

EXAMINING THE FINANCING AND DELIVERY OF LONG-TERM CARE IN THE U.S.

HEARING BEFORE THE SUBCOMMITTEE ON HEALTH OF THE COMMITTEE ON ENERGY AND COMMERCE HOUSE OF REPRESENTATIVES ONE HUNDRED FOURTEENTH CONGRESS SECOND SESSION

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EXAMINING THE FINANCING AND DELIVERY OF LONG-TERM CARE IN THE U.S.

TUESDAY, MARCH 1, 2016

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

The subcommittee met, pursuant to call, at 10:15 a.m., in room 2322 Rayburn House Office Building, Hon. Joe Pitts (chairman of the subcommittee) presiding.

Members present: Representatives Pitts, Barton, Guthrie, Shimkus, Murphy, Burgess, Lance, Bilirakis, Long, Ellmers, Bucshon, Brooks, Collins, Schakowsky, Butterfield, Castor, Sarbanes, Matsui, Schrader, Ca AE1rdenas, and Pallone (ex officio).

Staff present: Rebecca Card, Assistant Press Secretary; Graham Pittman, Legislative Clerk, Health; Michelle Rosenberg, GAO Detailee, Health; Chris Sarley, Policy Coordinator, Environment and Economy; Jennifer Sherman, Press Secretary; Heidi Stirrup, Policy Coordinator, Health; Josh Trent, Deputy Chief Counsel, Health; Christine Brennan, Minority Press Secretary; Jeff Carroll, Minority Staff Director; Tiffany Guarascio, Minority Deputy Staff Director and Chief Health Advisor; Rachel Pryor, Minority Health Policy Advisor; Samantha Satchell, Minority Policy Analyst; Matt Schumacher, Minority Press Assistant; and Andrew Souvall, Minority Director of Communications, Outreach and Member Services.

OPENING STATEMENT OF HON. JOSEPH R. PITTS, A REPRESENTATIVE IN CONGRESS FROM THE COMMONWEALTH OF PENNSYLVANIA

Mr. PITTS. The subcommittee will come to order. The chair will recognize himself for an opening statement.

Today the Health Subcommittee will examine the financing and delivery of long-term care in the U.S. Long-term care largely differs from health coverage or medical care. I know every member of this committee wants to ensure that frail, elderly seniors, or disabled individuals across the country receive high quality care.

We want to see each person treated with the dignity and respect that they deserve, and we want a long-term care system that empowers each person and respects individual preferences. Unfortunately, as we will hear from our witnesses today, many experts warn that we are facing a coming crisis in the provision of long-term care. Most notably, we face a demographic headwind with 10,000 baby boomers turning 65 every day.

Additionally, as life expectancy increases so too does the need to provide care for aging individuals, yet our private market is not as robust as needed. Our public payers are strained and many individual Americans face high out-of-pocket costs for providing a long-term care for themselves or a loved one. Unfortunately, too few Americans are currently prepared to pay for even a modest amount of long-term care whether through insurance or savings.

As we engage in today's hearing, I think it is important to remember our long-term care crisis affects all Americans. If the long-term care challenge is left unaddressed it will impact the elderly who require services, the middle-aged who are often responsible for caring for their aging parents, and the children who could be left responsible footing the bill for public programs.

As we embark on examining how we can confront the long-term care challenge, it is important we learn from failed ideas of the past. For example, in 2010, the ACA created a new federal entitlement program called the CLASS Act. The statute required that the CLASS Act be solvent over a 75-year period, and the program failed to meet tests for actuarial solvency. CLASS Act was found to be fiscally unsound; was ultimately repealed in subsequent legislation.

This committee knows all too well what financially unsound programs look like. Medicaid and Medicare are both facing growing financial strains as costs soar and demand increases. Medicaid is consuming increasing portions of state budgets, Medicare's long-term unfunded obligations are estimated over \$35 trillion in today's dollars. So it is understandable that many members of this committee are wary of proposals that resemble a new entitlement, but caution against new entitlements does not equal close-mindedness to new approaches.

There are many ideas about ways to improve the outlook for financing and delivering of long-term care in the country. For example, just in February, three bipartisan proposals have been offered. So today's hearing provides members an opportunity to learn more about the state of long-term care in our country and to examine the types of policy choices facing Congress if it wants to reform the current system to provide high quality care without bankrupting future generations.

Clearly, we need to find better ways to encourage private market solutions. We need to understand what the research tells us about what is working in the private and public sectors. We need to know barriers to efficient high quality care exist in our public programs, and we need to better understand how to encourage individuals and their families to plan for the future.

I appreciate our witnesses being here. We look forward to your testimony. Is anyone seeking time on our side? If not, I yield back, and at this point recognize Ms. Matsui of California filling in for Ranking Member Green as ranking member.

[The prepared statement of Mr. Pitts follows:]

PREPARED STATEMENT OF HON. JOSEPH R. PITTS

The Subcommittee will come to order.

The Chairman will recognize himself for an opening statement.

Today, the Health Subcommittee will examine the financing and delivery of longterm care (LTC) in the U.S. While long-term care largely differs from health coverage or medical care, I know every member of this Committee wants to ensure that frail elderly seniors or disabled individuals across the country receive highquality care.

We want to see each person treated with the dignity and respect that they deserve. And we want a long-term care system that empowers each person and respects individual preferences.

Unfortunately, as we will hear from our witnesses today, many experts warn that we are facing a coming crisis in the provision of long-term care. Most notably, we face a demographic headwind, with 10,000 Baby Boomers turning 65 each day. Additionally, as life-expectancy increases, so too does the need to provide care for aging individuals.

Yet, our private market is not as robust as needed, our public payers are strained, and many individual Americans face high out-of-pocket costs for providing longterm care for themselves or a loved one. Unfortunately, too few Americans are currently prepared to pay for even a modest amount of long-term care—whether through insurance or savings.

As we engage in today's hearing, I think it's important to remember our long-term care crisis affects all Americans. If the long-term care challenge is left unaddressed, it will impact the elderly who require services...the middle aged who are often responsible for caring for their aging parents...and the children who could be left responsible footing the bill for public programs.

As we embark on examining how we can confront the long-term care challenge, it's important we learn from failed ideas of the past. For example, in 2010, the ACA created a new federal entitlement program called the CLASS Act. The statute required that the CLASS Act be solvent over a 75-year period, and the program failed to meet tests of actuarial solvency. The CLASS Act was found to be fiscally unsound and was ultimately repealed in subsequent legislation.

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So, today's hearing provides Members an opportunity to learn more about the state of long-term care in our country—and to examine the types of policy choices facing Congress if it wants to reform the current system to provide high quality care without bankrupting future generations.

Clearly, we need to find better ways to encourage private market solutions. We need to understand what the research tells us about what's working in the private and public sectors. We need to know barriers to efficient, high-quality care exist in our public programs. And we need to better understand how to encourage individuals and their families to plan for the future.

I appreciate our witnesses being here and we look forward to your testimony.

I yield the remainder of my time to _____.

OPENING STATEMENT OF HON. DORIS O. MATSUI, A REPRESENTATIVE IN CONGRESS FROM THE STATE OF CALIFORNIA

Ms. MATSUI. Thank you, Mr. Chairman. And thank you very much for having this important hearing on a critical issue that affects millions of Americans—the financing and delivery of long-term care. And I want to thank our witnesses for being here today.

Long-term services and supports are medical and personal care assistance services for people who have difficulty completing daily living activities over a prolonged period of time, from feeding or bathing to meal preparation or management of medications. Approximately 12 million Americans of all ages require long-term care

for medical needs associated with developmental disabilities, traumatic injuries, behavioral health or chronic conditions. Elderly individuals in particular are at increased risk requiring long-term care.

So who is providing and paying for this care in our country? Unfortunately, we don't have a robust system in place that works for families. In fact, much of both the care and financing often falls on the family. Unpaid caregiving service as a front line across the country, 70 percent of working adults provide unpaid care for family members or friends. This is an estimated \$470 billion annually in labor costs. This lost productivity is estimated to the economy \$34 billion a year.

Oftentimes, women are the ones who disproportionately bear the burden of providing unpaid long-term care. Women often are called on to care for their family members at a time when they may not be able to reenter the workforce. Women also live longer. They find themselves unable to save for retirement when supporting family members. Our daughters, granddaughters, or mothers should not have to carry the weight of this broken system any longer.

Despite the growing need for long-term care due to our aging population, there is no viable financing system in this country to support it. It is a common misconception that Medicare covers the long-term care in this country. However, it only covers limited circumstances such as care immediately following a hospital stay.

In fact, Medicaid is the single largest payer of long-term care in the United States. However, most middle class families do not qualify for Medicaid and must pay out of pocket to spend down their assets before receiving benefits. And for Americans with disabilities, successful employment can lead to a loss of Medicaid coverage and thus create a disincentive to participate in the workforce. We need to create a system that allows recipients to receive services and support while remaining employed.

Without Medicaid or private insurance, on average families are spending about \$140,000 on long-term care for their loved ones. For working families who are trying to pay their mortgage, send their children to college and take care of the long-term medical needs of their loved ones these costs are devastatingly high. The reality is clear. Long-term care financing is in a crisis state in this country and is one of the greatest threats to retirement security for seniors and the adult family members who care for them. It is time for us to act to protect our seniors, people with disabilities and those who care for them.

Today we will hear about major bipartisan reports which have independently agreed on three major actions Congress must take. First, we must strengthen and simplify Medicaid long-term care. Second, we need to build a more consumer-friendly long-term care private insurance market. Finally, we must create a program that will be there for those with catastrophic long-term care costs. Together we must commit to finding a sustainable means for financing and delivering quality long-term care to our loved ones because our families deserve more.

Mr. Chairman, we received many statements for the record for this hearing. I ask unanimous consent to submit statements from our good friend and colleague Representative Debbie Dingell who

has certainly worked on these issues for a long time, the Christopher and Dana Reeve Foundation, and the National Academy of Elder Law Attorneys. And I ask that these be submitted for the record.

Mr. PITTS. And I will add to those statements from the American Health Care Association, the National Center for Assisted Living, and America's Health Insurance Plans.

Without objection, so ordered.

[The information appears at the conclusion of the hearing.]

Ms. MATSUI. Thank you, and I yield back.

Mr. PITTS. The chair thanks the gentlelady. Now in the place of Chairman Upton, the chair recognizes Dr. Burgess 5 minutes for an opening statement.

**OPENING STATEMENT OF HON. MICHAEL C. BURGESS, A
REPRESENTATIVE IN CONGRESS FROM THE STATE OF TEXAS**

Mr. BURGESS. Thank you, Mr. Chairman. I appreciate the recognition. I actually had not prepared or planned on delivering an opening statement, but it does occur to me that we have had similar hearings multiple times in the past. Ms. Matsui just asked the question who is paying for long-term care. Mr. Chairman, you wondered aloud if there was a private sector solution, and indeed there are private sector solutions.

The private insurance market in long-term care was hurt by the introduction of the CLASS Act and then the abandonment of the CLASS Act. I think it was very disruptive in the market. Look, long before I ran for Congress, my father was disabled and my mother told me that I needed to get long-term care insurance. She said if you don't buy it now before you are 50, you won't be able to afford it when you really need it. And it turns out that was good advice that she gave. Long-term private long-term care policy is expensive. Premiums run between 1,500 and \$2,500 a month. Yes, they are after-tax dollars.

But I can really think of no more loving gift that a parent can give their child than to prepare for what may happen in the future. For me, it just seems like responsible financial planning and I do wonder why it is not more of the financial planning that people do in their lives.

Look, 11 years ago, this committee, this subcommittee and this full committee passed language in the Deficit Reduction Act for what was known as the Partnership Program. This allowed for the protection of some assets in an estate. If a person had a private long-term care insurance policy, then the amount of the spend-down was protected to the extent of the private policy that they had. It was not as robust as perhaps providing full deductibility of a long-term care insurance premium, but it at least provided some incentive for people to consider a private long-term care insurance policy.

Again the CLASS Act was very disruptive. It was disruptive to the marketplace. We have seen our premiums go up over the last 10 or 15 years. That is unfortunate. But I do think this subcommittee and this committee should do what it can to get people my age to understand that this is important for you to do for your family.

Yes, there need to be safety net programs. No argument there. There need to be valuable programs for people who don't have other resources or other places to go. But I just remember my mother who was the primary caregiver for my father who was disabled by a stroke in 1989 and lived until 2005. You need to be prepared for these sorts of things. They can happen to you.

So Mr. Chairman, I appreciate the time that you have given me today. I will be happy to yield back and I am anxious to hear the testimony of our witnesses and what has happened over the last ten years in this space. I yield back.

Mr. PITTS. The chair thanks the gentleman, and now recognizes the ranking member of the full committee, Mr. Pallone, 5 minutes for an opening statement.

OPENING STATEMENT OF HON. FRANK PALLONE, JR., A REPRESENTATIVE IN CONGRESS FROM THE STATE OF NEW JERSEY

Mr. PALLONE. Thank you, Mr. Chairman, and thank you for holding this hearing today to discuss long-term care, an issue that is very important to me.

Today we face a long-term care crisis that is forcing millions of Americans to drain all of their resources before they get any support from the federal government. This crisis is not only affecting those that need long-term care but also their families, sons and daughters who have no other choice than to spend hours every week caring for their parents.

This simply cannot continue and I hope that today's hearing is the beginning of an ongoing conversation that leads to real action to address this crisis. After all, the crisis is not new. Congress has been discussing a solution for decades. I worked with the late Senator Kennedy and Mr. Dingell on the inclusion of a public benefit for long-term care in the community setting as part of the Affordable Care Act. While this provision known as the CLASS Act was not a perfect piece of legislation, the ideas behind it were worth fighting for, namely, the idea that there is a desperate need for a strong federal program to help with long-term care costs.

This hearing is timely in that it falls just weeks after three separate and independent reports authored by those across the political spectrum have agreed on just that point. The three reports have all independently agreed on three actions Congress must take. The first is to strengthen and simplify Medicaid long-term care; the second, to build a more consumer-friendly long-term care private market; and third, to create a strong federal program that will be there for those with catastrophic long-term care costs when they need it.

And I could not agree more and that is why I plan to introduce legislation some time this year to provide a federal role in long-term care financing. Seventy percent of Medicare seniors will someday need long-term care services and support and they deserve a better option when faced with catastrophic out-of-pocket costs rising into the hundreds of thousands of dollars. Congress must do more to improve the quality and the affordability of these services, and I believe that we can achieve some of these goals by establishing a Part E option in the Medicare program to provide for this

care. Now this can be done in many different ways, but whatever form this effort takes we must act with a sense of urgency.

The current system forces people to sell off all their assets in order to become eligible for Medicaid. While Medicaid was put in place to help our most vulnerable, it is currently funding 51 percent of long-term care expenditures, a full third of the program's total spending. And because many people never purchase one of the available albeit expensive plans on the market, private insurers only pay for about eight percent of care.

The fact that both public and private insurance plans provide so little in terms of long-term care benefits means that these costs are left to be shouldered by the elderly, the disabled and their families. These direct out-of-pocket costs account for \$53 billion of long-term care spending and this is too great a burden for many who do their best to manage without care, who often depend on family caregivers to provide health assistance free of charge.

An estimated 52 million unpaid caregivers make it possible for their loved ones to stay out of nursing homes and hospitals. As anyone who has ever cared for a loved one knows, this is often an arduous task and often means missing work. These costs to society add up and not fully tracked, but conservative estimates have found that 17 percent of working adults provide unpaid care for family members or friends providing an estimated \$470 billion annually in labor costs.

The federal government must be part of the solution and I stand ready to work with anyone on any of these options to start addressing this crisis because I think I simply can't, I just don't think we can afford to wait any longer. I thank you, Mr. Chairman. I yield back.

Mr. PITTS. The chair thanks the gentleman. As usual, all members' written opening statements will be made a part of the record.

That concludes the opening statements and now we will go to our panel. And I would like to thank our panel for coming today. I will introduce them in the order of their presentation. First, Dr. Alice Rivlin, Ph.D., Co-chair, Long-Term Initiative, Bipartisan Policy Center, Senior Fellow, Economic Studies Program, The Brookings Institution. And then Dr. William J. Scanlon, Ph.D., Consultant, West Health Institute and National Health Policy Forum. And finally, Ms. Anne Tumlinson, CEO, Anne Tumlinson Innovations, Founder of Daughterhood.org.

Welcome. Your written testimony will be made a part of the record. You will each be given 5 minutes to summarize. So at this point, the chair recognizes Dr. Rivlin 5 minutes for your summary.

STATEMENTS OF ALICE RIVLIN, PHD, CO-CHAIR, LONG-TERM CARE INITIATIVE, BIPARTISAN POLICY CENTER, SENIOR FELLOW, ECONOMICS STUDIES PROGRAM, THE BROOKINGS INSTITUTION; WILLIAM J. SCANLON, PHD, CONSULTANT, WEST HEALTH INSTITUTE AND NATIONAL HEALTH POLICY FORUM; AND, ANNE TUMLINSON, CEO, ANNE TUMLINSON INNOVATIONS LLC AND FOUNDER OF DAUGHTERHOOD.ORG

STATEMENT OF ALICE RIVLIN

Ms. RIVLIN. Thank you very much, Chairman Pitts. And glad to see my old friend, Congresswoman Matsui, and especially to have Mr. Pallone here because he has been such a champion for long-term care for such a long time. I am happy to be back before this subcommittee which is never afraid to take on complex issues and to work in a bipartisan manner. The last time I was here we were talking about the SGR, so you are not afraid of the tough stuff.

I have worked on long-term care services and supports for a long time and I have recently had the privilege of co-chairing the Long-Term Care Initiative at the Bipartisan Policy Center along with several distinguished former elected officials. Nobody ever elected me to anything. But we produced just last month a report entitled "Initial Recommendations to Improve Financing of Long-Term Care," which is appended to my testimony and which is one of the three reports that have been referred to already.

I don't need to remind this committee that the need is increasing and that the burden on families, on seniors themselves and on the public programs, especially Medicaid, is increasing very, very rapidly and will certainly increase more as the baby boomers age.

Many efforts have been made to find a comprehensive solution to long-term care financing. The chairman and several of you have referred to the CLASS Act. Recently, a growing consensus has formed among a number of groups that steps, incremental steps, could be taken to improve the availability and affordability of long-term services and supports to America's most vulnerable populations. And so we have addressed ourselves to that problem.

One thing that is important and this committee knows very well is that over the last few years the whole emphasis has shifted from institutional care and nursing homes to ways of keeping people in the community where they are happier and where they often can be served cheaper.

So the group that I worked with addressed ourselves to the question, is there a set of practical policies that could command bipartisan support and improve care for older Americans with disabilities, take significant pressure off families and Medicaid and not break the bank? We came up with four proposals. One is a major effort to make private long-term care insurance more affordable and more available. Long-term care should be an insurable risk and if more people bought long-term care insurance during their working years there would be less pressure on their savings, their family resources and Medicaid when they became disabled.

Our report recommends developing a new type of private insurance product, which we call retirement long-term care insurance, which would cover long-term care for a limited period after a substantial deductible or waiting period and would have co-insurance.

This is not Cadillac long-term care insurance. This is bare bones but we believe it would help. It would have inflation protection and a nonforfeiture benefit. Employers would be encouraged to offer such policies as the default option as part of a retirement package. These policies if offered through employers and public-private insurance exchanges could, we estimate, cut premiums in half. We also suggest that penalty-free withdrawals be allowed from retirement plans such as 401(k)s beginning at age 45 for the purchase of such insurance.

We will also recommend designing a long-term care option, a federal long-term care option, for those with catastrophic costs. We would recommend streamlining the Medicaid home and community-based care options to encourage more effective care in lower cost settings. The Congress has already moved in this direction, but the waiver process is unbelievably complicated and we think it could be simplified.

And finally, we recommend ensuring that working people with disabilities in need of long-term care services and support do not lose their access to those services under Medicaid as their earnings increase, a cheaper buy-in for just those services. Thank you, Mr. Chairman and members of the committee, and we will be happy to work with you over the longer run and to answer any questions.

[The prepared statement of Ms. Rivlin follows:]

Testimony of Alice M. Rivlin*

Co-Chair, Long-Term Care Initiative, Bipartisan Policy Center
 Senior Fellow, Economic Studies Program, The Brookings Institution

U.S. House of Representatives Committee on Energy and Commerce
Subcommittee on Health Hearing: *Examining the Financing and Delivery of Long-Term Care in the U.S.*
March 1, 2016

Chairman Pitts, Ranking Member Green: I am happy to be back before this Subcommittee, which is never afraid to take on complex issues of great importance to millions of Americans. I have worked on long-term services and supports (LTSS) for a long time and have recently had the privilege of co-chairing the Long-Term Care Initiative at the Bipartisan Policy Center (along with former Senators Bill Frist and Tom Daschle and former Governor and Secretary of Health and Human Services, Tommy Thompson). Our February 2016 report, *Initial Recommendations to Improve the Financing of Long-Term Care*, appended to my testimony, outlines a set of doable, practical changes in both public and private programs that could improve the availability and affordability of long-term services and supports.

I don't need to remind this committee that Americans are living longer, and many of us will need help with the ordinary activities of daily living and suffer cognitive impairments that make it dangerous for us to cope alone. The number of people needing LTSS is rising and expected to double in the next 35 years or so.

Responsibility for LTSS is shared among seniors and people with disabilities themselves, family, friends, and volunteer care-givers; communities, state, and federal government. This shared-responsibility system is severely stressed, and will become increasingly unable to cope as the numbers needing care increase. Growing burdens fall on families, often daughters and daughters-in-law, who must manage daily conflicts between earning a living, caring for children, and meeting the needs of elderly or disabled relatives. Growth in Medicaid, the largest payer of long-term services and supports at about \$123 billion per year, stresses state and federal budgets as spending for older Americans and individuals with disabilities competes with budgets for education and other investments in young people.

Many efforts to find a comprehensive solution to long-term care financing have failed—evidenced by passage and subsequent repeal of the Community Living Assistance Services and Supports (CLASS) Act and failure of the federal Long-term Care Commission to reach consensus on financing recommendations. Recently, however, a growing consensus has emerged around a set of incremental steps, which, if taken together could greatly improve the availability and affordability of long-term services and supports to America's most vulnerable populations and take some of the burden off families and Medicaid in a fiscally responsible way. In recent weeks, The Bipartisan Policy Center and The Long-term Care Collaborative have offered similar sets of recommendations, as has LeadingAge, a key provider association.

* The views expressed in this statement are my own and do not necessarily reflect those of staff members, officers, or trustees of the Brookings Institution or The Bipartisan Policy Center.

While policymakers failed to agree on big legislative solutions, amazing progress has been made at the community level in finding new ways of keeping older Americans and people with disabilities out of institutions and in the community where they are happier and less isolated and can be served more effectively and cheaper. There has been an explosion of assisted living facilities, continuing care communities, senior villages, senior centers, senior daycare, and use of home health aides of various sorts. Growth in home and community-based services (HCBS) has been rapid, while the population served by traditional nursing homes has been virtually flat. Medicaid, with the support of both parties in Congress, has moved to increase the availability of home and community-based services.

The group working on the Bipartisan Policy Center's Long-Term Care Initiative addressed the question: Is there a set of practical policies that could command bipartisan support that would improve the care of older Americans with disabilities, take significant pressure off families and Medicaid, and not break the bank? We came up with four proposals.

Make private long-term care insurance more affordable and available. Long term care ought to be an insurable risk. If more people bought Long-Term Care Insurance (LTCI) in their earning years, there would be less pressure on their savings and family resources and Medicaid when they became disabled. But both demand and supply of LTCI are weak and falling. Potential customers are reluctant to buy because it is costly and the need seems remote and hard to think about. Carriers find it difficult to price a product that will be used far in the future and fear losing money if customers live and use services for a long time. Many insurance companies have stopped offering LTCI.

Our report recommends developing a new type of private insurance product: "retirement long-term care insurance," which would cover long-term care for a limited period (2-4 years) after a substantial deductible or waiting period and would have coinsurance. The insurance would provide inflation protection, which helps to ensure benefits keep pace with the rising costs of care, and a non-forfeiture benefit, which allows lapsed policyholders to access a limited benefit. Employers would be encouraged to offer such policies as a default option as part of a retirement plan. These policies, if offered through employers and public and private insurance exchanges, could cut premiums in half according estimates done by Milliman, LLC, for the Bipartisan Policy Center and other organizations. Penalty-free withdrawals would be allowed from retirement plans, such as 401(k) plans and IRAs, beginning at age 45, exclusively for the purchase of retirement LTCI.

Design a federal long-term care insurance option for those with catastrophic costs. Part of the reluctance of carriers to offer LTCI relates to the difficulty of predicting costs far in the future and the fact that a few policy holders may have extremely high costs for a very long time. A public program, covering truly catastrophic long-term care spending, could overcome this reluctance and reduce the cost of private LTCI. Catastrophic insurance, combined with retirement LTCI from the private market, could substantially relieve families and Medicaid. The cost of this program should be fully offset so as not to add to the deficit.

Streamline Medicaid home and community-based care options to encourage more effective care in lower-cost settings. While Congress has been proactive in encouraging state Medicaid programs to shift care settings from institutions to home and community-based care, states continue to face a daunting federal waiver process and multiple state options. Securing waivers requires complex negotiations between states and the federal government, and each of the existing state options have disincentives.

Home and community-based options should be simplified into a single streamlined state plan amendment process.

Ensure that working people with disabilities in need of long-term services and supports do not lose access to their long-term services and supports as earnings increase. Individuals with modest employment incomes risk losing access to services that permit them to remain on the job. Existing Medicaid “buy-in” programs are often costly. Building on the “Achieving a Better Life Experience,” or “ABLE” Act, states could be given the option to offer a lower-cost, Medicaid buy-in for long-term services and supports designed to “wrap around” private health insurance or Medicare. Under this option, working individuals with disabilities would pay an income-related, sliding-scale premium.

Mr. Chairman and members of the Committee, thank you again for the opportunity to share my thoughts on this issue. It is one of America’s big challenges, but it’s an even bigger opportunity for a constructive bipartisan policy process. I look forward to continued dialogue and will keep you apprised of forthcoming recommendations by BPC’s Long-Term Care Initiative in 2016 and 2017.

Mr. PITTS. The chair thanks the gentlelady and now recognizes Dr. Scanlon five minutes for your summary.

STATEMENT OF WILLIAM SCANLON

Mr. SCANLON. Thank you very much, Mr. Chairman and members of the subcommittee. I am very pleased to be here as you discuss the issue of financing and delivery of long-term care services. Long-term care services and financing have been an area of concern during my entire career on health policy which is now about a 40-year period. Much of what you are going to hear from me also will be in agreement of what you heard from Dr. Rivlin, because I think we have recognized the nature of the problem for the long term and that the issue is finding the right set of options in terms of trying sort of to address it. The need to address it has become more acute as the aging of the baby boomer generation sort of adds sort of to the numbers of people needing long-term care so that it is a critical issue today.

In my view, long-term care is quite distinct from other health care services both in the nature and the provision of those services and its financing. Unlike medical care, which aims at treating or managing diseases or conditions, long-term care as you have heard involves assistance that determines how one lives one's life in the presence of a disability. It is the assistance with activities to daily living like bathing, dressing, eating, and toileting that we all would do ourselves but those with disabilities cannot. Long-term care is not provided solely by health professionals, as you have heard family members are probably the principal suppliers of sort of long-term care services. Long-term care is also quite distinct in its financing. There is very little sort of insurance. The predominant payer is state Medicaid programs which constitute about two-thirds of all spending, with out-of-pocket spending comprising another one-fifth of total spending.

Medicaid as the primary source of payment is problematic for both individuals and the programs. Only individuals with limited resources are eligible for Medicaid. Some people outlive their savings and become Medicaid-eligible when a long-term care need arises, others exhaust their savings paying for long-term care needs that they have incurred.

What services a Medicaid beneficiary receives depends greatly on where one resides. The options for home versus nursing home care differ by state. Medicaid offered in-home services supplement what families provide, do not replace them. An individual's preferences or relief of the burden on family caregivers may not be significant enough factors determining what services are offered.

For Medicaid programs, long-term care is the largest share of their spending and generally has been the fastest growing part of the program. States have had some success in moderating spending growth as there has been a substantial shift from nursing homes to home and community care following the enactment of the Medicaid waivers. States have also restricted the number of nursing home beds through moratoria on new construction of new beds and sort of a stricter certificate of need. As a result, today we have one million fewer beds than we would have expected given the size of the elderly population.

The challenge for the future magnified by the Baby Boom generation involves reforming long-term care financing in ways that improve the well being of people with disabilities and their caregivers and that are affordable and sustainable. Unlike medical care, a solution is unlikely to be found in finding efficiencies that reduce spending. Medicaid programs efforts and individuals paying out of pocket sensitivity to costs have likely prevented considerable inefficiency already.

The need to find another way to finance long-term care is not a new idea. Serious discussions about alternatives to the current system began in the early '80s and with the primary focuses on expanding private long-term insurance. This seemed and is a reasonable approach as needing long-term care is an insurable event, a risk not a certainty, and insuring for that risk rather than saving for it makes more sense.

Despite multiple efforts, the private long-term care insurance market remains limited. Only three percent of adults and 11 percent of elderly currently have any coverage at all, and recently the number of policies sold sort of annually has declined. While the limited growth in long-term care insurance has generally been seen as a demand problem, today there is a need to consider the potential for a supply side problem as well. In 2002, 102 companies were selling long-term care insurance. The number declined to 20 by 2014 and additional companies have since left the market.

Long-term care insurance has always been a difficult product for insurers. There was and is uncertainty about the likely benefit use with the presence of insurance. There is an additional problem now though and that is the limited returns on the investment of premiums that have been associated with the low interest rates we have experienced over the last 8 to 9 years. The ability to invest premiums is key for insurers in setting premium rates and having a sustainable product.

I would like to conclude with some considerations that might be taken into account as you are examining sort of long-term care financing options. Encouraging personal preparedness should be a priority. While that might be perceived by some as limiting public expenditures, I see it as essential to providing individuals with more choice in how they live their lives when they have a disability and how their families will be impacted.

Insurance as I mentioned is preferable to savings as the primary means of preparation, yet we now have concerns about insurer participation. What actions can be taken to assure that insurers will be interested and able to market long-term care policies with reasonable benefits and premiums? The proposals that you are going to hear today sort of offer some sharing of risk which may be sort of key to the participation of insurers. It may also be key to giving a clear message to individuals that preparation sort of is an important personal responsibility.

Finally, what the Baby Boom generation means for state Medicaid programs deserves attention. States already differ significantly in the shares of their population needing long-term care and the cost of providing services. As the numbers needing long-term care increases and as economic activity may shift geographically, some states may be disproportionately affected. What assistance

they may need should be considered. Thank you very much, Mr. Chairman.

[The prepared statement of Mr. Scanlon follows:]

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Testimony of

William J. Scanlon, PHD

On

The Financing and Delivery of Long-Term Care in the U.S.

The Subcommittee on Health

US House of Representatives' Committee on Energy and Commerce

March 1, 2016

I am pleased to be here as you review the financing and delivery of long-term care. I am an economist who has been involved in health policy research for 40 years. Until 2004, I was the managing director of Health Care Issues as the US General Accounting Office. I also have been a member of the Medicare Payment Advisory Commission and the National Commission for Quality Long-Term Care. Currently, At present, I am a consultant on health policy issues, principally with the West Health Institute and the National Health Policy Forum. My views today are my own and do not reflect those of any organization with which I have been affiliated.

I am going to present a brief overview of long-term care services and current arrangements for financing them and then discuss some of the implications of the aging Baby Boom generation and the growing demand for long-term care for the future. I will

conclude with some factors you may consider as you examine long-term care policy options.

The Present

Long-term care (LTC) or a more recently described as long-term services and support (LTSS) is distinct from other health care both in the nature and provision of the services and its financing¹. LTC involves assistance with usual activities of daily living, such as dressing bathing, moving around, toileting, or eating, or maintaining a household, or supervision to avoid harm. The presence of different types of disabilities creates the need for these services that individuals would otherwise perform themselves. LTC is not provided only by health professionals. In fact, families and friends are a principal source of LTC support. CBO has estimated that the family of such informal care exceeds the spending on paid services².

We generally hope medical care involves treatments proven to be effective for given conditions and are willing to experience inconvenience, sometimes pain, and expense to obtain that benefit. LTC services provide needed assistance for survival, but they also determine how one lives one's life in the presence of a disability. How LTC services are delivered—by whom, with what frequency, in what location, are critical factors affecting an individual's quality of life and satisfaction. In other words, individual preferences play a more significant role in LTC than they do for medical services.

¹ For simplicity, I will refer to long-term care throughout as it is the term applied to private insurance and this testimony focuses on financing.

² Congressional Budget Office, *Rising Demand for Long-Term Services and Supports for Elderly People*, June 2013, Accessed February 2016 at: <https://www.cbo.gov/sites/default/files/113th-congress-2013-2014/reports/44363-LTC.pdf>

LTC is also distinct in terms of financing. There is little insurance for paid LTC services. The predominant payer is state Medicaid programs which accounted for 61 percent of the \$220 billion spent in 2012³. Out-of-pocket payments, at 22 percent, constitute the second largest source. Private LTC insurance policies only accounted for 12 percent. Medicaid as the primary source of payment is problematic for both individuals and the programs. Only individuals with limited resources are eligible for Medicaid. Some Medicaid beneficiaries may not have been poor most of their lives. However, they may have limited resources when the need for LTC arises. Disabilities can often develop 20 to 30 years post retirement and savings and other resources may have been depleted. Other individuals may spend down to Medicaid eligibility exhausting their resources after becoming disabled paying for LTC services before becoming Medicaid eligible.

What services a Medicaid eligible receives depends greatly on where one resides. State programs vary widely in the share of spending for home and community based services versus spending for nursing home. Programs also vary in terms of the levels of spending that affects the numbers of persons with disabilities served and the services each receive. An individual's preferences may not be a significant factor in what services are received as state programs can be quite prescriptive regarding what services will be covered for each recipient.⁴

³ Carol V. O'Shaughnessy, *National Spending for Long-Term Services and Supports (LTSS)*, 2012, March 2014 Accessed February 2016 at: http://www.nhpf.org/library/the-basics/Basics_LTSS_03-27-14.pdf

⁴ US GAO, *Long-Term Care: Availability of Medicaid Home and Community Based Services for Elderly Individuals Varies Considerably*, Sept. 2002, GAO-02-1121. Accessed February 2016 at: <http://www.gao.gov/assets/240/235824.pdf>

LTC is the largest share of Medicaid spending comprising about one third of spending on all beneficiaries and almost two-thirds of spending on aged beneficiaries.⁵

Considerable attention has been focused on the large expenditures for beneficiaries eligible for both Medicare and Medicaid (duals). In terms of Medicaid spending, LTC is the principal reason. It comprised 70 some percent of total Medicaid duals spending. Less than one-third of duals receive LTC services. Spending on those duals receiving LTC was about \$37,000 per beneficiary in 2011 or more than 15 times that spent on duals not receiving LTC.⁶

Medicaid LTC spending growth has moderated some as states have transformed their programs. In the early days of the Medicaid, LTC benefits were limited to nursing home care in almost all states. Following the enactment of the Medicaid waiver authority for home and community based services in 1981, state programs began to use these services in lieu of nursing home care. Other state policies, such as moratoria on new nursing home construction and stricter certificate of need, constrained growth in the supply of nursing homes to facilitate the shift away from institutional care to home and community based care. A related development was the growth of assisted living facilities. These facilities generally serve individuals with lesser degrees of disability than nursing homes and provide a less institutional-like setting. While Medicaid programs do not finance room and board in these facilities, some states have used

⁵ Medicaid and CHIP Payment and Access Commission, *Distribution of Medicaid Benefit Spending by Eligibility Group and Service Category*, Accessed February 2016 at: <https://www.macpac.gov/wp-content/uploads/2015/01/EXHIBIT-18.-Distribution-of-Medicaid-Benefit-Spending-by-Eligibility-Group-and-Service-Category-FY-2012.pdf>

⁶ Sally Coberly, *Background on the Heterogeneity of Dual Eligibles*, National Health Policy Forum Briefing, January 27, 2012. Accessed February 2016 at: http://www.nhpf.org/uploads/Handouts/Coberly-slides_01-27-12.pdf

waivers to provide LTC services to assisted living facility residents as a cost effective substitute for nursing home care.

Currently, states are moving to managed LTC as a means of obtaining more control over Medicaid LTC spending. About half the states have already engaged or are in the process of engaging managed care plans to administer LTC benefits as either a stand-alone package or combined with other Medicaid medical benefits. What this shift to managed care will mean for either the delivery of LTC services or spending growth is uncertain. Medicaid LTC has not been an unmanaged fee for service benefit where beneficiaries and providers determine what services are used and then submit claims. Because of the costliness of nursing home care and the fear that there would be too much demand for home and community based care, state programs attempted to aggressively manage LTC benefits. For example, pre-admission screening programs for nursing homes established levels of disability required to qualify for nursing home coverage. For home and community based services, case managers determined the types and numbers of services an eligible beneficiary could receive.

The Future

Two major questions for the future would seem to be: whether and how the well-being of persons with disabilities and their care-givers might be improved and how to finance LTC in an affordable and sustainable way. The backdrop for this is demographics—the aging of the Baby Boom generation that will result in large increases in the LTC population within the next few decades. The demographics are critical because they strongly imply that a new means of financing must be found. A solution built on finding

efficiencies in the delivery of or payment for services is unlikely. That might be a possibility with respect to medical care where the perception of substantial inefficiency exists. The same would not seem to be true for LTC. The biggest payers, state Medicaid programs and individuals paying out of pocket, have likely prevented considerable inefficiency from developing especially in terms of excess utilization and somewhat in terms of excessive pricing.

The need to find another way to finance LTC is not a new idea. Serious discussions about alternatives to the current system began in the early 1980s. The primary focus was on expanding private LTC insurance which was starting to be marketed at that time. That focus made sense from two perspectives. First, individuals with insurance that develop a disability would have more resources or purchasing power to obtain services more in line with their and their family or other informal caregivers' preferences. Second, there would be a reduction in Medicaid LTC expenditures as insurance would result in fewer people spending down to become Medicaid eligible.

Having LTC insurance would seem reasonable from an individual perspective. Using paid LTC is an insurable event. Such use is a risk not a certainty. For persons turning 65 between 2015 and 2019, almost half (48 percent) will have zero LTC expenses before they die.⁷ Another 15 percent will have expenses less than \$50,000. And 15 percent are at risk for catastrophic expenses of more than \$250,000. While insurance will change the likelihood of using paid services, the wide distribution of spending will undoubtedly remain.

⁷ Melissa Favreault and Judith Dey, *Long Term Services and Supports for Older Americans: Risks and Financing* Research Brief, Assistant Secretary for Planning and Evaluation DHHS, July 2015. Accessed February 2016 at: <https://aspe.hhs.gov/basic-report/long-term-services-and-supports-older-americans-risks-and-financing-research-brief#table1>

Even if one could save to pay for likely LTC expenses, there is more than a 50 percent chance that all or most of those savings would remain unused when one died. Saving would help prepare one for LTC needs, but also prevent the monies saved from being used for other purposes. Insurance is a superior alternative. Insured individuals would have more funding available to deal with their LTC needs if a disability arose. They would presumably spend on premiums than what would have been saved. The difference would be available to spend as they wish.

Considerable efforts have been made to increase coverage with LTC insurance. The National Association of Insurance Commissioners (NAIC) created model laws and regulations to create standards for insurance policies being marketed to increase consumer confidence. This was an important undertaking as some early LTC policy offerings had restrictive coverage provisions that compromised their value. NAIC has also attempted over the years to deal with issue of premium stability which has been a source of considerable concern to potential purchasers. The Health Insurance Portability and Accountability Act of 1996 created a tax incentive for qualified LTC policies. The Act allowed the deduction of premiums as a medical expense. Qualified policies were those that met the NAIC standards at the time of passage. A Partnership Program was created, first as a demonstration in 4 states and then the Deficit Reduction Act of 2005 made it an option for all states. The Partnership Program allowed persons receiving benefits under policies meeting certain standards to retain some of their assets and still qualify for Medicaid. About 40 states have initiated a program. An

education campaign, 'Own Your Future' was funded by HHS in 2005.⁸ The campaign's main component was a letter from a state's governor to households with someone over 45 years of age to make them aware of LTC risks and offer an opportunity to receive more information. Letters from the governor were sent in 25 states to more than 18 million households.

Despite the potential advantages and the promotion efforts, the market for private LTC insurance never developed much momentum. Today only 3 percent of adults and 11 percent of adults over 65 have a private LTC insurance policy⁹. Moreover, growth in the number of covered lives has declined dramatically. That growth was 12 percent a year between 1998 and 2005, but only 1.5 percent a year between 2005 and 2011.

While the limited growth in LTC insurance has generally been seen as a problem of demand, today there is a need to consider the potential for a supply side problem. In 2002, 102 companies were selling LTC insurance. By 2014, the number had declined to 20 and additional companies have since exited the market.¹⁰

LTC insurance has always been a difficult product for insurers. When policies were first offered in the 1980s, there were very little data on disability prevalence and LTC utilization. There was absolutely no experience with how utilization would respond to the presence of insurance. Companies protected themselves by offering limited benefits and setting premiums at higher levels to avoid losses. Both naturally dampened

⁸ Tell E J, Cutler J A. *A National Long-Term Care Awareness Campaign: A Case Study in Social Marketing. Cases in Public Health Communication & Marketing*. 2011;5:75-110. Accessed February 2016 at: http://publichealth.gwu.edu/departments/pch/phcm/casesjournal/volume5winter/peer-reviewed/V5w_Case4PR.pdf

⁹ Congressional Budget Office, op.cit.

¹⁰ Marc Cohen, *The Current State of the Long-Term Care Insurance Market*, Presentation for the 14th Annual Intercompany Long-Term Care Insurance Conference, March 2014 Accessed February 2016 at: http://iltcconf.org/2014/index_html_files/44-Cohen.pdf

demand. While there is much more information available to insurers today, there is still considerable uncertainty. In the 30 plus years LTC insurance policies have been marketed, the provision of LTC services has shifted dramatically. As noted, there has been a major reduction in nursing home care and substantial growth in assisted living and home and community based care. There have also been debates about future disability prevalence; whether future cohorts of elderly will be more or less likely to suffer a disability. At one point, it was hypothesized baby boomers might experience less disability as they did not have the disadvantages of being raised during the Depression or World War II. The increasing prevalence of obesity and its correlation with disability might question that hypothesis.

The additional factor that has impacted LTC insurers is the economic downturn that began in 2007-8 and the low interest rates that have persisted since then. The model for LTC insurance is to charge premiums for policies; invest those premiums; and pay benefits to policyholders 25-35 years later. The limited returns on investments that have been available in recent years conflict with the assumptions insurers used to set premiums on previously sold policies. While raising premiums to cover anticipated losses may be an option, adjustments to premiums on existing policies have generated considerable negative publicity and likely reduced demand among potential purchasers. Similarly, a strategy for future policies of charging higher premiums to compensate for smaller returns on investment is likely to dampen demand.

Conclusion

I wish to conclude with some considerations that might be taken into account as you examine LTC financing. They are not specific recommendations for two reasons. First,

specific proposals will almost always involve decisions about the roles of the private and public sector. Those are decisions for elected officials not for an analyst such as myself. An analyst can tell you the implications of any decision in terms of achieving different goals. Second, I have not done that type of analysis for any proposal. Such analyses will be quite challenging. There are multiple outcomes to consider (e.g., satisfaction of individuals' with disabilities needs and preferences, impacts on families and other caregivers, impacts on the workforce, and spending). As all outcomes will be dependent on the responses of individuals, providers and insurers, strong effort should be made to minimize uncertainty in estimating projected outcomes.

Encouraging personal preparedness should be a priority. While that may be perceived by some as a means of limiting public expenditures, I see it as essential to providing individuals with more choice in how they live their lives when they have a disability and in how their families will be impacted by the disability. Both increasing awareness of the importance of preparedness and its affordability should be considered. While there have been attempts to increase awareness about the realities of LTC and its financing, they have had limited success. To give you an example of our limited progress, 30 years ago about 80 percent of seniors believed Medicare would cover their LTC needs. Our education efforts may have reduced that percentage to around 50. Our education efforts simply have not been good enough. Today reports from multiple federal agencies indicate the percent of LTC spending paid by Medicare with footnotes indicating this is for short term LTC services. This is simply wrong. Medicare pays for services delivered by providers that also deliver LTC services paid by others. The message to the public needs to be clear and straightforward: Medicare pays for NO LTC.

Making personal preparedness more feasible or affordable also must be considered. Insurance, as mentioned, is preferable to savings as the primary means of preparation. Yet we now have concerns about insurer participation. What actions can be taken to assure insurers will be interested and able to market LTC policies with reasonable benefits and premiums. Some proposals have suggested that there be a public sector assumption of some of the risk for LTC. What might be seen as ironic is that depending on how a public sector initiative is structured, the private insurance market may be strengthened. In addition to relieving insurers of covering a segment of the risk, a public initiative that clearly delineated what would and would not be covered could enable consumers to understand the importance of supplementary coverage. Those possibilities should be explored.

Informal or unpaid care provided by family members and other caregivers is another important consideration. These caregivers are the primary source of care for persons living in the community. That care can involve physical, emotional, and economic costs to those care givers. Assuring that the burden on individual caregivers is not excessive is one consideration. The social costs of lost productivity as caregivers reduce their participation in the labor market is another, particularly as the share of the population that is working-age declines in future decades.

The Medicaid program represents a commitment to maintaining a safety net to assist people unable to do so on their own. State Medicaid programs vary considerably in the

levels of assistance and the persons served. Part of this relates to differences in states' capacities to fund services. There is variation in the proportions of a state's population likely to need services and the costs of delivering services. Today federal assistance to states is determined by the Federal Medical Assistance Percentage (FMAP). Per-capita income, the FMAP's basis for distributing federal funds, does not capture the differences in either the relative need for services or cost differences among states. As the numbers of persons needing LTC increases and as economic activity shifts geographically, some states may be significantly affected and what assistance they may need should be considered.

Mr. PITTS. The chair thanks the gentleman and now recognizes Ms. Tumlinson 5 minutes for her summary.

STATEMENT OF ANNE TUMLINSON

Ms. TUMLINSON. Thank you. Chairman Pitts and members of the committee, thank you very much for the opportunity to testify today. I really appreciate your focus on this issue.

The perspective that I am about to share comes from a variety of experiences over the past 25 years. I work at the Office of Management and Budget on the Medicaid program as a researcher and a consultant to long-term care providers and most recently serving as a facilitator between the economic modeling work done at the Urban Institute and Milliman and several of the very brave groups working on long-term care financing reform. I also write a blog for family caregivers.

We have a very serious and significant financing gap between the services and supports that people need and the funds available to pay for them. I am going to make just three points that I hope will frame today's discussion and shape the work of this committee.

First, as we have heard already, having a need, a high need for long-term care in old age is not an inevitable part of old age. And what I mean by high level of long-term care need is when you get to the point that you need help with two or more activities, basic activities of daily living like bathing, eating or dressing, or if you are living with a severe cognitive impairment.

And what we are learning from the recent work done by the Urban Institute and Milliman is that there is a huge variation in whether and the degree to which individuals will actually experience this high level of long-term care need in old age. The researchers project that over the older adult population there is roughly a 50 percent chance that if you live to age 65 that at some point over the rest of your old age you will experience that high level of need for long-term care.

Now there is also a smaller, a 15 percent chance that a person will live with that level of need for five or more years. Just imagine living with two or more activities of daily living limitations for five or more years. These situations are incredibly expensive. If you are among the top 15 percent of spenders, the Urban Institute projects that your care will cost at least, at least \$250,000 over your lifetime. The bottom line is that the risk here is large and it is uncertain.

So the second point I want to make is the way we finance these costs as we have all heard is inadequate to the need. Individuals and families face huge financial risks. Generally what the Urban Institute research is telling us is that on average over half of lifetime costs are actually financed through individuals' income and savings through out-of-pocket spending. But when and if these resources run out, Medicaid plays a very important role. It finances about a third of lifetime costs on average and makes the biggest contribution for people who need care for very long periods of time.

The reliance on individual resources and Medicaid has created huge gaps in the system. We have already talked about this, but we rely very heavily on unpaid family caregiving and this is in part

because this is often the only option that families feel like they have.

But I want to talk about another gap that we see, which is that we often simply just fail to meet needs. In a recent survey, about a third of individuals with long-term care needs reported serious consequences from going without needed services. For example, individuals who have difficulty preparing their own food or difficulty eating and can't get help with that often go without eating, and this unmet need gets addressed in the emergency room and the hospital which is of course where Medicare pays.

So my third point is that the risk of needing long-term care is one that is well suited for insurance, but shifting all or even a part of our financing to insurance will be very challenging, so I am the Debbie Downer here. So even when we estimate a twofold increase, a twofold increase, in voluntary participation in long-term care insurance we still don't see it moving the needle that much on how much we spend on Medicaid and how much out-of-pocket contributions are made. So I want to be careful here and say that this doesn't mean it wouldn't be helpful to increase insurance participation under a voluntary approach. It would. It just wouldn't dramatically change the role of Medicaid or out-of-pocket spending. To do that, we need everyone to participate. But even when we assume that everyone is covered it is still hard because that new coverage soaks up so much of the unmet need that it increases overall spending almost as much as it offsets other sources of payment.

So in grappling with these tough issues, where the groups I have worked with have landed as you have heard is that some sort of private market and public insurance partnership solution is needed and that the appropriate role of public insurance is to cover that catastrophic risk; that 5 years or 4 years or 3 years, but the part that is the most expensive for individuals. But that is only going to work, that catastrophic risk coverage will only work as long as we can stimulate the private market and reform Medicaid to better cover the earlier risk.

But everyone has more work to do. We have to develop details. We still have to work on financing strategies. But we have to move forward no matter how challenging it might be, because our stop-gap patchwork system has serious implications for future economic productivity, public program spending and for the functioning of the American family. Thank you.

[The prepared statement of Ms. Tumlinson follows:]



Testimony of Anne Tumlison

CEO, Anne Tumlison Innovations LLC and Founder of Daughterhood.org

**U.S. House of Representatives Committee on Energy and Commerce
Subcommittee on Health Hearing on Long-term Care Financing
March 1, 2016**

Chairman Pitts, Ranking Member Green, and Members of the Committee, thank you for the opportunity to testify today about the financing and delivery of long-term care in the U.S. I greatly appreciate your focus on this issue, which has enormous implications for the future of American families.

In this testimony, I describe the way the current long-term services and supports (LTSS) financing system works, the major challenges we face, and recent work to address these challenges.

Current LTSS Financing System

The U.S. spends more than \$200 billion a year on LTSS for younger and older adults who need them. But these payments represent just one way in which we “finance” care for individuals with a need for LTSS.

We also finance this care by relying on close to \$500 billion in unpaid family care, by leaving needs unmet and through unnecessary hospitalizations and ER use.ⁱ

When we look at a point in time, we estimate there are about 6 million older adults who have a very severe need for LTSS.ⁱⁱ But, that point-in-time estimate does not convey *the unpredictable risk we all face for needing lengthy and expensive LTSS in our own old age, or the risk we face that someone in our family will need high levels of care for a long period of time.*

The Urban Institute projects that a fairly large portion of older adults – about 70 percent of everyone who lives to age 65 – will need help doing one of the basic activities that we take for granted, such as eating, bathing, or dressing.ⁱⁱⁱ A smaller group – closer to 50 percent – will

develop an **even higher level of need** for help with *two or more* of these very basic activities or have severe cognitive impairment.^{iv}

What I know from my work with families, from my research and from new research emerging from the Urban Institute is that when families face a high level of need, they tend to meet it first through their own resources – out-of-pocket payments and unpaid family care. Over time, if a person's needs continue, the individual and family's financial resources run out, as do emotional and physical resources, --- that is the point when we observe Medicaid contributing.

In its economic model, the Urban Institute projects that, of the individuals who have a high level of need, their care will cost about a quarter of a million dollars over their lifetime and ***a little over half of this amount will be paid for through out-of-pocket payments. Another third will come from Medicaid.***^v The majority of Medicaid dollars spent on LTSS are spent for people who have longer periods of high need, such as five years or more.

What does not exist in our financing system is a significant role for insurance – private, public or otherwise. According to the Urban Institute, private insurance contributes about three percent to average lifetime expenditures.^{vi}

Challenges

The result is that our LTSS delivery system is about as under-financed as any system can be... meaning that there is a big gap between the care that individuals need and the money available to pay for it. Our system inadequately protects today's older adult population from the financial devastation of a long-term disabling condition such as Alzheimer's disease or stroke. It leaves children and adults with disabilities with few options for independence.

While our patchwork LTSS system **today** is failing families and individuals with need, this patchwork will fray to the point of unsustainability, as demographics change and the numbers of people with need rise. There are three ways it will fail apart.

- **Medicaid.** Contrary to some reports that LTSS is growing rapidly today, LTSS *is not a growing percentage of state Medicaid budgets*. Total Medicaid LTSS increased 3.4 percent in FY 2013 from \$141 billion in FY 2012. Average annual growth in the three-year period including FY 2011 through FY 2013 was 1.6 percent, which is slower than historical averages. LTSS was 34 percent of total Medicaid spending for each of the three years 2011, 2012, 2013, which is the lowest percentage it has been in almost 20 years.^{vii}

But, as demographics change and more people need Medicaid-financed LTSS, state Medicaid programs will be forced to either dramatically increase total spending or to reduce the amount of money they spend on each person with need, which will impact access and quality.

- **Caregivers and Families.** We know today that gaps in financing are filled by unpaid caregiving, and that this has a huge impact on their financial, emotional and physical well-being. But, as the number of available unpaid caregivers decreases relative to the people with need, families will face untenable choices between economic productivity, financial stability, childcare, and eldercare. When the number of working-age individuals in this country declines as a percentage of adults age 85 and older, the country will no longer be able to sustain shifting so much of the financing burden onto unpaid family caregivers, who are very often women.
- **Care Delivery Innovation.** Current trends suggest that the vast majority of even the frailest older adults will live in a conventional, single-family dwelling. But, so far the market has largely failed to deliver services in a manner that meets the needs of frail older adults living at home. In fact, evidence suggests that it is dangerous to live at home if you are a frail older adult – you are more likely to experience adverse events related to unmet needs and you are more likely to use expensive health care. Even relatively high incomes individuals report to me that they have trouble finding and buying services that match their needs and are of good quality.

Our inadequate delivery system is a product of an inadequate financing system. Without a new and reliable source of financing, I believe we will fail to attract capital necessary to invent and innovate the delivery system we need in the future.

Solutions

We have unfinanced need today and we will have even more in the future.

In an effort to evaluate a broad array of options for financing future need, The SCAN Foundation, Leading Age, and AARP jointly funded research by the Urban Institute and Milliman, Inc., which analyzed three basic insurance approaches. The first would provide coverage from the inception of high need through end of life (comprehensive). The second would provide coverage from the inception of high need through two years (front-end). And, the third would provide coverage starting after two years of need and continuing through end of life (catastrophic). Each of these is then further evaluated in scenarios assuming full participation and voluntary take-up.

The modeling work allowed us to compare different designs across consistent measures, such as likely participation rates, affordability, estimated out-of-pocket spending, and the effect on Medicaid spending.²⁻⁴

Policy groups -- The Bipartisan Policy Center, the Long-Term Care Financing Collaborative and Leading Age -- who helped develop technical specifications for the modeling have subsequently released policy recommendations in February 2016, building largely from the modeling work. These reports as well as the underlying Urban Institute and Milliman research can be accessed at [The SCAN Foundation's website](#).

Several common themes emerged from the research and the groups' work.

- *Defining the Problem.* Older adults and their families are unprepared for the risk of needing LTCLTSS; both in terms of high out-of-pocket spending and the resulting need for Medicaid. The reports recognize the significant role of unpaid family care, the dominance of out-of-pocket costs in financing covering the average spending over a lifetime, and evidence of unmet need as indicative of a system that will be unsustainable as support need rises.
- *Multi-Pronged Solution.* Increasing insurance-based coverage will require multiple solutions, utilizing the strengths of both the private and public sectors.
- *Private Market Solutions.* The solution set should include reforms to the private insurance marketplace to provide lower priced policies for the purpose of insuring against the risk of needing a high level of LTSS over a relatively short period of time.
- *Public Catastrophic Coverage.* The solution set should include insurance specifically designed to protect against the risk of high LTSS need that occurs over long periods of time, to at least consider further research into development of a catastrophic insurance program where all Americans would be covered.
- *Refocusing Medicaid's Role.* Medicaid should be strengthened as the safety net program, which has an important but smaller role in a refashioned, insurance-based LTC financing system.

Even within these options, there are significant budgetary implications and trade-offs. For example, in choosing to focus public insurance on catastrophic risk rather than front-end risk, many people who need insurance for high needs over short durations may not get it. Correcting for this problem through a comprehensive program design results in higher costs. And, it is important to remember that, because the system is currently under-financed, any change that insures a significant portion of the population with need will result in more overall spending rather than less.

The researchers and the groups issuing recommendations would all agree that this is a very hard problem and we have a great deal more work to do. But they and many others recognize that we cannot afford to give up.

Endnotes

ⁱ *Valuing the Invaluable: 2015 Update.* Susan C. Reinhard, Lynn Friss Feinberg, Rita Choula, and Ari Houser, AARP Public Policy Institute, July, 2015.

ⁱⁱ *Microsimulation Analysis of Financing Options for Long-Term Services and Supports.* Melissa M. Favreault and Richard W. Johnson, The Urban Institute, November 2015.

ⁱⁱⁱ Financing Options for LTSS, Rich Johnson (Urban Institute) Presentation, January 27, 2016

^{iv} *Long-Term Services and Supports for Older Americans: Risks and Financing Research Brief*, Melissa Favreault, Urban Institute and Judith Dey, DHHS Office of the Assistant Secretary for Planning and Evaluation, Initially published July 2015 and revised February 2016.

^v Favreault and Dey 2015

^{vi} Favreault and Dey 2015

^{vii} *Medicaid Expenditures for Long-Term Supports and Services (LTSS) in 2013: Home and Community-Based Expenditures were a Majority of LTSS Spending*, Steve Eiken, Kate Sredl, Brian Burwell, Paul Saucier, Truven Health Analytics, June 30, 2015

Mr. PITTS. The chair thanks the gentlelady. That concludes the opening statements. We will now go to questioning and I will recognize myself 5 minutes for that purpose.

Dr. Rivlin, you have suggested Congress create a state plan amendment for home and community-based services in Medicaid. If home and community-based services are more cost effective and offer preferred settings, why aren't states making full use of existing authorities to provide such services under Medicaid?

Ms. RIVLIN. I don't know the answer to that for all states. Many states would like to and get caught in the complicated waiver process, and we are simply saying let us make it easier. Let us make it simpler for states to do this and hope that they do and that therein can be encouraged broadly to get with it and use the authorities that are there.

Mr. PITTS. And why does the Bipartisan Policy Center feel the federal government needs to create incentives for states to increase the adoption of home and community-based options?

Ms. RIVLIN. Because it is not happening and we think that some incentives might help.

Mr. PITTS. OK.

Ms. RIVLIN. And the simplification is really very important. The Congress has wanted to do this and has done it, but as so often happens in policy as you know we end up with a complexity that could be simplified.

Mr. PITTS. Ms. Tumlinson, I was particularly struck by the sentence in your written statement, "it is important to remember that because the system is currently underfinanced, any change that ensures a significant portion of the population with need will result in more overall spending rather than less." Would you explain more about what you are suggesting? Is it that there is cost shifting currently going on, or we just buckle up and spend more nationally, or are you suggesting we need to approve large new expenditures now for promised savings tomorrow?

Ms. TUMLINSON. Oh, there we go. No. The way that our system works right now, we have a lot of care that is being financed so to speak without paying for it, so we are financing care through unpaid family caregiving. We are financing care through unmet need, so to speak, and we are financing care kind of back door through the health care system.

So when we put an insurance program in place, what the modelers estimate is that we have something called induced demand. In other words that people do actually, who have been essentially kind of holding back will actually come in and use their insurance benefits as we would expect them to. And as a result of that we will see, absolutely, we will see a replacement of some Medicaid dollars. It does reduce Medicaid dollars. It reduces out-of-pocket dollars.

But the insurance itself is, there is also kind of a place in the spending where the insurance brings in new dollars so we will have new dollars in the system. It is actually, it is good news. It is just that I think that this idea that our system somehow is, is we have out of control spending is a fallacy. We actually have a very tight, very efficient long-term care system right now.

Mr. PITTS. All right. Dr. Scanlon or Dr. Rivlin, do you want to comment on that?

Mr. SCANLON. I would agree with Ms. Tumlinson. It is very clear that there have been pressures to control costs that are present for both Medicaid programs as well as individuals buying out of pocket. And the reason that we will have an expansion of spending if we were to get insurance is the fact that at this point families are probably doing more than they really can bear in terms of the burden of caregiving and if given an option they will seek to provide some additional outside resources. We don't want to supplant family caregiving, but we want to make sure that we do not have it sort of create too much of a cost or burden on those family members.

Mr. PITTS. Dr. Rivlin, do you have any thoughts on this?

Ms. RIVLIN. No, I agree with that.

Mr. PITTS. Dr. Scanlon, in your written testimony you state that Medicaid as a primary source of payment is problematic for both individuals and the programs. Can you explain why you believe it is problematic for Medicaid to be the primary payer for long-term care?

Mr. SCANLON. I feel it is problematic for the Medicaid program because of the sort of the enormity of its obligation in terms of trying to deal with sort of long-term care as the only financier. Secondly, there is the difficulty of defining what services should be provided by Medicaid programs.

Historically, we have relied exclusively on nursing home care and we recognize the shortcomings of that but as we move to having more care in home, we also have to face the difficulty of deciding how much care is appropriate to both benefit the individual as well as protect the program. And the reality there is we do not want to supplant sort of family care, we want to support it in a very positive way.

Mr. PITTS. The chair thanks the gentleman. My time has expired. The chair recognizes Ms. Matsui 5 minutes for questions.

Ms. MATSUI. Thank you, Mr. Chairman. Our long-term services and support system are challenges that threaten our seniors' retirement security, young people with disabilities, the ability to both work and afford needed services, and our nation's families who are attempting to either pay for their loved ones' services or to provide the care themselves.

Unpaid caregiving particularly impacts women, as daughters most likely step out of the workforce to take care of their aging parents and mothers are most likely to take care of their disabled children. This leaves women with less retirement savings and Social Security accrual, and women need more as we also live longer. As we know, approximately 12 million Americans require long-term care and that number is expected to grow as the baby boomer population ages.

Given that the need for long-term care is driven by increased functional limitation whether it be from the aging process or untoward circumstances in life, isn't it fair to assume we need to approach this issue from a point of universality so that all Americans have a safety net without being required to become poor and significantly disabled in order to access the services and supports that

they need? And I would like each of you to comment on that. Dr. Rivlin?

Ms. RIVLIN. In an ideal world I think I would say yes, let us cover this in a universal way. But right now the idea of and creating a new entitlement program primarily for older people seems to me both unlikely to happen and probably not desirable. I worry that we are spending so much on older people for good reasons that we are squeezing out investments in the young and in education both at the federal level and at the state level and for which reason I think it was important to take some of the burden off Medicaid.

Ms. MATSUI. Right. Mr. Scanlon?

Mr. SCANLON. Yes. I agree that in an ideal world we would have a system where there is all needs that are going to be met, but I think that we need to also look at long-term care as something that is not just another health care service; that long-term care is about how you live your life in the presence of a disability. So it is not just the question of need, it is the question of your preference and your satisfaction.

And while we can have insurance that is aimed at making, and public programs aimed at making needs being met, there is this question of what additional services one might want. That is where I think personal preparation comes into play, where individuals can be able to exercise their preferences and the preferences of their family.

Ms. MATSUI. Ms. Tumlinson?

Ms. TUMLINSON. Yes, thank you. Well, I can't figure out how to change the current system unless everybody is in it. We have three different populations that need that universality—children born with developmental disabilities, adults who develop disabilities, or individuals who develop disabilities as adults and older adults.

And I think that as somebody who has worked on the budget side of Medicare and Medicaid for many years, I share Dr. Rivlin's concern about spending on older adults. At the same time, I think that we cannot back door finance this off of women who are giving up huge amounts of work time and their own financial resources in order to take care of their parents.

I certainly know from my work with caregivers that not only do they spend a lot of time, they also spend a lot of their own money. And that is not even in our model right now. We don't model that.

Ms. MATSUI. I want to address long-term care insurance. The vast majority of employers as we know do not offer long-term care insurance to their employees. The federal government does offer long-term care insurance. However, over 80 percent in the general workforce does not have access through employers. Some have recommended requiring or incentivizing employers to offer long-term care insurance as an opt-out basis. What roles do you recommend employers play in education and enrollment in long-term care insurance? Dr. Rivlin?

Ms. RIVLIN. I think employers could play a major role, especially if it were not so expensive and if they thought of it as the selling point as protect your retirement resources, your savings, by buying this relatively inexpensive long-term care insurance which we are offering you, and not only that we are enrolling you unless you opt out.

Mr. SCANLON. I agree that the employers would be a trusted source of information, and I think education is the key to sort of having consumers understand sort of the value of insurance.

Ms. TUMLINSON. I agree with Dr. Scanlon and Dr. Rivlin.

Ms. MATSUI. OK. Thank you, and I yield back.

Mr. PITTS. The chair thanks the gentlelady. I now recognize the vice chair of the subcommittee, Mr. Guthrie, 5 minutes for questions.

Mr. GUTHRIE. Thank you. Thank you for all being here for this important issue that we need to figure out a way to address. And I have a question for the panel, a couple questions for the panel. Generally, the home represents the individual's largest asset. Medicaid payments prevent certain individuals with substantial home equity from receiving coverage for long-term care. After adjustments for inflation, states' current home equity limits range from \$552,000 of home equity to \$828,000.

I have introduced H.R. 1361, legislation to encourage the use of home equity to finance long-term care by eliminating the option for states to increase the home equity allowance above \$500,000 adjusted for inflation. Are there other policies that could be implemented to encourage—this is a question. Are there are policies that could be implemented to encourage individuals, especially elderly individuals, to tap the equity interest in their home to help finance long-term care needs?

Ms. TUMLINSON. OK. So first of all, thank you for that question. We also know that individuals—one of the ways, the main ways that individuals access assisted living is by selling their homes and getting access to the home equity and then spending that down. That is what we hear from assisted living providers. So it is a really important set of assets that we would like to be able to tap better. I think we have been around and around about reverse mortgages, and I think that that is definitely an area where we could definitely do some more work in understanding how to make those financial instruments that basically allow people access to that equity without having to move out of their house.

Mr. GUTHRIE. OK. Thank you. OK, the second question then, use of personal care in home health services in Medicaid has been growing rapidly. For example, in 2011, Medicaid costs for personal care services totaled 12.7 billion, a 35 percent increase since 2005. At the same time, the Office of Inspector General found that fraud in personal care services is on the rise, representing more cases investigated by state Medicaid fraud control units than any other type of Medicaid fraud.

Another bill I have introduced is H.R. 2446, which would reduce the level of fraud and improper payments in personal care services by requiring the adoption of electronic visit verification systems for personal care and home health services under Medicaid. We can protect some of the most vulnerable Medicaid beneficiaries and ensure they receive the care they need.

Given most people's preference to remain at their home and growing demand for long-term care services, do you each think it is important to use technology such as electronic visit verification systems to ensure that the vulnerable beneficiaries receive the services they need and for which Medicaid is paying?

Mr. SCANLON. I definitely do. I think that in the statistic that you have cited in terms of the growth of expenditures there is actually a positive side of that which is those expenditures have been growing because we have been reducing reliance on nursing homes. I saw some data recently that in 2013, while the numbers of dollars spent by Medicaid programs on home care increased significantly, the numbers of dollars spent on nursing homes had actually declined, which is rather surprising.

Monitoring the integrity of home care is one of the most difficult things to contemplate if you are running a program when you think about it, this care being delivered in homes across one's jurisdiction. Using any technology that would aid in that is a plus, but I also think we need to think for the future in terms of this, if we are talking about service delivery for long-term care, what other roles can technology play?

To be quite honest, as the Baby Boom generation grows and needs more long-term care, the idea of withdrawing people from the labor force to provide that care has very serious implications for our economy.

Mr. GUTHRIE. Yes. Thank you very much. And the third question for Dr. Rivlin, I understand the recommendations the Bipartisan Center released last month are just an initial recommendations in that the Center continues to work on additional recommendations regarding the financing of long-term care. Can you share with us some of the additional areas that will be the focus of the Center's continued efforts?

Ms. RIVLIN. The primary one is to work out some details for the catastrophic insurance. That we believe has to be a federal program and universal, but it is complicated to work out and we wanted to put some more effort into that. We also want to work on how long-term supports and services could be integrated with Medicare Advantage.

Mr. GUTHRIE. Thank you very much and I yield back the balance of my time.

Mr. PITTS. The chair thanks the gentleman. I now recognize the ranking member of the full committee, Mr. Pallone, 5 minutes for questions.

Mr. PALLONE. Thank you, Mr. Chairman. I wanted to ask Ms. Tumlinson, we will see how much time there is. Maybe the others could respond as well. Two things about the spend-down provision and just about affordability of long-term care. I don't want to put words into Dr. Burgess' mouth because he is not here right now, but I think he said between \$1,500 and \$2,500 a month for long-term care insurance. Was that accurate? Let us assume it is \$2,000, which is halfway between, right.

Mr. SHIMKUS. For over 50.

Mr. PALLONE. For over 50. So you think about that that is what, \$24,000 a year, right. Will we say nursing home care now is about maybe \$100,000, a little less than that? So I mean, it doesn't even seem worth it, I mean in the sense that you could, say you are 50, or of course even if you were younger and you put away that \$25,000 for 10 years or so that would be—I don't know. That would pay for at least 2 years of nursing home care.

So it seems to me that—and then a lot of times those policies don't even cover more than 6 months or a year of care. So I think a lot of people just look at this and say it is not worth it. In other words—and that is what I wanted you to comment. I think a lot of people just look at it and say, look, it is so expensive I could just as easily put the money in the bank or in some kind of a mutual fund and have enough to cover it.

The real issue really is catastrophic, if you had to be in a nursing home for 5 years or so which I know is unusual but not totally unheard of. So I just wanted you to comment on that. I mean, I don't see, practically speaking it doesn't even seem like the long-term care insurance is even worth it given its cost and limitations. And is that why you talk, all of you were talking primarily about catastrophic and what would that catastrophic entail?

Ms. TUMLINSON. All right. So I think it is the case that today it is very hard to buy private long-term care insurance for catastrophic risk. Most of the insurers are not interested in lifetime policies, selling lifetime policies anymore, so policies that would cover the care that you might need after a certain period of time. And so that is one of the reasons why we have all, all of these groups have been interested in a public program to cover the catastrophic risk.

Mr. PALLONE. And the catastrophic would be covering like what, after a couple years?

Ms. TUMLINSON. So, right. After, well, defining that is part of the work that we have to, still left to do, but in the modeling that we did we started it after 2 years. So you have 2 years of high need and that at year two that is when the catastrophic piece of the insurance would kick in.

Mr. PALLONE. Well, see that seems to me to make the most sense if we are talking about a public program, extension of Medicare or something else after that 2 years, because otherwise from what I see on the market it is just not worth it.

Well, let me ask you the second question. We haven't really talked much about it, but to me the biggest scandal, if you will, in this whole system is the spend-down provision. I don't like to talk about values, but I mean, from a value, we say that we are trying to instill certain values in what we do here, and it seems to me that that is like the most valueless, if that is the right word, thing that we ever created is the spend-down provision. And all I hear from my constituents is how do I get around it. What can I do to transfer my assets before the deadline so that I don't have to spend my savings or whatever, and then I can go on Medicaid.

I mean, I have to go be honest with you, practically speaking is one thing, but just from a value point of view I think it is outrageous because this is what people do. Yes, would you comment on that? I mean, in your experience this whole spend-down and people's efforts to get around it and what does that do to the family and the fabric of things from a moral point of view, I guess, is what I am asking.

Ms. TUMLINSON. Sure. Well, so what I observe in what we are seeing, I think, in the data, is actually that in part because of Medicaid, because access to, even though access to home and community-based services is much better than it used to be through Med-

icaid, but because it is not guaranteed, in many cases, still, the only way you can use Medicaid is if you are in a nursing home.

And many, many, many families, most of the families that I talk to or that I deal with would much prefer to spend their own money in assisted living, senior housing, they would prefer to provide unpaid caregiving. One of the home care providers in California told me they had folks maxxing out their credit cards to pay for home care themselves. So I don't really see people really working to sort of get rid of their assets in order to qualify for Medicaid because in many cases that just simply means a nursing home for their family member and they would prefer to avoid that.

Having said that there is a huge amount of diversity out there, and absolutely, once you have made that decision that a nursing home is where it is going to have to be there is, maybe the incentives are in place to try to figure out how to make that work in a way that is financially best for your family. But generally speaking, I don't really see people gaming it given how much out-of-pocket spending is happening.

Mr. PALLONE. I appreciate what you are saying, but I hear it so often and it just galls me to think that we have set up a system where people are encouraged to basically get around it. And I know we can talk about it another day, but it is one of my biggest concerns. Thank you.

Mr. PITTS. The gentleman yields back. The chair recognizes the gentleman from Illinois, Mr. Shimkus, 5 minutes for questions.

Mr. SHIMKUS. Thank you, Mr. Chairman. Welcome. This is a great hearing and something that we have been struggling with forever since I have been on the subcommittee. And I really appreciate Ranking Member Pallone's comments, because I do have frustrations with that and elder law attorneys who try to find these ways to protect assets when those assets should be used. I mean, we can't take it with us when we die, right. So I think maybe we will continue to talk about that because there has got to be a way to incent and keep and encourage, and I think a lot of different ideas are being thrown out here.

And I have always been, I have spent a lot of time talking about the budget as a whole, Dr. Rivlin, and whatever 2014 numbers, the 3.4 trillion and really the 1.900 billion or the 1.1 trillion discretionary budget that we always seem to fight about when the real challenge is our entitlements. People are entitled to these services and then the mandatory money then follows because you are entitled for these programs. So those are the right words and I think are rightly used.

But in the Bipartisan Policy Center when we talked about the failure of the CLASS Act, because you all talk about the new programs, how would we fund something like a CLASS Act to help people coverage? I mean, what would be a possible funding mechanism? Or is that to be answered in—it is kind of a follow-up from the other discussions.

Ms. RIVLIN. The CLASS Act was very expensive and that was one of the problems. If you are funding something less expensive like catastrophic care, then I think you still have the usual options. It could be a small payroll tax. It could be some other kind of tax. And I don't know exactly what the cost would be because we

haven't done that work yet, but I think it has to be funded, in my opinion, and the less pressure you put on the federal budget, the easier it is to fund it obviously.

Mr. SHIMKUS. Because we are going to continue to fight budget debt, deficits, and the like and we will have to make sure that we have a funded program so it doesn't add to the deficit because then we are just continuing in the spiral down. Let me also go, we know the benefits of employing our disabled community and keeping them, but long-term services and long-term support and services help them stay in the workforce.

But there is that balance, right, of how you continue to provide Medicaid support so that they can then be active citizens and in employment without getting into the other—oh, now, you are making money or you are not making money and we are going to kick you off services or we are going to add you to services. So do you have any comments on that?

Ms. RIVLIN. Yes. We suggest a limited buy-in to Medicaid just for the long-term supports and services not for the whole Medicaid package because they may not need that. They may, if they are employed have insurance.

Mr. SHIMKUS. Ms. Tumlinson, you are smiling, so do you want to add?

Ms. TUMLINSON. Well, I agree with the Dr. Rivlin side. The BPC has got a really interesting solution that they have put forward, but I go back to if we had, the other option of course is to create an insurance system that if you, so that if you sort of unexpectedly face a disability as a working age adult that you have access to those long-term support and services through that insurance program. That is what the CLASS Act was designed to do, but it was a voluntary program.

Mr. SHIMKUS. Right. Thank you. And I want to finish up. There has also been debate, we are talking Medicaid, but recently we are also following the Puerto Rican debt crisis, health care dilemma, et cetera, et cetera, et cetera. But there is some confusion. I want to go to Dr. Scanlon. I don't think all Americans understand that the Puerto Ricans do not pay federal income tax as a protectorate, but the question is does Puerto Rico even provide long-term care which is mandatory Medicaid service?

Mr. SCANLON. My understanding of that and this is based on some GAO work that was done in 2000 and sort of in '05, is that Puerto Rico does not cover either nursing facilities, or at that point it was identified as home health. The home health portion sort of is not really long-term care. I think one of the things in educating the public is to stop confusing them about sort of what home health is. In terms of the nursing facilities there is the question of whether they, outside of Medicaid, support any other types of residential care.

Mr. SHIMKUS. Yes. So the only way—if Mr. Chairman, I will just in my summary—it is a debate between block grants and per capita grants and there is a confusion, then to lump what states are doing with what is going on in Puerto Rico is not appropriate. So with that I will yield back.

Mr. PITTS. The chair thanks the gentleman and now recognizes the gentlelady from Florida, Ms. Castor, 5 minutes for questions.

Ms. CASTOR. Thank you, Mr. Chairman, and thank you to the panel for sharing your expertise with the committee.

It is very important as you know to families across America and it is in our national interest to strengthen long-term care across the spectrum from home and community-based care to skilled nursing. And Dr. Rivlin, you suggested working on practical bipartisan solutions and I wanted to recommend one to my colleagues.

Congressman Gregg Harper, my Republican colleague, and I are cosponsoring H.R. 3009. That is the RAISE Family Caregivers Act. RAISE means Recognize, Assist, Include, Support and Engage Family Caregivers Act. It would create a national caregiving strategy based upon the input from advocates and experts and families across the country. And the reason I really recommend it to you is it passed the Senate. The Senate version has passed, and we the House should take action. So I would ask my colleagues to take a look at that and help us move forward on some of these practical solutions.

And Ms. Tumlinson, thank you very much for bringing up the fact that long-term care right now is often funded in a back door way by women and families who take time off their job, who cut into their salaries and overtime, and there must be a solution for that. And all of the witnesses have mentioned this as well. So thank you.

Another concern I have is that American families do not fully understand the availability or more accurately the lack of availability of financed long-term care services. Specifically, many Americans mistakenly believe that Medicare provides for long-term care services. Ms. Tumlinson, in your testimony you described Medicaid's role in long-term services and supports. Can you briefly talk about Medicaid's current role, and if no Medicaid reforms are taken here in the near future what do you believe is the outlook for financing long-term care through Medicaid?

Ms. TUMLINSON. So in other words what happens under status quo.

Ms. CASTOR. Yes.

Ms. TUMLINSON. We do nothing for Medicaid. So the modelers did what we call a baseline estimate of Medicaid, so what happens to Medicaid spending in the absence of current law, and it certainly starts to decline fairly rapidly. Just the long-term service and supports portion for older adults is the piece that they did, and it starts to decline very rapidly hitting 500 billion fairly soon, and so we are going to see rapid growth. But that is just kind of a modeler's view of the world, not that there is anything wrong with that.

But asking of myself practically, what does that mean because can states and the federal government actually really absorb that? And I think that what I worry about is that when you have all of these people coming through the system who are entitled to these services and you can't change that entitlement, your only other choice is to use all of the leverage at your disposal to reduce spending on a per person basis.

So that what we will start to see is this compression around what is available through Medicaid, further putting pressure on families and personal finances at exactly the same time when we are going to see this rapid decrease in the availability of family

caregivers relative to the number of older adults. So this is a perfect storm of unsustainability.

Ms. CASTOR. So could you expand on some of the most promising Medicaid reforms going on at the state level? It would seem that to your point a moratorium on skilled nursing beds is a false reform. And that is what you are talking about is the compression and the—if we don't have the ability to make these reforms it is simply going to shift costs to families.

Ms. TUMLINSON. Right. That is a good example of ways in which it is, states can reduce spending on a per person basis for home and community-based services, they can increase waiting lists, they can put moratoriums on beds, they can reduce payments to nursing homes to the point where their margins are negative for Medicaid.

But in the states that are very innovative, what we see, for example, in Minnesota is a combination of efforts to use sort of central information systems called aging and disability resource centers to help people who are starting to have a need for a long-term services supports and have potentially financial eligibility to actually get tracked into the right level of appropriate care for them so that they don't end up in an institution unnecessarily, and so that, for example, if all you really need is a wheelchair ramp then you get a wheelchair ramp. You don't get 12 hours of personal care a week if that is not what you need. So developing personalized care plans that are specific to the individual needs of the people.

The thing about long-term care is that it is a universal. Universally it is an issue that we all in our families and our lives may face, but each situation is in fact fairly personalized. And so what I like about what Minnesota is doing is that it is allowing those individuals to get the right level of care.

Ms. CASTOR. Thank you very much.

Mr. PITTS. The chair thanks the gentlelady and now recognizes the gentleman from Texas, Dr. Burgess, 5 minutes for questions.

Mr. BURGESS. Thank you, Mr. Chairman. And first off, let me apologize to Mr. Pallone if I misspoke, or if he misheard let me correct him. The premium that I pay for a long-term care insurance policy right now is \$1,500 to \$2,500 per month. Now I am used to talking about the exorbitant premiums I pay in healthcare.gov—did I say it is per month again? I meant per year. The healthcare.gov premiums are per month.

And so I am used to the exorbitant premiums per month, but that is for the ACA coverage. The long-term care coverage is \$1,500-\$2,500 per year. Still a significant amount of money out of a household budget, \$100 or \$200 a month amortized over the course of a year, but an amount of money that perhaps is achievable for middle-class families. And what worries me about what we are doing or what we have done with the discussions we have on long-term care insurance is we pretty much have taken the middle class out of it. Sure, we are going to provide benefits, we are going to provide the safety net for the most vulnerable populations—the blind and disabled children—that continues unabated. But what we are talking about are people my age, people in the 55- to 75-year age group who are aging into a situation where their families now may be called upon to provide long-term care.

So wouldn't it be great if people would at least consider whether or not that makes sense for them and their families? And again I am not even talking about the tax consequences. I am talking about the actual consequences for your family. Again, I referenced the loving gift that a father, mother, father can give their children, which is to provide for that care and not be a burden to their offspring at a time when, correctly, under the normal circumstances of living their offspring are actually raising their offspring and life goes on.

But back to practicalities. Now, Ms. Castor just talked about bipartisan solutions, so Dr. Scanlon, let me just ask you. Independence at home was something that was worked on in this subcommittee and this committee. Actually, the demonstration project was then, I believe, extended and that was just signed into law during this Congress, so that is one of the achievements in health care that can be correctly attributed to this Congress. But can you perhaps fill us in a little bit more on the Independence at Home program and ongoing what it actually means for families?

Mr. SCANLON. Certainly. The Independence at Home program also could be called the Home Based Primary Care program in which sort of individuals are enrolled in primary care practices that will deliver their medical care services in their homes. It is aimed at individuals that have very serious chronic conditions that make it very difficult to be receiving their medical care in physicians' offices and other settings.

The idea behind it is that it will generate savings by preventing these individuals from having their conditions be exacerbated where they will have to visit emergency departments or end up being hospitalized. As you mentioned, the demonstration is underway. I think we are now in the third year of that demonstration and the early results have been positive in a number of the practices.

And so there is this question of how can we make this potentially practical on a widespread basis, what are the types of patients that are best served, what kind of practices should be serving them?

Mr. BURGESS. And would you suggest that the results are positive? Not just positive from a family care-patient care standpoint, also positive from a standpoint that it was self-sustaining and in fact did result in a negative score by the Congressional Budget Office; is that not correct?

Mr. SCANLON. In the first year results. We do not yet have the second and third year results. But I would say again, in terms of this hearing, this is about your medical care needs. This is not about your long-term care or long-term service and support needs.

Mr. BURGESS. Well, let me just ask of the panel for anyone who wants to answer. I referenced the Partnership Program that we did, now, I guess, 10, 11, 12 years ago under the Deficit Reduction Act of 2005. Those hearings that led up to that inclusion in the Deficit Reduction Act, the inclusion of the Partnership Program, there are lawyers who make a business of impoverishing families so that they can then be Medicaid eligible.

And the idea of the Partnership Program was there are a certain number of assets that you can then protect as a family and you don't have to do this to yourself. And one of the unfortunate things

about people who enter into long-term care is most will not actually overspend or outlive, if you will, the ability of premiums to cover their term in long-term care. There are limits on the policies, but most people don't exhaust those. Unfortunately, whatever the problem is that brought them to long-term care is going to claim them before the amount is exhausted.

But for families to have that option to fall back on, to give an incentive for families to actually participate in this program, do any of you have any thoughts on that?

Mr. SCANLON. Well, I think it is a positive to allow families to have this option. And in my discussions sort of with people in the insurance industry, they have said that it has had a positive impact in terms of the number of people buying policies with there is maybe a 15 to 20 percent increase sort of in sales of policies.

The problem, overall, for what we are discussing today though is we are talking about a 15 to 20 percent increase on an incredibly small base. If you raise 5 percent by 15 or 20 percent, as you know we only are increasing it by one or two percentage points.

Protecting your assets in order to pass them on to heirs is potentially one very positive thing that families may value in terms of partnership policies, but I also think that they shouldn't overlook the fact that the policy is going to increase your purchasing power. It is going to be able to allow you to get more services that are potentially going to relieve families of some of the excessive burdens that they may be incurring. That is a second aspect of insurance that I think we really have to focus on.

Mr. BURGESS. OK. Thank you, Mr. Chairman, I will yield back.

Mr. PITTS. The chair thanks the gentleman and now recognizes the gentleman from Oregon, Dr. Schrader, 5 minutes for questions.

Mr. SCHRADER. Thank you very much, Mr. Chairman. I appreciate it. I appreciate the hearing. This is a good area of bipartisan ship. We can all agree that the rising cost of the baby boomers coming into long-term care need situation is going to be untenable and unacceptable.

My state has been a pioneer, I guess, in the community-based services. We don't emphasize nursing homes at all. We are primarily an assisted living, foster care, or in-home-based long-term care state. We have great success. It is wildly popular. People prefer to be in these settings than a nursing home, at least in my area. It is also a lot cheaper for the taxpayer and I think for the individuals that are at risk here. So I urge the rest of my colleagues to look at the Oregon program and maybe try and create some similar situations in their own home state.

We have talked a lot about Medicaid. The ranking member and others have talked about the spending down provisions that seem relatively unconscionable. You can't get good care until you are poor, until you spend yourself into poverty. And that is certainly not a great pattern for success, I don't think. It is something that the greatest nation on earth should not be striving for as a way to provide long-term care services.

And Medicaid is expensive for the taxpayer. Now, as was alluded to by several of my colleagues, it is one of the fastest growing parts of our budget. The safety net programs are the long-term debt deficit conundrums that we face. And I think it has also been said

here today that it is a little untenable to have another program added into these otherwise already slightly untenable programs at high cost to the taxpayer.

So there has got to be some other alternatives out there. Dr. Rivlin, you mentioned very briefly about before we get into the higher cost Medicaid programs that maybe there is something that could be done in the Medicare Advantage arena for seniors seeking home and community-based services. Could you elaborate on that please?

Ms. RIVLIN. I mentioned that in the context of a question of what else do we need to work on, and I think that is certainly one. A Medicare Advantage plan, which is a comprehensive approach to health care anyway or should be, could, if we figure out how to do it, offer long-term supports and services as part of a package and that would help with integrating the health care with the LTSS.

Mr. SCHRADER. And I appreciate that. And to that end, there is a bill that Congressman Lance, Congressman Meehan, Congresswoman Linda Sanchez and I are putting forward, H.R. 4212. It is a bill based on Community-Based Independence for Seniors Act, and basically it is a demonstration project picking five MA plans across the country. It is budget neutral.

Please look at a way that these MA plans, which we have great success with in the state of Oregon, most of our seniors are frankly on MA plans not fee-for-service, and see if they can't integrate with a cap so you can't spend too much, but a cap on how much senior per month so that they can get this in-home care in their home care setting or at least in their community before they have to spend themselves down into the much more expensive Medicaid programs, which are much more expensive for the individual and their family as well as the taxpayer.

So I would urge the committee to please look favorably upon Mr. Lance and my proposal and see if we can't at least get something going, one part of this problem with long-term care our country faces. So I appreciate the opportunity and would yield back my time then.

Mr. PITTS. The chair thanks the gentleman and now recognizes the gentleman from New Jersey, Mr. Lance, 5 minutes for questions.

Mr. LANCE. Thank you very much. And Congressman Schrader and I are working together and I hope the panel will look at the proposal we have. And our cosponsors are Linda Sanchez and Pat Meehan of Ways and Means, so we have Ways and Means and Energy and Commerce working together for precisely the reasons the distinguished congressman has suggested as a model moving forward.

Does anyone on the distinguished panel know how many Americans age 65 or older are currently in nursing homes?

Mr. SCANLON. It is probably about 1.75 million.

Mr. LANCE. All right. And I know there are others who go to nursing homes, younger people, for other reasons, but the Medicare, Medicaid, the Medicare population 65 or older, about 1.75 million. How many in those nursing homes in that age category are funded by Medicaid?

Mr. SCANLON. About 60 percent of them are funded by Medicaid.

Mr. LANCE. Sixty percent of those 65 years or older in nursing homes funded by Medicaid, so not private payment at all?

Mr. SCANLON. That is correct. But at the same time, one of the features of the Medicaid program is that if you become a nursing home resident that you pay your entire income less a personal needs allowance for your care, which in the personal needs allowance is around \$50 a month.

Mr. LANCE. Yes. Yes. And Medicaid is a program funded partially by the federal government and partially by the states. And in the state of New Jersey, for example, we fund it mightily. Our contribution is significantly higher than many other states. Is that accurate?

Mr. SCANLON. That is correct.

Mr. LANCE. And this may be a more difficult figure. Of the Medicaid population in nursing homes, 60 percent of almost two million so it is roughly a million people, I suppose, what percentage have had their assets spent down and have been impoverished?

Mr. SCANLON. That is a number I can't give you. I do not know it.

Mr. LANCE. Yes. I come from a family law firm, and on occasion people come into the law firm saying we want to impoverish our parents. And I am vigorously opposed to that and we don't do it, so they just go next door to somebody else who helps them. Has there ever been a study as to this phenomenon in the United States?

Mr. SCANLON. There has been some GAO work sort of on this issue. It has been a number of years, I think, since it has been looked at.

Mr. LANCE. And I want to work with others in the Congress on a program that helps senior citizens stay in their residences. I think it will be cheaper, vastly cheaper over the foreseeable future and that is why the congressman and I are working on a bill that we hope that you will examine.

Is there any discussion in the academic community or the fine work you do at Brookings as to this challenge regarding impoverishing one's parents? Dr. Rivlin?

Ms. RIVLIN. I think we are all aware that we are not doing research on it.

Mr. LANCE. Anyone else on the panel? Ms. Tumlinson?

Ms. TUMLINSON. Yes. Well, I think a lot of people have tried really hard to research this because it is has been this persistent question for years and years, as long as I have worked on long-term care for 25 years, and it is hard to get any real conclusive evidence. And the reason is because there is so much—well, it is challenging to analyze what is really going on in people's financial lives, and there is some data sets that we have used.

But Josh Wiener and I did some work and we were not able to find evidence of a significant amount of asset transfer or improper use of assets in order to gain eligibility for Medicaid. And again, I would just emphasize that even though that certainly does happen and it sounds like quite a bit in New Jersey from what I am hearing from you—

Mr. LANCE. I don't think in New Jersey to any differently from any other state that I might respectfully place on the record.

Ms. TUMLINSON. Certainly. Sorry. But that there is in fact quite a bit of—

Mr. LANCE. New Jersey is a state, if I might reclaim my time, that sends funds to Washington. We are either number one or number two in the percentage we send as opposed to what we get back. I am sure that this is a state where we send a lot of money to Washington, Ms. Tumlinson.

Ms. TUMLINSON. So we know that at least a third of all spending on assisted living comes from adult children. So for as many children who are seeking to impoverish their parents there are probably just as many who are seeking to pay for them.

Mr. LANCE. I am sure that is the case. That doesn't mean there isn't a problem with the former category. Thank you, Mr. Chairman.

Mr. PITTS. The chair thanks the gentleman and now recognizes the gentlelady from Illinois, Ms. Schakowsky, 5 minutes for questions.

Ms. SCHAKOWSKY. Let me just say I would hope that those who are interested in figuring out how many ordinary families are trying to figure out how to be able to pay for long-term care that we might look at how the wealthiest among us figure out how to pay lower taxes than many of their secretaries. So I would urge that.

I just came from, the National Institute on Retirement Security is having their national conference. I spoke to them. And they just issued a report today, "Shortchanged in Retirement: The Continuing Challenges to Women's Financial Future." And among the things that I pointed out in my speech was that the average yearly out-of-pocket costs for a patient living with dementia is \$61,522, and the average annual cost of a semi-private nursing home is over \$80,000 a year. And we are talking about significant, ending up with significant out-of-pocket costs.

But it is also as Bankrate tells us, two-thirds of Americans don't have enough savings to handle a \$500 emergency car repair. A lot of people are not able to set money aside for the kinds of contingencies that we are talking about, or perhaps inevitabilities that we are talking about.

So I am really happy that we are having this conversation. I think it is just the beginning of how we can work together to truly improve or maybe even create a long-term care system in the United States. We have to improve the quality of our long-term care facilities. We need to increase access to community and home-based services. We need to drastically expand our caregiving workforce, and most importantly we need to have that serious conversation, in my view, about universal social insurance for long-term care.

I would like to just address quickly one of the most persistent issues in long-term care and that is nursing home quality. And I believe one of the best ways to find efficiencies in our long-term care system and better protect taxpayer dollars is to improve the quality of patient care offered at long-term facilities and especially nursing homes and skilled nursing facilities.

So currently, federal law only requires a nurse to be present 8 hours a day at nursing homes and skilled nursing facilities. I personally was shocked to find that out and I think most Americans,

especially putting their parents in nursing homes, would be. This means that for 16 hours a day patients can be left without a nurse on staff at all, and as a result residents are experiencing avoidable injury, increased illness acuity and premature death due to the lack of direct care from an R.N. So I have legislation, H.R. 952, to put, it is called Put a Nurse in the Nursing Home Act that would require nursing homes and SNFs to have an R.N. on staff 24 hours a day.

But Mr. Scanlon, do you believe that efforts to improve the quality of care offered at nursing homes and SNFs would improve efficiencies in our long-term care system and help save federal tax dollars?

Mr. SCANLON. Those types of efforts to improve quality in nursing homes would certainly improve sort of our long-term care system. And in fact we actually have experience with what you are suggesting. If you go back into the 1980s, there was a demonstration program called the Teaching Nursing Home where the amount of nursing services in nursing homes was increased. What resulted was both an increase in the quality of care and a reduction in hospitalizations which are very expensive. Because the reality is that nurses in nursing homes can deal with many of the kinds of problems that lead today to hospitalizations such as pneumonia and other infections.

Ms. SCHAKOWSKY. Thank you so much for telling me that because I think that would be good evidence for this legislation.

The other thing, where was it that I wanted to ask you. So the National Association of Insurance Commissioners, again Mr. Scanlon, you mentioned, previously worked to develop model laws and regulations for long-term care insurance. Unfortunately, the regulations surrounding long-term care insurance have not been updated for over, well, a decade and a half. I previously introduced legislation with Congressman Lloyd Doggett to require HHS to ask the insurers to update their model laws and regulations for long-term care insurance every 5 years and to require their update to be incorporated into the model act and regulations used by HHS.

Do you believe that Congress should work with NAIC to update the standards and regulations pertaining to long-term care insurance?

Mr. SCANLON. I think we need to assure ourselves that the standards are up to date. I don't know what is on NAIC's agenda at this point. In the past it would appear that sometimes that they have updated the standards, the model laws and regs, in response to some crisis that has appeared. That has actually, might alleviate the problem for the future, but it has the negative effect of the crisis erodes consumer confidence and really undermines sort of the ability to convince people that long-term care insurance may be a positive idea.

Ms. SCHAKOWSKY. Thank you. I want to thank all the witnesses, but I want to say a special welcome to Dr. Rivlin. It is so good to see you once again.

Ms. RIVLIN. Very good to see you.

Ms. SCHAKOWSKY. Just wanted to comment, if I could, Mr. Chairman.

Mr. PITTS. The chair thanks the gentlelady. I now recognize the gentleman from Florida, Mr. Bilirakis, 5 minutes for questions.

Mr. BILIRAKIS. Thank you so very much, Mr. Chairman. Thank you also for holding this hearing, and I thank the panel for their testimony.

This is a question for the entire panel. Back in the 1990s, Congress experimented with a demonstration program called the Cash and Counseling. This allowed Medicaid recipients with disabilities to pay for long-term services. The government provided funds to the beneficiary to establish a personal budget for personal assistance services that would best meet the personal needs and paid financial counseling services. This participant-directed personal assistance service allowed flexibility for caregivers and flexibility for beneficiaries to pay for nontraditional services such as respite services and hiring family members as the caregiver. Can you take lessons from this program and other programs to build a better system to promote greater flexibility within the long-term care program, and can we promote more home and community-based care so that seniors may tailor the program to best fit their needs? Who would like to begin?

Ms. TUMLINSON. I will just go first. Yes, I think that that program, the Cash and Counseling programs have been game changers in the way that we think about how we finance and pay for long-term service and supports. In the sense that as I was saying earlier the experience of having a long-term care need is very personal and the individual and the family caregiver is very integral to that. And so making the funds available based on that person's need as opposed to what the services that they buy is a way that we can actually incentivize, I think, a lot of innovation in the marketplace and give people control over their own personal care needs.

Mr. BILIRAKIS. Very good. Thank you.

Mr. SCANLON. I think this program illustrates an important aspect of long-term care that long-term care is not like medical care, where you are willing to accept a prescription because you hope there is science behind that prescription which says this is going to deal with your condition or your disease. Long-term care is about how you live your life. And having personal direction and sort of affecting sort of that is a critical dimension of sort of the satisfaction you are going to get sort of in terms of living your life.

The counseling part of this, I think, is very important because it is not just a question of money. It is very difficult to navigate the market for long-term care services even if you have money. It is not the kind of very visible market that we have for many other services. So being able to assist people to be able to exercise their choices is a very critical piece.

Mr. BILIRAKIS. Thank you.

Ms. RIVLIN. I agree with all of that. Let me just pick up on one thing you mentioned and that was respite care. And I think that is in our list of things we would like to work more on because it is very important.

Mr. BILIRAKIS. I agree. Thank you.

Dr. Scanlon and Ms. Tumlinson, the Deficit Reduction Act of 2005 provides states the option to create a Long-Term Care Part-

nership Program which is a joint federal-state policy initiative to promote the purchase of private long-term care insurance. What can you tell me about the success of this program both in terms of the extent to which it increased use of private long-term care insurance and the extent to which it reduced Medicaid costs? Are there changes that we could make to improve the program? Yes, please.

Mr. SCANLON. At this point I think it is too early to look for its impact on Medicaid costs, because the issue of the long-term insurance is one buys a policy and then hopefully over, say, a 20- or 30-year period, there is going to be a 20- or 30-year period before one goes into benefit and starts to receive the benefits under the policy.

My conversations, as I mentioned with the insurance industry executives, have indicated that the Partnership Program has a positive effect on the sale of insurance policies. It is a modest effect of maybe 15 to 20 percent on a base that is small, of maybe five or six percent.

One of the difficulties in the Partnership, for while it has got positive aspects, actually adds to this problem. If you talk to brokers or agents for long-term care insurance they will tell you this is a complicated product to explain to consumers; that is not fun to try and sit down and convince somebody that they should buy a policy. The Partnership aspect of this creates additional value to that product, but is also another complexity to have to explain sort of how that is going to work.

Ms. TUMLINSON. Yes. I will just add very quickly that part of the challenge is that brokers tell us is that they are both selling against Medicaid and then also for Medicaid at the same—so you want long-term care insurance to avoid Medicaid, but then if it runs out you get Medicaid. So that is a hard sell, but the concept of the partnership is a really powerful one, and I think it is one that the groups have built on to try to, maybe if it is not Medicaid as the backstop it is something else. So the idea that the private insurance could sell against a public backstop is still a really good idea.

Mr. BILIRAKIS. All right. Well, thank you very much. I yield back, Mr. Chairman.

Mr. PITTS. The chair thanks the gentleman and now recognizes the gentleman from Maryland, Mr. Sarbanes, 5 minutes for questions.

Mr. SARBANES. I want to thank the panel. This is a fascinating and sobering topic. Speak a little bit to the actuarial dimension of needing to come up with some products, whether they be hybrid, public-private products or whatever they may be, sooner rather than later, just because the way the trajectory is going you are going to get this huge influx of people hitting at a certain time in terms of their needs and at that point it will be prohibitively expensive to try to solve the problem. You want to have had the benefit of people paying in obviously earlier when they are healthier.

So against where we are headed with the demographic trends, I don't know if anyone has computed with each passing year what the extra cost is that we are talking about in terms of even the kind of bare bones solution that you are offering up. But I imagine

that dynamic is something very present in all of these considerations, so maybe you could just speak to that.

Mr. SCANLON. I think that is a very important point. One of the strong differences between medical insurance where actually premiums are covering the cost of services during a single year, what we are talking about with long-term care insurance is trying to build the reserves that are going to be able to pay for benefits 25 or 30 years later. And as we talked about premiums for long-term care insurance here today, if you look at those premiums they rise dramatically with age, essentially telling everyone if you start too late this is going to become prohibitively expensive and that applies both at the individual level and for the population of the whole.

Ms. RIVLIN. That is clearly right, and that is why we were looking for ways to get people in their earning years to more likely buy long-term care insurance, even if it is a limited long-term care insurance, and to establish a catastrophic program which will take some of the pressure off both the carriers and the beneficiaries.

Ms. TUMLINSON. This is definitely one of the most challenging parts of thinking about the financing of anything that we are contemplating, because we have a lot of cross, what we call cross-cohort challenges with asking very young people to pay as much as we ask older people to pay who are going to be in that level of need much more quickly. And so there are ways in which I think we need to continue to work on the financing so that we can arrange it so that we have kind of the ability to not shift the costs for that population that is nearly there onto the younger people entirely, so we are asking them to pay more, for example.

Mr. SARBANES. There is a little bit of a moral hazard dimension here in that you can imagine people saying, well, I don't necessarily want to step in now and be the guinea pig if it doesn't look like structurally the system is actually going to get fixed. I will just assume that at some point when the whole thing crashes we are not going to let people just be without any kind of recourse, and then I will step in and benefit from whatever that fix is at that time. So you have that dynamic at work too.

It is not helped by the fact that people don't really understand this product. That many as was mentioned, I think, by Representative Castor have gotten confused and assume that it is somehow bound up in Medicare and Social Security and these other programs and benefits that are available to them. So I appreciate your testimony. Thanks very much.

Mr. PITTS. The chair thanks the gentleman and now recognizes the gentleman from Indiana, Dr. Bucshon, 5 minutes for questions.

Mr. BUCSHON. Thank you, Mr. Chairman. I am going to take a little bit different approach. I am going to, well, our conversation today has mostly been addressing coverage and how to finance a system in a system that needs to be changed in another area and that is how much it costs on the front end, not just how to finance a system that has been growing in cost for decades much faster than the rest of our economy. The ACA addressed mostly coverage. That is one of the issues I have with it not really affecting cost.

And what I mean by cost is I am not talking about the cost to a program overall, what I am talking about is the cost to the gov-

ernment or private insurance companies on an individual care basis when services are rendered. So even if less services are rendered overall, yes, the cost to the Medicaid program is down, but on a case by case basis that is probably not the case. The cost to the system continues to go up.

And if we are going to reform many of these programs, one of the things we really are going to have to do is figure out on the front end how it costs us less, but rather than just talking about how we are going to figure out how to pay for what it currently costs or what the cost in the future will be. Does that make sense?

Mr. SCANLON. Yes.

Mr. BUCSHON. And so I am going to get to the question in a second. So one of the things that I am really focused on is trying to work on that and in a number of areas. Price transparency for the consumers is extremely important. Quality transparency for consumers is extremely important. And we are really going to have to look at a number of things that are in place legally and otherwise that are impinging on our ability to address those issues.

Why can't consumers know exactly what something costs? It starts all the way from the bottom at a hospital or at a long-term care facility, the cost of a gauze pad or the cost of a diaper or whatever in the health care system. It can be way up there compared—a gauze pad is essentially a little square of cotton fabric, but it is sterile and it—it costs almost nothing except if you have to buy it, if you are a hospital and you have to buy the product. I am a free market guy so we need to look at how to fix this in a free market way, in my opinion. Price fixing is not an answer to the question.

So my question for all of you is, are any of you looking at what the actual cost of providing long-term care is on the front end and so that we can help decrease the actual outlay of payments on the back end, and what are the drivers, currently, drivers of the actual increasing costs to provide the care? Again, not the cost of what the insurance company or the government has to pay, but buying the product. What are the drivers? Have you looked at it? Because we are going to have to address that.

Ms. TUMLINSON. One of the sad things about long-term care is that because so much of it is paid for out of pocket there is more natural transparency in the system. And so I would, I am sure Dr. Scanlon will want to say this too, but I just want to stress that there really are some—medical care and what we are used to in terms of the lack of transparency in medical care that is so frustrating to everybody, especially consumers, is it is medical care and long-term care act very differently sometimes.

And one of the ways that they do is that much of the spending is out of pocket and the other way is that long-term care is primarily labor. It is not a high tech business, it is a hands-on business. So you really just have two things. There is a price for the hour of labor and then you have the amount that people are using per person. And so we know fairly well what it costs to hire a home care aide, for example, per hour.

Mr. SCANLON. I have spent a lot of my career looking at the differences between Medicare and Medicaid and looking at exactly at this issue that you are talking about which I will call unit costs. And I will have to say that the Medicaid programs, in terms of

nursing homes at least, have done sort of much more sort of effective job in terms of trying to keep those costs down. I wish that actually sometimes we could take some of the lessons from those Medicaid programs and apply them sort of within sort of Medicare.

There is actually a concern that I think should be raised that relates to your question for the future, which is that as we have sort of more what I will call purchasing power, more people wanting to buy services, we have to worry about what is going to be the impact then on unit costs, because we don't want to necessarily create a system that is so formalized that we build in a lot of overhead. That gauze pad is expensive in a hospital because you pay the overhead as well as the cost of the pad. And we want to avoid that when we are paying for more long-term care services.

Mr. BUCSHON. Briefly, my time is running low.

Mr. PITTS. The chair thanks the gentleman and now recognizes the gentleman Mr. CA AE1RDENAS for questions.

Mr. CA AE1RDENAS. Thank you very much, and thank you, Mr. Chairman, for holding this hearing. But I just, for those of you who came here and had to change your schedule, I want to quote a very knowledgeable famous legislator in California, and I will clean up the phrase a little bit because it was made about 70 years ago. He says, hold on to your horses and your spouses, the legislature is in session. So let us just hope that we have some good constructive not only dialogue but outcomes from this hearing, this legislative hearing.

My first question is for you, Ms. Tumlinson. Until the new policy options are available, what is your thoughts on ensuring that Medicaid remains stable and adequately funded? I mean, in our current environment.

Ms. TUMLINSON. So I think that what probably the most productive thing that we can do around Medicaid right now is just continue to work on ways in which we can ensure that individuals who are eligible and for the program are getting the supports and services that they need in the most appropriate setting and the most efficient way possible through the use of aging and disability resource centers, for example.

I think that from a budget perspective it is funded through general revenues and the challenge, really, is on the per person level for the states to manage those funds as efficiently as they can while at that same time ensuring access to high quality care.

Mr. CA AE1RDENAS. Now when it comes to access to high quality care the dynamic is changing, because the demands on that care with the baby boomers seems to be shifting this whole environment. So that being the case, what should we not do right now before we have a more comprehensive solutions and changes? Yes, Ms. Rivlin. Dr. Rivlin.

Ms. RIVLIN. Well, I think we should do some of the things that the three reports that have been mentioned are recommending. And one, to come back to the question of saving costs as well as improving quality, is to make it easier to use home and community-based care and make it easier for the states to do that because there is plenty of evidence that it is just better and cheaper if it is done well.

Mr. CA AEIRDENAS. And also, when it comes to home care I think of the information that I have received, not speaking ill of hospitals or what have you, just because it is an environment where you have so many people with an array of illnesses and reasons why they are there, there is a higher likelihood that somebody is going to catch an infection in a hospital, correct, than they would maybe if they were in a different adequate environment, et cetera.

So there are other tertiary reasons why we should make sure that our panoply of solutions takes into account the whole range of reasons why it is a better solution, or better way in which we should deliver care.

Ms. RIVLIN. Right. Hospitals are dangerous places to be. But I think working on hospital safety is another aspect.

Mr. CA AEIRDENAS. And I just want to make sure that I am not casting aspersions on hospitals. One of the most unfair, dumbest statements I have ever heard is that more people die in hospitals than anywhere else. Well, for god's sakes that is where the people are in the worst condition, but more people, their lives are saved because that hospital is there and they have the facility and the professionals to actually put people back together and keep them alive for god's sakes. So I just want to make it clear that this is not a bashing point, it is just trying to remind everybody how involved this very important issue is especially with an aging population.

You were going to say, Doctor?

Mr. SCANLON. No, I mean, I am in total agreement, I think, and physicians and hospitals, I think, would also agree with you. I mean, we have seen this decline sort of in length of stay because they recognize that it is in their patients' interests to have them out of there as quickly as possible.

Mr. CA AEIRDENAS. And these are not funny issues. I will use a very personal example. My father used to say, why do I want to go to the doctor, so they can tell me I am sick? But little did he realize that when he finally went to the doctor he was 60-some years old, only God knows how long he was a diabetic and had he gone to a doctor and enlisted the help of professionals he would have had a better quality of life. He would have lived longer, et cetera.

And it is not just about my father, it is about the kids and grandkids, et cetera, who don't have him around because unfortunately he thought he was being funny and cute, but what he should have been is a little bit more responsible with all due respect. And so I just want to point out that this is incredibly serious. And again, seriously, Chairman, thank you for holding this hearing.

Mr. PITTS. The chair thanks the gentleman and now recognizes the gentlelady from Indiana, Mrs. Brooks, 5 minutes for questions.

Mrs. BROOKS. Thank you, Mr. Chairman. The figures I have seen and that we hear repeated over and over are that we have about 10,000 Americans turning 65 every day and aging into the system, and so the numbers are off the charts. But what we also, I think, are realizing is that the retirees are astoundingly unprepared.

In my district, in 5th district of Indiana, CNO Financial, one of the nation's largest long-term care insurers is headquartered in my district, and I have talked with them on many occasions and they

have studied this issue pretty significantly and some of the stats they have found are pretty astounding. What they have found is that half of middle income boomers report investable assets of less than \$100,000, with a third reporting assets of less than \$25,000. And so they have found at CNO two-thirds of the middle income boomers express doubts whether or not they will have money to live comfortably throughout retirement, eight in ten have not received any specialized training or education on retirement financial security, and six in ten don't receive any professional financial guidance at all.

And so my question to the panel is, I think there is a severe lack of education and of understanding for middle income America about what is coming at them and what they should expect with respect to retirement, and so I am really curious as to what your thoughts are about how we as a country do a far better job. And I would like each of you, what do we need to be doing to share with people what is happening because so many people actually, I think, believe that Medicare is going to take care of them in long-term care and that is not the case. And so how do we bridge this gap of a significant under education?

Dr. Rivlin, any ideas?

Ms. RIVLIN. Well—

Mrs. BROOKS. The reports are great with a lot of ideas, but we just have so few Americans really understanding what is coming at them in retirement.

Ms. RIVLIN. That is certainly true. And it is hard to know how to reach the people. It is the people in their middle earning years that you really need to reach. If you do education in school, nobody is going to pay attention because they are too young to worry about it. And so I don't know exactly how we do this, but I think employers are key.

One of the things that I think has come out of behavioral economics in recent years—economists do some useful things—is the notion that if you tell people you can opt out of this, whether it is a savings plan or a long-term care plan, we are not forcing you to take it but the default option is you are in that really works. More people save and we think more people would buy long-term care insurance if it were the default option.

Mrs. BROOKS. Thank you, Doctor.

Mr. SCANLON. I think approaching this as a retirement question is really the right way to go as opposed to thinking that this is only a health care issue. This is a portion of sort of your thinking on planning for retirement. Now the reality is that as some of the statistics that you indicated for us, it is a challenge to think about all your needs in retirement given the resources that you are going to have available. But we need to think about bringing this into the discussion so that people can recognize it and, if possible, prepare for it.

On the issue of being confused that Medicare is going to cover this service, I think we have to stop doing a disservice to Americans at the federal level by talking about Medicare covering some long-term care. It covers no long-term care. Skilled nursing facilities and home health agencies may provide long-term care services, others, but they are paid by another source when they are pro-

viding long-term care services. The services they provide to Medicare are not long-term care. We cannot expect the public to read the footnotes to understand that Medicare is not covering long-term care.

Mrs. BROOKS. Thank you. Ms. Tumlinson?

Ms. TUMLINSON. Yes, I just agree very much with what Dr. Rivlin and Dr. Scanlon said. And the only thing I would add here is just that I think that this is an odd kind of silent crisis in every American family, and for whatever reason we are not having a national dialogue about the fact that our whole demographic structure is going to shift from now on and that retiring at age 65 is maybe not a reasonable expectation if you are going to live to be 95.

So we have to rethink how we think about work, how we think about our old age and that I guess my brilliant idea is I think we need to have much more of a public conversations in our districts, at national level with leadership and even among the private capital and investor community.

Mrs. BROOKS. Experts—oh, I am sorry. I guess my time is up.

Mr. PITTS. That is all right.

Mrs. BROOKS. Thank you.

Mr. PITTS. That is all right.

Mrs. BROOKS. I yield back.

Mr. PITTS. The chair thanks the gentlelady and now recognizes the gentleman from New York, Mr. Collins, 5 minutes.

Mr. COLLINS. Thank you, Mr. Chairman. I want to thank the witnesses from coming in. I am the last one, I think, to ask questions.

Just a little brief history in my case. My dad passed back in January of 2010, but prior to that he was through some levels of dementia unable to care for himself at all. So for 3 years we had a team of seven women who cared for him 24/7. It took seven full-time individuals to care for one person 24/7. Six hour shifts with four individuals with him every second of every day, and then you throw in the weekends. That is the staggering amount of individual time it takes. And the cost for seven full-time individuals was a significant burden, but we determined in our family's case my dad had earned money, it was the right thing to spend it for him to be safe, clean, and well fed. But that was not an easy thing to do.

But when I come back again to what Mrs. Brooks was talking about and Dr. Scanlon, would you think it would make sense in the Medicare & You handbook in some bold print to point out Medicare pays no part of this? I mean, we have got a federal handbook that people get.

Mr. SCANLON. I think the no has to be sort of in bold print. I mean, I think that this issue of trying to kind of split hairs and tell them what it covers and what it doesn't cover is confusing people. Because years ago we were doing a survey and 80 percent of the people would say Medicare covers long-term care. It is now maybe around 50 percent would say that.

Mr. COLLINS. Big bold letters right, top, bottom, in the middle, Medicare does not cover any type of long-term care. I think we have got a vehicle in the Medicare & You handbook that we could do a better job at.

My other question, really, carrying it in the same vein is about advance directives, individuals making sure the family knows. I know in our case again with my dad we had a DNR on the refrigerator for emergency personnel just to make sure the wishes of the family were well known, my dad's wishes as well.

But in that regard, I think the federal government now is trying to address that problem of very few people having these advance directives for long-term care in talking about paying physicians to have a small conversation. And Representatives Diane Black, Peter Welch and myself introduced H.R. 4059 which would actually have a small incentive paid by Medicare to individuals to put together a plan. If you are putting together a plan you have to be thinking it through.

I mean, what we were just talking about with Representative—and myself is the lack of education, people being in denial and so forth. So the bill we are promoting is a very small payment to get somebody attention just would ask if you have any opinions on something like that.

Ms. TUMLINSON. Yes, sure. I think that is really creative, actually. And it is absolutely the case that you can even, once somebody is even educated about advance directives that they are still very reluctant to have that conversation. Having that conversation between the family member and the older adult is very hard to do. I have tried to do it and my mom said, “do you think I am dying?” Not yet.

So I think it is a really creative idea. I think we have to continue to come up with it those because ultimately having a good advance directive someplace can be cost saving.

Mr. COLLINS. Well, it lets the family be more at ease with what we are talking about. End of life decisions is what our country seems to be unwilling to have discussed.

Mr. SCANLON. I think our education efforts, some clearly is sort of not working, part of it is the message that we have been delivering, but also a part of it is getting the attention of the people that we want to deliver the message to. So your idea is very innovative.

Ms. RIVLIN. And part of it is medical education in medical schools, getting young doctors to recognize this is part of your practice. You need to be talking about death and dying.

Mr. COLLINS. Well, I want to just thank all the witnesses for coming in. This is a discussion we need to be continuing to have as more and more old folks are—since I was there last May I can joke about it. I have got my card.

Mr. Chairman, I yield back.

Mr. PITTS. The chair thanks the gentleman and now recognizes the gentleman from Missouri, Mr. Long, 5 minutes for questions.

Mr. LONG. Thank you for recognizing me, Mr. Chairman, even though Mr. Collins failed to do so, and when you are talking about elderly you would think that you would at least recognize me.

Dr. Rivlin, I am interested in the Bipartisan Policy Center's recommendation for creating lower cost, limited benefit, retirement long-term care insurance policy options. Can you provide more details on what a policy like that would look like and how it differs from existing options?

Ms. RIVLIN. Yes. What we are suggesting, what we call retirement long-term care insurance, is a bare bones policy. It is not fancy. It would have a high deductible or waiting period and it would have co-insurance and a limited period for which it covered benefits. That doesn't make it sound very desirable. It has other desirable features, but it would cost much less than long-term care insurance typically costs now. And we think if it was marketed properly as part of a retirement plan by employers, and if it were the default option in your retirement plan and if you were allowed to pay the premiums out of your 401(k) beginning at age 45, those are all small changes that we think would make it more attractive and more people would buy it.

Mr. LONG. Are there any current statutory or regulatory barriers to preventing companies from offering those policies today?

Ms. RIVLIN. Yes.

Mr. LONG. There are?

Ms. RIVLIN. There are in that as you know this kind of regulation is at the state level, and so what we are suggesting is that the NAIC be asked to prepare model regulations that states could then adopt.

Mr. LONG. So legislative action that would be something that you would recommend even with at the state level?

Ms. RIVLIN. Right.

Mr. LONG. OK. And this is for any of you or all of you on the panel that want to respond. In recent years, state Medicaid programs have been shifting long-term care into a managed care environment. From 2004 to 2012, the number of states with managed long-term services and support programs doubled from 8 to 16, and the number of beneficiaries receiving these services grew from 105,000 to 389,000. What have been the experiences of these new programs in terms of improving services for beneficiaries and controlling costs?

Ms. TUMLINSON. So there is really a diverse set of experiences with managed long-term services and supports throughout the country, but certainly in certain states what we have seen is that the states have been able to use the managed care mechanism to enable a fairly dramatic shift out of nursing home setting and into home and community-based services settings, because the managed care plans are on the ground level with care managers helping to ensure appropriate, and with significant financial incentives to do so to ensure a persistent home care.

I think that it is not, from my perspective, a way that necessarily the state is going to save money over the long term and in many cases the managed care plans are actually able to get paid based on their costs and their experiences, and so I am not sure it is—I think it is a great mechanism for shifting the services and maybe over time the state would realize some savings from that. But at the same time, I am not sure that I see it as an immediate cost saver.

Mr. LONG. Dr. Scanlon, do you care to weigh in?

Mr. SCANLON. No, I would agree, because I think that states when they have not used managed care have been still managing the benefits sort of much more than for medical care services. In looking to the managed care organizations, I think they are work-

ing to sort of make sure that there is a capacity to continue to sort of manage that benefit as best as possible, but over time it is likely to be inflation in the numbers of people that need services is going to drive the cost.

Mr. LONG. Dr. Rivlin, last 30 seconds, do you care to weigh in on that?

Ms. RIVLIN. No, I think it is a work in progress.

Mr. LONG. OK. Thank you all and thanks for being here today. Mr. Chairman, I yield back.

Mr. PITTS. The chair thanks the gentleman, and I have a UC request. I would like to submit a statement from the National Association for Home Care & Hospice into the record, and without objection, so ordered.

That concludes our questions of members present. We will have some follow-up questions in writing. We will send those to you. We ask that you please respond. I remind members they have ten business days to submit questions for the record and that means they should submit their questions by the close of business on Tuesday, March 15.

Excellent, excellent hearing. Excellent testimony. Thank you very much for being here on this very important issue. This is a discussion that our society really needs to have today. Without objection, the subcommittee hearing is adjourned.

[Whereupon, at 12:22 p.m., the subcommittee was adjourned.]

[Material submitted for inclusion in the record follows:]

The Honorable Debbie Dingell
Statement on House Committee on Energy and Commerce Subcommittee on Health Hearing
“Examining the Financing and Delivery of Long-Term Care in the U.S.”
March 1, 2016

Today’s hearing is an opportunity to begin a serious conversation about the pressing need to address the financing and delivery of long-term care in the United States. I want to thank my good friend Congressman Frank Pallone, the Ranking Member of the House Committee on Energy and Commerce, for submitting this statement on my behalf.

Our nation faces a rapidly-aging population which will require increased access to long-term services and supports (LTSS). LTSS is unique and different from most health services, which includes helping people with activities of daily living like eating, bathing and getting dressed. The demand for these services is expected to double in the next 40 years as our nation continues to age. In 2014 alone, our country spent approximately \$340 billion on LTSS, and this number will only continue to rise in the future.

Today’s system for providing LTSS is fragmented, uncoordinated and expensive. The lack of comprehensive and integrated long-term care programs results in poor health outcomes for patients and places undue burdens on family caregivers. There is not a single place where people can find answers to their questions regarding long-term care and other services. Families are often unclear about where they can receive the care they or a loved one needs at an affordable cost. The lack of clarity and resources makes coordination of care difficult, discourages efficiency and promotes uncertainty among individuals seeking care.

Many in Washington talk about this issue as a looming catastrophe resulting from an aging population. But we should think of it as an opportunity to create a new paradigm for caring for our seniors and people with disabilities. Several well-respected outside groups have come forward with serious proposals that deserve the attention of this committee and the entire Congress. Reforming our long-term care system is not only the right thing to do for our seniors and people with disabilities, but it can help improve the efficiency of our health care system while also saving money in the long run. I stand ready to work with my colleagues on common sense proposals to improve the financing and delivery of long-term care in this country and I hope this hearing is just the beginning of a serious national discussion on this important issue.



Statement for the Record
U.S. House of Representatives
Committee on Energy and Commerce, Subcommittee on Health
Hearing on “Examining the Financing and Delivery of Long-Term Care in the U.S.”
Tuesday, March 1, 2016

The Reeve Foundation is dedicated to curing spinal cord injury by funding innovative research, and improving the quality of life for people living with paralysis through grants, information and advocacy.

We would like to thank the committee for holding a hearing on this important topic. People with paralysis will need long-term care (also known as long-term services and supports) across the lifespan. And while most long-term care attention focuses on older adults, younger people with disabilities represent a significant demographic of long-term services and supports (LTSS) users.

The story of our namesake – Christopher Reeve – paints a vivid picture: that for anyone, anywhere, and at any time, your life can change in an instant, and with it your need for long term services and supports. According to data collected by the Reeve Foundation, the leading causes of spinal cord injuries are accidents at work, motor vehicle crashes, recreational activities, falls, and acts of violence.¹ These are not events for which a family can plan. People with paralysis often need assistance with basic daily functions, including bathing, dressing, and grooming. LTSS are these fundamental supports and services that people with disabilities rely on for daily life.

LTSS financing is a central concern of the estimated 1.25 million people overall with spinal cord injury, and 5.6 million with all forms of paralysis living in the US right now who will need LTSS for the rest of their lives.² Spinal cord injury affects people across the lifespan, and often occurs in young adulthood. Nearly half of all injuries occurring between age 16 and 30.³ At this age, people are not planning for their long-term care needs or thinking about purchasing long-term care insurance. They are attending high school or college, beginning their careers and starting families. After injury, they are most interested in returning to those lives with as much independence as possible; many will need LTSS to do this. According to the National SCI Statistical Center, 57% of people with SCI were employed at the time of their injury, but only 12% were employed 1 year later. That figure climbs to only 35% 20 years after injury.⁴ While some people have disabilities so significant they cannot return to work, many are hindered by their need for LTSS and a system that would remove their daily supports if they returned to work for a living.

When someone develops a need for LTSS, they find that Medicaid often their only option; few families can afford to privately pay for in home supports. Medicaid is the primary financier of LTSS in the US, and LTSS is a large part of the Medicaid program. In FY 2013, the most recent year for

¹ http://www.christopherreeve.org/site/c.mtKZKgMWKwG/b.5184189/k.5587/Paralysis_Facts_Figures.htm

² <http://www.christopherreeve.org/atf/cf/%7B3d83418f-b967-4c18-8ada-ade2e5355071%7D/8112REPTFINAL.PDF>

³ Ibid.

⁴ Ibid.



which data is available, LTSS accounted for 34% of Medicaid spending, down from a high of 40% in the mid 1990's.⁵

While Medicaid is a crucial lifeline for people with disabilities, it has drawbacks. Designed as a safety net program, it has strict income and asset limits for eligibility that limit economic advancement of people with disabilities. Many people are caught in a Catch-22: If they return to work at any substantial level they will lose their Medicaid-funded LTSS, the very services they need to get up in the morning and enable them to go to work in the first place. Faced with this dilemma, people choose to stay on Medicaid, rather than risk being unable to afford their LTSS needs. While smart policymakers have devised several work-arounds over the years, many involve complex financial maneuvering, are limited by age or other rules, and are uneven across states. We need a permanent solution that insures against the risk of life-long LTSS needs, provides people with disabilities supports in their homes and communities, and bases eligibility on functional need, not income or assets.

We encourage the committee, when discussing long-term care financing, to remember the needs of working age people with disabilities – many of whom acquired their disabilities early in life and need LTSS for independence and productivity – and the significant benefits of an LTSS system that encourages economic independence. We recommend the committee consider the approach discussed in the most recent Bipartisan Policy Center report “Initial Recommendations to Improve the Financing of Long-Term Care” that builds on the existing Medicaid program and private LTC insurance systems to insure against the “catastrophic risk” of needing lifetime LTSS.⁶

⁵ <https://www.medicaid.gov/medicaid-chip-program-information/by-topics/long-term-services-and-supports/downloads/tss-expenditures-fy2013.pdf> (Page 11).

⁶ <http://bipartisanpolicy.org/wp-content/uploads/2016/01/BPC-Health-Long-Term-Care.pdf> (page 22)



March 01, 2016

The Honorable Fred Upton
Chairman
Committee on Energy and Commerce
2125 Rayburn House Office Building
Washington, D.C. 20515

The Honorable Frank Pallone
Ranking Member
Committee on Energy and Commerce
2125 Rayburn House Office Building
Washington, D.C. 20515

Dear Chairman Upton and Ranking Member Pallone:

The National Academy of Elder Law Attorneys (NAELA) thanks you for holding the hearing, *Examining the Financing and Delivery of Long-Term Care in the U.S.*, on March 1, 2016.

America lacks a coordinated, comprehensive approach to long-term services and supports (LTSS) that demands Congress's urgent attention. We hope the Energy & Commerce Committee will use this hearing as a starting point to develop a solution to a problem that impacts millions of American families.

NAELA is a national, non-profit association comprised of 4,500 attorneys who concentrate on legal issues affecting seniors, people with disabilities, and their families. The mission of NAELA is to establish NAELA members as the premier providers of legal advocacy, guidance, and services to enhance the lives of people with special needs or a chronic illness at any age.

Persons requiring LTSS are extremely vulnerable, needing assistance with two or more activities of daily living (ADL) to live. ADLs include being able to feed oneself, using the bathroom, getting dressed, moving out of bed, or walking. These needs can arise from a myriad of conditions, including cerebral palsy, a spinal-cord injury, multiple sclerosis, or Alzheimer's disease.

Virtually all of those who need LTSS hope they will not become impoverished, can remain at home, and do not become a burden on their families as a result of their condition. Sadly, the current system causes many to lose all of their retirement savings, be unduly sent to an institution, and rely heavily on family caregivers under enormous strain.

The unseen heroes of our LTSS system are American spouses, sons, and daughters who sacrifice their lives to support another. But without a comprehensive program, many face an insurmountable level of stress, often to the point of exhaustion. According to one study by AARP, family caregivers provide approximately four times more in economic terms of unpaid caregiving than Medicaid LTSS provides in paid services.

As presently constructed, options available to finance LTSS are wanting. Neither private long-term care insurance nor Medicaid provide the solutions Americans need. Insurance provides protection to only a few, due to business issues such as the current low interest rates and difficult-to-calculate actuarial assumptions, and to consumer issues such as medical underwriting, risks of premium spikes, and potential loss of coverage due to lapsing a policy.

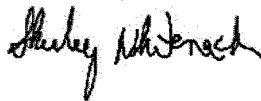
The Medicaid program today plays a critical role covering the majority of paid LTSS and accounts for over half of all LTSS spending. But Americans, facing a LTSS crisis, find that the program has strict means-testing requirements, is institutionally biased, and lacks portability between states. Medicaid is a critical backstop, but we can do better.

NAELA believes that America needs an economically sustainable model for LTSS that protects against impoverishment and provides services in the least restrictive setting. NAELA believes that any new LTSS system should:

- Offer consumers access to a broad array of support options, including a continuum of home and community-based supportive services and residential options.
- Promote independence and dignity across the broad continuum of care by ensuring beneficiaries the right to control and choose what services they receive, how and where they are delivered, and who provides them.
- Recognize a shared responsibility between government, individuals, and the private sector.
- Provide a strong foundation of protection while providing opportunities for personal planning that include a role for private sector options, such as long-term care insurance.
- Support family caregivers and recognize and support the central role families and other informal caregivers play in planning for and providing long-term care.
- Ensure that any changes for future participants don't penalize or leave behind those who need care now.

Thank you for your consideration of this important issue. If you have any questions, please contact David Goldfarb, NAELA's Public Policy Manager (dgoldfarb@naela.org or 703-942-5711 Ext. #232).

Sincerely,



Shirley B. Whitenack
President
National Academy of Elder Law Attorneys

**Statement for the Record Submitted to the U.S. House of Representatives Energy and
Commerce Committee, Subcommittee on Health**

**Hearing on Long-Term Care Finance Reform
Tuesday, March 1, 2016**

**By
American Health Care Association and the National Center for Assisted Living
(AHCA/NCAL)**

Introduction

AHCA/NCAL is the nation's largest association representing post-acute and long term care providers. The Association currently represents 1.05 million nursing center beds, 200,000 assisted living center beds, and 4,000 intellectual and developmental disability beds.

Additionally, the majority of AHCA/NCAL members have diversified into other long term services and supports (LTSS) areas including home and community-based services delivered in the home or in congregate settings, adult day care and care coordination services. The Association is pleased that discussions on long term care (LTC) financing once again are part of Congressional deliberations.

Context

Due to demographics alone, LTSS spending for older adults may increase more than two-and-a-half times from 2000 to 2040, and could nearly quadruple between 2000 and 2050 to \$379 billion, according to some estimates. The challenges of caring for a substantially larger number of older adults by 2020 — less than four years away — will involve: (1) making sure society develops payment and insurance systems for LTSS that work better than existing ones; (2) taking advantage of advances in medicine and behavioral health to keep older adults as healthy and active as possible; (3) changing the way society organizes community services so that care is more accessible; and (4) altering the cultural view of aging to make sure all ages are integrated into the fabric of community life.

At the crux of the challenge is how to finance LTSS for a growing population. If nothing changes, the Medicaid program will remain the primary payer for all LTC. The impacts of failing to address these challenges and alleviate Medicaid budgetary pressure with solid policy solutions raises questions about how funds might be garnered cover the costs of care, implications of slowed economic growth due to high services costs that preclude other social investments, and the general wellbeing of future generations of workers, which might be worse than that of their predecessors due to service costs and income transfers.

The discussion has significant implications for public policy and for private sectors focused on developing an effective care system for the 21st century. Public policy goals related to an aging society must balance the need to provide adequate services and income transfers with an interest in maintaining the economic and social well-being of the nonelderly.

Little discussion on these issues has occurred since submission of the LTC Commission Report in September 2013. And, the 2013 LTC Commission was the first time Congress established an entity to undertake a comprehensive look at the LTSS needs of older adults and persons with disabilities since the Pepper Commission more than two decades ago. However, while sketching out an array of key areas and policy concepts, the Commission was unable to reach consensus on financing solutions.

Much earlier, as noted above, the U.S. Bipartisan Commission on Comprehensive Health Care was called the Pepper Commission after its congressional sponsor and first chairman, the late Florida Democrat Claude Pepper. The Pepper Commission's final report was released in 1990, and many of its recommendations are reflected in more recent legislation.

The Pepper Commission was charged with finding ways to provide uninsured Americans with insurance coverage and access to health services, and to improve the financing of long-term care. A majority of Commission members recommended five steps to achieve those goals: 1) require employers to provide health insurance or pay a new payroll tax; 2) establish a federally mandated basic minimum package of health tax to pay for government-provided insurance benefits for all insurance policies; 3) introduce a redesigned and expanded public assistance program similar to Medicaid for all lower income Americans and families lacking employer-provided insurance; 4) place substantial new restrictions on how health insurers write policies and conduct business; and 5) create a new federal entitlement program to pay for most of the long-term care costs of higher income retirees, whose assets or income currently make them ineligible for public assistance through Medicaid. In its final report the Commission estimated that its recommendations would cost taxpayers \$68.8 billion per year when fully implemented.

LTSS Finance Reform Considerations

The Association believes serious and thoughtful discussion aimed at defining affordable, viable LTSS finance policy solutions in the short term is critical for a number of interrelated reasons:

- ***As is well documented, the baby boom generation began retiring in 2010, significantly increasing pressure on LTSS funding, services and delivery systems.*** By 2020, less than four years away, the number of people 85 and older will double. People age 85 and older are more likely to need long term care.
- ***The vast majority of Americans have not saved for LTSS needs nor are prepared for early-in-life need for LTSS.*** The need for such services can occur at any point life via accident, congenital or progression conditions that result in the need for LTSS, as well as age-related LTSS. Researchers have documented this phenomenon in an array of studies.
- ***Private financing options are challenging to secure.*** In recent years, traditional private financing options, such as private long-term care insurance (PLTCI), have become unaffordable or are no longer available (e.g., most of the major PLTCI

carriers are no longer issuing new policies). Furthermore, for people with existing policies, many have experienced significant premium increases and their policies only will cover a fraction of their costs. Researchers continue to struggle with strategies to encourage new products to be brought to market.

- ***In future, informal caregiver capacity will decline.*** Recent research indicates that the estimated value of informal caregiving is \$470 billion per year. Due to the graying of American and other labor trends, the availability of informal caregiving delivered by spouses, adult children and others in the community will decline in coming years. Such a decline will result in mounting demand for paid LTSS. A recent AARP Public Policy Institute study documents the monetary worth of such critical care and the decline in our society's capacity to continue to delivery such unpaid care.
- ***Lack of private financing options significantly increases Medicaid budgetary pressure.*** For decades, Medicaid has served at the primary source of LTSS financing. The lack of private financing options is particularly challenging because the baby boomers have begun to enter retirement age, and the number of individuals over age 80 (e.g., the age at which the probability of needing LTSS significantly increases) now has begun to rise. Because of the lack of savings and declining informal caregiving capacity, the vast majority of these individuals will turn to Medicaid for assistance. AHCA/NCAL offers a specific example of how the lack of private financing options will impact Medicaid. Forty states operate an LTC Partnership program.¹ The dearth of PLTCL options essentially has frozen participation in LTC Partnership programs because new policies generally are not available for purchase or are far too costly. The National Association of Insurance Commissioners (NAIC) recently requested that the U.S. Department of Health and Human Services resume its collection and dissemination to states on LTC Partnership data to better aid the states in maximizing the potential desired impacts of the Partnership program (e.g., Medicaid savings).

Solutions for LTC financing are elusive and challenging. Today's "long term care system," despite efforts such as Aging and Disability Resource Centers and similar specialized care coordination programs, remains fragmented and confusing for older adults and their families and inefficient, as well as often underfunded, for providers struggling to delivery critical services. In preparation for an LTC financing discussion, AHCA/NCAL crafted a set of reform principles to frame our policy positions.

¹ Under an LTC Partnership program, states offer residents the option to preserve certain amounts and types of assets if they purchase qualifying PLTCL policies. For more information, click [here](#).

PAC/LTC Reform Principles

- *Promote beneficiary access through better private long term care financing options.* Individuals should have stronger incentives and more opportunity to participate in planning for and funding their long term care needs and, in doing so, reduce reliance on public funding. One unexplored option is how life insurance coverage could be converted into a product which covers LTC costs.
- *Meet consumer long term care needs and preferences. Consumers are key stakeholders in long term care policy decision making.* The long term care benefit should be patient/resident-centered, taking into account individual preferences as well as clinical needs and acknowledge the key role that family care givers play.
- *Maximize value and cost-effectiveness.* Reimbursement for post-acute and long term care supports and services should ensure that care is provided in the setting most appropriate to the consumer's needs and preferences. Payment systems should encourage the most appropriate setting and should be designed to foster and support quality.
- *Preserve and improve the public long term care benefit for low-income individuals.* For low-income populations, including the dual eligibles, who are unable to privately finance care, the safety net should be maintained and improved.
- *Better coordinate acute care and long-term care.* Care, especially to dual eligibles, is delivered in a patchwork manner. Overall program costs can be lowered and overall health care quality improved if care were to be delivered in a more integrated and coordinated manner.



The Financing and Delivery of Long-Term Care in the United States

**Submitted to the
House Energy and Commerce Committee
Subcommittee on Health**

March 1, 2016

America's Health Insurance Plans (AHIP) is the national association representing health insurance plans. Our members provide health and supplemental benefits to the American people through employer-sponsored coverage, the individual insurance market, and public programs such as Medicare and Medicaid. AHIP advocates for public policies that expand access to affordable health care coverage to all Americans through a competitive marketplace that fosters choice, quality, and innovation.

We appreciate this opportunity to provide our perspectives on the financing and delivery of long-term care services. Our membership, which includes companies that offer long-term care insurance and Medicaid health plans, is strongly committed to meeting the long-term care needs of our nation's aging population and individuals with disabilities.

This statement focuses on: (1) the value of private long-term care insurance for individuals, families, and taxpayers; and (2) best practices implemented by Medicaid health plans to promote the delivery of managed long-term services and supports, including programs tailored to meet the needs of individuals with disabilities.

The Value of Private Long-Term Care Insurance

Private long-term care insurance provides valuable financial protection and peace of mind to the approximately 7.4 million Americans who currently carry this coverage. It also reduces stress for family caregivers who often face challenges in navigating and finding services for their loved ones.

A November 2014 report¹, commissioned by AHIP and prepared by LifePlans, found that long-term care insurance offers critical protection and needed flexibility for millions of families managing the significant costs associated with long-term care. This analysis found that long-term care insurance provides a more cost-effective way to pay for health care expenses later in life – such as nursing homes, assisted living, or in-home care – rather than relying on personal savings or depleting assets in order to qualify for Medicaid.

The report's findings demonstrate the important protection consumers receive by purchasing long-term care insurance:

- A 60-year-old would have to put aside \$1,666 a month over 22 years to pay for the same amount of services that would otherwise be covered by long-term care insurance with a monthly premium of \$188.
- Individuals who are covered by long-term care insurance reduce their out-of-pocket costs by \$3,000 to \$5,000 a month (depending on the service setting) compared to those without coverage.
- Individuals with long-term care insurance receive on average 35 percent more hours of care than those without coverage.
- The vast majority of consumers are satisfied with the way their long-term care insurance company has serviced their claims. Ninety-four percent of people filing claims reported either having no disagreements with their insurance company or that any disagreements were resolved to their satisfaction. Only about four percent reported that their claims were denied.
- Most individuals with long-term care insurance said their coverage provided greater access and flexibility as they seek to obtain the services of their choice.

The LifePlans report also discusses the value of long-term care insurance to the Medicaid program, noting that current policyholders are expected to save the Medicaid program about \$50 billion over their lifetimes. At a time when state governments and the federal government are facing significant budget constraints, this is an important point for policymakers to consider when advancing legislation to address the financing and delivery of long-term care services.

¹ *The Benefits of Long-Term Care Insurance and What They Mean for Long-Term Care Financing*, LifePlans, Inc., November 2014

The Role of Medicaid Health Plans in Serving Individuals With Long-Term Care Needs

Medicaid health plans are making important contributions toward helping state Medicaid programs use their limited resources to expand access, improve quality, and better meet the health care needs of beneficiaries. A recent AHIP issue brief² shows that enrollment in Medicaid health plans continues to grow, with approximately 35 million beneficiaries – 56 percent of all Medicaid beneficiaries – enrolled in these plans as of July 2013. Thirty-six states, the District of Columbia, and Puerto Rico had Medicaid health plan programs in place in 2013 and states are increasingly partnering with Medicaid health plans to address the needs of vulnerable populations.

Medicaid health plans have demonstrated strong leadership in offering integrated health care delivery systems, conducting outreach and health education efforts, helping to manage chronic conditions through patient-centric disease management programs, and facilitating access to non-medical services. An increasing number of states are relying on Medicaid health plans to serve beneficiaries with complex needs, including individuals with disabilities and those requiring an institutional level of care in managed long-term services and supports (MLTSS) programs.

Managed Long-Term Services and Supports

Working with the states, Medicaid health plans have developed successful MLTSS models that encourage and provide opportunities for beneficiary self-direction of services and supports, take a holistic approach, apply person-centered care, and employ multiple providers and additional services, including community and social supports, to address the many issues that affect a beneficiary's health, well-being, and ability to live in the community. These models include the active use of care coordinators who have been trained in integrating physical health services with home and community-based services, and work actively with beneficiaries and the provider community to address key needs. MLTSS models also ensure that beneficiary needs and preferences are addressed through in-home assessments, care planning, care and service coordination, and care management that engages the consumer, supports families, and monitors the delivery of services.

MLTSS programs also promote active engagement between Medicaid health plans and community-based partners – such as community-based and faith-based organizations and in-home health and services agencies – that can provide critical, individualized services, including:

² *Issue Brief: Medicaid Health Plan Enrollment and Participation Trends*, AHIP, February 2016

- Personal care/assistant services;
- Homemaker services;
- Respite care (in home or out-of-home);
- Nutritional and home-delivered meals;
- Home maintenance and home modifications;
- Family supports;
- Employment supports;
- Independent living skills;
- Operating expenses for use of Medical Emergency Response Systems;
- Assistive technology; and
- Non-emergency medical transportation.

A key ingredient to the success of MLTSS programs is ensuring transparent communication and providing avenues for feedback from beneficiaries and providers to facilitate a smooth transition from fee-for-service coverage to managed care. Medicaid health plans devote considerable resources to training their staffs on MLTSS benefits and the needs of the beneficiaries these programs serve, which is based on direct input from people with disabilities and older adults.

Tailored Programs for Individuals with Disabilities

To address the unique needs and circumstances of individuals with disabilities, Medicaid health plans develop with beneficiaries and their families, individualized, person-centered approaches that incorporate self-direction and address the specific needs and preferences of each member, to support independent living including housing, transportation, and employment. Research has demonstrated health plans are effective in ensuring individuals enrolled in programs in which beneficiaries self-direct care receive the services they need when they need them and in the most appropriate settings³.

In 2007, AHIP and ADAPT, a national disability rights organization, developed guiding principles for serving individuals with disabilities through Medicaid health plans. These principles continue to provide the foundation for best practices Medicaid health plans have adopted for working closely with each person with disabilities to meet their individual needs. For example:

³ For example see JEN Associates, Incorporated, *MassHealth Senior Care Options Program Evaluation: Pre-SCO Enrollment Period CY 2004 and Post-SCO Enrollment Period CY 2005 Nursing Home Entry Rate and Frailty Level Comparisons* (June 2008)

- Medicaid health plans engage in ongoing dialogue with stakeholders, including individuals with disabilities, in the development of Medicaid health plan contract requirements and program design including eligibility, rates, community integration principles, and program requirements. For example, Medicaid health plans have established advisory committees including individuals with disabilities, advocacy groups, and community-based organizations that serve as key forums to review existing programs and make recommendations for improvement.
- Medicaid health plans have established strategies to ensure all individuals with disabilities, regardless of age, have the information they need to be knowledgeable about the programs and services available to them. These efforts include use of community-based organizations, wherever available, in the development and implementation of outreach activities.
- Medicaid health plans work with individuals with disabilities to promote independence and control of their activities of daily living, instrumental activities of daily living, and health maintenance activities.

AHIP and our member plans continue to build relationships and work closely with the cross-disability community to incorporate these best practices and share experiences about how to implement them as well as to maintain an active dialogue on evolving issues.

