Typical Resident

The typical assisted living resident is an 80-year-old woman who is mobile but needs assistance with two activities of daily living.

Number of Residents Nationwide

Approximately 800,000 people nationwide live in assisted living settings.

Activities of Daily Living

Nineteen percent of assisted living residents need no help taking care of their activities of daily living; others need help to varying degrees.

Moving In

Residents come to assisted living facilities from a variety of settings:

- 46 percent move from their homes.
- 10 percent come from a nursing facility.
- 20 percent come from another assisted living residence.
- 14 percent come from hospitals.

Cognitive Impairment

Approximately half of all residents in assisted living have Alzheimer's disease or other dementia.

Sources

National Center on Assisted Living, 2000 Survey of Assisted Living Facilities, 2001.

Alzheimer's Association. People with Alzheimer's Disease and Dementia in Assisted Living Fact Sheet. 2004.

Home and community-based waivers are the primary Medicaid funding vehicle for low-income persons requiring assisted living services. Medicaid coverage of assisted living services is increasing, albeit gradually. In 2002, Medicaid helped pay for services for approximately 11 percent of assisted living residents in 41 states.[2] In contrast, Medicaid is the primary source of payment for 58 percent of nursing home residents.[3]

Assisted living remains primarily private pay. As of 2000, 67 percent of assisted living residents paid with their own funds, and 8 percent received support from family members.[4] Long-term care insurance paid for assisted living costs for only 2 percent of residents.

Because of their high cost and lack of public subsidies, assisted living residences are often unaffordable for older persons with low or moderate incomes, many of whom are women. For the typical woman over the age of 65 with a current average annual income of $15,615, paying for assisted living is virtually impossible[5]. Families are frequently called upon to help with the costs of assisted living. However, many families could not begin to take on this level of financial responsibility, no matter how much they love their parents or other family members. For those older adults, assisted living may very well be out of the realm of possibility.

Quality, Accountability, and Oversight

A critical challenge in assisted living is ensuring the quality of assisted living services. Many quality-related issues are of concern to older women, including inadequately trained staff, insufficient staff, medication errors, resident abuse, and the retention of individuals who need more care than the assisted living residence is able to provide.

Unlike nursing homes, assisted living facilities are not subject to federal regulations or uniform quality standards. Each state develops its assisted living regulations. Some states began developing such regulations as facilities began operation in their state. Others lagged in this effort and only began addressing the issue in the past several years. States also vary in the frequency of facility inspections (ranging from once a year to none), licensing

Because of their high cost and lack of public subsidies, assisted living residences are often unaffordable for older persons with low or moderate incomes, many of whom are women.

requirements, quality standards, and monitoring and enforcement activities.[6] Because of budget cutbacks, some states have reduced oversight of assisted living residences in such areas as inspections and enforcement of state regulations.

Some states use accreditation in lieu of state regulatory inspections. Such accreditation may cover several years, thus eliminating annual inspections of assisted living residences. Many advocates are concerned that a multi-year time span is too long, as potential operational or management changes may also impact the current level of quality in the residence. In 2005, six states already had language in their regulations that allowed for (or will allow for) third-party accreditation for either assisted living or continuing care retirement communities.[7]

To ensure quality assisted living residences, states will need to expand current efforts and make sure that these facilities are adequately funded. Areas where state efforts are often weak include staff training, disclosure of information to consumers, and services to meet the needs of residents with cognitive impairment. The ALW report can be useful to policy-makers as they consider ways to improve assisted living quality in their states. Additional research is needed to better understand the effectiveness of various approaches to improving quality.

One very real concern debated by assisted living providers and advocates is the effect of Medicaid, in the form of increased regulatory requirements. While recognizing that one mission of the Centers for Medicare and Medicaid Services includes assuring public accountability and quality long-term care services—especially those subsidized by the

Medicaid program—some assisted living advocates believe that reliance on existing nursing facility regulations will essentially transform assisted living into nursing facilities. Other advocates maintain that regulations are important in assuring quality and that the goal should be to set realistic but flexible standards.

Staff Retention and Training

Issues related to direct-care workers in assisted living are extremely important to women because the vast majority of assisted living workers are midlife and older women caring for older women. A concern among consumer advocates is who will replace these older workers in the future.

Effective recruitment, staff training, and retention practices lead to enhanced quality of life for both residents and staff members of assisted living residences. These practices have direct and significant implications for both residents (with respect to the quality of care and services they receive) and workers (with respect to job effectiveness and job satisfaction). A major concern related to staff training is that every state has different requirements for initial staff training and continuing education, both in the curriculum used and in the number of hours of training.

High turnover and inadequate staffing levels in the long-term care workforce has long been associated with poorer resident outcomes, as it places greater and often unrealistic and unmanageable workload demands on remaining staff. Decreased worker effectiveness, increased levels of stress, and mounting job dissatisfaction have all been cited as negative outcomes of, and potential triggers for, more staff turnover. Absent a resolution of these issues, the question of "who will take care of me" in assisted living will remain unanswered.

Resident Care and Care Management

This issue focuses on the services provided by an assisted living facility before and during a stay there. For example, many states require that assisted living facilities conduct initial assessments and prepare service plans for each resident. Even if the state does not have such requirements, a well-run facility will use them. A resident service plan is a blueprint for care that describes the resident's needs and preferences and the specific manner in which such care will be delivered. Prepared thoroughly and thoughtfully, the service plan can help a resident achieve the highest level of function and quality of life. A well-developed plan uses an interdisciplinary approach and includes the resident, the family (if the resident wishes), the facility nurse and resident service coordinator, and possibly the activity and dining directors.

Care management is another critical component of quality care in assisted living. With the increasing age of assisted living residents, it is ever more important for care coordination to be conducted among the health care professionals, such as physicians, pharmacists, and physical and occupational therapists, and in the areas of hospice care and lab work, to manage existing health conditions and prevent new problems from occurring.

Inability to manage medications for chronic and acute conditions is a major reason for the admission of older adults to assisted living facilities. Medication management continues to be a challenge once they enter an assisted living community. Consumer understanding of the services provided and safe and effective management of the resident's medication regimen are major concerns. Many assisted living residents provide some level of assistance with medications. A resident's ability to self-administer is determined during the admissions process. If a resident needs support, there are various levels of medication management. Some states have strict guidelines stating that only licensed nurses can administer medications, while others allow unlicensed caregivers to administer medications if they have successfully completed a state-approved course.

Also within the realm of resident care management are dementia care and wellness programs. Some people will be admitted to an assisted living facility with cognitive impairment; others will become cognitively impaired as time passes. Assisted living staff can be trained to recognize the signs and symptoms of cognitive

impairment in residents. All staff should receive this training, even if the assisted living facility has a special dementia care unit, since some residents who are not in that unit may have or develop cognitive impairment over time.

Wellness programs can improve quality of life for residents, and, in some cases, prevent illness from occurring by using a holistic approach to care. Such programs may include health screenings, nutritional counseling, physical exercise programs, and spiritual enrichment.

Policy Recommendations

ALW developed the following recommendations for the above issue areas for the U.S. Senate Committee on Aging. The complete ALW Report and recommendations can be found at www.aahsa.org/alw.htm.

Affordability

- Create a new consumer-directed federal long-term care program that includes assisted living and expands service eligibility to meet the needs of people who are not nursing home eligible.
- Continue to expand funding for the Medicaid 1915(c) Home and Community-Based waiver program to cover needed services.
- Allocate additional federal and state funding to meet the needs of affordable assisted living.

Quality, Accountability, and Oversight

- Congress and the states should provide adequate funding for the Long-Term Care Ombudsman Program to fulfill its responsibilities under the Older Americans Act, including resolving complaints and representing resident interests in licensed assisted living communities.
- The federal government should exercise its jurisdiction to oversee assisted living and enforce the law in the following areas: protection of consumers from unfair and deceptive acts and practices under the Federal Trade Commission Act; enforcement of the Medicaid waiver for assisted living; national abuse registries and criminal background checks; civil rights laws such as the Americans with Disabilities Act (ADA); and any other laws and standards that apply.
- State regulatory agencies should make available information that is helpful to consumers and others regarding assisted living residences, including electronic access to statutes and regulations impacting assisted living. States should maintain as public records, for a minimum of three years, all survey and inspection reports and plans for corrections. States should take steps to offer low-cost access to these reports, such as by posting them on state Web pages.

Staff Retention and Training

- State regulatory agencies should develop or adopt a tool for use by surveyors to determine the adequacy of staffing levels to perform tasks specified in the assisted living residents' services plans. This tool should be shared with and used by assisted living residences and by ombudsmen and consumers.
- Direct-care staff in assisted living should be required to complete a state-approved comprehensive training program, including both a classroom and a clinical skills practicum, and to pass a written examination and skills competency test. The training should include components on the philosophy and concepts of assisted living, resident rights, care techniques related to activities of daily living, the aging process, CPR, first aid, responding to falls and other emergencies, environment and safety, and understanding the particular care needs of persons with dementia and challenging behaviors.

Resident Care and Care Management

- Assisted living residences should be required to have or implement policies and procedures for the safe and effective distribution, storage, access, security, and use of medications and related equipment and services by trained and supervised staff.
- Assisted living residences should be required to have in place procedures to: (1) increase staff awareness of signs and symptoms of cognitive impairment/dementia; (2) evaluate or obtain an evaluation of the resident's cognitive status as it relates to the resident's ability to manage his/her own affairs and direct his/her own care; and (3) adapt the resident's service plan to meet his/her needs, given the resident's cognitive status.

NOTES

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Assisted Living
Personal Story: Jackie's Father

JACKIE IS THE DAUGHTER OF AN 88-year-old widower who began living in an assisted living community six years ago. When he entered the community, Jackie's father was cognitively sharp, relatively independent, and mobile, requiring little staff assistance.

Since that time, his chronic heart failure and Parkinson's disease have worsened. For the past three years, he has required a walker and has become progressively unsteady in gait and mobility. Ever since an acute cardiac hospitalization and rehabilitation episode two years ago, he requires medication management and far greater personal assistance from the staff. He is now embarrassed that he has so much trouble getting in and out of his chair in the dining room. Last spring, he developed acute pneumonia, which caused yet another round of hospitalization, rehabilitation, and further weakening of his general health. A year ago, Jackie arranged for a supplemental private duty aide to live in her father's apartment, since he now spends most of his time in his wheelchair.

It is difficult for Jackie to use the term "affordability" when she thinks about her father's assisted living fees. While the average monthly rate for assisted living is less than $3,000, that rate varies considerably depending on the facility's location. Jackie's family pays $5,000 a month for her father's assisted living facility in the northeast and an additional monthly fee for medication management. His pension, Social Security, and savings don't begin to cover these costs, so the financial responsibility has fallen upon Jackie and her sisters.

Jackie believes that she and her family are indeed fortunate that their father's assisted living residence is in a state that has appropriate regulations and oversight. However, these safeguards are still not enough to truly ensure quality of care in assisted living. Jackie believes that one of the best ways to ensure quality care for her father is for her to be involved with the administrators and staff members at his facility. Jackie is an active participant in family council meetings, maintains open communications with the staff, and views herself as part of his "care team." Jackie's family is proactive in bringing up any concerns they may have so that they can all work together to resolve them. She believes that their caring, respectful, appreciative manner toward the other residents, staff, and administrators these past six years have gone a long way toward ensuring that her father will be treated in a similar caring and respectful manner.

It's difficult for Jackie to use the term "affordability" when she thinks about her father's assisted living fees.

The amount of time and energy devoted to finding an appropriate facility for Jackie's father and the continuing challenge of checking on the quality of his services have been enormous, yet worth it. Jackie's involvement has made a significant difference in improving her father's quality of care. Her advice to assisted living residents and their caregivers is to be as proactive as possible in advocating for improved services.

Nursing Home Care

Alice H. Hedt, Executive Director
National Citizens' Coalition for Nursing Home Reform

AS WOMEN EXPLORE COMMUNITY long-term care alternatives to nursing home placement, they must constantly be thinking about the unthinkable—what will happen to me when I am so frail that I can no longer stay in my own home and in the community where I have lived independently?

The stark reality is that 40 percent of all women will need some type of facility-provided care at least once in their lifetimes—for short-term rehabilitation or long-term living—and oftentimes the need for 24-hour care and nursing services can only be met in a nursing home or an assisted living facility with appropriate medical and social services.[1] Most of these women will seek placement due to family factors, rather than critical health needs.[2] In addition, a 65-year-old woman needs to prepare to live another 19.5 years with the increasing chance that she will have a chronic condition and/or a physical or cognitive disability. Should nursing home care be needed, she can anticipate that this will cost at least $192 a day, or $70,080 a year (2006 dollars), and that her length of stay will be nearly two and a half years.[3]

Individual and Systemic Issues

The cost of nursing home care, both to individuals and to society, is a primary issue in long-term care. Nursing homes account for three-fourths of all long-term care spending, more than $111 billion a year, with Medicaid funding 46 percent, Medicare 12 percent, and 28 percent coming from the pockets of individual residents.[4] Nearly 70 percent of all nursing home residents are on Medicaid and use most of their personal income for the cost of care, supplemented by Medicaid to pay the difference.[5]

The 1.26 million women currently in nursing homes (67 percent of all residents),[6] and those of us who will need nursing homes in the future, face additional barriers—individual and systemic.

As individuals, we must remember to speak up and speak out so that we can give voice to what gives quality to our lives and be a part of decision-making.[7] The Nursing Home Reform Law (NHRL) of 1987 provides basic protections for residents. It guarantees residents' rights, setting forth the vision that each individual resident should be "cared for in such a manner and in an environment that will promote maintenance or enhancement of the quality of life" in nursing facilities that "must provide services to attain or maintain the highest practicable physical, mental, and psychosocial well-being of *each* resident."

As individuals, we must remember to speak up and speak out so that we can give voice to what gives quality to our lives.

Residents' Rights

Women, however, must *know* their rights and take advantage of the opportunities to exercise them in the nursing home environment. High-quality facilities will support residents' well-being by:

- Encouraging full participation in individualized care planning that spells out essential aspects of the female resident's day-to-day life as well as involvement in resident and family councils.

- Promoting person-directed care and a facility culture that revolves around the preferences and schedule of the resident, rather than forcing the resident to adapt to the routines of the institution.[8]
- Fostering respect for workers and residents and building relationships between caregivers and care receivers based on adequate staffing and dignity.
- Ensuring that the environment is safe—from fire (sprinklers), from abuse (criminal background checks), and from neglect, which, if left unchecked, can result in suffering, pain, and premature death.
- Being part of a surrounding neighborhood that is involved with the residents and provides resident access to community services, legal support, and meaningful activities.

The primary barrier for women in need of nursing home care, however, is *lack of access* to a facility that provides such high-quality care. Despite 30 years of advocacy, congressional hearings, legislation, and regulations, nursing home care in this country is not consistent, or—in some cases—even safe. Over 90 percent of nursing home facilities in the United States do not have the 4.1 hours per resident day of nurse staffing needed to provide basic care, and 50 percent of nursing homes do not have enough staff to prevent harm.[9] Turnover rates of 40 to 300 percent result in women residents not knowing from day to day who will be providing their most intimate personal care. Too often facilities have only "yo-yo" compliance with the NHRL regulations, resulting in survey deficiencies that occur year after year. Residents report that some facilities step up their performance prior to the annual survey through increased staff, new linens, and better food, with noticeable declines occurring once the inspection has been completed. African American women are four times more likely to be living in a nursing home with the worst staffing levels and inspection records.[10]

While it is important to realize that many American women do not have a choice of nursing homes—because there are no good homes in their community, because of discrimination based on race or Medicaid eligibility, or because they have no family to help them get into a good facility. Those who do have options need information to help them choose wisely. They should use information now available on the Internet[11] and seek guidance from a long-term care ombudsman, who can provide facility-specific information. It is very important that women visit facilities and see for themselves the kind of care and quality of life offered there, asking questions about staffing levels, training, and facility priorities.

Policy Recommendations

Pass NCCNHR's minimum staffing standard of 4.13 hours per resident day.[12]

Developed by consumers and validated by a consensus panel of stakeholders, the NCCNHR staffing ratio is very close to the government report ratio of 4.1 needed to provide essential care. In addition, public policy should support comprehensive staff training, adequate living wage compensation, and benefits that recognize the important work performed by direct care workers.

Ensure adequate funding and staffing levels for agencies tasked with protecting the rights and well-being of nursing home residents.

These federal and state regulatory agencies must be required to respond to complaints in a timely manner. Further, public policies must protect residents' ability to exercise political will to levy and collect penalties and other sanctions when facilities do not provide the care for which they are paid.

Require all nursing home facilities to implement fully the components of the NHRL.

Nursing home facilities should be required to fully implement the components of the NHRL, including individual care planning, family and resident empowerment through independent councils, freedom from fear of retaliation for residents and their families, and an environment that allows residents to make and execute meaningful decisions in all aspects of their lives. Federal and state

regulatory agencies must promulgate and enforce regulations that guarantee residents' rights and individualized care and decision making, and that provide incentives for incorporating the philosophy and vision of deep culture change that respects resident autonomy.

Require nursing homes to provide all residents access to a long-term care ombudsman program. Each program must be adequately funded to meet or exceed the ombudsman-to-resident ratio, as identified in the 1995 Institute of Medicine study *Real People: Real Problems*. Each ombudsman program should operate in an environment that is free of conflict, with full capacity to represent resident interest to public officials and to be effective advocates for residents, as described in 712(a)(4)(B)(i) of the Older Americans Act.

Ensure that the long-term care financing system protects caregivers and nursing home residents. Congress must establish a long-term care financing system that, first, honors the caregiving roles of women by ensuring that public benefits, including Medicaid, are available when needed and, second, denies Medicare and Medicaid benefits to providers who consistently provide poor care.

Promote nursing home accountability and transparency.
The Centers for Medicare and Medicaid Services should be required to post in every nursing home accurate, audited data on nursing staff levels (including ratios of nursing staff to residents), fire safety information (including inspection findings and whether or not the facility is sprinklered), all state and federal sanctions imposed for poor care, and information about who owns and manages the facility.

Protect residents' right to civil justice remedies. Congress must ensure that all women retain the right to civil justice when they are neglected or abused in a nursing home. Attempts to cap jury awards for pain and suffering (noneconomic damages) are particularly unjust for unpaid caregivers and nursing home residents, who have no earned income to replace with economic damages. Medical malpractice reforms that cap noneconomic damages deny the protection of the law to those who are most vulnerable and need it most.

NOTES

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Nursing Home Care
Personal Story: Judith

JUDITH IS A NURSING HOME RESIDENT in Indiana. She is 51 years old and has been in a long-term care facility since she was 21 years old. Judith, who needs around-the-clock nursing care, suffers from lupus and pulmonary fibrosis and is an above-the-knee amputee on her left side.

When Judith began her experience in the long-term care system, there were no long-term care ombudsman programs in place. If she had a problem with her care, she had to stand up for herself. In order to make her voice be heard, she learned to be her own care advocate. When her mother moved into the same nursing home facility where Judith lives ten years ago, she became her mother's advocate, too.

> *She feels that a lot of residents are treated as though they were children rather than adults.*

Judith's mother must rely on the nursing home staff to feed her, since she cannot do so herself, but the way she has been treated at mealtimes has been difficult for her. When she says something to the staff, she feels as though they just want her to be quiet, as if they don't want to be bothered. Judith feels that many other residents also try to advocate for themselves, but they too often have a hard time getting anyone to listen to their concerns.

Judith has often felt she had to speak up about her treatment and her rights, as well as the situations of others. She feels that a lot of residents are treated as though they were children rather than adults. They are told to wait for medication when they are in pain, and some are even told to wait if they need assistance to use the restroom. When Judith reports mistreatment like this, it seems nothing is done about it. Nonetheless, Judith is determined to continue speaking up when something isn't right.

Long-Term Care Workers

Milly Silva, President
Service Employees International Union (SEIU) 1199NJ

ONE OF THE MAJOR CHALLENGES facing our nation is how to meet the growing need for long-term care services among older Americans. The looming demographic explosion of Americans over age 65 begs the question that forms the title of this report: Who will care for us?

To answer this question satisfactorily, we need to look at who is providing care now, what the current problems are, and what steps must be taken to ensure a trained and qualified workforce of long-term caregivers that older Americans can count on in the coming years.

Who are Long-Term Care Workers?

Women make up the overwhelming majority of-long-term care workers regardless of setting.[1] About half of long-term care workers are people of color, and the median age is 41 years for home health aides and 39 years for nursing home workers.[2]

Chances are that if you receive long-term care services, you do so from a woman in her early forties—either a member of your family working through a state home care program, or someone who is sent from an agency or works in a nursing home.

Whatever the type of care, it is hard work that is physically and emotionally draining. It involves tending to the intimate and very personal care needs of an individual, providing assistance with bathing, toileting, dressing, and other activities of daily living.

Individuals often have a mix of paid and unpaid care over a period of time. Together, paid and unpaid caregivers create an interdependent but often fragile web of supports that is the infrastructure of the long-term care system.

Employed Persons by Selected Occupations, Sex, Race, and Hispanic or Latin Ethnicity, 2005

	Percentage of Total				
Occupation	*Total Employed*	*Women*	*Black/African American*	*Asian*	*Hispanic/Latino*
Nursing, Psychiatric & Home Health Aides	1,900,000	89%	33%	5%	15%
Personal & Home Care Aides	668,000	86%	24%	5%	16%

Source: U.S. Department of Labor, Bureau of Labor Statistics Household Data Annual Averages

Caregivers Living in Poverty

Unfortunately, the direct-care worker is generally the lowest paid of all health service support workers. A personal care worker employed by a home health agency earns an average of $8.18 per hour, but that figure is deceptive in terms of annual income since very few workers can find full-time work.[3] Wages are just slightly higher for certified nurse assistants, about $10 per hour.

The result is that direct-care workers leave in droves, and those who stay live in poverty. More than one-quarter live below the federal poverty line, and they are more likely than other workers to lack health insurance and to rely on public benefits to supplement their wages. Among single-parent nursing home and home health aides, 30 to 35 percent receive food stamps.

Access to health insurance is a problem for direct-care workers. About 40 percent of home care workers lack health insurance, and 25 percent of nursing home workers are similarly uninsured.[4] As a result, many direct-care workers must rely on publicly funded health care.[5]

> *Unfortunately, the direct-care worker is generally the lowest paid of all health service support workers.*

High Turnover Jeopardizes Quality of Care

Given low pay and lack of benefits, it is no great surprise that chronic shortages and high turnover rates characterize this workforce. Serious shortages of direct-care workers have been reported in 35 states.[6] A 2003 survey of North Carolina direct-care workers found they earned more after leaving the field, an indication of lagging opportunities.[7]

This is not a temporary phenomenon, nor just a function of the business cycle. The shortage of long-term care workers is the rational response of people, mostly women, to lousy wages and working conditions at a time when far better economic opportunities are available.

The Growing Need for Long-Term Caregivers

Demand is soaring for personal care providers. An estimated 5 million direct-care workers will be needed by the year 2030 to match growth in the elderly population, which is expected to increase by 40 percent by 2030.[8] The shrinking number of women age 25-40, their higher levels of educational attainment, and greater economic opportunities available elsewhere are steadily creating a "care gap" in the U.S. Fewer and fewer women go into long-term care work, and those who do often leave for better paying jobs in other fields.[9] Smaller families and greater geographic mobility among American families mean even informal care is affected.

Policy Recommendations

Increase wages and benefits of direct-care workers to improve quality of care.

The shortage of direct-care workers can only be solved by improved wages and benefits. Such a fundamental economic change will, no doubt, require a shift in attitudes toward workers and the work itself. Current working conditions for direct-care workers are marked by lack of respect for the work. The abundance of informal caregiving gives the false impression that direct-care workers in the formal economy can get by on minimum wage and no benefits.

The labor market for long-term care workers is easily influenced by changes in wages and working conditions. A study of California home care workers who organized through SEIU found that raising wages and providing health insurance and other benefits reduced turnover by almost two-thirds. The pay raises had the support and encouragement of consumers, who rightfully believed it would increase their ability to get help and reduce their anxiety over disruptions in service caused by workers getting offers for higher paying jobs elsewhere.[10] This confirmed a study of Los Angeles home care workers that found that providing health insurance to these workers improved retention.[11]

The *status quo* is not acceptable. The current system impoverishes direct-care workers, and high turnover adds unnecessary costs to the entire

system. According to one recent study, the average direct cost of a long-term care worker's leaving was $2500—money that would be better spent in wages and benefits, particularly for a society on the precipice of a demographic revolution.[1 2]

Improve staffing levels in institutional settings to improve quality of care.

A major research study commissioned by the U.S. Department of Health and Human Services (HHS) recommended nurse staffing levels that would allow at least 4.1 hours of direct nursing care per resident in nursing home settings.[13] Congress has yet to adopt these minimum recommended standards. Pending legislation introduced by Rep. Henry Waxman (D-CA) would establish minimum staffing standards for nurses and nurses' aides in skilled nursing facilities following the recommendations of the HHS report.[14]

Expand consumer-directed programs that address workforce issues.

The advent of consumer-directed services represents one of the most promising developments in long-term care. The theory behind this idea is that individuals living in the community should determine who will care for them and how that care will be provided. In practice, consumer-directed care enables consumers, not home care agencies, to select and direct caregivers in a setting they choose, typically the consumer's own home. Consumers are able to hire friends and family to care for them—one way of meeting the growing need for caregivers.

Consumer-directed care is a humane and compassionate approach to caregiving, but programs built on consumer direction need to be structured to support the direct-care workforce. Consumer-directed care is a breakthrough in the paradigm of care, but without an adequate workforce, it usually does not succeed. Where workers are employed solely by the consumer, it is often impossible for the worker to earn adequate wages or get health benefits. Small employers can rarely afford to provide benefits, and with means-tested programs where the "employer" is poor, such benefits are impossible.

Workforce policies should support consumer-directed services by establishing wage rates and group health benefits that will attract and retain high-quality workers, and by making a public entity a co-employer. This can be done without sacrificing the consumer's control over care or the caregiver. Without policies like those found in California, Oregon, Washington, and Michigan, workers in a consumer-directed program may be further isolated from the real economy and at risk of losing the legal protections they enjoy under federal labor law.

Similarly, proposed federal legislation like the Community Living Assistance Services and Support (CLASS) Act, co-sponsored by Senators Mike DeWine (R-OH) and Edward Kennedy (D-MA), demonstrates the ability to create a program for the disabled centered around notions of consumer-directed care, but structured to ensure a stable and expanding workforce.[15] This legislation shows promise in its efforts to unite consumer direction with fair treatment of workers.

Support direct-care workers having a voice.

Consumers, workers, and providers share common cause in the development of a long-term care system that meets consumer needs for choice of setting and high-quality long-term care. When workers have a voice in the system, they will use it to address the problems they face as an invisible and largely neglected workforce. Their gains in wages and benefits and access to training programs and career ladders, won through collective bargaining and other methods of collective action, directly affect the availability and reliability of direct-care services.

Providers who use public funds to fight their workers' attempts to unite are missing an opportunity to work with other stakeholders to stabilize and expand the workforce and to improve quality of care. Better enforcement of laws requiring public funds to be used for public services in long-term care will allow workers more opportunities to join the movement that has brought gains to a half million workers in the United States.

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Long-Term Care Workers
Personal Story: Virginia

VIRGINIA, 57, HAS BEEN A HOME-care worker for most of her adult life. She provides care for a 56-year-old man with developmental disabilities and an 83-year-old woman who is deaf and has mental impairments. This is in addition to caring for her own mother, who is elderly and has several health impairments.

Each day starts around 6 a.m., with Virginia passing out medication, cooking meals, helping her clients take baths, cleaning up after them, and taking them to doctors' appointments. "It's God's work. I like to work with those who need help," says Virginia.

The state gives Virginia a total of $475.75 a month to care for her two clients—about $1.16 an hour for her constant 12-hour days. "That's what I get, it's as simple as that. It's not easy. You have no safety net at all."

The state pays Virginia a total of $475.75 a month to care for her two clients—about $1.16 an hour for her constant 12-hour days.

One of Virginia's biggest challenges, aside from finances, is finding health care coverage for herself. She has lived without health insurance for much of her life, getting by with over-the-counter remedies and a weak safety net of free clinics.

Within the past five years, she has had surgery for carpal tunnel syndrome and was hospitalized for injuries suffered in a car wreck. The health care bills totaled $8,000, which she was unable to pay. The accounts were turned over to a collection agency, and her credit is ruined.

Long-Term Care Advocacy—A Call to Action

Laurie M. Young, Ph.D., Executive Director
OWL, the voice of midlife and older women

THIS REPORT PRESENTS THE VOICES of the nation's key stakeholders in the increasingly loud discussion about the current and future landscape of the American long-term care system. Collectively, these voices are women's voices, as we learn through this report that long-term care remains in the hands of women. This is true throughout the continuum of service settings: home and community-based care, assisted living, and nursing homes. By bringing together the national organizations represented in this report, we focus on the critical issues we must address to deliver the quality long-term care services our seniors and disabled Americans require.

Last December, delegates from across the country convened at the 2005 White House Conference on Aging. The focus of this mandated conference—held only once a decade—was on preparing for the impact of America's aging baby boomers. We know all the statistics about how many boomers will soon turn 65 and start using the safety support network for seniors. For decades to come, the number of Americans over the age of 65—and over 85—will continue to increase dramatically. Delegates at the conference rightly identified long-term-care as a priority requiring a comprehensive national public policy overhaul.

I came to OWL following my own life experience as a member of the "sandwich generation." While raising a young daughter, I became my mother's caregiver during her end-of-life journey. In spite of my profession as a mental health advocate, I was unprepared for the daily experience of confronting the unnecessary barriers to quality care during my mother's last months. I learned quickly that decisions must often be made and actions taken in moments of crisis, and that there is a long learning curve when it comes to maneuvering the long-term care system, particularly in nursing homes. A hastily made decision when faced with hospital discharge can lead down a path that, while expedient at the time, ends in a maze of confusion regarding who is in charge of care and how effective caregivers can be in monitoring quality of services. The outcome of that confusion can be deadly.

It is clear that services must be delivered in a manner that ensures a higher quality of life for all—the care recipients and the paid and informal caregivers. To achieve a positive outcome and a healthy, responsive service system, all these stakeholders—all these women, who are predominantly in midlife and older—must be considered. Long-term care *is* a women's issue. In the brief on family caregivers, we learn that these individuals are "more likely to be caring for someone over the age of 85, and more than half of the spousal caregivers were 75 years of age or older." In addition, "[o]lder caregivers are most likely to be providing care to a spouse, and most of the spousal caregivers

> *I learned quickly that decisions must often be made and actions taken in moments of crisis, and that there is a long learning curve when it comes to maneuvering the long-term care system.*

are women." In fact, the existing system of long-term care in this country could not function without the contributions of millions of women as formal and informal caregivers of the nation's aging and disabled populations.

To move forward with a more progressive system of care, a cycle must be broken. It is imperative to understand how the contributions of midlife and older women as caregivers directly impact their own long-term care needs as they age, and their ability to find and secure affordable and appropriate long-term care. Too often, as the report notes, due to the demands of caregiving, women lose time out of the workforce, receive little or no pension income, and therefore become more reliant on Social Security for much of their retirement income. Caregiving, in turn, results in a loss of Social Security credits due to years out of the workforce, or part-time employment. We know that caregivers are at increased risk of mental and physical impairments, adding to the experience of many older women of managing multiple chronic diseases—often without the necessary financial or health insurance coverage.

In the brief on informal caregivers, we learn that "caregiving for an older parent increases the risk of living in poverty and relying on Supplemental Security Insurance (SSI) for income" and that "women who were caregivers were more than twice as likely to live in poverty and five times more likely to receive SSI than were non-caregivers." And so the cycle continues; today's caregivers are like to be tomorrow's care-recipients. According to the brief from the National Citizens' Coalition on Nursing Home Reform, "[the] stark reality is that 40 percent of all women will need some type of facility-provided care at least once in their lifetimes—for short-term rehabilitation or long-term living—and oftentimes the need for 24-hour care and nursing services can only be met in a nursing home, or an assisted living facility with appropriate medical and social services."

What can women and men then expect when faced with institutionally based care? We learn from the Service Employees International Union (SEIU) brief that the paid workforce faces formidable challenges in providing quality care:

> A personal care worker employed by a home health agency earns an average of $8.18 per hour, but that figure is deceptive in terms of annual income since very few workers can find full-time work. Wages are just slightly higher for certified nurse assistants, about $10 per hour. The result is that direct care workers leave in droves, and the ones who stay live in poverty. More than one-quarter live below the federal poverty line, and they are more likely than other workers to lack health insurance and to rely on public benefits to supplement their wages. Among single-parent nursing home and home health aides, 30 to 35 percent receive food stamps. Access to health insurance is a problem for direct care workers. About 40 percent of home care workers lack health insurance, and 25 percent of nursing home workers are similarly uninsured. As a result, many direct care workers must rely on publicly funded health care.

Thus, we learn from this brief that the unintended consequences for our frail elderly can be devastating when we devalue the work of the paid caregivers, predominantly midlife women, and often women of color.

Despite all the problems and barriers to a quality long-term care continuum of services, we know there is good news as well. The National Association on Area Agencies on Agency tells us that, given the choice, most older women want to "age in place." The desire to stay in their homes and communities is powerful, and through the successes of the Aging Network and the Older Americans Act, a range of services are available. This brief describes in detail the comprehensive services and outreach that exist within home communities.

Through the Older Americans Act and the Aging Network, we know how to meet the needs of our aging population. The technology of service

delivery is known and the needs of "over eight million older adults and 660,000 caregivers are met each year." It is often the case that public policy lags behind best practices, hindering their widespread implementation on the ground. Despite the fact that we know what to do, we still have an unnecessarily complicated process for funding the best in home and community-based care for aging seniors.

It's Time for Change

Neglect of these situations and of the mechanisms by which they perpetuate hardship and inequality for women will only magnify the problem for current and future generations of midlife and older women. OWL, as always, is committed to working with our membership, allied organizations, and policy-makers to ensure that the necessary changes, many of which are outlined in this report, are made. Our history of outspoken advocacy and activism on the issue of long-term care, our mission, and our sense of both outrage and optimism demand no less.

The policy recommendations of each of our authors are presented in three ways:

1. *We must provide adequate and appropriate levels of funding for Older Americans Act programs and the Aging Network.* The reauthorization of the Older Americans Act was the top priority resolution of the 2005 White House Conference on Aging. Along with proper funding levels, such barriers as the continued institutional bias in Medicaid funding impede the translation from best practices into best services. Services must include affordable housing and accessible transportation to make the system work. Policy-makers need to think of cost-shifting as well as cost-saving in making home and community-based services more readily and easily available. While additional funding will be needed during the decades to come with the aging of the baby boomer generation, it is not just how much money we spend, but how we spend it that makes for better public policy.

2. *We need a national policy to address the needs of informal caregivers in this country, who bear the greatest burden of service provision to the aging and disabled community.* Through legislation, we can begin to ameliorate the unfair financial burden carried by informal caregivers, which adds to the probability of financial distress or crisis as the caregiver herself ages. Legislation to provide paid family and medical leave benefits will be a critical step. Caregivers can no longer afford to be punished for the caring and loving choices they must make. Tax credits for caregivers and the ability to "earn" Social Security credits during work absences for caregiving responsibilities represent the beginning of compensation for caregivers and can help break the cycle in the transformation for caregivers to care recipients.

3. *We must increase the wages and benefits of the paid workforce in long-term care.* Providing care to the aging and infirm must be seen as the important, difficult, and challenging work it is. Raising wages and benefits will impact the quality of care across the board, from home and community-based care to assisted living and nursing homes. With a well-compensated, well-trained, and highly valued workforce, the rights of the residents of assisted-living and nursing homes will be ensured. Along with appropriate compensation, the institutions must be required to provide adequate staff to meet the needs of the residents. Too often, poor quality care and dangerous treatment is experienced because work shifts carry too few employees

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to meet residents' needs. With adequate compensation, more people will be willing to work in this industry. Workers must be able to organize to ensure that workplace protections, wages, benefits, and training will be addressed appropriately.

It's Time to Act

These policy recommendations require the following actions:

- *Key decision makers must move forward the legislation called for in the policy recommendations in each brief and summarized in this call to action.* This must occur on all three levels of government: local, state, and national. National policy must ensure that all Americans will have access to the quality of long-term care they deserve.
- *As constituents of policy makers, we all must be unrelenting in our efforts to educate decision makers about our needs and priorities.* We must continue to raise our voices and express frustration about the failure to value the aging and the infirm and those who care for them. We must educate ourselves about the devastating consequences of failing to develop a humane and comprehensive system of long-term care. And we must insist that there is an appropriate governmental role in ensuring that quality care is available, affordable, and accessible to all who need it.
- *We must demand a national program to help informal caregivers understand—long before a crisis occurs—how to use the long-term care system.* This program must educate those who are aging to plan for themselves and with their caregivers, so that informed decisions can be made both before and during a crisis.

OWL's 2006 Mother's Day Report is a call to action for all of us.

Contributing Organizations

The organizations listed below generously submitted briefs for this report. OWL is pleased to share their insights and analyses, and we urge interested readers to visit their Web sites to learn more about their efforts to improve the U.S. long-term care system.

The Consumer Consortium on Assisted Living (CCAL) is the only national consumer education and advocacy organization focused on the needs, rights, and protection of assisted living consumers and their caregivers and loved ones. CCAL educates consumers, trains professionals, and advocates for assisted living issues. CCAL works collaboratively with a broad spectrum of people and organizations to support quality assisted living and to provide options for individuals with low incomes. www.ccal.org

The National Alliance for Caregiving is a nonprofit coalition of national organizations focusing on issues of family caregiving. Alliance members include grassroots organizations, professional associations, service organizations, disease-specific organizations, a government agency, and corporations. The Alliance's mission is to be the objective national resource on family caregiving with the goal of improving the quality of life for families and care recipients. www.caregiving.org

The National Association of Area Agencies on Aging (n4a) is the leading voice on aging issues for Area Agencies on Aging (AAAs) across the country and a champion of Title VI (of the Older Americans Act) Native American aging programs in our nation's Capital. n4a also provides training, technical assistance, and support to the national network of 650 AAAs and 240 Title VI agencies to assist them in achieving the collective mission of building a society that values and supports people as they age. www.n4a.org

The National Citizens' Coalition for Nursing Home Reform (NCCNHR) is a nonprofit membership organization founded in 1975 by Elma L. Holder to protect the rights, safety, and dignity of America's long-term care residents. www.nursinghomeaction.org

The Service Employees International Union (SEIU) is an organization of more than 1.8 million members united by a belief in the dignity and worth of workers and the services they provide and dedicated to improving the lives of workers and their families and creating a more just and humane society.
www.seiu.org

Additional Resources

Listed below are organizations and programs cited in this report. Please visit their Web sites for more information.

AARP
http://www.aarp.org

Aging Network
http://www.ianet.org

Alzheimer's Association
http://www.alz.org

Assisted Living Workgroup
http://www.aahsa.org/alw.htm

Center for Excellence in Assisted Living
http://www.theceal.org

Centers for Medicare and Medicaid Services
http://www.cms.hhs.gov

National Center on Assisted Living
http://www.ncal.org

National Family Caregivers Support Program
http://www.aoa.gov/prof/aoaprog/caregiver/caregiver.asp

National Long-Term Care Ombudsman Program
http://www.ltcombudsman.org

Pioneer Network
http://www.pioneernetwork.net

Urban Institute, The Retirement Project
http://www.urban.org/toolkit/issues/retirementproject/index.cfm

Glossary

Activities of Daily Living (ADL) - Simple tasks performed on a day-to-day basis, such as getting dressed, eating, or brushing your teeth.

Americans with Disabilities Act (ADA) - The Americans with Disabilities Act gives civil rights protections to individuals with disabilities similar to those provided to individuals on the basis of race, color, sex, national origin, age, and religion. It guarantees equal opportunity for individuals with disabilities in public accommodations, employment, transportation, state and local government services, and telecommunications.

Assisted Living Facility - A residential care setting that combines housing, support services and health care used by people who are not able to live on their own, but do not need the level of care that a nursing home offers.

Cognitive Impairment - Deterioration of conscious intellectual activity. Symptoms may include short- or long-term memory impairment, impaired judgment, difficulty managing routine tasks, disorientation to time and place, fearfulness or paranoia, wandering, and repetitive actions.

Community-Based Care - Assistance with daily activities that generally helps people with disabilities to remain in their homes. Community-based services include personal care, chore assistance, transportation, and group meals. People who use these services live in a range of settings: their own homes or apartments, assisted living facilities, adult foster homes, or other supportive housing.

Consumer-Directed Services (CDS) - This allows consumers or their guardians or designated representatives to be legal employers of record for the service providers. Under CDS, consumers have greater control and responsibility for their care.

Continuing Care Retirement Communities - Residential communities set up to provide residents with easy access to health care.

Direct Care Workers - Direct care workers are people who care for individuals of all ages who have disabilities or impairments and need their assistance. They can work in someone's home or in a nursing home.

Family and Medical Leave Act (FMLA) - Passed in 1993, the U.S. Family and Medical Leave Act mandates up to 12 weeks of unpaid medical leave in a 12-month period of time, for employees of companies with more than 50 employees. Under this act, people can also take leave to care for a sick child, parent, or spouse.

Informal Caregiving - Caregiving provided by families and friends, who offer unpaid assistance for the physical and emotional needs of a loved one, ranging from partial assistance to 24-hour care.

Long-Term Care Insurance - Coverage that, under specified conditions, provides skilled nursing, intermediate care, or custodial care for a patient (generally over age 65) in a nursing facility or his or her residence following an injury.

Medicaid - A program sponsored by the federal government and administered by states that is

intended to provide health care and health-related services to low-income individuals.

Medicaid Home and Community-Based Waiver Programs – Programs which can be used to fund services not otherwise authorized by the federal Medicaid statute, such as respite care, home modifications, and non-medical transportation. Waivers can also be used to provide optional Medicaid services for waiver participants not offered to other adult Medicaid beneficiaries, such as case management and personal assistance services.

Medicare - A federal health insurance program for people age 65 and older and for individuals with disabilities.

Nursing Home Reform Law (NHRL) – The objective of this law is to ensure that residents of nursing homes receive quality care that results in their ability to achieve or maintain their "highest practicable" physical, mental, and psychosocial well-being. To secure quality care in nursing homes, the NHRL requires the provision of certain services to each resident and establishes a Residents' Bill of Rights. Nursing homes receive Medicaid and Medicare payments for long-term care of residents only if they are certified by the state to be in substantial compliance with the requirements of the NHRL.

Older Americans Act - Federal legislation created to form a network of state and area agencies on aging. These agencies help plan and fund programs and services for persons over the age of sixty.

Social Security - A federal program that provides retirement income, health care for the aged, and disability coverage for eligible workers and their dependents.

Supplemental Security Insurance (SSI) - A federal income supplement program funded by general tax revenues (not Social Security taxes). It is designed to help aged, blind, and disabled people who have little or no income; and it provides cash to meet basic needs for food, clothing, and shelter.

U.S. Senate Special Committee on Aging - The United States Senate Special Committee on Aging was initially established in 1961 as a temporary committee, and became a permanent committee in 1977. As a special committee, it has no legislative authority, but it studies issues related to older Americans, particularly Medicare and Social Security.

Wellness Programs – Programs provided by employers to employees that are designed to improve awareness of the factors that can affect health and longevity and to enable employees to take increased responsibility for their health behaviors.

White House Conference on Aging - A national event held once a decade to develop recommendations for the President and Congress on aging-related issues, policy, and research.

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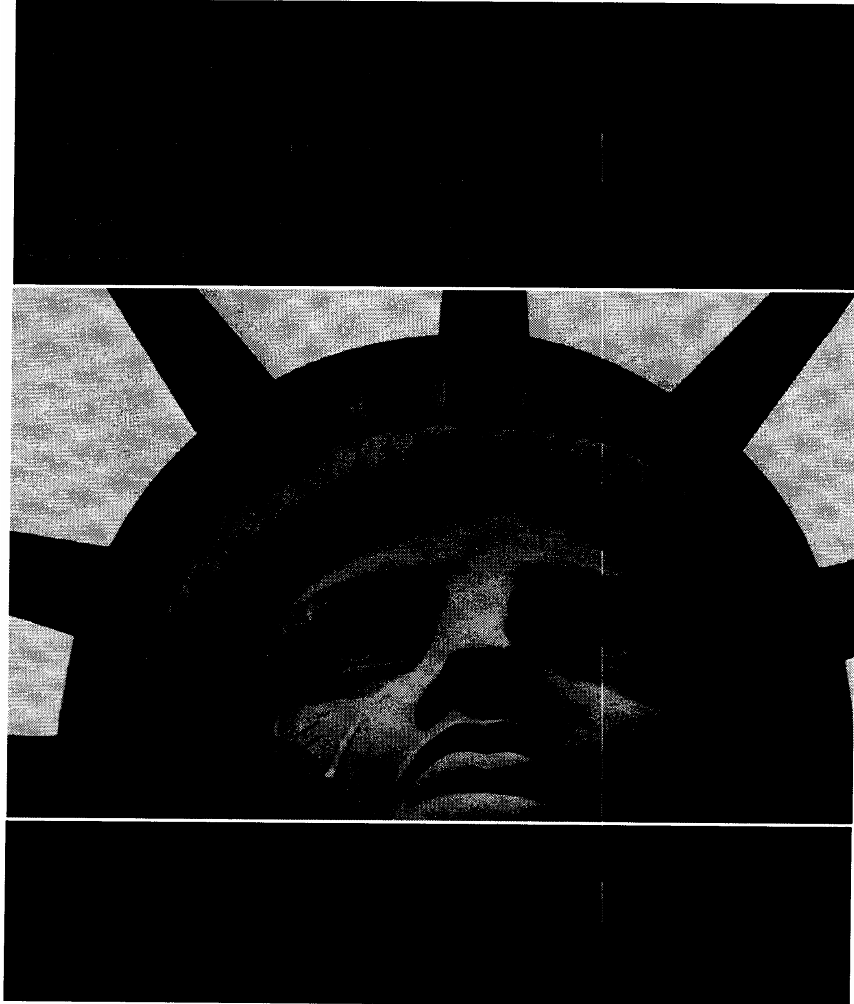

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