

**THE FUTURE OF LONG-TERM CARE POLICY:  
CONTINUING THE CONVERSATION**

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

FIRST SESSION

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## **THE FUTURE OF LONG-TERM CARE POLICY: CONTINUING THE CONVERSATION**

**WEDNESDAY, DECEMBER 18, 2013**

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

The Committee met, pursuant to notice, at 2:15 p.m., in Room SD-562, Dirksen Senate Office Building, Hon. Bill Nelson, Chairman of the Committee, presiding.

Present: Senators Nelson, Whitehouse, Manchin, Baldwin, Warren, Collins, Ayotte, and Scott.

### **OPENING STATEMENT OF SENATOR BILL NELSON, CHAIRMAN**

The CHAIRMAN. Good afternoon.

Long-term care is an issue that comes up repeatedly. It is an issue that many of us not only have a legislative interest in, but a personal stake, as well. Many of us have spoken in prior hearings about caring for our parents as well as planning for our own futures to alleviate some of the decisions for our children.

Currently, about 12 million Americans have long-term care needs, and that number is rising rapidly. Across the country, middle-class families are going through the same tough choices on how best to care for elderly parents. Medicare and most traditional health insurance plans do not cover long-term care expenses, and while private long-term care insurance is available, most people do not have it because they see long-term care as something that they will never need. Well, additionally, who is going to deliver long-term care services? Do we have the right workforce? With nursing home costs rising, some families are turning to assisted living facilities or trying to provide care at home. All of these situations raise additional questions and potential challenges.

All of us have heard from constituents about the trade-offs that they have to make to provide care for their loved ones. I will give you an example. Karen from Englewood shared that she is a full-time caregiver for her 79-year-old mother, who is paralyzed after a stroke. She wrote that “every cent I have goes into helping my mother at home.” Her mother cannot cook, clean, or even wash herself. So, I am sure that many of our colleagues here would share similar stories because they are obviously quite common.

More than half of the long-term care in this nation is delivered through family caregivers. CBO estimates that the value of such care is roughly \$234 billion annually. And despite these enormous costs, most Americans have done little or nothing to prepare for

their future long-term care needs, according to a recent study from the SCAN Foundation.

So, our current system of providing long-term care is unsustainable for both the government and for families. CBO predicts that expenditures for long-term care are likely to increase from 1.3 percent of GDP to as much as 3.3 percent of GDP by 2050.

But, as we continue to struggle to find ways to address it, let us not be naive to believe that we are going to find a solution in just one hearing, but we need to start. The panel that we have assembled will give us a wide array of ideas for us to debate as we strive to find a bipartisan solution, and so I want to thank our witnesses.

I want to thank our bipartisan co-leader, Senator Collins, and Senator Collins, if you would share with us.

#### **OPENING STATEMENT OF SENATOR SUSAN M. COLLINS**

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

As you have indicated, more than 12 million Americans rely on long-term care services and supports to perform the routine activities of daily living and to maintain their quality of life and their independence, if possible. I appreciate your calling this hearing to explore the options for improving our current long-term care financing and delivery system.

As the Senate Co-Chair of the bipartisan Congressional Task Force on Alzheimer's disease, I am particularly concerned and sensitive to the complex care needs of Alzheimer's patients and their caregivers. I, therefore, particularly look forward to discussing ways to provide more support to the 62 million family caregivers who in 2009 provided an estimated \$450 billion in uncompensated long-term care, more than double the value of all paid long-term care.

Long-term care is the major catastrophic health expense faced by older Americans today, and these costs will only increase as our nation ages. It is not just that there will soon be a greater number of older Americans, it is also that older Americans are living longer. Americans 85 and older, our so-called oldest old, are the fastest growing segment of our population, and this is the very population that is most at risk of the multiple and interacting health problems that can lead to disability and a need for long-term care.

At the same time, declining birth rates mean that there will be fewer family members and paid caregivers to care for our nation's growing aging population. Today, there are approximately seven potential caregivers for each person over 80, as this chart indicates. By the year 2030, there will be only four. And by 2050, the number drops to fewer than three. As a consequence, more people will have to rely on fewer caregivers.

What does that mean? What are the implications for the quality of care that will be given? It is clear that we have to do more to support family caregivers and to recruit and retain a robust and competent long-term care workforce.

While there is a need for both public and private financing of long-term services and supports, I do believe that we must do more to encourage Americans to provide for their own long-term care needs. Many mistakenly believe that Medicare or their private medical insurance policies will cover the cost of long-term care

should they develop a chronic illness or cognitive impairment like Alzheimer's. Unfortunately, far too many do not discover that they simply do not have coverage until they are confronted with the difficult decision of placing a frail parent or loved one in a long-term care facility and face the shocking realization that they will have to bear the costs themselves.

Americans should consider their future long-term care needs just as they plan for their retirement or purchase life insurance to protect their families. Private planning for long-term care will not only provide families with greater financial security, but also will ease the growing financial burden on the Medicaid program and strengthen the ability of that program to serve as a long-term care safety net for those Americans most in need.

Again, Mr. Chairman, thank you for calling this hearing and I look forward to hearing from our witnesses.

The CHAIRMAN. Out of a spirit of beneficence and felicity, I would, in the spirit of the season, extend to our two most distinguished committee members the opportunity to say a word or two before we turn to our witnesses.

#### **OPENING STATEMENT OF SENATOR JOE MANCHIN, III**

Senator MANCHIN. Well, let me just say that, first of all, I appreciate, Mr. Chairman, you holding this committee, and Ranking Member Collins, because it is such an important issue.

I come before you as a son, a grandson, and a former Governor that dealt with these matters very personally, and I can tell you, there is not a greater thing that we can do to add dignity and respect to a person's life as they grow older than to try to have them live an independent lifestyle.

I will give you one story. My grandmother was 85 years of age. I used to stop and see her all the time. And one time I stopped and she was very, very lethargic and just kind of sitting there and I said, "Grandma?" And she said, "Oh, everything is okay, honey." And I could tell something was wrong, so I told my mother. I said, "Mom, you ought to go up and see Grandma again," because my mother always wanted her to live with us and she always wanted to be independent. And this one time, my mother went to visit her and she said, "Okay, honey. I will come down and visit the kids." Well, then she stayed for 15 more years, lived to 100 years of age.

[Laughter.]

Senator MANCHIN. And the thing about it was that she was lonely. She had poor nutrition. She was trying to feed herself and she was not cooking properly, all of these things. And we just—do you follow me? It is right before your eyes and you do not see it, and then when you do, you see the difference of a life it makes.

So, I took that with me when I became Governor, and the main thing I wanted to do is create programs that really drew attention to how people could live independently. We started some programs in West Virginia, I am not sure if other States had ever started them before. But I used my lottery funds and table games licensing fees and 100 percent went into my long-term care for independent living, and we called it FAIR. And the FAIR program, basically all it said was, whatever you could pay, you paid. We helped you. We sent people in to let you live independently. A lot of people did not

have family support. There is so much we can do, and government does not have to do it all, but we have to be the best partner they have ever had, and that starts from the Federal to the local levels.

But we had a Lighthouse program to allow long-term care needs to remain in their home for as long as the health allowed, and then we had the FAIR program. That was Families with Alzheimer's In-Home Respite. You just need a break every now and then, just a break. So, there are some compassionate things that we can do and it does not break the bank to do it.

I am just so thankful there are those of you who have dedicated your lives to helping those of us who have been on the front line. My mother is 91 right now, and if it was not for my sisters and my nieces, who take care of my mother, and around-the-clock care—we never put her in a nursing home, and that is not where she intends to be or where she wants to be, and most people do not. If they do not have the support, we have to give them that support that we can to live independently. You will help us do that and we look forward to your testimony.

Thank you.

The CHAIRMAN. Senator Scott.

#### **OPENING STATEMENT OF SENATOR TIM SCOTT**

Senator SCOTT. Thank you, Mr. Chairman.

I can tell that the holiday season has begun. We are sitting Democrat-Republican-Democrat-Republican. This is an odd thing for us in the Senate, so this is wonderful—

The CHAIRMAN. I am feeling lonely over here.

[Laughter.]

Senator SCOTT. Yes, sir. Yes, sir. I just did not want to get to your left, sir. It is not good for me, from South Carolina, to be to your left.

The CHAIRMAN. You are welcome anywhere, any time, Senator Scott.

[Laughter.]

Senator SCOTT. Thank you very much. We will figure it out in the second half.

I will tell you that for me, as Senator Manchin has talked about, the issue of long-term care is certainly an issue that I take seriously and have had to experience personally. I think through my grandmother at 77 when she passed on April 29, 2001. She had both Parkinson's and Alzheimer's, and for the last seven years of her life, my family—thank God for my grandfather and my mother and my aunt who spent an inordinate amount of time taking care of her at their home.

Fortunately, we had the resources to do so, and unfortunately, there are a lot of folks of color, specifically, when you look at the demographic breakdown of who could stay in a home and who cannot, unfortunately, minorities pay a heavy price for not having the resources and the adequate time to care for their loved ones. And so we had a unique experience in a very special way.

I think it is a wonderful opportunity to care for those who took care of you. There is an old saying that you are twice a child, and unfortunately, we have experienced that in this very powerful picture of those of us who have had the opportunity to care for our



loved ones. And that is why this issue is incredibly important for our country.

My second experience has been as a guy in the insurance industry for the last 23, 24 years, where I sold long-term care policies, and I understand the ADLs and the activities of daily living and how many people have not been properly educated on the opportunities to make a decision when you are young enough to make that decision so that the payoff is that you do not exhaust all your resources trying to get down to that \$2,000 or \$3,000 level where Medicaid kicks in. In South Carolina, that expense has been \$1.2 billion Medicaid has put out trying to help folks who have exhausted all of their resources.

So, to have that conversation about where we are going as a nation and how this government can play a role—an important role—I think is a very important decision. Thank God for a Chairman and a Ranking Member that have the foresight to put us in this position, and I look forward to having a robust discussion about the future opportunities and creativity in the marketplace that will provide the type of resources and future planning that gives us real hope that more Americans will retire and then live for the rest of their time in retirement with dignity, to include the last years of their life.

Thank you.

The CHAIRMAN. Thank you.

We are going to start with Ms. Anne Tumlinson. She is a Senior Vice President at Avalere Health. She will set the stage on what the current landscape is like.

And then we are going to hear from members of the Long-Term Care Commission. They are going to share. Dr. Bruce Chernof, the President and CEO of the SCAN Foundation—Dr. Chernof served as the Chairman of the Long-Term Care Commission. Dr. Mark Warshawsky—we are going to hear from Dr. Warshawsky, Adjunct Scholar at the American Enterprise Institute. He is the Commission's Vice Chairman.

And then Dr. Judy Feder, one of the Commissioners of the Long-Term Care Commission. Dr. Feder is a professor at Georgetown Public Policy Institute and a fellow at the Urban Institute and also served as the Pepper Commission's Staff Director under my former colleague, of which I was the President of the Claude Pepper fan club—

[Laughter.]

The CHAIRMAN. [continuing]. And she served for Claude Pepper.

And, by the way, I mean, there was an example. For those of you who were not here in Washington in that era, Claude Pepper and Ronald Reagan would go to it. But at the end of the day, they were personal friends, where then they could work it out together.

And one of the great examples of that, also with the leadership of the Speaker, Tip O'Neill, was when Social Security was within six months of becoming bankrupt in 1983. They said, we are going to take it off the table so that you cannot hit your opponent over the head with it. They appointed a blue ribbon panel. They made the recommendations on what to do, sent it to the Congress. We passed it overwhelmingly. And it made Social Security actuarially

sound for the next half-century. That was 1983. So, those folks knew how to get along.

Ms. Tumlinson.

**STATEMENT OF ANNE TUMLINSON, SENIOR VICE PRESIDENT,  
AVALERE HEALTH**

Ms. TUMLINSON. Thank you. Chairman Nelson, Ranking Member Collins, and members of the committee, thank you very much for holding this hearing and especially for the opportunity to testify today about the future of long-term care policy.

So, the perspective that I am about to share comes from my work over the past 20 years, first at the Office of Management and Budget as the person responsible for the Medicaid budget, and also the last ten or 15 years consulting to nursing home providers, assisted living providers, and working with a number of my colleagues here on the panel analyzing the budgetary impacts of a whole variety of ideas for reform, including the CLASS Act.

So, I just want to start by saying, as many of you have already noted, we spend well over \$200 billion, but we pay for very little care. We depend on over 60 million Americans to provide most of the care, and they provide it unpaid. And they do this because most Americans are not insured against the financial risks of long-term care and they really want to avoid a Medicaid nursing home bed.

So, the long-term care system is woefully under-financed for the job that it has to do now and for the job especially that it has to do in the future. All of the other problems that we talk about—the delivery system, the workforce, the quality of care—all of them stem from this fundamental fact of under-financing.

So, I am going to make three points to just frame out our discussion today that I hope will help you all in the work that you are doing in the future and that will make our discussion a very interesting one. So, I am going to start with something a little bit controversial, and hopefully, the former Governor will not come across the table at me.

The problem that we have to solve, in my opinion, most primarily, is actually not one that is a Medicaid budget problem, and I worked on the Medicaid budget for many years and I do not see this primarily, actually, a Medicaid budget problem. It is an issue, of course. States have to pay for, they have to fund their Medicaid programs, and there are people entitled to services under those programs. And Governors and State governments are going to face huge challenges as the population ages. That is definitely true.

But the real issue is that in managing these challenges, even more of a financing gap is going to be created, and that gap is going to have to be filled, as it currently stands, by families through their own personal finances and through unpaid caregiving.

Long-term care is actually shrinking as a percentage of the Medicaid budget. It is at its lowest percentage in two decades. Over the last ten years, Medicaid long-term care spending has grown at an average annual rate of less than five percent a year.

And it is true that we will have many more older Americans, as I said, but the larger concern is that in preparing for these demographics, States are doing very smart and logical things from a

budget perspective and they are already demonstrating that they can and they will exercise the budgetary levers that they have to both reduce the number of people who receive Medicaid long-term care services and the amount that they spend per person and they are going to do it in all settings, not just nursing home.

And, in fact, we see that reflected already in the growing interest among States in moving people into managed care for their long-term care services and out of fee-for-service. In other words, relative to the number of people who are going to need long-term care in the future, there is going to be a lot less Medicaid to be spread around and among those people.

So, secondly, my second point is that the inability of Medicaid to keep up with the growing demand points, in my opinion, to the real problem, that the under-financing of long-term care creates and contributes to enormous economic insecurity, which is already a major problem in this country, and this is a big part of it. And it is an insecurity for the majority of American families and when they think about what they might be facing in the future.

So, when they are faced with this crisis, most Americans, what they do, as many of you noted, is they cobble together a variety of resources to provide what they can. Less than two million of the 12 that we have talked about today who need long-term care are actually living in a nursing home, and that is because the rest live in the community where Medicaid dollars are the scarcest and where a third of all American families report providing some type of caregiving. A third of all American families are now providing some level of caregiving.

When they provide this care, they do it at a rate of 20 hours per week, and that time is spent doing the really hard, physically and emotionally challenging work of caregiving, and they do it while 75 percent of them are holding down another job.

And we know from industry data that over a million people are paying privately right now for assisted living or some other type of senior housing, and it costs \$42,000 per year, on average. This is not just for rich people. These services are being financed through the sale of homes, through contributions from adult children. And providers tell me that their residents exhaust their resources while in assisted living and have to move into a nursing home to continue their care under Medicaid, because Medicaid does not cover assisted living.

Very little of this, by the way, is captured in our national data. We do not have a good way of getting a handle on these expenditures.

So, after years of working directly with providers, analyzing data, my conclusion is that it is much more likely that Medicaid right now is generally viewed as something to be avoided rather than as a mechanism to exploit for wealth protection. And as someone whose job it was to work on improving the efficiency of Medicaid, to find scorable Medicaid savings, and who was not shy about it, I might add, I am telling you that there is not much here to suggest that we have enormous opportunity to further tighten Medicaid. In fact, it is quite the opposite.

My final point, and this is probably the least popular point that will be made here today, is that even when people are educated

about the risks of long-term care, and even when they are presented with the long-term care insurance policies, and even if we manage to do that for many Americans, we will not truly address under-financing without requiring everyone to participate in the risk pool. I say this after, by the way, being a proponent of expanding coverage through voluntary private approaches and analyzing the budgetary impacts of these.

I learned from that experience, and I am now of the view that in order to adequately protect Americans against the risk of long-term care need, in order to correct for the under-financing problem that we currently deal with, some part of the solution of the future must be mandatory participation. We have this vigorous debate over private versus public insurance options, but it does not really mean anything because neither works very well in actually covering enough people when the participation is optional.

It is an important debate, the debate between public and private, for sure, but not one we should be having without facing the reality of what it will really take to protect Americans, and in doing so, we will address the Medicaid budget issues in the process.

I look forward to your questions. Thank you.

The CHAIRMAN. Thank you.

Dr. Chernof.

**STATEMENT OF BRUCE CHERNOF, M.D., PRESIDENT AND  
CHIEF EXECUTIVE OFFICER, THE SCAN FOUNDATION**

Dr. CHERNOF. Thank you, Mr. Chairman, Ranking Member Collins, and members of the committee.

Dr. Warshawsky and I are pleased to be here today to present the vision and recommendations of the Long-Term Care Commission, and I want to begin by saying I am going to walk us through the highlights of the report, but this is work that Mark and I did together and it comes from a spirit of fundamental bipartisanship, which we think is the way forward. So, again, I am going to make some opening comments on behalf of the whole report and Mark will make some specific comments to follow.

As all of you know, the Commission had a very compressed timeline. We were set out with a six-month schedule, and after going through the appropriations process, we had roughly 100 days, somewhere between 90 and 100 days, to do our work. In that work, we actually had four public hearings with 34 witnesses, over 100 submissions of public testimony, and nine working sessions.

On September 12, as required by the law, the Commission voted by a bipartisan nine-six majority to issue the final report as the broad agreement of the Commission. I want to provide you with an overview of the Commission's work process and the development of the final recommendations.

I want to begin by saying that the Commissioners were a talented, knowledgeable, and really diverse group of people, and our expectations as Commissioners were that we would identify as much common ground as possible and establish that as a foundation for moving forward on long-term services and supports issues, that the discussion and areas of agreement and disagreement would be evidence-based, and that we would be open and willing

to challenge accepted thinking where we could not find substantial evidence.

We are really pleased with the collegiality and the amount of common ground reached. This makes the point that addressing long-term services and supports issues is not an intractable problem. This is something that we can work on in a bipartisan way.

In the process, each Commissioner was asked to submit proposals. All proposals for discussion are included in Appendix A of the report. Commissioners then selected the ideas they felt merited the most attention, and this subset was discussed and developed as potential recommendations. Proposals that could not achieve broad agreement were not included as final formal recommendations.

Let me state clearly that developing a thoughtful, comprehensive report in 100 days is an important success in and of itself and a direct result of the Commissioners' dedication.

Let me provide you an overview. So, the report itself is framed by a clear call to action. We think it is very important for the general public to understand this need, and that broad agreement for a shared vision for the problem that we are trying to solve together. The shared vision, then, really serves as a framework that supports 28 specific recommendations.

Let me touch on a few key points of the vision. It starts with the notion that we must have a fiscally sustainable and effective long-term services and supports delivery system. It is built on concepts of person- and family-centered care. It provides individuals with supports and services in the least restrictive environment appropriate for their needs. It is delivered by a well trained and adequately supported array of family caregivers and paid workers.

And, finally, the comprehensive financing requires an approach with really three prongs: A balance of public and private financing to ensure the most catastrophic expenses; encouraging savings and insurance for more immediate long-term services and supports costs; and, finally, providing a strong safety net for those without resources.

Now, the 28 recommendations, I could take you all through them and we do not have the time for that. So, what I would like to do is kind of box them up and highlight them for you in a way that is useful in our discussion today. The three key areas are service delivery, workforce, and financing.

With respect to service delivery, I think it really all hinges on the recommendation that we start with a better balance of community-based and institutional care choices. Finding that right balance is really important since most folks want to be and should be in the community.

Other recommendations include: A single point of contact. A uniform and standardized assessment that is used by all providers, and that it actually engages the family and individuals themselves. Accelerating the development of a new generation of quality measures that includes home and community-based services and the experience of the individuals receiving care. And, finally, promoting payment reforms that focus on outcomes rather than settings.

With respect to workforce, central to this set of recommendations was a variety of recommendations focused on improving training and support for family caregivers, including identifying a family

caregiver in the chart and assessing the family caregiver as part of the care planning and the care team. Other important workforce recommendations included taking on the scope of practice and delegation, integrating direct care workers more effectively in teams, and encouraging States to improve standards for home care workers.

Finally, in financing, given the 100 days, the Commission did not have a single recommendation on financing but did outline a common vision, as I have already noted, and then identified two different approaches that could be the basis for a broader discussion, one focused more on public social insurance solutions and the other based more in private market solutions.

Now, I will say, when you look at both of those approaches, there are some really interesting commonalities that sort of bring them together and are ripe for further work. I will say that the public policy details, the costs and funding mechanisms for both approaches remain to be specified, and many Commissioners felt it would require considerable new data, design work, and careful analysis of costs and consequences before a fiscally responsible proposal could be put forward.

Finally, there were five specific recommendations relative to Medicare and Medicaid.

Next steps, which is, I think, one of the things that brings us here today, the Commission felt very strongly that it is critical to have a follow-on body for the Commission to pass along the baton for critical economic modeling work that is still needed and not complete. We also called for a 2015 White House Conference on Aging in partnership with the National Council on Disability to focus on long-term services and supports issues.

With that, I really want to thank the Commissioners for all their hard work, all our staff, who really gave up their summer to get us a product done on time. I want to thank Mark one more time, because his knowledge, leadership, and engagement throughout this process was really important. We worked as a team from day one, and I think that is going to be critical to get this job done.

Thank you. Finally, I want to thank you for the opportunity to testify today.

The CHAIRMAN. Thank you.

Dr. Warshawsky.

**STATEMENT OF MARK J. WARSHAWSKY, VISITING ADJUNCT  
SCHOLAR, AMERICAN ENTERPRISE INSTITUTE**

Mr. WARSHAWSKY. Thank you, Chairman Nelson, Senator Collins, and members of the committee. My name is Mark Warshawsky and I would like to add to Bruce's discussion my own views on the financing issues in more detail.

The Commission did reach a consensus at a high level on the need for personal savings and insurance coverage and significant government support for the lower-income population, but we did not agree on structures or proportions. At least some of the divergence arose from a lack of empirical clarity on several aspects of the problem, which we tried to address in the Commission, but we did not have enough time and resources to resolve them.

In particular, I am referring to our debates on whether Medicaid is now an LTC insurance program for the middle-income or even higher-income households, whether there is significant capacity of working-age adults with severe functional limitations to participate in the labor force, and how to improve the private insurance market.

Focusing on the older population, some have expressed the view that Medicaid is now a program just for the poor, but I see that there is significant extent of Medicaid coverage for those who are solidly in the middle-income and above groups in their working years and through retirement. Evidence presented to the Commission as well as our understanding of the Medicaid eligibility rules indicated that in many States, significant housing, retirement, life insurance, and spousal assets are set aside in considering Medicaid eligibility, and many people who are in the middle-income group and above do, in fact, get Medicaid benefits.

Still, there is much to learn about how significant is spend-down. What is the true extent of gamesmanship in Medicaid eligibility? What would additional efforts by the States bring in through estate recovery? And how much do the elderly care about leaving bequests or having expanded care options beyond what Medicaid currently provides?

Some of us believe that one way to find out answers to all these questions is to set up an option for a Medicaid carve-out, whereby upon retirement, individuals would have the choice of receiving a lump-sum payment from the government for a significant portion of their expected value of their Medicaid benefits. This would be most for the poor, little or nothing for the best off. Retirees would use the payment to purchase private permanent long-term care insurance of the desired benefit design in the place of Medicaid coverage.

Turning to the working-age population with functional limitations, what little we heard and discussed indicated conflicting views about the extent of the capacity of return or to continue to work if significant supports were to be provided without the intended Medicaid requirement for impoverishment. To my understanding, past experience and data here is not encouraging about that capacity. But I did, and we all supported the Commission's recommendations to create a demonstration project and to assist States to achieve greater uniformity in State Medicaid buy-in programs for LTSS. Hopefully, we can learn much from these projects and changes.

But even assuming that the results are positive, it is likely that the indicated policy changes will be costly. In light of the severe fiscal condition of the nation, we must be willing to prioritize needs, such as by tightening the currently loose eligibility standards for workers above age 50 to qualify for disability insurance in Medicare.

Finally, there was a disagreement about the possibility to improve the functioning of the private long-term care insurance market. We all agreed that, currently, it is a mess, but there was lesser consensus on the "why's", which, of course, leads to the prescriptions put forward.

In my view, the problem is mainly one of inadequate demand arising from the crowd-out effect of the Medicaid program and also a lack of public understanding. At the same time, there are problems on the supply side, partly stemming from the restrictive State rules on insurance policy design and Federal tax law.

So, some of us proposed the following. First, provide a tax preference for long-term care insurance policies through retirement and health accounts, and we feel that in terms of the savings from Medicaid, this would cover the costs of lower tax revenues.

Second, we wanted to support combination policies, such as a life care annuity. Such products would marry immediate life annuities to long-term care insurance, allowing individuals to finance their care as well as their retirement. Combining long-term care insurance and life annuities would decrease the combined cost and considerably ease underwriting standards, enabling more seniors to afford and obtain coverage.

I would also like to note that although five of the six Republican Commissioners voted in favor of the report of the Commission, we all stated that the Commission's recommendations should not increase an existing budgetary commitment to health care faced by both State and Federal Governments. Likewise, we believe that raising taxes to fund additional entitlement commitments is unwise, especially given recent tax increases to pay for the ACA.

In closing, I want to echo Bruce by stating my appreciation for the tremendous effort of my fellow Commissioners. They did the impossible and produced an important product on a very tight schedule. I also want to thank Bruce for his incredible leadership. He was a great partner who worked diligently to install trust and create an environment conducive to collaboration and dialogue.

Thank you.

The CHAIRMAN. Thank you.

Dr. Feder.

**STATEMENT OF JUDY FEDER, PH.D., PROFESSOR, GEORGETOWN UNIVERSITY McCURT SCHOOL OF PUBLIC POLICY, AND FELLOW, URBAN INSTITUTE**

Ms. FEDER. Thank you, Chairman Nelson, Ranking Member Collins, and members of the committee for the opportunity to testify before you today on a path forward for long-term services and supports.

I appreciated at the outset, Mr. Nelson, your mentioning my service as the Staff Director of the Pepper Commission, which began about 25 years ago, so as you can see, I have been at this a long time and hope we will make some progress before I need long-term care. So, we definitely need to get on with it.

But, the experience most recently as a member of the Congressional Commission on Long-Term Care is what I am testifying before you today on as well as my experience, and I can tell you, there is a lot of work to be done. Although policymakers are grappling with the challenges of assuring Americans affordable access to quality health care, we have yet to seriously tackle the equally important issue of long-term services and supports.

Despite the continued political battle, even critics of the Affordable Care Act recognize the need for insurance to assure access to



health care and protection against financial catastrophe. But there is much less acceptance of the need for insurance when it comes to another health-related risk, one for which virtually all Americans are uninsured, the risk of needing expensive help with basic tasks of daily living, like dressing, bathing, or eating, generally referred to as long-term services and supports or long-term care.

On the financing that is critical to building an effective long-term care system, the recently concluded Commission stopped short of recommendations. But five of us Commissioners felt compelled to step up, did not support the Commission report, and offered an alternative report explaining, as charged, why and how Congress should accomplish this goal, and I request that you include that alternative report that I have submitted with my testimony in the record.

As you said, about 12 million people have a need for long-term care today, and I would remind us, while this is the Special Committee on Aging, that five million of these individuals are under the age of 65.

As you said, the vast majority of these individuals count on their families for help, but families can only do so much, and when people need paid care, whether at home or in an assisted living facility or a nursing home, its costs soon exceed most families' ability to pay. That is where insurance ought to kick in. But private health insurance does not cover long-term services and supports and few Americans have private long-term care insurance, which typically costs a lot, offers limited value, and is subject to premium increases that can cause purchasers to lose coverage they have paid into for years.

On the public side, Medicare, which older people and some younger people with disabilities rely on for health insurance, does not cover long-term care. The Federal-State Medicaid program does serve as a valuable last resort for people who need long-term services and supports, but its protections, especially home care, vary considerably from State to State and become available only when people are or have become impoverished taking care of themselves, and I would have to take issue with Mark's comments because the evidence that was presented to us is that Medicaid is not a program for the rich. Its benefits are overwhelmingly going to low- and modest-income people.

The need for expensive long-term services and supports is precisely the kind of catastrophic, unpredictable risk for which we typically rely on insurance to spread costs. These costs are obviously unpredictable for people under the age of 65, and I think we all get that. Only two percent of that population needs services. They are almost half the long-term care population because it is a small percent of a very large number of people.

But, the likelihood of needing long-term care and extensive expensive long-term care is also unpredictable for people when they turn age 65. An estimated three in ten people age 65 today are likely to die without needing any of these services, while two in ten will need more than five years—five or more years of service.

And when we think about the risks in financial terms, half of the people turning age 65 today will spend nothing on long-term care,

depending on their families when they need it, while a very small percentage will spend hundreds of thousands of dollars.

If, as you have indicated and is often claimed, we really want people to be financially prepared to manage this unpredictable catastrophic risk, we need to establish a reliable insurance mechanism, whether public or private or in some combination, to which they can contribute. It is easy for experts to agree that we need a public-private partnership, but the real challenge is what role is each sector going to play.

To effectively spread risk and reach the broadest possible population, public social insurance that really spreads risk and everybody participated in, as Anne emphasized, must be at the core of future policy. Private insurance can play a complementary role, but even its proponents recognize that building future policy around a private market will, at best, leave eight in ten Americans uninsured.

Public insurance can be designed in different ways. It can offer relatively comprehensive and defined benefits, like or even through Medicare. Or, it can offer basic cash benefits in a new program. And it can be funded in different ways, in part through taxes, like a surcharge on the income tax, and in part through savings from what Medicaid would otherwise have to spend, although I would emphasize what Anne said at the outset. Although there can be some savings to Medicaid, Medicaid is woefully underfunded and we need new financing to support a decent system in the future.

Regardless of its specifics, a public or social insurance program will protect all of us at risk and require all of us to contribute.

In closing, I want to emphasize that public insurance will not eliminate personal or family responsibility. Rather, it will make shouldering that responsibility manageable and affordable through private insurance, private resources, and family care. And no social insurance mechanism is likely to eliminate the need for an adequate public safety net, whether within it or through a continued, albeit smaller, Medicaid program.

The enactment and implementation of the ACA demonstrates that it will not be easy to enact long-term care insurance, a public long-term care insurance program, but we should not kid ourselves. Without it, our policies will continue to fail people young and old, now and in the future, who need care. Building an effective long-term care insurance system with public protection at its core is the only way to enable Americans to prepare for the risks we all face, and building it is our responsibility.

Thank you.

The CHAIRMAN. Thank you.

I am going to withhold my questions and I will do clean-up so that we can get to our members. Senator Collins.

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

About a decade ago, I authored legislation that became law to allow the Federal Government to provide a long-term care insurance program for Federal employees. It was not a subsidized program, but at least Federal employees would be offered that benefit and the advantage of a group program that they could buy into. And there have been some issues with the program, but one of them is that not many Federal employees signed up for the pro-

gram, which really shocked me, because if you look at the demographics of this country, one would think that one at a young age can buy affordable long-term care insurance and thus be protected.

I am curious, and Dr. Warshawsky, I will start with you on this issue because you talked about one of the reasons that the long-term care private insurance market is, quote, “a mess,” is inadequate demand. And I am wondering if most large employers offered this as a benefit, like Fortune 500 companies.

Mr. WARSHAWSKY. My understanding is that about half of large employers offer it as an optional benefit. Very, very few will contribute to it, so it is an employee pay-all benefit, but about half will offer it. But I think the experience is similar to what you have indicated in the Federal Government, that many do not use it. I think even very large well-paid organizations, about five or six percent of their workers use—purchase long-term care insurance, and I think there are a couple reasons for that.

As I indicated in the testimony, and as we heard by an eminent economist, that Medicaid does represent a type of social insurance and it is a crowd out of private insurance, and that is a significant factor.

Most other benefits, retirement benefits or health benefits, that are given by employers are tax advantaged, which certainly provides an enormous incentive to get the benefit. Clearly, long-term care insurance is not a tax-advantaged benefit.

And I would say it is a difficult subject, to be frank. Although health has its downside, it has its upsides. Retirement is usually something that people look forward to. Long-term care, unfortunately, is a difficult subject. In my opinion, I think it is a subject which is best handled at the point in retirement, which is why I have proposed, and some of the Commissioners supported this, creating combination policies which would be offered at the point of retirement, such as the life care annuity.

Senator COLLINS. I am very intrigued by that idea, and certainly if we made long-term care insurance tax preferred the way health insurance is, it seems to me you would see a larger uptake by employers and employees. On the other hand, we are all aware that that is the largest tax expenditure, if you will, that we have, with employer-provided health insurance. So, there is a cost to doing that, as well.

I continue to believe, though, that another issue is that people are under the misimpression that, somehow, the Medicare program is going to cover them, or their normal health insurance, or their supplemental insurance program is going to cover them. And as people are living longer, and if you look at the statistics on Alzheimer’s disease, which are truly frightening, the need for long-term care is only going to grow. So, I think we need to do a better job in making private long-term care insurance available and attractive to people.

Dr. Chernof, let me just ask one more question—my time is rapidly running out—and it has to do with home care. Most people I know would much prefer to receive home care rather than going to a nursing home, and yet we have a very outmoded definition for qualifying for home health care that has a homebound requirement. And that homebound requirement ignores the fact that we

have made technological advances that allow people who have disabilities to leave their homes at times, and I am wondering what you think of changing the definition or qualification for the home health benefit so that it is based on the patient's functional limitations and clinical condition rather than on some arbitrary limitation on absences from home.

I introduced a bill several years ago to change that. We were unable to get much traction for it. But it is my understanding that the Commission did address this issue, and if you could tell us what the Commission decided.

Dr. CHERNOF. Certainly. Thank you for that question, Senator Collins. You know, let me start just as a physician for a second and a general internist. From my years in practice, it is all about function. We need to start there, because function, and function in combination with serious clinical illness, is what drives cost and actually what really puts pressure on families and systems. So, by sort of starting there, I think you get to the right answer, which is a slightly different answer than the one we have today. And you are correct that as the Commission as a whole deliberated, the homebound requirement was one of those areas that we thought really needed to be revisited.

Now, let me say clearly on behalf of the Commission that I think people understand the risk that you do not want to create something that just radically grows a program and increases costs. So, this is something that would need to be done thoughtfully and it is about finding the new right definition that helps the right people get the right services in the right place. But the Commission as a whole, Republican appointees and Democratic appointees, came together to see this is a real place where there is a need for a new definition, one that is, frankly, more efficient, more effective, and more person-centered.

Senator COLLINS. Thank you.

The CHAIRMAN. Senator Scott.

Senator SCOTT. Thank you, Mr. Chairman.

This is an interesting panel, honestly, as it relates to the topic. You guys are certainly well educated on the topic and very passionate. I can see it in your eyes and maybe hear a little frustration in the number of years you have worked on this project without any actual progress. I certainly appreciate that. And you go from the mandatory, let us all get in the boat together, to let us find some free market solutions for it. Certainly, I am going to follow more on the free market side, but I do realize that even with the best case scenario, if we could take it from Dr. Feder's two-in-ten to three- or four-in-ten, we could improve drastically the results of it.

And having sold a couple of these policies, I will tell you that part of the challenge that we face, it seems to me, is that when you go into a large group, whether it is the United States Government or some of the larger groups that I dealt with, informing the individual who works for the company that the available benefit is there is a totally different conversation than getting them to sign up for that benefit. So, the real challenge is that when you have these large employers, unless you have enough agents or folks to help sell and market and motivate folks to take a second look at

what the actual benefits package includes, it is very difficult to get people to sign up for something that they are uninformed about as a part of the process, and that is really one of the challenges.

I would love to have Dr. Warshawsky—I am going to call you Mark because I am going to butcher your name the second time I say it—

[Laughter.]

Senator SCOTT. [continuing]. Talk about this part. So, I think the misinformation really takes away the motivation. So, the misinformation is that somehow, some way, your health insurance policy is going to cover this one day, and if that does not, then you become eligible for Medicaid and that will cover it. And they do not really understand that you have to exhaust all your resources before Medicaid becomes a part of it. So, there is a misinformation, in my opinion, that has to be addressed, number one. And there is a marketing opportunity, as well.

And then when you look at the hybrid combination policies of annuities merging with long-term care, are we looking for an opportunity to have the balance in your annuity create a different actuarial basis to then reduce the actual rate for the long-term care insurance so as to make it more accessible to those in the public and then adding a tax preference to that in an attempt to actually then create more affordability and more access to it? Is that where we are going with it? Is it similar to, in fact—the longest run-on sentence in American history right now—is that similar, in fact, to what the life insurance companies have started doing with the ability to get some of your life insurance benefit before you expire, the last 25 or 50 percent of your life, if you know what I am talking about?

Mr. WARSHAWSKY. I am familiar with those, yes.

The CHAIRMAN. Senator Scott, you have adapted to the Senate very well.

[Laughter.]

Senator SCOTT. They said, sooner or later, I would like to hear myself talk, and I am getting closer to that place now, so yes, sir.

[Laughter.]

Mr. WARSHAWSKY. Yes, we—

Senator SCOTT. One part of that five-part—

Mr. WARSHAWSKY. Yes, I will try to address many of those. I think, and also in support of what Senator Collins indicated, there is ample evidence that there is great confusion about what the government covers or what insurance covers and what it does not. There have been surveys done by Professor Howell Jackson at the Harvard Law School, Jeff Brown at the University of Illinois. I mean, it is really a quite pervasive lack of understanding.

And I think part of that is that there really is not a good structure right now. And in this, I think we all agree on the panel, you know, regardless of our viewpoints on other issues in terms of public-private emphasis, there is not a good structure. And I think part of the responsibility of government here is to create that structure in terms of our viewpoint in terms of emphasizing the private sector and private resources. That would include the tax incentive and it would also include, as we have indicated, encouraging the life care annuity.

Now, it is not—the motivation there is a little different than—  
Senator SCOTT. What I articulated—

Mr. WARSHAWSKY. [continuing]. The life insurance product that you have indicated. Basically, just in brief, the advantage is you create pooling of populations that currently are excluded from purchasing long-term care insurance because they are in poor health or the insurance companies think they might be likely to become disabled, and, therefore, they cannot purchase the long-term care insurance. But it is precisely those people that would be attractive to the insurance companies in terms of the life annuity segment of a combined policy.

If you combine the two, you attract both populations and it is fair to both populations because they are both getting a benefit that they would not otherwise, and it could be offered at a reduced cost. And, most significantly, it could be offered to pretty much everybody with very minimal underwriting, which is a great advantage in terms of creating the opportunity for more private long-term care insurance coverage.

Senator SCOTT. To that end, with the life annuity hybrid, that would work pretty well for those folks who are typically in your moderate income level and higher, perhaps. But those folks who are struggling to make ends meet, the life annuity premium would probably be still significant.

Mr. WARSHAWSKY. It would be. It would be. It is for people who have some retirement assets.

Senator SCOTT. I mean, clearly. Yes.

Mr. WARSHAWSKY. Yes.

Senator SCOTT. Thank you.

One final question, Ms. Tumlinson, on the mandatory—I wrote down what you said, but I have now written it on too many pieces of paper, so—

Ms. TUMLINSON. Right. On the idea that we need some type of mandatory enrollment into an insurance product in order to actually create economic security for most Americans.

Senator SCOTT. So, from my perspective—I wish we had more time, but my time is about up—I am not sure, do you get five minutes or seven minutes in this committee?

The CHAIRMAN. Well, given the felicitous nature of this—

[Laughter.]

The CHAIRMAN. [continuing]. Pre-Christmas meeting, please continue.

Senator SCOTT. Thank you, sir.

[Laughter.]

Senator SCOTT. No other Chairman on any of my other committees would do that—

[Laughter.]

Senator SCOTT. [continuing]. So that is why I had that incredibly long, compounded, run-on sentence, unfortunately.

Help me understand, because my perspective on our entitlements today is that we cannot afford the ones that we have—

Ms. TUMLINSON. Right.

Senator SCOTT. [continuing]. And the construct that we work with is that we have—forget the trillion-dollar, you know, multiple, \$17 trillion debt. That is nothing compared to what we are speak-

ing to. The real challenge that we have with our pension plans, that are, to me, underfunded, our health care that we already are exposed to, so we are talking about a couple hundred trillion dollars—trillion dollars—of unfunded liabilities. And if we add in a new component, I just do not know how we can pay for this.

Ms. TUMLINSON. Yeah. No, no. That is a great question. I am glad you asked it, because I will tell you, it is—again, because of my professional background, the last thing in the world I ever imagined myself doing as a budget analyst is suggesting to anybody that we needed a new government program, as I was trying to control the ones that we had.

But after looking at this for many, many years, and truly, you know, the idea—I have actually been a pretty big fan of—you know, there has got to be a way we can actually work with the private long-term care insurance market to create both changes on the demand and the supply side that would, in fact, really give many more Americans a true opportunity to insure, because right now, it is my view that there really is not a—you know, we say people are unprepared. Well, how can they prepare, really? It is not their fault they are not prepared.

There is really—I do not have long-term care insurance and I know a lot about it, although my parents are—

Senator SCOTT. I can get you good insurance.

[Laughter.]

Senator SCOTT. I know some agents that would help you today.

[Laughter.]

Ms. TUMLINSON. Okay. Well, I should point out that, actually, my parents are signed up under the Federal long-term care insurance for Federal employees, so thank you for that. I really appreciate it, especially.

[Laughter.]

Ms. TUMLINSON. But, I think that there are ways in which we can work with an insurance program so that it is financed in a way that is self-funding. And we worked on this a lot, actually, at my company when we were modeling the CLASS Act just a year ago. So, we were dealing with a situation where we were trying to analyze what the premium levels would be under a voluntary approach, and the big problem that we ran into over and over and over again was that you set the premiums low enough—if you set the premiums too high, you are not going to get enough people to enroll and you end up in this sort of actuarial—

Senator SCOTT. Adverse risk selection.

Ms. TUMLINSON. Exactly. Exactly. So, the fact of the matter is, I have not been able to figure out a way to come up with a public policy that would do what we need, what this country needs, without going in that direction, and I really do think that we know enough now to set it up in a way that the premiums would cover, or the tax base or however it is that you choose to finance it, and there are so many different ways, could, in fact, pay for the benefits that we would expect to pay out over the years.

But, you are right. It is a risk. I completely understand and agree with that.

Senator SCOTT. My deer in the headlights look is not unauthentic. It is real.

Ms. TUMLINSON. Yeah.

[Laughter.]

Senator SCOTT. So, my office will call your office and we will figure out what in the world you just said, but—

[Laughter.]

Senator SCOTT. [continuing]. That will be great.

Ms. TUMLINSON. Right.

Senator SCOTT. Thank you, ma'am.

Ms. TUMLINSON. Sure.

The CHAIRMAN. Senator Baldwin.

Senator BALDWIN. Thank you. I want to again thank and welcome our witnesses today and also offer my gratitude to our Chairman and Ranking Member for bringing us together today. Not only do you recognize that the current system of long-term care, financing, et cetera, is unsustainable, but you have a resolve to continue to convene this committee to focus in on this and I appreciate that very much.

I am hoping to maybe sneak in two questions for the whole panel, if I do not have too long of a run-on sentence. I am teasing.

The first focus I would like to have is sort of the role and value of State innovation in this and looking at this at the national level. Obviously, we have to tackle and debate long-term care financing at the national level, but I know lots of things are going on in the States.

In Wisconsin, we have a program called Family Care that currently operates in 57 of our 72 counties with plans to expand to all. And the gist of it is that it improves the cost-effective coordination of long-term care services by creating a single flexible benefit. It includes a large number and range of health and long-term care services that otherwise would be available in separate programs.

So, just as one example of what a State is doing, I wonder what we can learn from innovation that is going on in the States on how to address our long-term care crisis. I do not know if you all want to take a stab at it.

Dr. CHERNOF. Well, maybe I will start on behalf of the Commission as a whole. I think when it comes to delivery system and workforce, the answer is, absolutely. While there are some things that can be done on the national level, care is delivered locally. They are delivered based on the kinds of providers and array of services you have in a community, in a city, in a State. And it is based on the kinds of needs and desires of specific communities and there is wide variation amongst the States.

So, we, in conjunction with the Commonwealth Fund, produced a report card that the AARP Public Policy Institute looked at, or put out, looking at the performance of various States across the country, and Wisconsin was one of the top performers. It was number five in the country. It is the robustness and creativity and person-centeredness of those programs that really drives Wisconsin's results.

So, are there opportunities to leverage State innovation, particularly when it comes to how we deliver services, how we support families, and how we address some of the kind of operational workforce questions? Absolutely. You know, the single biggest challenge in building teams, for example, the ability to delegate functions



from doctors and nurses to other members of the caregiving team, is all State-based. That is all sort of professionally driven within State law. So, there are many opportunities and Wisconsin is a real leader in that.

I do think the financing question, quite honestly, is one that sort of comes back to a Federal level—

Senator BALDWIN. Yes.

Dr. CHERNOF. and I think this notion of a broader—finding the right framework, which is part of what our discussion here is today, the role of the Federal Government in providing some leadership and thinking about that would be really important.

States are where that care is delivered, and I think that there is a lot we can learn from and a lot of success out there.

Ms. FEDER. Senator Baldwin, I pick up on what Bruce said about financing because I think that really is, in many respects, the ballgame. I think we have seen a lot of innovation in some States, a move in many States toward much greater reliance on home and community-based care. That is encouraged through the Affordable Care Act, but needs more encouragement in terms of incentives to States to support that.

But, as Anne noted at the outset, States are already facing enormous pressure on their Medicaid programs and are not—you cannot innovate your way out of budget tightness. There is—even as we have seen improvements and innovation in some States, we see tremendous variation across States. That means that there is home and community-based care available fairly widely to some populations in some cases and very little, particularly to the elderly, in others. So, the States.

And, while Bruce says care is delivered at the local level, so is medical care delivered at the local level. Delivery is between the person and the caregiver. But the financing is critical to making those services available.

What we see at the State level, and again, I emphasize it at the outset, is that the States, in order to control their obligations, create waiting lists. It is not about State innovation and delivery. They farm it out to managed care plans that may or may not have any capacity and too often do not have the capacity or experience to deliver care. And so what it becomes is a shift of the risk and a decline in insurance protection rather than any kind of protection.

And, finally, I would say, as we go forward, and I am happy to provide you—we did some analysis supported by the SCAN Foundation to look at the future demands and the importance of Federal financing, as Bruce said, for long-term care, that if you look at the aging population, in every State, the numbers of elderly and the share of elderly grows substantially. But we continue to see enormous variation across States. All States are squeezed, having fewer young people to support more old people, but again, tremendous variation.

I can say and endorse what Anne said at the outset, that if we continue the financing that we have got, we already have tremendous variation and tremendous inadequacy in many places. That inequity and inadequacy is only going to grow if we do not create a Federal financing support.

Ms. TURLINSON. I would just pretty much agree with everything that Bruce and Judy said.

Mr. WARSHAWSKY. I will just quickly note that the Commission did hear testimony on some of these State programs. Rhode Island came in. They have a Medicaid waiver, and many of us were very impressed by that program. It is both intended to improve care and to save on cost. Minnesota also came in and gave an excellent presentation, and that is on our Web site.

Ms. FEDER. But, it is also true that Rhode Island, when they talked about a waiver, it actually gave them more money, not less money, whereas what we are seeing about in Federal policy to change Medicaid, we are seeing a proposal to take a whole lot of money out.

Senator WHITEHOUSE. Mr. Chairman, as Rhode Islander present, we basically got paid to have a waiver, because I think the administration at the time wanted to encourage waivers, so they baited this one to get Rhode Island in. But, I do not think that is going to be the common outcome.

The CHAIRMAN. You all are very progressive in Rhode Island.

Senator WHITEHOUSE. In so many ways.

[Laughter.]

The CHAIRMAN. Senator Ayotte.

Senator AYOTTE. Thank you, Mr. Chairman, and I want to thank the Ranking Member.

I just want to also thank Paul Forte, who is here from Portsmouth, New Hampshire, who is someone who works in this area, and I appreciate him being here today on this important issue.

I wanted to follow up on this issue of waivers because I think it is related, certainly, to the important issue that Senator Collins raised, which is how do we make sure that the definition fits to allow more community-based and home-based treatment so that we are allowing, obviously, people to stay in their homes longer, because the average cost for care in a nursing home is approximately \$80,000 a year. So, I can see this being certainly important in terms of cost, but also in terms of people having a better quality of life.

So, with regard to the waiver issue, is it—based on what the Commission found, are there—should we give States greater flexibility, particularly in this area, for innovative programs that are going to allow more flexibility on home and community-based care, because I think that also fits in with this. Obviously, it would be defined by the overall Federal definition that we would come up with. But I see this as an area where perhaps States are going to come up with better ideas than what we would come up with in Washington.

Dr. CHERNOF. Maybe I will start on behalf of the Commission and fellow participants can weigh in, as well.

You know, this was a place the Commission actually gave a lot of thought to, and I think as we listened to the States, it was an area of real interest for us. I think the take-home message from that listening—or two things. One, there is a recommendation that talks really about simplifying the waiver process. There are so many different kinds of waivers. Those waivers often work in conflict with one another. Sometimes, they are just that far apart, but

the problem is if you are the person caring for a family member that is in that little white space between those two waivers, you are in real trouble. You are not sick enough for this. You are not needy enough for that. You are too well for this but not sick enough—so, I think this notion of a much simpler approach to waivers was one that was endorsed by the Commission.

I think the other concern that was raised in that, obviously, is the issue of individual protections, beneficiary protections, that the waivers actually deliver on the services that need to be provided. So, in that balancing test is how do you create the kinds of flexibilities so you get programs like some of the ones that we heard from, but also make sure that in the process of providing more flexibility that we are not actually losing services for those who need them and that there is adequate oversight.

Ms. TUMLINSON. If I may, just to follow up on that point, you know, my experience in reviewing waivers and thinking about ways in which the Federal Government could do a better job of giving States flexibility has been that, over the years, over the past, maybe, five to six years, we have seen, really, a lot of loosening of those restrictions, to the point where States, in fact, have a tremendous amount of leeway, and the degree to which people do not have access to home and community-based services has a lot more to do with budgetary issues and the need to keep waiver programs limited to sort of numbers of people and certain spending per person than it has to do with flexibility around the Federal requirements about what States can do.

Mr. WARSHAWSKY. Senator, with regard to cost and whether the waiver process, and particularly moving people from nursing homes to home care, would save money or cost money was debated, and we heard evidence on both sides, both from witnesses that came in, ones that said we would, in fact, save costs, but actually some of the Commission members themselves who are providers of long-term care services and supports were skeptical of that. They said, you know, the system pretty much puts people in the right spaces already. So, we did not hear a consensus in terms of whether that would be a cost saver or a spender.

Senator AYOTTE. Fair point.

Ms. FEDER. Just to build on that, I think we have got a lot of experience with home and community-based care over the many years that we have been trying to expand it, and I think that there is general agreement that we get better value for the dollar when we are able to serve people at home and not in institutions when they do not need them. But we have so many people in need that we frequently—we need to build those systems and we are underserving today, so that when we offer more services at home, we actually serve more people, which is a good thing, but it costs.

And with respect to the issue of flexibility and savings, I think that I have heard representatives of the Governors and the Medicaid directors say that flexibility is not enough. They have got flexibility. What they do not have are the dollars, and for many, many years, until recently, and I think that is a function of politics, Governors in both parties have joined together to call on the Federal Government to take over the long-term care responsibility for dual eligibles, for Medicaid beneficiaries who are also Medicare

beneficiaries, recognizing that they are lacking the resources to do that job. It does not mean they cannot be involved, as we have said, in the delivery, and that there cannot be innovative delivery on the ground, but they are looking to the Feds for dollars.

Senator AYOTTE. Well, since I got one question in, but I appreciate all of your answers, I am going to submit some questions for the record and some of the follow-up on some things that you said. So, I appreciate all of you being here. Thank you.

The CHAIRMAN. Senator Warren.

Senator WARREN. Thank you, Mr. Chairman and Ranking Member, for holding this hearing, another important one.

You know, it just seems like, to me, this is another example of how middle-class families are getting squeezed. It is hard enough for any family to put aside anything for savings today, given the squeeze on families, and now we expect families to save for retirement and for long-term care at the same time that many are absorbing the costs of caring for an elderly family member. So, we have just doubled up here.

There is a growing conversation about the retirement crisis in America, and in the face of this, the lack of a basic safety net on long-term care is just more fuel to the fire on the kind of problems we are going to face. And, as you have made clear, retiring baby boomers are ill equipped to cover the full costs of their long-term care needs. You know, we have got fewer people—they have got lower savings as they hit retirement than their parents did. Only 18 percent have retired benefit plans. A third of all seniors have less, or as they approach their senior years, have less than a year's worth of income and a third have no savings at all.

So, that leaves us with Medicaid as sort of the back-up program here, which can cover some of the costs, but the current system forces seniors to spend most of their assets in order to qualify. Every bit helps, but to qualify when they have got to sell off all their assets, this has other economic implications.

So, where I wanted to start is to ask you, Dr. Feder, can you tell us a little about the financial instability that selling off assets causes our seniors.

Ms. FEDER. Well, thank you, Senator Warren. When people talk about seniors relying—ought to be relying on savings, I think that they are—to finance long-term care—I think they are insensitive to the variety of risks that come with getting older. There is the risk of—a concern about having adequate resources to cover your needs. You do not know how long you are going to live, so you have got to plan for that. There are ups and downs in what happens to your assets, as we have seen painfully with our recent economy, what has happened to resources in that period.

There is the ability to deal—to assist your children in taking on their new lives and enabling them to do what parents did for—grandparents did for the now-parents, and dealing with the fact that we have got many young people, even those with an education, not able to get jobs, and so needing more assistance from parents as they age. I am a grandmother and am looking forward to supporting my grandchildren and encouraging them in their education and building their independent lives. And there is uncertainty all the way around.

When people talk about relying on your assets in order to take care of those needs, what you are saying is that that is one lump, and when you use them, they are gone. So, you have so many risks, including—I did not even mention the health care risks and the uncovered health care costs that seniors face.

So, you are using your assets—that is what you have got—to protect you against a whole array of risks, and the catastrophic risk like a serious need for intensive long-term care is just beyond the capacity of this little—this nest egg, little or moderate, or in some cases larger, to take care of, and that is why it is so important that we need some kind of insurance mechanism to which people can contribute in order to give everybody security.

Senator WARREN. So, let me just build on that and frame the question a little bit differently and ask, if I can, Ms. Tumlinson, if you can explain why Medicaid is not a very good substitute for a predesigned, well-functioning long-term care system. If you could just kind of summarize that for us.

Ms. TUMLINSON. Sure. Okay. Let me be thoughtful in this response. So, I think the primary—when you think about what Medicaid was really designed to do, it was not designed to—it is not designed to protect individuals against risk. It is really designed to be there when everything else has failed, which is really the opposite of insurance. Is that succinct enough?

Senator WARREN. Yes. No, but go ahead—

Ms. TUMLINSON. Okay.

Senator WARREN. [continuing]. Point out. That is a very good point—

Ms. TUMLINSON. Right.

Senator WARREN. [continuing]. And I think it is critical to understanding. A lot of people think, well, we have got Medicaid, so I will be okay if there is a problem out there. And maybe another way to say it is to ask, is this a sustainable path, that is, counting on Medicaid to be the safety net—

Ms. TUMLINSON. Right.

Senator WARREN. [continuing]. And, at best, only modest savings that people are putting aside during their working years.

Ms. TUMLINSON. Right. And I think when I think about it, also, from the perspective of what I see people doing in the marketplace right now, which is essentially using their savings to purchase something that will keep them from being on the Medicaid program eventually. In other words, it is not—in theory, what you would want an insurance product to do is to enable you to purchase the services that you need in the setting that is actually most appropriate for your needs, whereas a safety net program is really, again, kind of designed simply to absorb sort of in the most, you know, kind of custodial and warehousing situation, bare-bones funded. It is really, again, kind of the opposite of what you would expect an insurance product, a good insurance product, to do.

And when my own parents, when I encouraged them to buy insurance, it was really—my dad said, well, my Federal pension will cover the cost of a nursing home, and I said, well, but would you not like to stay at home? Let us talk about, let us insure against being in a nursing home.

Senator WARREN. That is a nice point.

Mr. Chairman, could I ask Dr. Chernof also to respond.

The CHAIRMAN. Yes.

Senator WARREN. Dr. Chernof.

Dr. CHERNOF. Thank you. Yes, I agree. I mean, I think that we have public policy that is—I have said this before, I will say it in front of all of you—we have public policy that is sort of perfectly built for 1972, and the reality is that Medicaid is a program that, in its inception, was predominately focused on women of child-bearing age and their children. I mean, that was really its kind of constitutional core way back when. And the average life expectancy in 1965 was 69. As a physician, if I was in practice then, you would have just seen the first ICUs and CCUs. The likelihood of surviving a fairly morbid or mortal event, like a serious stroke or heart attack—I mean, we were in a very different time and place.

People are living much longer and will live with more serious chronic illness and functional limitations. The reality is, our public policy has not kept up with that, and the reality is that Medicaid—I agree with Anne's sort of description of the role of Medicaid, and I would just offer to all of you that the null hypothesis, if we do nothing, is incredibly expensive and that Medicaid will bear the burden of that, and it will bear the burden—I mean, we will all bear the burden. Families will bear the burden. States bear the burden. The Federal Government bears the burden in kind of an unstructured way.

So, I think as you think about the work of the Commission, while we did not make a specific financing recommendation, and we are having kind of a broad discussion here about the ranges of ways that one might consider solving it, every single Commissioner thinks that there needs to be a solve, and I think this notion of a different model and one that actually addresses, confronts the long-term care need this country faces as a way of taking pressure off some of the public programs, and what would it really take—what would it really take to design a program that fundamentally actually shores up certainly Medicaid, but also Medicare, to a degree, because I will just say, as a doctor—my last point and then I will stop, I promise—you know, the night light in this system is the emergency room.

So, I get the point that Medicare does not pay for long-term care, but at the end of the day, when something happens in somebody's family and you throw up your hands, it is a trip to the emergency room, and I will tell you that the emergency room doctor takes one look at that person and says, upstairs we go, and then the process begins.

So, I think what we are having together, us and all of you, is this sort of fundamental discussion about the need to think about a different structure to take on this issue in the process of shoring up our public programs.

Senator WARREN. Well, thank you. The questions addressed earlier to Ms. Tumlinson about how we are going to pay for this, you give us all the reminder, if we do not design a program, we are still going to pay for it. We are just going to pay for it in some really terrible ways, so thank you.

Thank you, Mr. Chairman.

The CHAIRMAN. Thank you, ma'am.

Senator Whitehouse.

Senator WHITEHOUSE. Well, I hesitate to jump in, because as far as closing words go, what Senator Warren just said, if we do not do something, we are still going to pay for it, we are just going to pay for it in really terrible ways, is kind of a good closing salvo for the whole thing.

But, I go after you——

[Laughter.]

Senator WHITEHOUSE. [continuing]. So I get to go ahead and foul up what was a great closing.

I did want to follow up with Ms. Tumlinson about what we are seeing in Rhode Island is people who have made the responsible choice, invested their money into a long-term care insurance policy, are now finding that the premium is going up pretty dramatically, to the point where, for some people, it is really no longer doable. And that is particularly frustrating because you have paid in all this time. You kind of have a connection to that policy, and to bail on it makes everything you have paid already look like money down the drain, which, in fact, it is.

So, it strikes me that in terms of relying on the private sector to handle this problem, they are actually going the wrong way in terms of where the prices are headed and where the likely market share of affordable long-term care coverage is headed. Is that your feeling nationally——

Ms. TUMLINSON. Yeah——

Senator WHITEHOUSE. [continuing]. Or is that just what is going on in Rhode Island?

Ms. TUMLINSON. Oh, no. No. That is definitely national. And, again, not to beat this drum too much, but my parents' premiums went up quite a bit and that was in a really good program, in a really, you know, about the best run, I think, employer-based long-term care insurance program that exists.

You know, I think it points to not necessarily that the private sector is not up to the task, but that we do not have enough people in the risk pool for it to be a stable financial bet for an insurance company, particularly when you are paying benefits on a set of products that are coming due 30 years after you have sold them. So, it is a very—you know, when we modeled this for the CLASS Act, it is an incredibly challenging thing to do. I mean, really, to the insurance companies——

Senator WHITEHOUSE. Out at the actuarial frontier?

Ms. TUMLINSON. Yes, it is. Exactly.

Senator WHITEHOUSE. Yes.

Ms. TUMLINSON. Yes. I wish I had thought of that. Yes. Exactly.

[Laughter.]

Senator WHITEHOUSE. Well——

Ms. TUMLINSON. That is where we have been standing, and it is not very comfortable——

Senator WHITEHOUSE. [continuing]. Given the problems that they have, let me turn to Ms. Feder, and we have known each other for a while, so, Judy, welcome. Good to be with you. Thank you for being here.

What do you think—you talk in your testimony about private-public models. What would a couple of what you think the most

likely and sensible models look like very generally in terms of bringing private contribution and public participation into this?

Ms. FEDER. Well, as I said, Senator—and it is a pleasure to see you—that a public benefit has to be at the core. And what I have begun to consider and would like to see us spend more time on, and think there is some interest in, is thinking of a limited public benefit that would be available to people after a waiting period that would be determined—and I am thinking now of the retiree population, we would adapt it for the younger disabled population—but the waiting period would depend upon what your earnings, your lifetime earnings looked like at retirement so that would give a clear indication to families of what they were expected, what the whole they were expected to pay before a public benefit would kick in.

It would give insurance companies, and I was interested to see recently that Genworth has been talking about—

Senator WHITEHOUSE. But, you would know in advance what the waiting period would be—

Ms. FEDER. What you will—that is right, what your whole—

Senator WHITEHOUSE. [continuing]. From the public program—

Ms. FEDER. Correct.

Senator WHITEHOUSE. [continuing]. And so you would have to buy the first months or years or whatever of it, and you would know that going on.

Ms. FEDER. Right, and people who had not earned much would have a shorter waiting period, and people who had earned a lot would have a longer waiting period. So, it would be adjusted to income.

And what I think—Genworth is looking at something like this because the insurance companies, the insurance industry has the biggest problem when you—out on the actuarial frontier—with the tail, the biggest expenditures. And so there, essentially, you are giving them some protection at the back end. So, I think that is something to explore.

I think it is very important as we explore options, there is another option, which is that you give a limited benefit up front, that everybody gets it. But that leaves the tail for the insurance industry to cover and that may be less comfortable for them. But, I think we need to look at these options and see what is it that the public sector can do and guarantee that creates some space for private sector innovation, and that is where I would like to see us explore.

Senator WHITEHOUSE. Okay. The last thing I will ask, and it is a question for the record, is if any of the witnesses have information on what you believe the government's present exposure to long-term care liability is right now as we speak, your null hypothesis model, Dr. Chernof, if you have any way to quantify what the cost is of that. That will help our discussion in terms of being able to try to work with CBO and other people to figure out—I mean, if we are going to pay for this to a degree anyway and there is a smarter way to do it, I would like to have that conversation, bearing in mind what the experts say, we are going to pay for this anyway.

Mr. WARSHAWSKY. Senator Whitehouse, I seem to recall that CMS at one point did a present value calculation, sort of a mini-



Trustees' report for that number. I do not know if they continue to do it—

Senator WHITEHOUSE. I do not know, either. That is why I made it a question for the record.

Mr. WARSHAWSKY. Okay.

Senator WHITEHOUSE. If anybody who has information could get back, I would appreciate it, and I yield back to the Chairman and thank him and our wonderful Ranking Member for all their leadership on these issues.

The CHAIRMAN. Well, it is not clear to me where we go. We have had two different opinions expressed. Dr. Feder argues that a public benefit is the answer. Dr. Warshawsky, why do you not give us an opinion by setting aside the financial and political difficulties. Why would not a public benefit help?

Mr. WARSHAWSKY. Well, those are very large set-asides, Senator.

The CHAIRMAN. I understand.

[Laughter.]

The CHAIRMAN. Particularly in these times.

Mr. WARSHAWSKY. I think people need to be given choices. I think they need to design things as best fit their situation and to be given the support they need in a prudent way. So, certainly, there is a role for government, but I think they need to be provided as much in the way of choices and opportunities as they can, and that provides the right incentives, because we certainly do want people who can afford, and I think many can, to finance these costs and to insure these costs, that they do so and that it is not an unfair burden on others for that to happen.

And, furthermore, I think they really do need—I think it is a strong possibility, a strong likelihood, that the private sector, with the right structure, would design different options and different policy designs that would appeal to different situations and different needs, which I think is really impossible for a public program to do.

Public programs, in order at all to be efficient and to be able to be administered—and we are seeing this right now in the ACA—have to be very simple and have to be very straightforward. That is why Social Security works. If you have—if you, in fact, give people choices through a public program, it is just administratively extremely difficult.

The CHAIRMAN. And herein lies the dilemma, because it is another public program that we would be creating. But I can tell you from my experience—before I came to the Senate, I was the elected Insurance Commissioner of Florida, and the behavior of humans with regard to buying insurance, unless they think they absolutely need it, they are not going to buy it. And this is almost out of sight, out of mind. If you want to spread that base by getting the young as well as the old into it, it is going to be very, very hard to get people to buy this insurance.

What do you think, Dr. Feder?

Ms. FEDER. I agree with you, Senator Nelson, and we have a lot of experience with that. I am always interested, when we talk about private insurance and long-term care, that we look at—we are at the same time looking at our experience with the non-group, the individual insurance market for health care, and we know that

is a market that is riddled with problems because, in part, of a desire of insurers to avoid people with preexisting conditions and to limit their risk, and that is what you see unless you have everybody participating.

And the idea that I was discussing with Senator Whitehouse that I put before the Commission and hope we will all consider in the future is that I think that there—is based on a view that we can better educate and help people prepare and help an industry respond if we do, as has been said—Bruce said it—set up a structure that creates some clarity about how you can prepare, so that if a public program takes on the tail risk in some ways and tells people, based on their resources, what they have to prepare for, you can better educate around participation and preparation.

But that back-end Federal program is one, as Anne has emphasized, that everybody is participating in, whether through taxes or premiums or whatever we are calling it. It needs to be a shared risk in order to work.

The CHAIRMAN. Dr. Chernof, I cannot help but smile, thinking about how you could get people to buy this insurance well ahead of time. You could have an individual mandate, and if that sounds familiar, we have just had quite a debate about that, and it was declared constitutional by the Supreme Court, but it is not easy.

Let me ask you, on a completely different kind of subject, we have really had some problems in Florida with assisted living facilities basically taking advantage of seniors, nursing homes. Do you have any suggestions? I mean, we have got people that are starting these things up that are unlicensed. Obviously, they are breaking the law. But we are talking about the care and nurturing of our seniors. Did your Commission suggest any things that we ought to be doing?

Dr. CHERNOF. So, you raise a really important question, Senator Nelson, and actually, as a Commission, this is not an area that we had a lot of focus on directly. I think, indirectly, we had a real concern that we do not really understand how to think about or measure quality in the space. It is—this is a space that has a lot of resources that are paid for privately or come out of—or voluntary services, so it lives in a different place than the rest of health care lives. And kind of our rubric, then, for both regulatory oversight, kind of quality control and integration, need a lot more work.

But the Commission itself, to answer your question directly, did not specifically go into great detail about these sort of alternative forms of community-based support, their oversight and regulation.

Ms. FEDER. Actually, I think we had more testimony on that than you are remembering, Bruce. I think that we had a lot of discussion about—we had it on the workforce side, and we had a great deal of discussion and concern about—and we also—actually, it affected—we had testimony as to problems, quality problems, in nursing homes as well as assisted living facilities. We have been—over the years, there has been a lot of policy effort to try to mitigate those, particularly on the nursing home side, but they persist, inadequate standards and poorly trained staff. And because Medicaid does not cover, does not finance assisted living facilities, there is a real concern about an absence of standards, as you say.

So, I believe that we heard a lot of testimony, and I know in the alternative, our alternative report, we made recommendations about—we addressed it on the staff, on the training side. There has been an expose recently, a particular assisted living facility, of grossly inadequate training for staff while claiming to be offering specialized care for Alzheimer's patients, or residents. It was both embarrassing and appalling when you saw it on national TV and it is not a lone example.

So, we did hear testimony not only about the need for, but examples of training programs—I believe the one that we heard from was in the State of Washington—both better standards and training for workers who—which is better for, obviously, for the patients whom they serve, and also creates better jobs accompanied by better pay for the workers who we are relying on to care for our families.

Dr. CHERNOF. But I would say, and the Commission made many recommendations on workforce. Your specific question, Senator, was about sort of the oversight and regulation and management of these new delivery entities, and while we did hear a little bit of testimony in that space, that is not a place where the Commission made any recommendations. And the workforce piece is only a part of what it means to operate these different kinds of environments.

From the health care perspective, the people are only one piece of it and the oversight of things like assisted living organizations and other kinds of residential care options that are sort of multiplying in front of our eyes, that is a completely different question, and the workforce is just a—is an important, but it is only one piece of that discussion.

So, the question you raised merits a lot of careful thought, and candidly, the Commission itself did not get that far into the issue.

The CHAIRMAN. Do you want to comment with regard to long-term care for seniors who also have disabilities? Does the system work?

Dr. CHERNOF. That is a great question, Senator Nelson, and let me back it up a step. The system we have now does not work well for hardly anybody. I do not think it works well for older individuals with serious chronic illness or functional limitations or cognitive impairment. It is a very fractured, very provider-centric system, and it leaves individuals and their families to do the care coordination, which is basically missing from most models and most systems of care.

Now, we heard about some models that were better, and there are sort of paths to better processes of care. But the Commission lays out a whole series of recommendations of things that could be better.

So, to your question, I think it is even harder for younger individuals. Many of the systems that serve them were actually not built for them. They may have been built for older people or built for a different population, and I think for younger individuals with serious functional limitations or cognitive impairments, they have their whole lives ahead of them. I mean, they have a different—they are in a different place in their life trajectory than an older person is and have different desires and family, work.

So, I do think we have a long way to go and it is a particularly long way to go for younger folks with serious needs.

The CHAIRMAN. Suppose we enacted a plan for private insurance. Then the question comes, who is going to regulate it? Would we turn it over to the State insurance commissioners or the State health regulatory agencies? Ms. Tumlinson.

Ms. TUMLINSON. Well, that is a good question. So, I think if we move in the direction of creating more incentives for people to purchase private long-term care insurance or try to reform the marketplace to improve demand and supply and all of those kinds of things, I mean, we would continue to regulate it at the State level the way that it always has been, but there has to be more of a Federal—there have to be more—more of a Federal role in kind of setting the bare bones sort of standards and, I guess you could call it parameters around which some of these policies would be designed and how they would work, because, fundamentally, the marketplace is not working, so we need some actual marketplace reforms, and I think those have to come from the Federal level. I think issues around the regulation, around the insurance pools and that kind of thing could continue to operate at the State level.

Mr. WARSHAWSKY. Senator Nelson, I will just point out, in the current set-up, regulatory set-up, obviously, the States have the main regulatory responsibility, but as part of tax issues, the Federal Government already does have some role in terms of design of long-term care insurance policies, and one would imagine that if there were additional tax incentives provided, just naturally it would go that there would be an increased responsibility.

I will also note that one of the reasons for the increases in premiums is related to Federal policy, and that is the policy of the Federal Reserve Board with very low interest rates. Those policies were probably assuming six percent interest rates, which clearly we are nowhere near that.

So, there is an interesting mix of Federal and State issues at hand.

The CHAIRMAN. The Commission recommended that you remove the requirement that a patient must stay in the hospital for three days before they can receive services in a skilled nursing facility. Now, there are a few of us up here that agree with that. Can you tell us why you ended up recommending that?

Dr. CHERNOF. Sure. I think that there was a sense that rule was created in a different time and place, and I would say that the Commission felt that what it needs to be is revisited. It does need to be replaced, but it needs to be revisited and sort of the model of care re-thought through, because the reality is length of stay has come down over time. We want—the goal should be to get people to the right care by the right provider. So, by having this three-day length of stay requirement, there are people who maybe could step down to a lower level of care sooner but are not able to access that level of care and/or are put in a higher level of care, because the higher level—or a different level of care, for example, acute rehab, which is actually more expensive than the skilled nursing facility might be.

So, I think our call was for there to be an opportunity to revisit and remove that three-day length of stay and replace it with an ap-

proach that is more sensible and consistent with current care practices, again, being mindful that it was put there for a reason, which was really a cost control mechanism more than anything else, and that taking it away creates new opportunities. But, we do think in the current environment, it is not serving that cost control goal that it was originally put in place to try to achieve.

Mr. WARSHAWSKY. I will add that was a consensus of the Commission, and another element of it was that there has been a trend of patients being in hospitals, thinking they were admitted and never actually being admitted, and, therefore, that does not count even if they are in the hospital for five days. And that struck us as just plain wrong.

But, it does raise the question of what is the mechanism that does control that next phase, as Bruce indicated, and we did not have enough time to figure out the replacement. But the three-day rule struck us as not the right one.

The CHAIRMAN. We are going to include in the record an article by Bloomberg News that illustrates how difficult it is for seniors to be able to afford long-term care.

This is our last hearing of the year, save for some unusual thing that we might be in session on New Year's Eve, like we were last year.

[Laughter.]

Senator COLLINS. Will you bring the champagne if we are?

[Laughter.]

The CHAIRMAN. As a matter of fact, you remember. New Year's Eve, we were all on the floor, and I spotted one of my dear friends in his tux sitting in the gallery, and I went over to him and I said, Charlie, what in the world are you doing here? He said, "Jackie and I went out to dinner and we decided this was the best entertainment in town."

[Laughter.]

Senator COLLINS. Except, perhaps, for the performers.

[Laughter.]

The CHAIRMAN. Well, you all have been great. Thank you. It is a tough issue, and so thank you for helping us get into it and start to peel back the onion. We appreciate it.

Happy holidays. Merry Christmas. Happy new year.

The meeting is adjourned.

[Whereupon, at 4:08 p.m., the committee was adjourned.]



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## **APPENDIX**

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**Prepared Witness Statements and Questions  
for the Record**

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**The Future of Long-Term Care Policy: Continuing the Conversation**

Statement of

Anne Tumlinson  
Senior Vice President, Post-Acute and Long-Term Care  
Avalere Health

Before the  
Senate Special Committee on Aging

December 18, 2013

Chairman Nelson, Ranking Member Collins, and Members of the Committee, thank you for the opportunity to testify today about the future of long-term care policy.

In 2011, the U.S. paid over \$200 billion for long-term care. And yet, the American system is bare-bones. It inadequately protects today's elderly 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. The U.S. long-term care system relies on over \$400 billion in estimated economic value of unpaid caregiving to sustain the vast majority of people with long-term care need. So, while at any point in time there are only 11 million people needing long-term care, it has a huge effect on American life, involving a third of all households in caregiving activities.<sup>i</sup>

Families provide this care because the only other option is to pay privately, out-of-pocket for services until they exhaust their resources. When this happens, individuals with long-term care need must rely on Medicaid, which offers few choices other than institutionalization. While only one in five Americans will need help for five years or more, that help will bankrupt those individuals and subsequently force them into a Medicaid nursing home bed, no matter how well they have saved for their retirement.<sup>ii</sup>

In this testimony, I describe the population needing long-term care and how this diverse group of Americans and their families piece together financing and services for long-term care. I briefly discuss the fundamental challenge inherent in rationalizing the financing system.

#### **Population Needing Long-Term Care**

The unifying characteristic of the long-term care population is the need for help with highly personal activities that are a basic part of everyday life. Disease, a disabling chronic condition, an accident, a developmental disability, can occur at any age and impair a person's ability to function in every-day activities such as bathing, eating and dressing. A child born with cerebral palsy or mental retardation may need long-term care as could an adult coping with multiple sclerosis or an elderly person with Alzheimer's disease.<sup>iii</sup>

When researchers examine data from national surveys asking people about their level of functioning, they find about 11 million people with some need for assistance with daily activities, broadly defined.<sup>iv</sup> Of this total, 44 percent, almost five million are under age 65 and most of them live in the community. Slightly over six million are elderly and about 1.3 million live in nursing homes. The elderly population needing long-term care tends to be much more comprised of low-income, widowed women than the overall elderly population.<sup>v</sup> In the non-elderly population needing long-term care, only about half are women and the median income is half that of people without long-term care need.<sup>vi</sup>

#### **Service Use**

Because long-term care involves providing individuals assistance with basic activities of daily life, the delivery system and its financing are linked inextricably to where these individuals live. The setting in which an individual lives has a significant and varying impact on how much support is provided, what it costs and how it is financed. For any American needing long-term care, the formula each person uses to pay for it will include a combination of three elements: personal financial resources, unpaid caregiving and Medicaid. The contribution of each of these elements depends to a great degree on factors such as the length and severity of functional impairment, family configuration and resources, and geography.

Many of the 1.5 million people who live in a nursing home end up there because supporting them in the community has drained the emotional, physical and/or financial resources of their families. Nursing home residents often begin their long-term care journey in a single-family dwelling, relying on a mix of unpaid family and community members (e.g., church friends, neighbors) and paid home care. Sometimes simple assistive technology can be helpful in supporting someone's ability to remain at home. Wheelchair ramps, specialized spoons for self-feeding, and bathroom seats can add important support to the work of paid and unpaid caregivers.

***Unpaid Help in the Community.*** The work of providing care to people with long-term care need falls overwhelmingly on unpaid caregivers from family and the community. At most, only just about one-fifth of the long-term care population living in the community reports using paid help.<sup>vii</sup> As a result, ***almost a third*** of all U.S. households reports that at least one person has served as an unpaid family caregiver within the last twelve months.<sup>viii</sup> Spouses, parents and adult children provide care that is intensive in terms of their time and the physical and emotional effort involved. The most common task they perform is helping the care recipient get in and out of beds and chairs, helping with dressing and assisting with bathing or showering. And, they spend an average of 20 hours per week providing this care while most (75 percent) hold down some type of job.<sup>ix</sup>

***Paid Help in the Community.*** Among the community-dwelling long-term care population paying for help, about a quarter funds a portion privately out of their own resources. Those individuals will pay, on average, about \$20 per hour, although the rate fluctuates significantly for geography.<sup>x</sup> If a person living at home with long-term care need has low enough income and assets to meet the Medicaid financial requirements, Medicaid may pay for some home care. States offer home and community-based or "personal care" services through Medicaid. States limit these programs -- either through restrictions on the number of people they serve or the amount of services they cover. Of the total Medicaid spends on long-term care for elderly and people with physical disabilities, only 35 percent of spending covers home and non-institutional care.<sup>xi</sup>

Because of the challenges associated with supporting an individual at home through unpaid and paid care, many individuals and families facing a long-term disability find that they have to look to other living options. If resources are already limited, Medicaid coverage of a nursing home stay is almost always the only option. However, if some

personal resources are available, families can consider housing alternatives, such as assisted living.

**Housing with Services (Assisted Living).** Roughly, about one million people live in some type of housing with services.<sup>xii</sup> An assisted living facility costs about \$42,600 per year, on average, and is rarely paid for by Medicaid.<sup>xiii</sup> If the depletion of personal resources begins in the home setting with paid home care, it can accelerate as individuals and family members pay for assisted living. Many senior housing providers report, anecdotally, that their residents often sell their homes to finance senior housing fees. Research shows that private payment for assisted living has displaced some private payment for nursing home care.<sup>xiv</sup> This means that individuals who are in assisted living often stay in this setting until they have run through their home equity and savings, at which point they must move to a nursing home where their care can be financed by Medicaid.

**Nursing Home Care.** The benefit of nursing home care is that Medicaid will pay for it when an individual depletes all other means of private payment. In some cases, individuals will pay privately for nursing home care when the care needs are so significant that even the most robust community-based services can no longer support an individual safely. Like assisted living residents, private pay nursing home residents are also in the process of depleting their personal assets due to costs that run between \$81,030 and \$90,520 per year.<sup>xv</sup>

#### **Financing Sources**

Of the formal sources of financing, not including the value of unpaid caregiving, Medicaid has played a key role, with a \$136 billion contribution in 2011. However, the inability to accurately measure private out-of-pocket contributions makes it difficult for analysts to know the relative role of private spending and Medicaid. The result may be a skewed view of the degree to which Medicaid coverage of nursing home care is seen by most Americans as a last resort rather than an opportunity to protect wealth.

**Private Out-of-Pocket.** Private out-of-pocket spending is challenging to assess because much of what individuals spend on these services is not captured in the national health expenditure data. The spending that is captured amounts to only between \$45 and \$53 billion in 2011, depending on the service categories included.<sup>xvi</sup> And, this likely represents an underestimation of what individuals and families are spending on these settings and services. When researchers attempt to quantify the value of unpaid caregiving, it increases this amount by over \$400 billion per year.<sup>xvii</sup>

**Medicaid.** Medicaid spending is available because states report their expenditures by service category. The federal government and states spent \$136 billion on long-term care in 2011.<sup>xviii</sup> More importantly, the average annual growth in spending from FY 2006 to FY 2011 was 4.8 percent compared to 6.3 percent for the total Medicaid program – thereby reducing the share of Medicaid that is spent on long-term care to 33.1 percent – the lowest it has been in two decades and the continuation of a downward trend. Over this time, the mix of spending between institutional and non-

institutional has also shifted from an institutional, non-institutional spending ratio of 63 to 37 percent in FY 2006 to a 53 to 47 percent mix in FY 2011.<sup>xix</sup>

While the shift in resources towards non-institutional care demonstrates progress towards providing people services they prefer, the Medicaid program will face enormous pressure from budget challenges, competing health care priorities and a growing population of very old. These pressures will require Medicaid to reduce the number of people who receive long-term care services and the amount spent per person – regardless of setting. And, in fact, we see that reflected already in the growing interest among states in shifting from fee-for-service long-term care programs to capitated arrangements with managed care plans.<sup>xx</sup> These trends point to the possibility of a growing gap between public program financing and the need for financing.

**Medicare.** Medicare comes up frequently in discussions about long-term care even though it does not pay for long-term care. Medicare beneficiaries with long-term care needs use much more health care than Medicare beneficiaries without long-term care needs, even when we control for the presence of chronic illness. In other words, a Medicare beneficiary with chronic illness is much more likely to have very high health care spending if he or she also has a significant need for long-term care. Avalere research found that Medicare spent about 50 percent or \$11,000 more per year for seniors with any chronic condition and functional impairment compared to seniors with any chronic condition and no functional impairment.<sup>xxi</sup>

The long-term care population uses significant amounts of hospital and post-hospital care. Spending on post-acute services such as skilled nursing facilities and home health agencies is the most variable, indicating a great deal of inefficiency in this area of the health care system. Accountable care organizations and bundled payment participants have significant opportunities provide better post-acute care at a lower cost.<sup>xxii</sup> To do so, they will need to integrate acute-post-acute and long-term care for the long-term care population.

**Private Long-Term Care Insurance.** Even more difficult than assessing the financial contribution of out-of-pocket payments is quantifying the role of private long-term care insurance in paying for long-term care. Currently, 7 to 7.7 million individuals have coverage, translating into about 12.4 percent of the population over age 65.<sup>xxiii xxiv</sup> Again, the national health expenditure data that we rely on to capture payments made by insurance is not sufficient to give us a good picture of the contribution of this type of financing. It does not disaggregate payments made by private long-term care insurance from those made by private supplemental health insurance policies that pay for skilled nursing facility copayments during the post-acute episode. Further, long-term care insurance claimants report using their insurance to pay for assisted living facility care, which as stated above, is not captured in the data. With these limitations in mind, the private insurance payments attributable to home health and nursing home care equal about \$17 billion in 2011.<sup>xxv</sup>

#### **Implications and Considerations**

Over the next 20 to 25 years, the percentage of the population age 65 and older is going to increase dramatically with a substantial bump in the percentage over age 85. Avalere projects that the number of individuals needing long-term care will increase with this trend, growing to 14.6 million by 2040.<sup>xxvi</sup>

Despite many years debating and considering long-term care policies aimed at increasing the number of people covered by some type of insurance coverage, the U.S. remains a nation almost entirely dependent on Medicaid, personal savings and unpaid family caregivers for long-term care. At this juncture, in the wake of CLASS' repeal, policymakers could continue to debate the merits of increasing coverage under the existing private insurance market or under some type of social insurance, but that debate – while very important – must also consider whether any effort, public or private, is sufficient without some component that requires everyone to contribute to a risk pool.

Having analyzed the budgetary impact of both a private/public partnership with a federal catastrophic benefit, and the CLASS Act and similar social insurance options, my experience suggests that, in either case, the challenge lies chiefly in the question of persuading individuals to enroll in an insurance program that they do not know they need and won't use for up to 30 or 40 years. Research suggests that, without sufficient participation, any program – whether private or public – will fail to fill the financing gaps in our current system. As challenging as it may seem in the current policy and political environment, some type of mandatory approach to insurance appears to be the only way to protect most Americans from the financial devastation of long-term care need.<sup>xxvii</sup>

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JOINT TESTIMONY OF  
DR. BRUCE CHERNOF AND DR. MARK WARSHAWSKY  
COMMISSION ON LONG-TERM CARE  
BEFORE THE U.S. SENATE SPECIAL COMMITTEE ON AGING  
DECEMBER 18, 2013

Mr. Chairman, Senator Collins, and Members of the Committee:

My name is Bruce Chernof. I am the President and CEO of The SCAN Foundation and was, until recently, Chair of the Commission on Long-Term Care. I am accompanied by the Commission's Vice Chair Mark Warshawsky, who is an Adjunct Scholar at the American Enterprise Institute. Dr. Warshawsky and I are pleased to be here today to present the vision and recommendations of the Commission and discuss the Commission's work with you.

The Commission on Long-Term Care was established under Section 643 of American Taxpayer Relief Act of 2012 (P.L. 112-240), signed into law January 2, 2013. The statute called for the President as well as House and Senate Leaders to appoint 15 Commissioners. The Commission was given six months from the day of the final Commissioner's appointment to convene, to develop a plan for organizing and financing a comprehensive, coordinated, and high-quality system of long-term services and supports (LTSS), and to vote on a report based on the plan, including recommendations for legislative or administrative action.

The Commission was delayed three months pending congressional action to appropriate necessary funds. With funds appropriated, the Commission elected a Chair and Vice-Chair on June 10 and proceeded to hire staff and convene its first meeting on June 27. It held four public hearings with testimony from 34 witnesses. It solicited extensive comments from the general public. It worked through 9 executive sessions to develop broad agreement on the report and recommendations. On September 12, as required by statute, Commissioners voted 9 to 6 in favor of putting its Final Report forward as the broad agreement of the Commission.

Throughout this process, the Commission worked to identify areas of broad bipartisan agreement. The common vision and 28 recommendations presented by the Commission reflect the input and areas of agreement among Commissioners. Initial recommendations from Commissioners that were broadly opposed were either modified for inclusion or removed.

Through this process, the Commission produced a strong bipartisan vision of a fiscally-sustainable and effective LTSS service delivery system built on concepts of person- and family-centered care; a well-trained and adequately supported array of family caregivers and paid workers; with a comprehensive financing approach that would balance public and private

financing to insure the most catastrophic expenses, encourage savings and insurance for more immediate LTSS costs, and provide a strong safety net for those without resources.

Below is a summary of the 28 recommendations in the areas of Service Delivery, Workforce, Financing, and Next Steps that align with and would make progress toward the shared vision developed by the Commission.

#### *Service Delivery*

In the area of service delivery, the Commission called for “a more responsive, integrated, person-centered, and fiscally-sustainable LTSS delivery system that ensures people can access quality services in settings they choose.” To this end, the Commission recommended changes that would lead to a balance of home- and community-based care and institutional care options, integrate LTSS and medical care, implement a uniform assessment tool in support of the LTSS care plan, use information technology more effectively across settings, ensure consumer and caregiver access to information, and improve LTSS quality through outcomes-focused care management.

#### *Workforce*

In the area of paid and unpaid caregiving, the Commission called for “an LTSS system that is able to support family caregivers and attract and retain a competent, adequately-sized workforce capable of providing high-quality, person-and-family-centered services and supports to individuals across LTSS settings.” To this end, the Commission recommended changes that would: focus LTSS on the person with cognitive or physical functional limitations and the family caregiver, involve family caregivers and their needs in care planning and as part of the care team, improve caregiver training, and encourage an array of interventions to support family caregivers. The Commission also recommended changes to improve the paid workforce, including revising scope of practice to broaden opportunities for professional and direct care workers, creating opportunities for direct care workers to advance, integrating workers in care teams, encouraging states to improve standards for home care workers, and collecting data on the LTSS workforce.

#### *Financing*

In the area of financing LTSS, the Commission called for “a sustainable balance of public and private financing for LTSS that enables individuals with functional limitations to remain in the workforce or in appropriate care settings of their choice.” This vision would be accomplished through a financing approach that “(1) provides the tools and protections to enable Americans to better prepare for the financial risk of needing LTSS; and (2) ensures that individuals with limited financial resources or for whom the cost of their care exceeds their financial resources

have access to needed high-quality services and supports.” The Commission reaffirmed the importance of an effective – and improved – publicly-funded safety net. It also stressed the importance of creating viable mechanisms for insuring what is for many an insurable risk, including the need to provide catastrophic insurance for the most devastating costs in order to encourage savings and private insurance for the more immediate LTSS costs.

The Commission offered two different approaches for mechanisms to move toward this end – one relying largely on private options and the other largely on public social insurance. The private options approach centered on providing new market-based incentives to improve uptake of private long-term care insurance (e.g., tax incentives, life care annuity, allowing a Medicaid carve-out), as well as establishing an ongoing public awareness campaign. The public social insurance approach described two possible models – create a comprehensive Medicare benefit for LTSS or create a basic LTSS benefit within Medicare or a new public program – both allowing for private sector involvement. These approaches are not meant to be mutually exclusive, and various features could be combined in the effort attain a “sustainable balance of public and private financing.”

The Commission did not come to an agreement on a single comprehensive plan for financing LTSS. Many Commissioners believed it would be irresponsible to put forward a specific proposal, particularly involving public financing, when it is not currently possible to reliably estimate the scope or magnitude of the cost that would be financed and to determine the amount of tax and or premium dollar that would have to be raised to pay for it. Many Commissioners believed designing a viable approach to LTSS risk protection, public or private is possible, but that it would require a considerable amount of new data, design work, and careful analysis of costs and consequences before a fiscally-responsible proposal could be put forward that would gain broad support. What the Commissioner did develop was a bipartisan vision and core principles that should guide the next phase of technical work needed to move toward viable policy solutions.

The Commission did recommend several changes in the financing arena that focused on Medicare and Medicaid. Recommendations included improving access to Medicare skilled nursing facility and home health care benefits, providing support through Medicaid for working adults with LTSS needs, and allowing families to save through tax-favored accounts for an individual’s LTSS expenses.

#### *Next Steps*

The broad bipartisan agreement the Commission achieved on a vision statement and specific recommendations is a strong foundation for the additional work that needs to be done and

could not be completed in the time allowed. The Commission recommended significant follow-on efforts to take this vision and these recommends further. Specifically, the Commission recommended the creation of a "...subsequent national advisory committee to continue this work and consider the Commission's recommendations and potential financing frameworks as a starting point for its own assessments and recommendations." The Commission also recommended convening the White House Conference on Aging in 2015 to include LTSS in partnership with the National Council on Disability.

Mr. Chairman, we appreciate the opportunity afforded us and our fellow commissioners by the Congress to focus on the tremendous challenge this country faces in meeting the growing needs in the population for long-term services and supports. With the limited time and resources we were allowed, we were able to establish a solid bipartisan base for further consideration of this important issue. We urge you and your colleagues to consider, build on, promote, and where appropriate, enact into law the 28 recommendations in order to meet the human and fiscal challenges facing Americans with substantial cognitive and physical functional limitations.

**Questions from Senator Ayotte  
Addressed to Mr. Warshawsky, American Enterprise Institute**

1. Mr. Warshawsky, in your opening testimony, you stated that policymakers should look at ways of tightening eligibility standards for workers above age 50 to qualify for disability insurance. Could you further discuss some of the challenges associated with the current eligibility standards for these workers? Could you also offer any possible policy solutions that could address some of the concerns associated with the current eligibility requirements?

In recent years, the incidence of workers claiming and getting disability insurance from Social Security has increased rapidly. These growing costs are consistently and significantly above what the actuary has been projecting. A rising share of disability payments are going to individuals ages 50 and above (until the full retirement age, when the disabled benefit is converted, without reduction, to a retirement benefit). In 2010, nearly 10 percent of the population age 55 to 59 was getting disability benefits; for those ages 60 to 64, the percentage of the population getting benefits was 13 percent!

The Social Security Administration determines whether an insured individual not working currently is disabled through a multi-step process. First, it sees if the person has a severe disability meeting one of its medical listings. If the person does not meet the listings or the equivalent, he may still be determined to be disabled through a test of residual functional capacity for work. This test looks to see if the person can still perform his past work or failing that can do some other work in the economy. To determine the latter, SSA looks to an extremely outdated index of jobs in the economy, and considers the person's age, education, and experience.

Because the mental and musculoskeletal disorders that are increasingly being claimed are often hard for the SSA to judge on the basis of medical evidence alone, SSA's determinations are being made more and more on the basis of residual functional capacity. Here age plays a major role, so that "closely approaching advanced age" (above 50, or 45 for those who do not speak English) or experience (more than 35 years), sometimes combined with lower educational attainment, means that the SSA does not need to consider jobs and careers beyond what the claimants have doing heretofore and that the disability only need be judged more than "not severe" in order to grant eligibility for benefits. Owing to the aging of the baby boom generation and increased immigration, combined with weak labor markets, these loosened standards apply to a growing share of the labor force. Moreover, given that some administrative law judges deciding a disproportionate share of all of cases have been shown to have a high propensity to grant appeals of denied benefits, the existence of the eased rules above age 50 allows these judges an ample basis to grant the claim.

These eased criteria come from a different age and economy, perhaps appropriate to the 1950s and 1960s, but no longer. When life expectancies were much lower, when average retirement ages were dropping with the advent of employer pensions, when devices to aid the disabled did not exist, and when medical treatments were not very sophisticated, the reasonable expectations of both workers and employers was that being age above 50 combined with some level of physical disability should be accommodated through disability benefits. Now, however, lifespans expectancies are much higher and pensions are disappearing so that work even past age 67 is more and more common and moreover is still consistent with a long retirement period. The technology of assistive devices has improved dramatically as have the effectiveness of medical treatments. More and more claims involve mental disorders, and not physical disability. The availability of retraining through, for example, community colleges, is now more widespread. Similarly, when most of the workforce has a high school education at least and many have at least some college education, the significance of educational levels to the ability to do work at older ages is quite different now than when high school and especially college educations were much less common. Finally, in the past, physical capability was a major component of work capacity for many, perhaps most, workers. Now, given changes in technology and the industrial make-up of the US economy, physical capability, in general, is less important to work capacity.

I recommend that the SSA should be tasked with updating its index of occupations quickly. Similarly, it should work with the medical community to be more precise in its judgments of mental and musculoskeletal disability. The relevant ages or years of experience for weaker adjudication standards should be increased by five years across the board. And the influence of educational level criteria should be reviewed and perhaps removed entirely. I believe these changes could take place through administrative and regulatory actions.

Finally, because of the scheduled increases in the full retirement age to 67, there are larger and larger reductions in retirement benefits claimed before the full retirement age. As mentioned above, these reductions do not currently apply to those getting disability benefits who subsequently convert automatically to retirement benefits at the full retirement age. Hence, there is a growing incentive for older workers to apply and get disability benefits, as opposed to early retirement benefits. Therefore, I recommend that for workers who get disability benefits at ages 55 or older, upon reaching the early retirement age, 62, they should get a reduction in benefits consistent with those first claiming retirement benefits at age 62. Workers applying for disability benefits at ages above 62 should simply be given the appropriate early retirement benefit. These changes would require legislation.

2. Mr. Warshawsky, what do you believe can be done to encourage people to be more prepared to pay for long-term care on their own?

In the current system, there are disincentives as well as a lack of incentives to prepare one for long-term care expenses through private insurance or personal savings. These incentives must be reversed. The disincentives arise because government programs – Medicare and especially Medicaid – already serve as free insurance for long-term care needs, even for the wealthier segments of the population. Medicare will pay any elderly or disabled person for skilled nursing and home health care for up to 100 days if it is medically necessary after a 3-day hospital stay, and it pays for hospice benefits if the individual is judged to have less than six months to live. Medicaid will pay for even custodial and personal care in a nursing home or through home health care if the elderly individual has run through his assets, but housing (below \$802,000 in value), retirement accounts, life insurance, jewelry, cars, artwork and furniture are excluded from consideration, so even wealthy people can and do become eligible for Medicaid.

These eligibility conditions must be made more restrictive to remove the disincentives to personal financial planning. Although the 3-day hospital stay rule is outmoded, eligibility for Medicare payments for skilled nursing and home health care should be reduced to 50 days or even less, to make sure that long-term care services and supports are not covered by what is supposed to be a health insurance program. Similarly, Medicare should not pay for more than six months of hospice benefits, forcing providers to better judge and take the risks for providing those services to individuals most in need of them. Also, Medicaid eligibility needs to be tightened. Housing, retirement and life insurance assets and the market values of personal articles should be counted toward the asset eligibility tests, above a de minimus amount of, say, \$25,000. These assets would not need to be sold, however, to pay for long-term care expenses; rather, they could be accessed through mechanisms such as reverse mortgages, immediate straight life annuities, or loans.

On the positive side, incentives are useful ways to encourage appropriate behavior. That is the theory for and experience with the individual income tax advantages for the employer provision of health insurance and retirement plans or IRAs. Currently, long-term care insurance does not have such tax advantages and it should. In addition or alternatively, the government could encourage the purchase of permanent long-term care insurance through the provision of credits, weighted toward lower-income people, created through a Medicaid carve-out program, as described in the LTC commission report. Finally, the federal government could allow the tax-favored purchase of the life care annuity, a combination of long-term care insurance and an immediate life annuity, through retirement accounts.

3. Mr. Warshawsky, as the Affordable Care Act continues to be implemented, we are seeing what overregulation can do to insurance markets—premiums are skyrocketing in order to cover the costs associated with the law's many mandates. Do you believe it makes sense to consider ways to appropriately relax some regulations for private long-term care insurance policies? Is there

a way that we can ensure that appropriate regulations prevent predatory business practices but also allow for policies that might be something akin to catastrophic coverage—making long-term care insurance more affordable to those considering purchasing coverage?

The federal and state rules governing the required terms of long-term care insurance are quite restrictive. There must be an offer of insurance with benefits increasing at 5 percent, even nowadays when general price inflation is running below 2 percent. The requirement should be changed to CPI inflation plus one percent. Similarly, if the insurance company providing long-term care insurance experiences losses, it may petition the state insurance commissioner for a general price increase. This petition is an arduous and uncertain process. Instead, “participating” long-term care insurance should be allowed, whereby price increases could occur automatically if the state or federal governments determine that macroeconomic or demographic situations have sufficiently changed, e.g. the level of interest rates has plummeted. To be fair to consumers, this process should be reciprocal, that is, if changes in general conditions improved insurer profits, those profits should be shared with consumers in the form of lower premiums.

4. Mr. Warshawsky, do you believe that there is a way to encourage the formation of a transparent private market, free of unnecessary government regulations, that would allow individuals to choose the best plan for their personal needs from a series of long-term care insurance policies?

The roll-out and design of health exchanges in the ACA have been disastrous. Nonetheless, the idea of competing private insurers offering clearly explained products, assisted by a government website, is a good one, as demonstrated by Medicare Advantage plans offered under Medicare. Such a system could be designed for private long-term care insurance in the Medicaid carve-out program we have put forward.



**Testimony of Judy Feder, Ph.D.**

**Before the**

**Special Committee on Aging, U.S. Senate**

**On**

**The Future of Long-Term Care Policy: Continuing the  
Conversation**

**December 18, 2013**

Judy Feder is a professor at the Georgetown University McCourt School of Public Policy and an Urban Institute Fellow. During the summer of 2013, she served as a member of the Congressional Commission on Long-term Care. This testimony, a commentary on her service, was posted on the Urban Institute's Metrotrends blog, <http://blog.metrotrends.org/2013/10/long-term-services-supports-path/>

The blogpost was co-authored with four other commissioners (Laphonza Butler, Henry Claypool, Judith Stein, and Lynnae Ruttledge) who joined her in offering the alternative report that is submitted with this testimony and available at <http://mspp.georgetown.edu/document/1242802199302/LTCC+Alternative+Report+09.23.13.pdf>

The views expressed are those of the author and should not be attributed to Georgetown University or the Urban Institute, its trustees, or its funders.

Chairman Nelson, Ranking Member Collins and members of the committee, I am pleased to testify before you today on a path forward for long-term services and supports. I have spent my career examining the challenges to assuring affordable health and long-term care services to people who need them—most recently as a member of the Congressional Commission on Long-term Care. And I can tell you, there is much work to be done. Although policymakers are grappling with the challenges of assuring Americans affordable access to quality health care, they have yet to seriously tackle the equally important issue of long-term services and supports.

Despite the continued political battle, even critics of the Affordable Care Act recognize the need for insurance to assure access to health care and protection against financial catastrophe. But there's much less acceptance of the need for insurance when it comes to another health-related risk, one for which virtually all Americans are uninsured: the risk of needing expensive, extensive help with basic daily tasks—like dressing, bathing, or eating—generally referred to as Long-Term Services and Supports (LTSS). On the financing that is critical to building an effecting long-term care system, the recently concluded Long-term Care Commission stopped short of recommendations. But five of us commissioners felt compelled to step up, with an alternative report explaining, as charged, why and how Congress should accomplish this goal. I request that you include the alternative report, submitted with my testimony, in the record.

About 12 million people have LTSS needs today, roughly 5 million of whom are under the age of 65. The vast majority of these individuals count on their families for help. But families can only do so much, and when people need paid care—whether at home, or in an assisted living facility or nursing home—its costs soon exceed most families' resources.

That's where insurance ought to kick in. But it doesn't.<sup>1</sup> Private health insurance does not cover LTSS. And few Americans have private LTSS insurance which typically costs a lot, offers limited value, and is subject to premium increases that can cause purchasers to lose coverage they've paid into for years. On the public side, Medicare—which older people and some younger people with disabilities rely on for health insurance—does not cover LTSS. The federal-state Medicaid program does serve as a valuable last resort for people who need LTSS, but its protections (especially home care) vary considerably from state to state and become available only when people are or have become impoverished taking care of themselves.

The absence of private or public LTSS insurance is a market and a policy failure. The need for extensive, expensive LTSS is precisely the kind of catastrophic, unpredictable, risk for which we typically rely on on insurance to spread costs. These costs are obviously unpredictable for people under the age of 65, only two percent of whom need LTSS. But they're also unpredictable after age 65.<sup>2</sup> An estimated three in ten people aged 65 today are likely to die without needing any LTSS, while two in ten will likely need care for five or more years. And, in financial terms, half the people turning age 65 will have no private out-of-pocket spending for LTSS, while a small percentage are projected to spend hundreds of thousands of dollars out-of-pocket.

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<sup>1</sup> Judy Feder and Harriet Komisar, "The Importance of Federal Financing to the Nation's Long-term Care Safety Net," Georgetown University, February 2012. [http://www.thescanfoundation.org/sites/thescanfoundation.org/files/Georgetown\\_Importance\\_Federal\\_Financing\\_LTC\\_2.pdf](http://www.thescanfoundation.org/sites/thescanfoundation.org/files/Georgetown_Importance_Federal_Financing_LTC_2.pdf)

<sup>2</sup>Peter Kemper, Harriet Komisar and Lisa Alecxih, "Long-term Care Over an Uncertain Future: What Can Current Retirees Expect?" *Inquiry* 42: 335-350 (Winter 2005/2006). <http://alisprotect.com/UncertainFuture.pdf>

If, as is often claimed, we want people to be financially “prepared” to manage this unpredictable, catastrophic risk, we need to establish a reliable insurance mechanism, whether public or private, to which they can contribute. It’s easy for experts to agree on the need for a public-private partnership in establishing this mechanism. What’s hard is agreeing on precisely what role each sector should play.

To effectively spread risk and reach the broadest possible population, public social insurance must be at the core of future policy. Private insurance can play a complementary role, but even its proponents recognize that building future policy around a private market will, at best, leave eight in ten Americans uninsured. Public insurance can be designed in different ways. It can offer relatively comprehensive and defined benefits, like, or even through, Medicare; or it can offer basic or cash benefits in a new program. And it can be funded in different ways—in part through taxes, like a surcharge on the income tax, and in part, through savings from what Medicaid would otherwise have to spend. Regardless of its specifics, a public or social insurance program will protect all of us at risk and require all of us to contribute.

Public insurance will not eliminate personal or family responsibility. Rather it will make shouldering that responsibility manageable and affordable—through private insurance, private resources, and family care. And no social insurance mechanism is likely to eliminate the need for an adequate public safety net — whether within it or through a continued (albeit much smaller) Medicaid program.

The enactment and implementation of the ACA demonstrates that it will not be easy to enact public LTSS insurance. But let's not kid ourselves: without it, our policies will continue to fail people, young and old, now and in the future, who need care. Building an effective LTSS insurance system with public protection at its core is the only way to enable Americans to prepare for the risks we all face. Building it is our responsibility.



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**Additional Statements for the Record**

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**A COMPREHENSIVE APPROACH TO LONG-TERM SERVICES AND SUPPORTS**

Long-Term Care Commission

September 23, 2013

**Commissioners**

Laphonza Butler, Vice President of SEIU, and President of SEIU-United Long Term Care Workers  
Henry Claypool, Executive Vice President, American Association for People with Disabilities  
Judith Feder, Urban Institute Fellow and Professor, Georgetown Public Policy Institute  
Lynnae Rutledge, Co-Vice Chair, National Council on Disability  
Judith Stein, Executive Director, Center for Medicare Advocacy, Inc.



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**Summary**

Congress established the Long-term Care Commission in recognition of the current and increasing nationwide need for long-term services and supports (LTSS). The statute establishing the Commission sets out our charge:

“The Commission shall develop a plan for the establishment, implementation, and financing of a comprehensive, coordinated, and high-quality system that ensures the availability of long-term services and supports for individuals in need of such services and supports, including elderly individuals, individuals with substantial cognitive or functional limitations, other individuals who require assistance to perform activities of daily living, and individuals desiring to plan for future long-term care needs....”  
[Emphasis added.]<sup>1</sup>

The authors of this statement acknowledge the efforts of the entire Commission and staff. But, given the unusually compressed timeframe for our work, the final report does not fulfill this charge. We issue this statement to express our shared vision of what is necessary to meet Congress’s mandate to establish and finance a high-quality, comprehensive LTSS system for Americans who need such services. The authors’ vision is to create such an inclusive LTSS system for people of all ages – a system that will meet individual’s functional and cognitive support needs with quality care in the most integrated setting. We are convinced that no real improvements to the current insufficient, disjointed array of LTSS and financing can be expected without committing significant resources, instituting federal requirements, and developing social insurance financing.

Accordingly, our recommendations follow.

1. To spread the risk for the costs of long-term services and supports as broadly as possible, provide benefits to people of all ages who need them, and allow individuals and families to meet their responsibilities, a public social insurance program that is easily understood and navigated must be established. That program could provide comprehensive benefits or a more limited package. But a social insurance program must be at the core of an effective LTSS financing system. A social insurance core would not eliminate the roles of private insurance or of family financing or caregiving. Rather, it would make these roles more manageable.
2. To ensure high-quality services for individuals and their families in all service settings, the law must assure that direct-care workers are paid a living wage, are well trained, and have opportunities for career advancement.

3. To integrate family<sup>1</sup> caregivers into a comprehensive LTSS system, public programs providing services to LTSS beneficiaries must appropriately engage family caregivers and address their needs.

While the nation moves to a comprehensive system for LTSS, and to supplement it as necessary, we recognize that improvements are needed in current programs. Among the improvements suggested by individual Commissioners are the following:

4. To meet the needs of those who qualify for Medicare, the current Medicare program must be adapted to reduce counterproductive, outdated and unreasonable barriers to outpatient therapies, home health and skilled nursing facility care.
5. To strengthen Medicaid, existing financial incentives to states for quality home- and community-based services must be extended and streamlined to make it easier to rebalance Medicaid LTSS. In addition, Medicaid's benefits must be improved for people who rely on Medicaid's services.
6. To provide news ways to access LTSS for persons with disabilities, tax-preferred savings accounts must be provided for people and their families who are not currently receiving LTSS through the Medicaid program, the Medicaid buy-in program for workers with modest earnings must be expanded, and a new program for workers with significant disabilities who have higher earnings must be piloted.

In the text below the authors explain and expand on each of these recommendations in turn.

### **How We're Failing People Who Need Long-Term Services and Supports (LTSS)**

Although the risk of needing LTSS rises at older ages, people of all ages are at risk. The LTSS population includes older adults and people with disabilities associated with chronic conditions including Alzheimer's disease, osteoporosis, heart failure, and stroke. The LTSS population also includes children and young and working-age adults with disabilities, including people disabled from birth who have intellectual and developmental disabilities or other cognitive and physical limitations, and people who develop disabling chronic conditions and illnesses (such as Parkinson's disease, multiple sclerosis, and stroke) or who sustain a disabling injury later in life (a spinal cord injury or traumatic brain injury, for example). Among people under the age of 65, less than two percent have LTSS needs, but they represent nearly five million of the 11 million people who need LTSS. Among people now turning age 65, an estimated three in ten will never need any LTSS, while two in ten will need five or more years of LTSS.<sup>2</sup>

Most people who need LTSS (over 80 percent of people with LTSS needs living at home) rely solely on family and friends to provide them and do not receive paid services.<sup>3</sup> Some people also receive supplemental assistance from paid caregivers, usually home care aides, and only a small

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<sup>1</sup> We use the word "family" broadly, to refer to all friends and community members who assist an individual who needs LTSS.

percentage of people with LTSS needs living at home (less than 10 percent) rely exclusively on paid care.<sup>4</sup>

There are no comprehensive private or public sector mechanisms for pooling the risk of needing LTSS and spreading the cost for those services. Few people with LTSS needs today, or who are at risk of needing LTSS in the future, have purchased private insurance to meet those needs. With respect to people with current needs for LTSS, few, if any private policies are even offered. Medicare and Medicaid provide substantial assistance to many people with LTSS needs, but neither program provides effective insurance that assures access to appropriate services and supports or protection against financial catastrophe for people who need LTSS. Medicare – which provides health benefits for people 65 years old or older and people with disabilities who receive Social Security benefits for 24 months, regardless of income – does not pay for LTSS. Medicaid, in contrast, provides substantial assistance to people with LTSS needs, but the program is means-tested and requires people to be or become impoverished to qualify for assistance. The services covered by Medicaid – especially home and community-based services, vary widely across states. Waiting lists are common, and the lack of services can lead to unmet needs and human suffering and can force people into institutions. Further, for people with disabilities who are willing and able to work, Medicaid’s stringent means-testing can force people with disabilities not to work, or not to work up to their potential, in order to remain eligible for financial assistance with the cost of LTSS.

People with disabilities who need LTSS, as well as caregivers, friends, and others who assist people who need LTSS, know about the challenges and frustrations, the costs, and, for some, the indignities and suffering that arise as a result of the nation’s woefully inadequate approach. Although needs and circumstances vary widely, the personal stories of people who need care invariably reveal a number of truths about LTSS today: the central role of families, both in terms of caregiving and personal financial resources; the challenges in finding out how to navigate disparate and often inadequate programs; the difficulty in piecing together a plan for supportive services and keeping it in place; the high cost of services relative to the financial resources of frail older adults and younger persons with disabilities; the barriers to financial assistance with the cost of care for people with even modest financial resources; the importance of Medicaid to people with limited resources and costly LTSS needs; and the barriers to work and independence for people with disabilities who need supportive services.

Here are just a few profiles of real people that shed light on a number of these truths about LTSS today:

- **Evelyn Greenberg** was a 76-year-old wife, mother and grandmother when, in 2001, she suffered a serious brain-stem stroke that left her almost completely paralyzed. After much physical therapy, she was only able to regain limited use of her left arm. She required constant supervision and relied on substantial assistance from family members and home health aides to meet her daily needs. Evelyn lived at home in Florida and relied on her husband, Arthur, (who was 71 years old at the time of her stroke) as her primary caregiver for over 7 years until his death at the age of 79 from pancreatic cancer. Evelyn’s children also spent considerable time providing caregiving assistance, which provided respite to their

father. They also provided caregiving to both parents during Arthur's 18-month fight with cancer.

Following Arthur's death, the family struggled to maintain Evelyn in her home in Florida. Evelyn's daughters took shifts taking care of her for 2-week periods of time or longer. But, after 6 months, it became apparent that this situation was not a long-term solution since her daughters had full-time jobs and did not live in Florida. Evelyn moved to Seattle to live with one of her daughters. There, she received assistance from family and friends, and relied on the assistance of a paid caregiver during the day while her daughter was at work. She paid for these formal, supportive services out of her accumulated savings and also contributed to household expenses.

After two years, as her care began to place increasing personal and financial strains on her daughter, Evelyn returned to Florida, choosing to live in a nursing home near her son's home. For roughly two years, Evelyn paid for her nursing-home care out of her own savings. When those resources were exhausted, Medicaid financed the final year of her nursing-home care. Sadly, in March of 2013, after living 12 years with a serious disability, Evelyn suffered a fall from her wheelchair and died several days later at the age of 88.

Although decades earlier—when they retired to Florida at ages 62 and 67—Evelyn and her husband had tried to purchase private LTSS insurance, they were rejected by several companies or offered plans at an unaffordable rate because of Evelyn's osteoarthritis and hypertension and her husband's previous heart attack.

- **Sue Kelly** was a 40-year-old wife, mother and schoolteacher when she was diagnosed with multiple sclerosis in 1985. Over the next decade and a half, Sue became increasingly disabled, using a cane, a walker, and then a wheelchair, and, by 2000 was bedridden and needed 24-hour supervision and support. With her husband Jack at work and their daughter in school, the Kellys exhausted both their personal savings and the savings they had set aside for their daughter's college education paying for home health aide services, at a cost of roughly \$40,000 annually. In 2005, Jack applied for assistance from the Connecticut Department of Human Services. The application was approved and Sue began receiving assistance from a home care aide to feed, bathe, and care for her under the guidelines of the state Department of Rehabilitation. A year later, Sue's eligibility was reviewed and she was again approved for assistance. But three months later, following a review of the family's finances, Jack received the news that Sue was no longer financially eligible for assistance. The family's assets exceeded the program's limits. All assistance ended in September 2006. Jack and Sue were advised to cash in on the cash value of their life insurance policy and to reduce the amount in his retirement savings account and pay bills with his "excess" savings. He did not pursue those options. Instead, his daughter arranges her schedule to be home from college a day or two per week, and his adult siblings (2 of 3 of whom are retired) help Jack defray the expenses of the aide Sue needs 3 or 4 days a week. Jack's consolation is that his life insurance and 401(k) are intact and available to help pay for his wife's care if he dies.
- **John Robertson** was born with spinal muscular dystrophy, which causes significant loss of muscle tone. John relies on complex rehabilitation technology (CRT) to use his wheelchair in order to live independently. He just graduated law school and is contemplating whether to

take a job at a law firm in a major metropolitan area in another state. The job has a good salary at \$120,000 but his personal care costs are approximately \$90,000 which are not covered by his employer-sponsored insurance. Since he would have to pay for all of this out-of-pocket, his salary would essentially be \$30,000, which is not enough to cover his rent and living expenses. He relied on Medicaid as a law student to cover his personal care needs, but Medicaid is not portable to the state in which he would work. He now has to face the tough decision of foregoing this job offer at a prestigious law firm just to maintain access to LTSS. This denies him the ability to live as independently as possible and become a taxpayer instead of someone who is forced to rely on a safety net program just to get these essential services.

- **Joyce McWain-Gray** is a 56-year old widow who resides in Washington, DC. Partially paralyzed by a spinal condition in 2007, she gets by on a modest Social Security benefit (\$710 per month). After a spinal condition paralyzed her legs six years ago, Joyce McWain-Gray crawled to her second-floor bedroom in a rowhouse and remained there for nearly a year. For her weekly medical appointments, the 56-year-old relied on District firefighters to carry her down the 12 steps from her room. McWain-Gray grew hopeless, she said, until a social worker told her about the District's Elderly and Persons with Physical Disabilities Waiver Program. Joyce was enrolled in the District's Medicaid program—specifically its Elderly and Persons with Physical Disabilities Waiver Program. The Medicaid program sent an aide to her house for 16 hours a day to help her bathe, dress, cook and clean. She got a motorized wheelchair and learned to ride the bus. Then one day her freedom ended. The District would no longer pay for her care during evening hours, she learned in a letter from her home health agency. Three days later, the aide left a stack of adult diapers and a cooler of food next to McWain-Gray's bed and left. Like dozens of other beneficiaries whose benefits were wrongfully terminated, Joyce's benefits were subsequently restored. She continues to live independently in her home.<sup>5</sup>
- **Sara Davis**, 46, has been a wheelchair user her whole life. She has lived on her own since college with the help of home care workers. These workers come in every day to help her get out of bed, dress, shower, do dishes, prepare food, and clean her house. Without them, she could not work full-time or participate in her community. However, she's been unable to keep the same aides for any length of time and consequently has not been able to form lasting relationships with the people who come in to perform these essential, and intimate, tasks. It takes time for workers to get to know how she likes things done and even longer for them to develop the kind of trust that makes everything go more smoothly. Her aides have been kind and helpful, but they often leave these jobs to work in fast food or retail where they can earn more, which means that she's constantly starting over. Some days, the agency is so short-staffed that they have no one to send to help her prepare for the day. Without family in the area, she fears that one day she will go without any help and end up in a nursing home.

## Recommendations for Reform

We recognize that enhancing and building a new LTSS system needed to satisfy the Commission's statutory charge will take time. But the people who currently need LTSS cannot wait. To transform today's inadequate LTSS system into one that works, we therefore recommend the creation of a new system and, until it is established, improvements to existing public programs to better meet the needs of older adults and younger people with disabilities. Our recommendations follow.

### 1. Create a Broader Financing Solution

Most people who need LTSS rely solely on family and friends to provide it and do not receive paid services. But families deliver that care at enormous cost and cannot always provide the full amount, intensity, or type of care that is needed. When paid care is necessary, its costs often exceed most families' resources. The resulting need for expensive, extensive LTSS is an unpredictable, catastrophic risk for people at any age.<sup>6</sup> People under the age of 65 have less than a two percent chance of having LTSS needs. And even among people now turning age 65, three in ten are likely never to need LTSS, while two in ten will likely need care for five or more years. Half of all people turning age 65 will have no private out-of-pocket spending for LTSS, while only about 5 percent are projected to spend more than \$100,000 out-of-pocket.<sup>7</sup>

Although, in theory, savings could help fill the gap between income and service costs, in practice, savings are inadequate to the task. For younger people who need LTSS, their disability often comes well before they have a chance to accumulate savings that might help pay for LTSS costs. Most older people also lack assets sufficient to finance extensive care needs. Given the unpredictable, catastrophic nature of extensive LTSS costs, insurance, not savings, is the most efficient and effective means of preparing for their possible occurrence.

The nation's public health care financing programs, Medicare and Medicaid, provide substantial assistance to many people with LTSS needs, but neither program provides insurance protection for catastrophic LTSS costs. Neither does the private insurance market. The high costs, limited value and uncertainty of private LTSS insurance limit its scope.<sup>8</sup> Analysts estimate that improvements in the marketplace would, at best, leave eight in 10 Americans without insurance protection.<sup>9</sup> Tax policies that some advocate to subsidize these policies would disproportionately benefit the better off. And, without substantial regulation, policies would likely fail to provide adequate protection when purchasers need care.

#### Recommendation #1

**To spread the risk for the costs of long-term services and supports as broadly as possible, provide benefits to people of all ages who need them, and allow individuals and families to meet their responsibilities, a public social insurance program that is easily understood and navigated must be established. That program could provide comprehensive benefits or a more limited package. But a social insurance program must be at the core of an effective LTSS financing system. A social insurance core would not eliminate the roles of private**

**insurance or of family financing or caregiving. Rather it would make these roles more manageable.<sup>10</sup>**

Today's public-private financing arrangement that concentrates burdens on the individuals and families of those who use services, backed only by a public program when they become impoverished, must be replaced with a public-private financing arrangement that truly spreads risk. That arrangement has room for, but cannot rely upon, private insurance as its core. To spread risk across the broadest population, social insurance must be the foundation of future policy.

That insurance could take a variety of forms.

**One way to develop social insurance for LTSS would be to include a comprehensive LTSS benefit in Medicare Part A.** This approach has the advantage of relying on a system that is already in place and has history of adapting to changes in its benefit and financing structure.

- Like the Medicare hospice benefit, added to Medicare Part A in 1983, a Medicare LTSS benefit would be triggered when an individual is certified to meet certain qualifying criteria. The demise of the CLASS Act teaches that to be viable, an LTSS program cannot be voluntary; hence the benefit should be added to Part A, which is mandatory. Under this model, a physician would be required to certify that the individual requires assistance with at least two activities of daily living, has needed such assistance for 90 days, and is likely to continue to need the services. Individuals could equally qualify based on certified ongoing and continued cognitive or mental health issues such that independence is impossible or contraindicated.
- Financing a Part A LTSS benefit might come from a combination of an increase to the current Medicare payroll tax and/or to Part A premiums. Of course, the cost of a Medicare LTSS benefit must be analyzed; it is possible that a new financing mechanism for LTSS could be designed to enhance the financial stability of the Part A trust fund.
- Qualifying individuals would be eligible for reasonable and necessary LTSS services such as:
  - Skilled nursing facility care without the need for a prior hospital stay or daily skilled care;
  - Home health care, including coverage for home health aide services, without the need for a skilled service;
  - Personal Care Attendant services;
  - Care management and coordination;
  - Adult Day Center services;
  - Respite care options to support family or other volunteer caregiver;
  - Outpatient therapies;
  - Other reasonable and necessary services.



- Any new Medicare LTSS benefit should not add to the complexity of Medicare and should not diminish the stability of the current program.
- Importantly, since not all people with LTSS needs are eligible for Medicare, consideration should be given to including those who meet the agreed upon benefit criteria, but who would otherwise not be part of the Medicare program. In the alternative, other social insurance funding should be developed to meet these individuals' needs.

**Another social insurance option is to create a more limited benefit, within Medicare or in a new public program.** This approach has the advantages of creating a manageable role for private insurers by limiting their exposure to catastrophic risk and by making clear the "hole" that people able to prepare in advance should plan to fill, through private resources.

- Under this arrangement, people assessed as meeting a specified threshold of functional impairment would qualify for benefits after a waiting period. The length of the waiting period (shorter for people with lower incomes and becoming longer at higher incomes) would be established at or near retirement age and tied to Social Security-reported income, averaged over a number of years. For younger people who become impaired, the formula relating waiting periods to income would be appropriately adjusted to reflect the lesser accumulation of resources at younger ages.
- To make the benefit available to people currently in need of assistance, an alternative to the proposed waiting period would be necessary, since private insurance to fill it may be unavailable or prohibitively expensive and people may lack the means to otherwise protect themselves. A broadly inclusive benefit would therefore replace the waiting period with an income/asset-related deductible for people who, at the time the new benefit is established, have significant disabilities or are age 75 or older.
- Benefits under this arrangement would be specified as a dollar-amount per day, vary with level of impairment and be applicable to the full range of LTSS services. Individuals could opt for a service rather than a cash benefit.
- Benefits could be financed through a combination of Medicaid savings (federal only or federal and state) and a surcharge on the income tax (higher for people currently near or at retirement age).

**Neither of these social insurance models eliminates the private part of the public-private LTSS partnership.** On the contrary, they mitigate risks and create a clear and manageable role for private insurance. To support supplementation or gap-filling, new regulations are needed for the private long-term care insurance market to, at a minimum:

- Standardize and limit the types of policies insurers can offer, as in the Medigap market, in order to facilitate comparison and competition.
- Create an electronic market and provide information and direct assistance to consumers, in order to facilitate comparison-shopping and educated choices.

- Create effective consumer protections to ensure people receive fair value and promised benefits.

Any social insurance program, and all private insurance offered alongside it, require adequate mechanisms to ensure coverage is provided for those who meet qualifying criteria and consumers receive fair value. Therefore,

- All social insurance and private LTSS plans must provide easily accessible, meaningful appeals to those who are denied coverage or other rights afforded by their social or private insurance.

Social insurance does not eliminate personal or family responsibility (witness Medicare and Social Security); it makes shouldering that responsibility manageable and affordable. No matter how generous, social insurance will not cover all service needs or eliminate the importance of personal financial contributions of family care. And no social insurance mechanism is likely to eliminate the need for an adequate public safety net — whether within it or through a continued (albeit much smaller) Medicaid program.

Until such a program is enacted and as part of or alongside it once enacted, we recognize that improvements are needed in current programs.

## **2. Adopt a National Strategy to Improve and Strengthen the LTSS Workforce**

Direct care workers provide most (70 to 80 percent) paid hands-on LTSS and are the fastest growing job classification in the country. These workers hold a variety of job titles including personal care assistants, home care aides, home health aides and certified nurse aides. The paid LTSS workforce has been largely invisible, undervalued, and underpaid. The paid workforce also faces a demographic challenge, a challenge that is magnified by low pay, few, if any benefits, heavy workloads, lack of control over their work and few opportunities for advancement—factors cause high turnover and reduce the quality of care.<sup>11</sup>

The demand for direct-care workers is projected to expand by 70 percent by 2020.<sup>12</sup> But as the need for direct-care workers increases, the LTSS labor pool is dwindling. The turnover rate for LTSS workers is high – 13 to 18 percent higher than the overall labor workforce and 20 percent higher than other service workers. And, the traditional caregiving workforce, women aged 25-54 is expected to grow only marginally over this period, leaving a wide gap between the future supply and demand for these workers.<sup>13</sup> The majority of states and employers consider LTSS workforce shortages to be a major priority and most have tried (unsuccessfully) to bridge this growing “care gap.”<sup>14</sup>

To address quality and access challenges in LTSS, more attention needs to be paid to the difficulties of recruiting and retaining a well-trained, direct-care workforce. The direct-care worker jobs available in today’s LTSS system often pay poverty wages and offer limited benefits. The median annual earnings for direct-care workers were \$17,000 in 2010. About half (47 percent) of all direct care workers live in poor or low-income households, with income below 200 percent of the federal poverty level and fewer than half have health insurance coverage.<sup>15</sup>

Home care wages have been suppressed by the reimbursement policies in public long-term care programs that pay for personal assistance services. For the most part, these rates are not subject to regular updating and are not usually based on cost reporting or tied to market rates. Furthermore, the proportion of the rate to be directed to direct-care labor costs is rarely if ever specified. As state Medicaid budgets grow tighter, legislatures have been quick to cut personal care programs, leaving the providers of these services constantly vulnerable.

State and federal standards, mostly lacking, also fail to provide adequate training for home care aides and career pathways that would improve job satisfaction and the quality of care by reducing turnover and attracting workers into the labor pool. This lack of training also contributes to the high on-the-job injury rates. Many direct-care workers receive little or no training before starting their jobs. The federal government requires 75 hours of training for certified nurse aides and home health aides, a standard that has not been updated in over 20 years. There are no federal training requirements for personal care attendants, and while states may choose to establish training standards, many don't. Other states establish standards of dubious quality and even these standards are often not enforced.<sup>16</sup>

A related problem is the lack of oversight and regulation of home care agencies. Most states do not require licensing and certification of home care agencies.<sup>17</sup> As a result, families are unable to determine whether agencies are adequately screening job candidates, providing reliable training and supervision, and overseeing their staff. Because there is no uniform or mandatory agency reporting, there is currently no mechanism for ensuring adequate wages for home care workers are paid out of agency reimbursements.

An estimated 200,000 new LTSS workers are required each year to meet the future needs of our aging population.<sup>18</sup> However, as the need increases, the LTSS labor pool is dwindling. The workforce crisis is a direct result of the fragmented and insufficiently funded LTSS system, which contributes to a poorly paid, insufficiently trained, undervalued, and inadequately supported LTSS workforce. Moreover, these workforce challenges (which lead to high turnover and job vacancies) result in delays in access to care services, and higher costs in the long run as individuals are forced into institutional settings.

#### **Recommendation # 2**

**To ensure the high-quality services for individuals and their families in all service settings, the law must assure that direct-care workers are paid a living wage, are well trained, and have opportunities for career advancement.<sup>19</sup>**

The efficacy and stability of the LTSS system are predicated on the relationship between the consumer and the caregiver, but workforce issues are rarely addressed in discussions of system reform. Even with financing reform, access and quality problems in LTSS will remain without proper attention to the wages, recruitment, and retention of the workforce that delivers these services. Thus, our recommendations are to:

- Establish federal requirements for competency and training standards for personal and home-care aides, and reimburse training costs for all direct care workers, update payment rates to provide for adequate wages across settings,<sup>20</sup> and collect comprehensive

workforce data. These requirements would build on efforts to identify core competencies, skills and knowledge to provide high quality, person-centered care. Under certain circumstances, personal and home care workers would be permitted to opt out of the training requirement.

- Set federal guidelines that require all states to license and certify home care agencies. Licensing and certification requirements will include routine monitoring and requirements for agencies to submit detailed cost reports to maintain that certification (including detailed employee and revenue information).
- Establish minimum percentages of service rates directed to direct-care labor costs (wages).
- Create a national program to attract individuals to direct care jobs.
- Require detailed workforce plans for federally funded LTSS programs.
- Create career ladders by promoting effective training, incorporating direct care workers into care teams, and revising scope of practice standards.

### **3. Adopt a National Strategy to Recognize and Support Families in their Caregiving Role**

Families bear the primary responsibility for LTSS. Most people who need long-term services and supports rely exclusively on their families to get them. The large majority (91 percent) of people who received any LTSS received services from family caregivers. Most (66 percent) received all of their care exclusively from family caregivers. Another quarter received some combination of family care and paid help; only 9 percent received paid help alone.<sup>21</sup> Most often, but not always, those caregivers are women – wives, mothers, daughters, and daughters-in-law – and although many caregivers are family members who willingly choose their caregiving roles, they are also often emotionally, physically and financially burdened by their caregiving responsibilities.

Caregivers provide assistance with the ordinary activities of life, but they are also increasingly care coordinators. Further, many family caregivers provide increasingly complex medical care, often with little or no training. When they seek assistance for themselves and a family member with a disability, caregivers face the challenges of navigating fragmented programs with differing administration, eligibility rules, and needs assessments. Caregivers also often experience financial burdens associated with caregiving, including lost work hours and reductions in earnings from work, poor health, and social isolation.

In 2009, an estimated 42.1 million caregivers provided more than 43 billion hours of unpaid care to an adult (aged 18 and older). The value of unpaid family caregiving is estimated at \$450 billion in 2009, exceeding the annual expenditures on LTSS of the Medicaid program, the primary source of public financing for LTSS.<sup>22</sup>

As the population ages and more people need care in the decades ahead, the potential pool of family caregivers is projected to decline. The ratio of people in the most common caregiving age

group (aged 45 to 64) to those most likely to need LTSS (aged 80 and older) is expected to fall to 4 to 1, compared with more than 7 to 1 in 2010. By 2050, the ratio could drop to less than 3 to 1.<sup>23</sup> A variety of factors will shrink the available supply of family caregivers, including rising divorce rates at older ages and declining family size. The working-age adults—often women—who typically provide family caregiving are working longer to secure their own retirements.

To assure that families are able to care for their loved ones today and in the future, family caregivers must be at the center of a comprehensive approach to LTSS reform. Families need real choices for affordable and coordinated services and supports for themselves and their loved ones, and they must be recognized and supported in their caregiving roles so that they can not only care for others but also maintain their own health and wellbeing.

In its 2008 report *Retooling for an Aging America: Building the Health Care Workforce*, the Institute of Medicine called for a new perspective on family caregivers: “The definition of the health care workforce must be expanded to include everyone involved in a patient’s care: health care professionals, direct-care workers, informal caregivers (usually family and friends), and patients themselves. All of these individuals must have the essential data, knowledge, and tools to provide high-quality care.”<sup>24</sup>

### Recommendation # 3

**To integrate family caregivers into a comprehensive LTSS system, public programs providing services to LTSS beneficiaries must appropriately engage family caregivers and address their needs. Thus, public programs providing LTSS or health care services to people needing LTSS should include family caregivers in all needs assessment and care planning processes, consistent with person-centered care and the wishes of the individual at the core of the care plan. Further, where the family provides care, the assessment and care plan should include the needs of the family as well as the individual receiving services.**

- The unit of service in all health and LTSS settings should be redefined to include both individuals with disabilities and their family caregivers, with the person and the family caregiver (as appropriate) treated as integral parts of interdisciplinary services teams.<sup>25</sup>
- The assessment and care planning process (including care transitions and coordination) must be person- and family-centered, not only identifying functional disabilities but also focusing on meeting personal goals for living as independently as possible.
- All family caregivers should have access to relevant information, educational resources, referral services, training opportunities, and professional supports.
- When an individual chooses to have family caregivers provide care and the care plan or discharge plan is dependent on them: their needs should be assessed along with the person receiving services; they should be included in health information systems that list all caregivers, their contact information, and their involvement in implementing care plans; and they should receive training (including on medical/nursing tasks), equipment, and support needed to carry out their roles.<sup>26</sup>

While the nation moves to a comprehensive system for LTSS, and to supplement it as necessary, we recognize that improvements are needed in current programs. Among the improvements suggested by individual Commissioners are the following:

#### **4. Strengthen, Broaden and Improve Medicare's Post-Acute Care Benefit**

Medicare – which provides health benefits for people 65 years old or older and some people with disabilities – regardless of income – does not pay for LTSS.<sup>27</sup> Although Medicare pays for some nursing home care, Medicare's skilled nursing facility (SNF) benefit is available only for those who require and receive daily nursing and/or therapy and not just custodial care. Further, Medicare's SNF coverage is limited to 100 days per benefit period for those beneficiaries who had a prior three-day inpatient hospital stay. (Recently, access for some patients with prior hospital stays has been eroded as hospitals have increasingly classified some stays as "outpatient observation status" rather than as inpatient admissions.<sup>28</sup>)

Similarly, Medicare covers home health care, including nursing services, physical, speech and occupational therapies, and home health aide services to eligible beneficiaries. But, to qualify for coverage, beneficiaries must be confined to home (often referred to as "homebound") and must need part-time or intermittent skilled nursing care or therapy. Home health aide services are covered only for people who also need and receive skilled nursing or therapy. Many people who require LTSS, however, do not have ongoing skilled care needs and thus cannot receive Medicare coverage at all for important, non-skilled home health aides services.

Incremental but significant improvements could be made to Medicare to improve the program's protections for all beneficiaries, including people who need LTSS.<sup>11</sup>

#### **Recommendation #4**

**To meet the needs of those who qualify for Medicare, the current Medicare program must be adapted to reduce counterproductive, outdated and unreasonable barriers to outpatient therapies, home health and skilled nursing facility care.<sup>29</sup>**

- Remove the 3-day hospital stay requirement for SNF coverage so people without the need for an acute inpatient hospital stay can at least get some Medicare nursing facility coverage.
- Revise the homebound requirement for Medicare home health coverage so that people who cannot obtain the services they need outside the home can obtain them at home.

<sup>11</sup> One way not to improve Medicare home health coverage is to impose cost sharing for home health care visits or to an annual coverage cap. Proposals being considered to so limit the Medicare home care benefit would further exacerbate the already limited ability of people to obtain home and community-based services.

- Eliminate hospital “observation status,” or, at a minimum, count all days spent in the hospital as “inpatient” for purposes of qualifying for Medicare coverage for subsequent medically necessary SNF stays.
- Eliminate annual caps on physical, speech and occupational therapy services so people with LTSS needs can receive the therapy services they need in the community throughout the year.
- Ensure that the *Jimmo v. Sebelius* settlement is effectively implemented, to eliminate the “improvement standard” requirement for determining Medicare coverage, and ensuring coverage is available for skilled services to maintain an individual’s condition or slow deterioration.

##### 5. Strengthen and Improve Medicaid

Unlike Medicare, Medicaid provides substantial assistance to people with LTSS needs. But Medicaid is means-tested and requires people to be or become impoverished to qualify for assistance, creating untenable choices for people with disabilities and their families. To be eligible for assistance with the cost of LTSS, people must contribute nearly all of their available income to the cost of care. Beneficiaries must demonstrate that they have very modest countable financial assets, generally less than \$2,000. Resource protections for a community spouse are often inadequate.

Medicaid’s protections also vary from state to state and, in most if not all states, fall short of meeting people’s needs. Eligibility for services varies widely across states in Medicaid, and services vary in availability, scope and quality across states.<sup>30</sup> Because of variation in financial eligibility rules, the proportion of low-income persons with disabilities who receive LTSS through Medicaid varies widely across the states.<sup>31</sup> There is even greater variation in benefit spending. Although in many states, community-based supports are available to poor and low-income people who need assistance to live at home, those programs have long been underfunded. Unlike most other Medicaid benefits, home- and community services, without which eligible individuals would need nursing home or other institutional care, are subject to caps on enrollment and waiting lists are common. The lack of services can lead to unmet needs and human suffering and can force people into institutions.

For people with disabilities who are willing and able to work, Medicaid’s stringent means testing can force people with disabilities to accept dependency in order to remain eligible for financial assistance with the cost of LTSS. To help provide access to affordable LTSS to working people with disabilities, Congress gave states an option to let working individuals with disabilities continue to receive LTSS through the Medicaid program when their income or resources exceed Medicaid’s normal limits through an option known as the Medicaid Buy-In (MBI). Although MBI programs offer opportunities for people with disabilities who work to continue to receive LTSS, the variation in state programs and some design flaws limit the effectiveness of these programs to support working individuals with disabilities. These variations and design flaws forcing people to refuse promotions to remain within income or resource limits, make it difficult,

if not impossible, to relocate to a better position, and make people less likely to work because they may not be able to get back onto regular Medicaid if their work attempt fails.

The gaps and inequities that characterize Medicaid today are likely to grow substantially worse in the decades ahead. The population's aging will increase LTSS needs and the demands on Medicaid. It is uncertain whether any state has the capacity to deal with the needs of an aging population, and especially whether states projected to experience the largest increase will be able to sustain, let alone improve, the adequacy of LTSS.

Improvements can be made to Medicaid to expand access to home and community-based services in Medicaid, to reduce inequities across states through increased federal financing, and to reduce work disincentives for people with disabilities who are able to work.

#### **Recommendation #5**

**To strengthen Medicaid, existing financial incentives to states for quality home- and community-based services must be extended and streamlined to make it easier to rebalance Medicaid LTSS. In addition, Medicaid's benefits must be improved for people who rely on its services.<sup>32</sup>**

- Require coverage of home- and community-based services in Medicaid and raise asset standards for community residents and spouses, addressing what is commonly referred to in the disability rights advocacy community as the "institutional bias."
- Rebalance Medicaid financing to support community living.
- Gradually increase the federal share of Medicaid financing for long-term services and supports, thereby reducing burdens on the states.
- Broaden access to LTSS in the community by expanding the existing infrastructure of one-stop shopping and worker registries for people not eligible for Medicaid; fully fund and implement these programs at a national level.

#### **6. Provide New Ways to Access LTSS for People with Disabilities**

The United States has made significant strides in changing the expectations of and attitudes toward people with disabilities. The passage of landmark civil rights legislation in the Americans with Disabilities Act (ADA) in 1990 contributed to this evolution of attitudes and creation of opportunities. Court decisions, such as the Supreme Court decision in the historic *Olmstead* case, have also called for the full integration of individuals with disabilities in society. While many doors have been opened, the lack of access to services and supports that allow people with significant disabilities to live and work independently while achieving even a modest level of economic security has hindered the progress that might otherwise have been made.



People with significant disabilities who require supports and services to work often face a catch-22. Currently, Medicaid is the only option available that provides access to the services and supports needed to get and keep a job. Private long-term care insurance is not an option for a variety of reasons, including denial of coverage, cost-prohibitive premiums if coverage is available, services and supports not available in a work setting, and/or short timeframe of authorized benefits. Self-financing the needed services and supports is out of the question for all but the highest earners. And although many working people have access to private health insurance, and more will gain it as a result of the Affordable Care Act, private health insurance does not cover or only inadequately covers many needed services and supports.

Although Medicaid is often the only option, it is an imperfect solution. Medicaid is intended to provide health care and related long-term services and supports to individuals with limited income (both earned and unearned) and resources. Medicaid work incentives allow working people with disabilities to continue their participation in the Medicaid program while allowing them to increase their earnings up to a set limit (usually 250 percent of the federal poverty level (FPL)) and, in some very limited cases, save for emergency expenses or life goals. These work incentives include, but are not limited to, the Medicaid Buy-In programs and the Social Security work incentives program (the 1619(b) program).<sup>33</sup> However, as Medicaid was designed to provide health care to low-income individuals with no other access to insurance coverage, its structure and eligibility rules make it difficult or impossible for working individuals with significant disabilities to achieve a middle-class lifestyle for themselves and their families.

People with significant disabilities often have extraordinary support needs that make it difficult, if not impossible, to get those needs met outside of public programs. People with disabilities often find themselves in the unenviable position of turning down jobs or promotions to maintain access to these vital services and supports. Upper limits on income and resources for program eligibility are often the drivers of career decisions rather than opportunities. The United States must provide people with disabilities a pathway to access service and supports that allow them to earn to their potential, save for their futures, achieve a middle-class lifestyle, and achieve the vision of the ADA.

#### **Recommendation #6**

**To provide new ways to access LTSS for persons with disabilities, tax-preferred savings accounts must be provided for people and their families who are not currently receiving LTSS through the Medicaid program, the Medicaid buy-in program for workers with modest earnings must be expanded, and a new program for workers with significant disabilities who have higher earnings must be piloted.<sup>34</sup>**

- Amend Section 529 of the IRS code to address the unique needs of families with individuals with disabilities, particularly those waiting for Medicaid home- and community-based services.
- Create a national Medicaid buy-in program (MBI) for workers significant disabilities whose incomes are below 250 percent of the federal poverty level who are likely to

continue their attachment to Medicaid because their earnings remain low or their work is sporadic or inconsistent.

- Pilot a new program for workers with significant disabilities whose earnings exceed 250 percent of the federal poverty level and who need LTSS and other health care-related coverage to remain employed.

### **Conclusion**

The authors of this report, five members of the Long-Term Care Commission, write on behalf of people with disabilities, older people, their families, and direct care workers. Our goal throughout this process was to offer Congress, the President, and the public a vision of what is truly necessary to meet the needs of people who require long-term services and supports today—and of any of us who may need them in the future. We're all at risk, and we're all responsible for building a comprehensive LTSS system. We sincerely hope our recommendations provide a direction for the action our nation so sorely needs.

## Notes

- <sup>1</sup> American Taxpayer Relief Act of 2012 (ATRA, P.L. 112-240) §643(a)(1)
- <sup>2</sup> Peter Kemper, Harriet Komisar, and Lisa Alecxih, “Long-Term Care Over and Uncertain Future: What Can Future Retirees Expect?” *Inquiry*, 42, No. 2 (Winter 2005/2006): 335-350. add comment re. PDV
- <sup>3</sup> H. Stephen Kaye, Charlene Harrington, and Mitchell P. LaPlante, “Long-Term Care: Who Gets It, Who Provides It, Who Pays, and How Much?” *Health Affairs* 29(1) (January 2010): 11-2, cited in: Judy Feder and Harriet Komisar, “The Importance of Federal Financing to the Nation’s Long-Term Safety Net,” (Georgetown University, February 2012), funded by the SCAN Foundation. Available at: [http://www.thescanfoundation.org/sites/thescanfoundation.org/files/Georgetown\\_Importance\\_Federal\\_Financing\\_LTC\\_2.pdf](http://www.thescanfoundation.org/sites/thescanfoundation.org/files/Georgetown_Importance_Federal_Financing_LTC_2.pdf)
- <sup>4</sup> Lee Thomson, “Long-term Care: Support for Family Caregivers,” Georgetown University, March 2004, <http://ltc.georgetown.edu/pdfs/caregivers.pdf>
- <sup>5</sup> Alexia Campbell, “Hundreds in D.C. Lost Medicaid Assistance Without Cause, Attorneys Say,” *Washington Post*, August 1, 2013, [http://wpost.com/local/dc-dropped-hundreds-of-people-from-medicaid-rolls-without-cause-attorneys-say/2013/08/11/63d9ec54-002e-11e3-9711-3708310f6f4d\\_story\\_1.html](http://wpost.com/local/dc-dropped-hundreds-of-people-from-medicaid-rolls-without-cause-attorneys-say/2013/08/11/63d9ec54-002e-11e3-9711-3708310f6f4d_story_1.html)
- <sup>6</sup> Much of this discussion draws on Judith Feder, Harriet L. Komisar and Robert Friedland, “Long-Term Care Financing: Policy Options for the Future,” Georgetown University, June 2007. <http://ltc.georgetown.edu/forum/ltcfinalpaper061107.pdf>
- <sup>7</sup> Peter Kemper, Harriet Komisar, and Lisa Alecxih, “Long-Term Care Over and Uncertain Future: What Can Future Retirees Expect?” *Inquiry*, 42, No. 2 (Winter 2005/2006): 335-350. The \$100,000 out-of-pocket spending estimate is a present discounted value.
- <sup>8</sup> Judith Feder and Harriet Komisar, “The Importance of Federal Financing to the Nation’s Long-Term Safety Net,” (Georgetown University, February 2012) Funded by the SCAN Foundation. Available at: [http://www.thescanfoundation.org/sites/thescanfoundation.org/files/Georgetown\\_Importance\\_Federal\\_Financing\\_LTC\\_2.pdf](http://www.thescanfoundation.org/sites/thescanfoundation.org/files/Georgetown_Importance_Federal_Financing_LTC_2.pdf)
- <sup>9</sup> Richard G. Frank, Mark Cohen, and Neale Mahoney, “Making Progress: Expanding Risk Protection for Long-Term Services and Supports Through Private Long-Term Care Insurance,” (March 2013) Funded by the Scan Foundation. Available at: [http://www.thescanfoundation.org/sites/thescanfoundation.org/files/tsf\\_ltc-financing\\_private-options\\_frank\\_3-20-13.pdf](http://www.thescanfoundation.org/sites/thescanfoundation.org/files/tsf_ltc-financing_private-options_frank_3-20-13.pdf)
- <sup>10</sup> For additional detail on these recommendations, see the proposals in the Appendix to this report, including “Reconfiguring LTSS Financing to Share Responsibility and Enhance Protection,” and “Adding a New LTSS Benefit to Medicare and Other Comprehensive Reforms.”
- <sup>11</sup> PHI (2012). Facts 3: America’s Direct Care Workforce. Available at: <http://phinational.org/sites/phinational.org/files/phi-facts-3.pdf>
- <sup>12</sup> PHI (2012). Facts 3: America’s Direct Care Workforce. Available at: <http://phinational.org/sites/phinational.org/files/phi-facts-3.pdf>
- <sup>13</sup> Direct Care Alliance. “Direct Care Worker Principles for Health Care Reform.” [http://blog.directcarealliance.org/wp-content/uploads/2009/04/dca\\_health\\_care\\_reform\\_principles1.pdf](http://blog.directcarealliance.org/wp-content/uploads/2009/04/dca_health_care_reform_principles1.pdf)
- <sup>14</sup> Robyn Stone. “Long Term Care Workforce Shortages: Impact on Families. Policy Brief No. 3” Commissioned for “Who Will Provide Care: Emerging Issues for State Policymakers.” October 2001. [http://www.caregiver.org/caregiver/jsp/content/pdfs/op\\_2001\\_10\\_policybrief\\_3.pdf](http://www.caregiver.org/caregiver/jsp/content/pdfs/op_2001_10_policybrief_3.pdf)
- <sup>15</sup> PHI (2012). Facts 3: America’s Direct Care Workforce. Available at: <http://phinational.org/sites/phinational.org/files/phi-facts-3.pdf>
- <sup>16</sup> Dorie Seavy and Abby Marquand, “Caring in America: A Comprehensive Analysis of the Nation’s Fastest Growing Jobs,” Bronx, NY: PHI, 2011. Available at: <http://phinational.org/sites/phinational.org/files/clearinghouse/caringinamerica-20111212.pdf>
- <sup>17</sup> Lindquist LA, Cameron KA, Messerges-Bernstein J, Friesema E, Zickuhr L, Baker DW, Wolf M.

“Hiring and screening practices of agencies supplying paid caregivers to older adults.” *J Am Geriatr Soc.* 2012, 60(7): 1253-9. <http://www.ncbi.nlm.nih.gov/pubmed/22724430>

<sup>18</sup> Genworth. “The Cost of Care. 10th Edition 2004-2013.” <https://www.genworth.com/corporate/about-genworth/industry-expertise/cost-of-care.html>

<sup>19</sup> For additional detail on these recommendations see the proposals in the Appendix to this report, including: “Proposals to Address Workforce Needs and Mechanisms to Continue Work Improving Long-Term Services and Supports.”

<sup>20</sup> Instruct MACPAC to conduct a thorough analysis of state HCBS reimbursement policies in order to develop guidance that CMS would direct to states regarding effective payment and procurement methods that generate rates adequate to elicit a sufficient supply of competent direct-care workers. Testimony by Carol Regan, before the Commission for Long-Term Care, PHI, July 17, 2013.

<sup>21</sup> Lynn Feinberg, Testimony to the Long-Term Care Commission, p. 1. [http://www.ltccommission.senate.gov/Feinberg%20Testimony\\_Commission%20on%20Long-Term%20Care.pdf](http://www.ltccommission.senate.gov/Feinberg%20Testimony_Commission%20on%20Long-Term%20Care.pdf)

<sup>22</sup> Lynn Feinberg, Susan C. Reinhard, Ari Houser, and Rita Choula, “Valuing the Invaluable, 2011 Update,” <http://assets.aarp.org/rgcenter/ppi/ltc/i51-caregiving.pdf>, and Lynn Feinberg, Testimony to the Long-Term Care Commission, Populations in Need of LTSS and Service Delivery Issues, July 27, 2013. [http://www.ltccommission.senate.gov/Feinberg%20Testimony\\_Commission%20on%20Long-Term%20Care.pdf](http://www.ltccommission.senate.gov/Feinberg%20Testimony_Commission%20on%20Long-Term%20Care.pdf)

<sup>23</sup> Donald Redfoot, Lynn Feinberg, and Ari Houser, “The Aging of the Babyboom and the Growing Care Gap: A Look at Future Declines in the Availability of Family Caregivers,” AARP Public Policy Institute, August 2013. [http://www.aarp.org/content/dam/aarp/research/public\\_policy\\_institute/ltc/2013/baby-boom-and-the-growing-care-gap-insight-AARP-ppi-ltc.pdf](http://www.aarp.org/content/dam/aarp/research/public_policy_institute/ltc/2013/baby-boom-and-the-growing-care-gap-insight-AARP-ppi-ltc.pdf)

<sup>24</sup> Institute of Medicine. “Retooling for an aging America: building the health care workforce.” Report Brief. Washington (DC): National Academies Press; 2008, p. 257. Cited in “Bridging Troubled Waters: Family Caregivers, Transitions, and Long-term Care,” Carol Levine, Deborah Halper, Ariella Peist, and David A. Gould, *Health Affairs*, January 2010, vol. 29, no. 1, pp. 116-124. <http://content.healthaffairs.org/content/29/1/116.full>

<sup>25</sup> See, for example, Lynn Feinberg, Testimony to the Long-Term Care Commission, p. 1. [http://www.ltccommission.senate.gov/Feinberg%20Testimony\\_Commission%20on%20Long-Term%20Care.pdf](http://www.ltccommission.senate.gov/Feinberg%20Testimony_Commission%20on%20Long-Term%20Care.pdf) and Susan C. Reinhard, Carol Levine and Sarah Samis, “Home Alone: Family Caregivers Providing Complex Chronic Care” AARP, October 2012.

<sup>26</sup> Mechanisms to address this may include assessment or care plan requirements, Medicare conditions of participation, accreditation or certification rules, and a caregiver bill of rights. It is important to identify the best points for intervention and follow-up, and to have a menu of options to provide the necessary training and support, such as in-person training or support groups, online resources, or a help line.

<sup>27</sup> Harriet Komisar, “Medicare Does Not Pay for Long-Term Care,” AARP, <http://blog.aarp.org/2013/08/22/medicare-does-not-pay-for-long-term-care/>

<sup>28</sup> Zanlian Feng, Brad Wright, and Vince Mor, “Sharp Rise in Medicare Enrollees Being Held In Hospitals for Observation Raises Concerns about Causes and Consequences,” *Health Affairs*, <http://content.healthaffairs.org/content/31/6/1251.abstract>

<sup>29</sup> For additional detail on these recommendations, see the proposals in the Appendix to this report, especially: “Adding a New LTSS Benefit to Medicare and Other Comprehensive Reforms.”

<sup>30</sup> Susan C. Reinhard, Enid Kassner, Ari Houser, and Robert Mollica, “Raising Expectations: A State Scorecard on Long-Term Services and Supports for Older Adults, People with Physical Disabilities, and Family Caregivers.” AARP Public Policy Institute (Washington, DC: AARP, September 2011).

<sup>31</sup> Judy Feder and Harriet Komisar, “The Importance of Federal Financing to the Nation’s Long-Term Care Safety Net,” (Georgetown University, February 2012) Funded by the SCAN Foundation. Available at:

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[http://www.thescanfoundation.org/sites/thescanfoundation.org/files/Georgetown\\_Importance\\_Federal\\_Financing\\_LTC\\_2.pdf](http://www.thescanfoundation.org/sites/thescanfoundation.org/files/Georgetown_Importance_Federal_Financing_LTC_2.pdf)

<sup>32</sup> For additional detail on these recommendations, see the proposals in the Appendix to this report, including “Reconfiguring LTSS Financing to Share Responsibility and Enhance Protection,” and “Proposals to Bolster Access to LTSS for Working Americans with Disabilities, Families of People with Disabilities, and Current Beneficiaries.”

<sup>33</sup> Medicaid Buy In (MBI) programs allow people to work and save and maintain access to Medicaid while paying co-pays based on income. Most states have MBI programs but income and resource limits vary significantly. 1619(b) programs allow people with disabilities to maintain Medicaid coverage while working, but do not raise resource limits. Every state participates in the 1619(b) program, but income limits vary significantly across states.

<sup>34</sup> For additional detail on these recommendations, see the proposals in the Appendix to this report: “Proposals to Bolster Access to LTSS for Working Americans with Disabilities, Families of People with Disabilities, and Current Beneficiaries.”

**REPORT APPENDIX**

**A COMPREHENSIVE APPROACH TO LONG-TERM SERVICES AND SUPPORTS**

Long-Term Care Commission

September 23, 2013

**Commissioners**

Laphonza Butler, Vice President of SEIU, and President of SEIU-United Long Term Care Workers  
Henry Claypool, Executive Vice President, American Association for People with Disabilities  
Judith Feder, Urban Institute Fellow and Professor, Georgetown Public Policy Institute  
Lynnae Ruttledge, Co-Vice Chair, National Council on Disability  
Judith Stein, Executive Director, Center for Medicare Advocacy, Inc.

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## **Reconfiguring LTSS Financing to Share Responsibility and Enhance Protection**

### *Long-Term Care Commission Recommendations of Commissioner Judy Feder*

**Goal:** To build a financing framework that a) provides meaningful protection against the risk of costly long-term care; b) is, to the extent possible, pre-funded by future users; and c) includes significant personal responsibility, an effective insurance market, and a strong safety net.

**Premises:**

- The need for expensive, extensive long-term services and supports (LTSS) is an unpredictable, catastrophic risk that, like similar risks, can be most efficiently, effectively met through insurance.
- Private insurers faces enormous difficulties in addressing this risk and, even with supportive public policy interventions and possible expansions (short of required purchase), can reach only a modest share of the population.
- A limited public insurance program can establish a financing framework that encourages the purchase of private insurance.
- Given responsible limits to public as well as private insurance, a public safety net will always be essential to assure access to adequate care for people with inadequate resources.

**Proposal:**

- A. Establish a basic public LTSS benefit available to people assessed as meeting a specified threshold of functional impairment after a waiting period of up to x years.** The length of the waiting period (shorter for people with lower incomes and becoming longer at higher incomes) would be established based on income at or near retirement age (based on data regularly reported for Social Security), averaged over a number of years. For younger people who become impaired, the formula relating waiting periods to income would be appropriately adjusted (shortened) to reflect the lesser accumulation of resources at younger ages. Benefits would be specified as a dollar-amount per day, vary with level of impairment and be applicable to the full range of LTSS services. Individuals could opt for a service rather than a cash benefit. With this type of benefit, people would know throughout their working years the risk or “hole” they should plan to fill (or the protection they might want to supplement) from personal resources or private insurance, should they become impaired.

The benefit could be financed through a combination of Medicaid savings (federal only or federal and state) and a surcharge on the income tax (higher for people currently near or at retirement age).

Costs and associated financing requirements would depend on whether the new benefit is made available only to people who turn age 65 or become disabled in the future or is made current elderly and disabled people. If the benefit is to be made available to everyone, it is necessary to find an alternative to the proposed waiting period, since private insurance to fill it may be unavailable or prohibitively expensive and people may lack the means to otherwise



protect themselves. A broadly inclusive benefit would therefore replace the waiting period with an income/asset-related deductible for younger people with disabilities and people aged 75 and older.

**B. To supplement public coverage, create an effective private insurance market** (for background and rationale see Richard Frank, Mark Cohen and Neale Mahoney [http://www.thescanfoundation.org/sites/thescanfoundation.org/files/tsf\\_ltc-financing\\_private-options\\_frank\\_3-20-13.pdf](http://www.thescanfoundation.org/sites/thescanfoundation.org/files/tsf_ltc-financing_private-options_frank_3-20-13.pdf))

- 1) Standardize and limit the types of policies insurers can offer, as in the Medigap market, in order to facilitate comparison and competition.
- 2) Create an electronic market and provide information and direct assistance to consumers, in order to facilitate comparison shopping and educated choices.
- 3) Require that alongside current level premium products, insurers offer people under age 65 products that index premiums and benefits in time blocks and apply “term pricing” (i.e., charge an annual premium covering the expected claim costs for a specified “term,” say of 1-5 years, rather than for a lifetime—in order to engage younger people in the purchase of long-term care insurance, provide them lower premiums reflect their own disability risks.
- 4) Established reinsurance arrangements, financed by private insurers, that establish parameters for risk management and mitigate risks to individual companies

**C. To address current LTSS inadequacies and inequities across states as well as the unequal burdens of aging, strengthen the Medicaid safety net with enhanced federal financing** (for background and rationale see Judy Feder and Harriet Komisar, [http://www.thescanfoundation.org/sites/thescanfoundation.org/files/Georgetown\\_Importance\\_Federal\\_Financing\\_LTC\\_2.pdf](http://www.thescanfoundation.org/sites/thescanfoundation.org/files/Georgetown_Importance_Federal_Financing_LTC_2.pdf))

- 1) Gradually increase federal financing for Medicaid long-term care benefits from existing match percentages to 100 percent.
- 2) Define a nationally-uniform benefit (including a mandatory benefit for home and community based care and an increase in the personal needs allowance), to vary with an individual’s level of impairment, as determined by a standardized assessment process. Provide federal match at current rates to states choosing to supplement the federal benefit.
- 3) Set federal payment rates to providers, adjusted for geographic variation in input costs.
- 4) Finance the new benefit in part with state contributions (as in Medicare Part D)—set initially to reflect their current long-term care spending (up to a maximum) and indexed to reflect inflation and economic growth ; the index would hold states “harmless” for increased demand associated with the aging of the population.

**Moving forward:**

Although this proposal is presented in the order it is to facilitate understanding of its intent and architecture, the timing its implementation (and likely its legislation), should start with section C.

- The highest priority should go to preservation and enhancement of the safety net for people who are most disadvantaged, which is currently at risk.
- Adoption of a long-term strategy for long-term care financing will be a long-term struggle, to which we should not hold this population hostage.



## **Add a New LTSS Benefit to Medicare and Other Comprehensive Reforms**

### *Long-Term Care Commission Recommendations of Commissioner Judith Stein*

**Overriding Goal:** To provide necessary, quality long-term services and supports for older people and people with disabilities in the least restrictive setting.

#### **Recommendations:**

- 1. Make the most of Medicare – the one national program we have now by removing current barriers to Medicare coverage for people with long-term and chronic conditions:**
  - a. Redefine the homebound requirement for Medicare home health coverage so that people who can not obtain the services they need outside the home can obtain them at home.
    - i. Currently the homebound definition restricts some people from getting care at home although they cannot consistently leave home to obtain the services they need.
    - ii. Do NOT add a cap or co-insurance to the Medicare home health benefit
      1. Proposals are being considered to limit home care, which would further exacerbate the already limited ability of people to obtain home and community-based services.
      2. The savings estimate, at \$730 million / ten years for the co-pay, does not warrant this further limitation on home care.
  - b. Remove the 3-day hospital stay requirement for skilled nursing facility (SNF) coverage so people without the need for an acute inpatient hospital stay can at least get some Medicare nursing facility coverage.
    - i. Absent removing the 3-day requirement, eliminate hospital “observation status,” or count all days spent in the hospital as “inpatient” for purposes of qualifying for subsequent SNF stays.
  - c. Eliminate the 24-month Medicare eligibility waiting period for people who qualify for Social Security Disability Insurance (SSDI).
  - d. Ensure the *Jimmo v. Sebelius* settlement is effectively implemented, to eliminate the “improvement standard” requirement for determining Medicare coverage, and ensuring coverage is also available for skilled services to maintain an individual’s condition or slow deterioration.

- 2. Add a new Long Term Services and Support (LTSS) benefit to Medicare.** The LTSS benefit would be triggered when an individual is certified to be dependent in two or more activities of daily living and/or has cognitive or mental health issues such that independence is contraindicated. In such cases the individual would be eligible for:
- a. Skilled nursing facility coverage for up to 150 days per calendar year;
    - i. Without the need for a 3-day hospital stay;<sup>1</sup>
    - ii. Without the need for daily skilled care (custodial care alone would be covered).
  - b. Home health coverage, including coverage for home health aide services, without the need for a skilled service;
  - c. Personal Care Attendant;
  - d. Care management and coordination;
  - e. Adult Day Center;
  - f. Respite care to support family or other volunteer caregiver;
  - g. Outpatient therapy without an annual cap;
  - h. Other reasonable and necessary services.

Note: The CLASS Act experience demonstrates that any such LTSS benefit must be mandatory in order to be financially viable.

- a. Various options are possible, but a new Medicare LTSS benefit should not add to the complexity of Medicare and should not diminish the stability of the current program.
  - b. Consider adding the LTSS benefit to Medicare Part A, with a defined % increase to current Part A payroll tax to pay for it. This additional may even strengthen Medicare Part A, which is mandatory for those with Medicare.
- 3. Provide quality long term services and supports for older people and people with disabilities in all settings.**
- a. Develop publically defined standards of care, throughout all long term care settings, that are enforced through a public regulatory structure. (In addition to market-based quality measures).
  - b. Develop enforceable quality measures through an objective regulatory system.
  - c. Ensure sufficient numbers of properly trained staff are present at all times in institutional settings
    - i. There is a high cost of poor care – improving the quality of care provided will improve health outcomes and overall savings when avoidable conditions and injuries are prevented
- 4. Ensure adequate numbers of quality LTSS caregivers are available and retained for community-based and facility care.**
- a. Pay living wages to caregivers in all settings
  - b. Establish a national Caregivers Work Force Advisory Panel to develop innovative and effective means of recruiting and maintaining a quality direct care workforce

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<sup>1</sup> The Medicare Catastrophic Coverage Act (MCCA) provided 150 days of SNF coverage per calendar year with no prior hospital stay from 1989 until 1991, when the law was largely repealed.

- c. Establish minimum federal training standards for personal care aides based on current state efforts
- 5. **Rebalance Medicaid so that institutional bias is removed, and people who qualify for Medicaid can obtain necessary LTSS in the least restrictive setting that meets their needs.**
- 6. **Protect consumers from inappropriate denials of coverage from any public or private LTSS financing system.**
  - a. Develop enforceable national consumer protections for all private long-term care insurance models.
  - b. Provide consumer-friendly, meaningful appeals in all public and private financing systems.

## **Proposals to Address LTSS Workforce Needs and Mechanisms to Continue Work Improving Long Term Services and Supports**

### *Long-Term Care Commission Recommendations of Commissioner Laphonza Butler*

#### *Proposal #1*

##### *Adopt National Strategies to Improve and Strengthen the LTSS Workforce*

Few dispute the aging of the population, the so-called “silver tsunami,” will generate increased need for long term care services and supports (LTSS) system capacity. In fact, the U.S. will need to recruit 200,000 new LTSS workers each year to meet future demand among our aging population.<sup>2</sup> However, as the need increases, the LTSS labor pool is dwindling. The turnover rate for LTSS workers in the U.S. is disproportionately high – 13 to 18 percent higher than the overall labor workforce and 20 percent higher than other service workers. The majority of states and employers consider LTSS workforce shortages to be a major priority and most have tried unsuccessfully to bridge this “care gap.”<sup>3</sup>

The workforce crisis is a direct result of the fragmented and insufficiently funded LTSS system, which contributes to a poorly paid, insufficiently trained, undervalued, and inadequately supported LTSS workforce. Conversely, the efficacy and stability of the LTSS system is predicated on the relationship between the consumer and the caregiver; the workforce is critical to LTSS but often receives little focus when talking about reforming the system. Indeed, turnover and vacancies result in delays in access to care services, and higher costs in the long run as individuals are forced into institutional settings. LTSS system reform will fail without proper attention to the recruitment and retention of the very workforce that delivers these services. In terms of interventions that address these issues, the Commissioner Butler offers the following recommendations that should be undertaken at the Federal level:

- All federally funded LTSS programs should be required to have a detailed plan for workforce recruitment, retention and development as a requirement to continue to receive public funds. Federal agencies should be directed to fund programs that improve working conditions and build career ladders. This includes directing CMS to fund and collect best practices on expanded home care worker role pilots, and to evaluate and expand Value-Based Purchasing Demonstrations that reward nursing home staffing.
- HHS should undertake a number of initiatives to ensure a more stable direct care workforce.

<sup>2</sup> Genworth. “The Cost of Care. 10th Edition 2004-2013.” <https://www.genworth.com/corporate/about-genworth/industry-expertise/cost-of-care.html>

<sup>3</sup> Robyn Stone. “Long Term Care Workforce Shortages: Impact on Families. Policy Brief No. 3” Commissioned for “Who Will Provide Care: Emerging Issues for State Policymakers.” October 2001. [http://www.caregiver.org/caregiver/jsp/content/pdfs/op\\_2001\\_10\\_policybrief\\_3.pdf](http://www.caregiver.org/caregiver/jsp/content/pdfs/op_2001_10_policybrief_3.pdf)

- Institute systematic methods for, setting, rebasing, or updating payment rates for Medicaid home and community-based services create greater parity of wages and benefits across long term care settings.
  - Continue the development of national training standards for home care workers not covered by current federal requirements, and have this serve as the minimum standard for training.<sup>4</sup>
  - Align government payment policies to create parity for reimbursing training costs across all direct-care occupations and provider types.
  - Require states to collect workforce data including data on wages, benefits, hours, job vacancies and turnover rates.
- HHS should create uniform Federal guidelines that require states to license and certify all home care agencies. Licensure and certification should include routine monitoring of agency compliance with all regulations and requirements for agencies to submit detailed cost reports to maintain their certification. Cost reports should include detailed employee, wage and revenue information.
  - Creation of a National Program to Attract Individuals to Direct Care Jobs

The Corporation for National and Community Service should develop a program called Direct Care Corp, modeled on its SeniorCorp Companion program, to provide direct care services to individuals in need of LTSS. SeniorCorp currently runs a companion program that matches senior companions for 15 to 40 hours per week with two to four adult clients that live independently in their own homes.<sup>5</sup> Under the Direct Care Corp model, individuals of all ages who enroll to become direct care workers would receive pre-service orientation, free training and certification, health insurance, and an hourly wage. As an incentive to participate in the program, if individuals agree to serve for a specified amount of time (2-4 years) in that direct care position they would be eligible for a Health Professions Opportunity Grant (HPOG)<sup>6</sup> to receive fully subsidized training for the health care profession of their choice. HPOG provides education and training to TANF recipients and other low-income individuals for occupations in the health care field that pay well and are expected to either experience labor shortages or be in high demand. HPOG Funds may be used for participant supportive services, including financial aid, child care, and case management.

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<sup>4</sup> These initiatives include the Personal and Home Care Aide State Training grants, US Department of Labor Registered Apprenticeship models, the Center for Medicare and Medicaid Services' Direct Service Workforce "Core Competency Road Map" and existing state and local training models including Labor Management Training programs.

<sup>5</sup> <http://www.nationalservice.gov/programs/senior-corps/senior-companions>

<sup>6</sup> HPOG is authorized by Social Security Act, Title XX, Section 2008, Public Law 111-148, 42 U.S.C 1397 and administered by the Administration for Children and Families..  
[http://www.acf.hhs.gov/sites/default/files/opre/opre\\_report.pdf](http://www.acf.hhs.gov/sites/default/files/opre/opre_report.pdf)

**Proposal #2*****Encourage State-Based Innovation in LTSS to Help Build to a Federal Solution***

States have an important role to play as laboratories of democracy in creating LTSS solutions and programs that move beyond the public safety net of Medicaid or public subsidies for private insurance products. States already administer much of the LTSS in this country through Medicaid. Those with advanced systems are in a position to innovate and build off of existing strengths, and those innovations can then serve as models for future federal solutions. To this end, HHS should encourage state and local experimentation in LTSS, and set aside grant funding for state and local agencies to develop and implement LTSS innovations, perhaps through the CMS Innovation Center,<sup>7</sup> that will ultimately remove some of the financial strain off of the Medicaid system. States could open up registries and infrastructure on a FFS basis to connect workers and those in need, advise on the array community based options through case management and the AAA's and ADRC's to expanded populations, and develop state-based funding and delivery models outside of Medicaid in order to provide an affordable and accountable means of access to services especially for the middle and lower income populations, similar to what has been proposed and is currently being explored in Hawaii.<sup>8</sup>

**Proposal #3*****Continue the Conversation around Building a Better LTSS System at the Federal Level***

This Commission was severely limited by the timeframe and resources allotted to it by Congress. While there is broad consensus among the Commissioners that LTSS in this country as it currently operates is not sufficient for current or future needs in this country, it was beyond the realistic scope of that body to propose a meaningful and comprehensive solution within the Commission's existing framework. Perhaps one of the most meaningful recommendations we can make is to propose a means for this work to continue in a meaningful and ongoing manner now that the Commission has concluded. Congress should create a bi-partisan LTSS reform task force, with appointed members from the Senate, House of Representatives, and the Secretary of Health and Human Services. The task force's charge should be similar to that of this Commission, and should use the Commission's work as a jumping off point for its own.

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<sup>7</sup> The Innovation Center was established by section 1115A of the Social Security Act (as added by section 3021 of the Affordable Care Act). Congress created the Innovation Center for the purpose of testing "innovative payment and service delivery models to reduce program expenditures ... while preserving or enhancing the quality of care" for those individuals who receive Medicare, Medicaid, or Children's Health Insurance Program (CHIP) benefits.

<sup>8</sup> See Hawaii LTC Commission Final Report. Available at:  
<http://www.publicpolicycenter.hawaii.edu/documents/HawaiiLTCCFinalReport.pdf>



Ultimately the Task Force will draft a full report, make recommendations, and propose legislation to be voted on by Congress. Additionally, the Office of Disability, Aging and Long-Term Care at the Office of the Assistant Secretary for Planning and Evaluation (ASPE),<sup>9</sup> should be charged with researching best practices and innovations at the state and local levels in LTSS around workforce, housing, access to services, LTSS education and public awareness, family caregiver support, and service delivery models to both inform the work of the Task force, and develop policy recommendations that can be pursued within HHS.

Additionally, legislation should be passed authorizing the White House Conference on Aging in 2015. The conference should have a focus on long-term services and supports. Decennial White House Conferences on Aging are now embedded in our national history. Past White House Conferences on Aging, first held in 1961 and again in 1971, 1981, 1995, and 2005 have been catalysts for aging policies and significant national programs such as Medicare, Medicaid and the Older Americans Act. The conference has traditionally been a source of innovative solutions, and an opportunity delegates across the country, political backgrounds and professional experiences, and would be extremely valuable in the further development of policy work on long-term services and supports. The scope of the conference should also be expanded to include people with disabilities, and the National Disability Council should be directly involved in the development and coordination of the Conference.

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<sup>9</sup> <http://aspe.hhs.gov/> "The Assistant Secretary for Planning and Evaluation (ASPE) is the principal advisor to the Secretary of the U.S. Department of Health and Human Services on policy development, and is responsible for major activities in policy coordination, legislation development, strategic planning, policy research, evaluation, and economic analysis."

**Proposals to Bolster Access to LTSS for Working Americans with Disabilities, Families of People with Disabilities and Current Beneficiaries**

*Long-Term Care Commission Recommendations of Commissioner Henry Claypool*

**Proposal One**

***Pilot a program for workers with significant disabilities whose earnings exceed 250% FPL and need LTSS to remain employed without support from the Social Security income assistance programs***

**U.S. Disability Support Systems Fail People with Disabilities**

The United States has made significant strides in changing the expectations of and attitudes toward people with disabilities. The passage of landmark civil rights legislation in the Americans with Disabilities Act (ADA) in 1990 contributed to this evolution of attitudes and creation of opportunities. Court decisions, such as the Supreme Court decision in the historic Olmstead case, have also called for the full integration of individuals with disabilities in society. And while many doors have been opened, the lack of pathways to access needed services and supports that allow people with significant disabilities to live and work independently while achieving even a modest level of economic security has hindered the progress that might otherwise have been made.

**Individuals with Disabilities Face Unique Challenges**

People with significant disabilities who require supports and services to work often face a catch-22. Currently, Medicaid is the only option available that provides access to the services and supports needed to get and keep a job. Private long-term care insurance is not an option for a variety of reasons, including; denial of coverage outright, cost-prohibitive premiums if able to get coverage, services and supports not available in a work setting, and/or short timeframe of authorized benefits. Self-financing the services and supports is out of the question for all but the highest earners and makes people with disabilities less economically competitive than their non-disabled peers. And although many working people have access to private health insurance, and more will gain it through the Affordable Care Act, private health insurance does not cover at all or inadequately covers many needed services and supports.

**Medicaid, While Vital, Doesn't Work for Many Working People with Disabilities**

Although Medicaid is the only game in town, it is also an imperfect solution. Medicaid is intended to provide health care and related long-term services and supports to individuals with limited income (both earned and unearned) and resources. Medicaid work incentives allow working people with disabilities to continue their participation in the Medicaid program while allowing them to increase their earnings up to a set limit (usually 250% of FPL) and, in some very limited cases, save for emergency expenses or life goals. These work incentives include,

but not limited to, the Medicaid Buy-In programs and the 1619(b) program<sup>10</sup>. However, as Medicaid was designed to provide health care to low income individuals with no other access to insurance coverage, its structure and eligibility rules make it difficult to impossible for working individuals with significant disabilities to achieve the things associated with a middle class lifestyle for a number of reasons.

- Upper limits on income and resources for program eligibility are often the drivers of career decisions rather than opportunities.
- Variations in state Medicaid programs (e.g. income and resource limits for MBI participation, income limits for eligibility, types of waivers and whether slots are available, and the package of services and supports available) make relocating for a better opportunity difficult, if not impossible.
- SSI/Medicaid's resource limits (e.g. a person can have no more than \$2000 in assets for an individual or \$3000 for a couple to be Medicaid eligible) are often problematic making it impossible for people with disabilities who work to save for emergencies and retirement, let alone save to purchase a home or start a business.
- People with significant disabilities often have extraordinary support needs that make it difficult, if not impossible, to get those needs met outside of public programs.

People with disabilities often find themselves in the unenviable position of turning down jobs or promotions to maintain access to these vital services and supports. The US must provide people with disabilities a pathway to access service and supports that allows them to earn to their potential, save for their futures, achieve a middleclass life style, and achieve the vision of the ADA.

#### **Proposed Solution**

A pilot program that provides access to the services and supports needed by employed individuals with significant disabilities (meet SSA definition of disability absent the inability to work assessment) combined with a waiver of rules that prevent people with disabilities to earn income and accumulate assets without jeopardizing access to services and supports. This program is designed to wrap-around health insurance products (offered by employer or through the state Marketplaces) and modeled on the 1619(b) program, specific program design elements include:

- Eligibility: To be eligible to receive wrap-around services and supports through this program, a person would have to be a working individual with a disability defined as:
  - Meeting or equaling the Social Security disability listings or qualify for quick disability determination/compassionate allowances for eligibility for the Social Security disability programs
  - Be working, defined as earnings at or above 250% FPL

<sup>10</sup> MBI programs allow people to work and save and maintain access to Medicaid while paying co-pays based on income. Most states have MBI programs but income and resource limits vary significantly. 1619(b) programs allow people to maintain Medicaid access while working but do not change resource limits. Every state participates in 1619(b) but income limits vary significantly.

- Pay applicable cost sharing based on income, employment –related disability expenses, as well as level of services needed.
- Wrap around Package: The program would offer access to services and supports that people with disabilities need to become and stay employed, fill coverage gaps that between what is offered by health care insurance products and the unique health care needs of individuals with significant disabilities. Services and support package available through the program would include: personal attendant care, assistive technology, durable medical equipment and other services and supports.

## **Proposal Two**

### ***Options for Helping Americans Meet Their LTSS Needs***

***Provide enhanced options counseling to help individuals better navigate LTSS in a “One-Stop-Shop/No Wrong Door (NWD)” way to avoid unnecessary institutionalization, promoting access to home and community-based services (HCBS) and prevent Medicaid spend-down. This should be modeled after the “Enhanced Aging and Disability Resource Centers (ADRCs) Options Counseling Program” initiative released by HHS in 2012. States should be able to access enhanced administrative Medicaid match to build this necessary infrastructure.***

Nearly 10 million Americans of all ages need some form of long-term services and supports (LTSS), and about 70% of the people now turning 65 will need LTSS at some point during their life. Yet, when consumers experience a need for LTSS – or want to plan ahead for their LTSS - they are often confronted with a complex and bewildering maze of public and private programs administered by a wide variety of agencies and organizations operating under different, sometimes conflicting, sometimes duplicative, rules, regulations and administrative procedures. Compounding this situation, people often confront the need for long-term support amidst a crisis, such as an unexpected injury, a hospital admission, or the collapse of a fragile unpaid caregiver support network. Under these circumstances, individuals and their families have little time to explore the many options that might be available, which may result in the unnecessary use of nursing facility and other expensive forms of LTSS. The fragmentation in our LTSS makes it difficult not only for our citizens to make informed decisions, but it also makes it challenging to ensure that our public expenditures on LTSS are deployed in the most cost-effective manner possible.

States develop Aging and Disability Resource Centers (ADRCs) programs – also known as One-Stop-Shop/No Wrong Door programs – to make it easier for consumers to learn about and access their LTSS options. The ADRCs program was based on best practices some states had developed to create “visible and trusted” sources of information, one-on-one counseling, and streamlined access to available LTSS options.

The importance of having an access program serve people of all income levels, not just those who qualify for Medicaid, since the vast majority of people who need LTSS are not Medicaid eligible but can be at high-risk of “spending down” to Medicaid.

**Proposal Three*****Create a national Medicaid buy-in (MBI) program for workers with significant disabilities up to 250% of FPL.***

Medicaid is the only affordable option to access long-term services and supports for millions of people with significant disabilities. Standard health insurance policies do not offer coverage for the long-term services and supports (LTSS) required for individuals with disabilities to live in the community. And, although private long-term care insurance coverage does exist, it is not a realistic option for working age individuals with disabilities. To help provide access to affordable LTSS to working people with disabilities, Congress gave states an option to let working individuals with disabilities continue to receive LTSS through the Medicaid program when their income or resources exceed Medicaid's normal limits through an option known as the Medicaid Buy In, or MBI, programs. States can implement MBI programs under two different authorities: the Balanced Budget Act of 1997 or the Ticket to Work & Work Incentives Improvement Act of 1999. Forty-six states currently have MBI programs and more than 200,000 workers with disabilities are currently working and receiving needed LTSS as result of this option. The different authorities impose different requirements states must follow in creating MBI programs:

	<i>Balanced Budget Act</i>	<i>Ticket to Work</i>
Age limits	None	16-64
Income Limits	Up to 250% of FPL	None
Resource Limits	Up to state	Up to state
Premiums	Based on sliding scale – no upper limit	Premiums and cost sharing based on income
Definition of work	States cannot define work	States cannot define work
Grace period for unemployment	Limited	Not allowed

Although MBI programs offer opportunities for people with disabilities who work to continue to receive LTSS, the variation in state programs and some design flaws limit the effectiveness of these programs to support working individuals with disabilities – forcing people to not take promotions to remain within income or resource limits, making it difficult, if not impossible to relocate for a better position, and making people less likely to work because of not being able to get back onto regular Medicaid if their work attempt fails.

The program would have no upper age limit, with a standard definition of work, grace periods for unemployment that recognizes the episodic nature of many disabilities, allows people to save for current and future needs and retirement, and disregards resources accumulated during MBI participation for access to Medicaid if a person can no longer work. Here are some specifics:

- Income limits vary from a low of 80% of FPL to unlimited income
- Resource limits vary from a low of regular Medicaid limits (\$2000 for an individual) up to unlimited resources
- No grace period for participation
- No pathway back to regular Medicaid if a person accumulated resources while participating in MBI
- Uncertainty regarding eligibility for Medicaid at age 65

#### **Proposal Four**

***Amend Section 529 of the IRS code to allow for a tax-advantaged savings account to address the unique needs of families with individuals with disabilities, particularly those waiting for Medicaid home- and community-based services.***

Across the country, an estimated 400,000 individuals are on waiting lists to receive long-term services and supports (LTSS); many of whom are children who will require these supports over their lifetime.<sup>11</sup> A tax-advantaged savings account will allow families of these children an opportunity to save for their needs. Currently, families are providing the bulk of their LTSS needs that in many cases comes at a significant cost to their ability to maintain and improve their economic circumstances, especially for the middle class.<sup>12</sup> AARP estimates that the economic impact of family caregiving for members with significant disabilities at \$350 to \$450 million per year. An account would encourage work, savings, and asset development for families and individuals with disabilities that reduces dependence on scarce public benefits.

A tax-advantaged savings account would allow funds to be withdrawn to cover qualified disability expenses such as healthcare, employment support, housing, transportation, assistive technology and education. These accounts would amend and follow the existing Section 529 of the Internal Revenue Code for Qualified Tuition Programs so that they would be consistent with all the requirements and regulations of a traditional 529 qualified tuition program: they are easy to open and available in any state, and families can make the same annual contributions and

<sup>11</sup> Of 3.5 million families with a member with a severe and chronic disability expected to last a lifetime, only 13% are supported by the states' public agency services (Braddock, Presentation to AIDD, February, 2013)

<sup>12</sup> In a national survey conducted by the Arc of the United States, 82% of families reported that their overall economic security is challenged. 73% reported not having adequate savings for retirement, which puts aging parents in particularly vulnerable situations. (*Still in the Shadows with Their Futures Uncertain*, Arc of the US, June 2011). According to Braddock (2013, above) there are 853,000 persons with developmental disabilities/intellectual disabilities (DD/ID) living at home with caregivers over the age of 65 years.

enjoy the same tax-free treatment as under 529 accounts.<sup>13</sup> In this respect, Section 529 accounts mirror a familiar and popular financial mechanism for many families.

#### **Proposal Five**

**To strengthen Medicaid, existing financial incentives to states for quality home- and community-based services must be extended and streamlined to make it easier to rebalance Medicaid LTSS. In addition, Medicaid's benefits must be improved for people who rely on its services.**

*The goal of this proposal is to structure a new long term services and support authority that brings together the best features of some of the 1915 series of waiver and state plan options into a single state plan authority that incentivizes HCBS services; sets a high priority for person-centered and participant-directed services; allows HCBS eligibility to be uncoupled from the institutional level of care; and streamlines the application, administration and reporting requirements for the states. Additionally we propose to include some of the ACA options and incentives that have been made available to encourage states to expand home and community based services, and reduce reliance on institutional settings.*

The vast majority of Medicaid beneficiaries of any age that require LTSS prefer to receive those services in their own home or in a community based setting instead of living in an institution. And serving Medicaid beneficiaries that meet a state's level of care for institutional services in community based settings has been proven to be a cost-effective way providing LTSS.

As we approach 2014, many states are fully engaged in studying, designing and implementing strategies to provide health care coverage to low income populations through a Medicaid expansion or other means. Additionally, many state Medicaid agencies are actively developing new aspects of their programs that will better integrate health care services for various populations that rely on both Medicare and Medicaid for basic health care coverage.

Although primarily focused on health reform and expansion, the ACA also enhanced and created new opportunities for states to provide home and community based services (HCBS) to beneficiaries that need these services through several new or modified Medicaid waiver and state plan options.

As a whole, the United States still over-relies on the institutional side of LTSS. Although there has been a growth from 2.1 to 3.2 million HCBS users since 2000, states still spend only 36.8% of their LTSS budgets for aging and physical disability populations on HCBS. The range varies widely with the highest performing state spending 62% on HCBS and the lowest 10%. Only 7 states spend more than 50% on HCBS (AARP 2011 Scorecard). Nursing home utilization also varies widely across the states, with only 84 persons per 100,000 of state population occupying NF beds in the lowest state to 838 in the highest.

<sup>13</sup> Income earned grows tax-free, withdrawals for qualified disability expenses are tax-free; there are rollover provisions to traditional 529 accounts, and the same reporting requirements apply as to a traditional 529.

On the Developmental Disability side only Mississippi spends less than 50% on HCBS. But of 4.9 million persons with developmental disabilities nationwide, 4.1 million live with their families, of which it is estimated that 25% of the caregivers or parents are over age 60. And many persons with developmental disabilities languish on long waiting lists (Two-thirds of 511,174 individuals that 38 states report on HCBS waiting lists (from the Kaiser 2012 data update).

Currently many state Medicaid programs are consumed exploring ways to expand health care to low income populations or to more efficiently served already covered populations. The capacity of these agencies to simultaneously overhaul and maximize the efficiency of their LTSS systems is under considerable strain. Partly for this reason many states are looking to managed care organizations to administer their Medicaid LTSS systems.

This paper outlines a few of the steps that would reduce the fragmentation and administrative burden across Medicaid, making it easier for states to provide community based services.

### **Background**

Title XIX of the Social Security Act has many provisions aimed at reducing the institutional bias of the Medicaid program by allowing states to provide services to individuals in their homes and communities. Though Section 1915(c), enacted through the Omnibus Budget and Reconciliation Act of 1981, remains the most widely used tool to deliver home and community based services (HCBS), there have been a myriad of other provisions added to the statute since that time, some temporary, some defunct, and some in use today that have sought to level the playing field so that individuals may access HCBS as readily as they can access institutional services. In more recent history, with the Deficit Reduction Act of 2005 and with the 2010 passage of the Affordable Care Act, additional options for HCBS were added and expanded, providing additional opportunities for states to design HCBS systems of care. In addition to the provisions specific to HCBS, there have been a number of tools enacted to enable better integration of physical, behavioral and long term services and supports.

Sections 1915(d), 1915(e), 1915(i), 1915(j), 1915(k), 1915(k), 1929, 1930 have all been attempts to further equalize the playing field or tip the balance of Medicaid to enable more streamlined and widespread use of HCBS. In addition to these provisions of law, there have been many grant programs similarly aimed at bolstering HCBS availability.

Importantly, the recently enacted options have emphasized the ability of consumers to exert maximum choice and control over the HCBS services they receive. Below is a brief discussion of provisions and incentives that have been added in recent years from which a consolidated benefit should emerge, aligning person-centered principles, incentives, quality and administrative functions in order to promote broader HCBS accessibility and consistency.

Money Follows the Person (MFP), enacted through the DRA of 2005 and expanded and amended through the ACA, allows states to draw down enhanced FFP for HCBS services for a full 365 days after a person is relocated from an institutional setting where the person has resided



for more than 90 days. MFP funds can also be used for start-up costs like utilities, first and last month rent, furnishings, and minor housing modifications. In the Affordable Care Act (ACA), Congress shortened the time period the MFP eligible person had to reside in the institution from 180 to 90 days. However only 30,000 persons have moved to community settings in the 6 years since the program's inception, and the shortened time period has had no noticeable effect since most individuals are at risk of losing many of their housing and natural supports prior to the 90 day minimum. Developing new and affordable housing options has proven to be the single biggest barrier to expanding the numbers of people served. Furthermore, this Medicaid option sunsets in 2016, although unspent funds can be carried over until 2020.

The ACA created the Balancing Incentive Program (BIP). Participating states with HCBS expenditures under 25% of total LTSS spending are eligible for 5% enhanced federal match over 4 years and states between 25 and 50% are eligible for a 2% enhanced match. Participating states must make systemic changes including designing a No Wrong Door for entry into LTSS, designing a core standardized assessment tool (or a core data set), and assuring conflict-free case management. States are expected to meet the 25% or 50% HCBS spending targets by the end of the fourth year. Unfortunately with the inclusion of Developmental Disability Services in the calculation of all LTSS expenditures (many states had exceeded the 50% HCBS spending mark in their DD programs already in the 90s) that left only Mississippi eligible for the 5% enhanced match. Without DD expenditures included, about 15 states could have benefited by the elevated 5% match. Currently 13 states are participating in the BIP. The BIP sunsets in 2015. And perhaps its biggest drawback was stopping at 50%. As demonstrated by nearly all the states in Developmental Disability Services, and to a much lesser extent in Aging and Physical Disability Services, the 50% target should just be a measurement in time against a much broader goal of pointing most LTSS expenditures toward home and community based services. States above 50% should equally be incentivized and rewarded for continuing to build out their HCBS systems.

In addition to these demonstrations, the DRA provided authorization for a demonstration to determine the efficacy of adding Psychiatric Residential Treatment Facilities (PRTF) to the allowable alternative level of care/institutional settings for comparison purposes for HCBS waivers. This demonstration enabled a number of selected states to operate 1915(c)-like waivers for children who would otherwise receive services in a PRTF.

The ACA also added a 1915(k) state plan option and modified the 1915(i). The "K" gives states an additional 6% increase in federal match for personal attendant and support services where individuals have a person centered plan and can direct their own care, including the ability to hire and fire their attendants or caregivers. However, the statutory eligibility for 1915(k) invokes the institutional level of care requirement for receipt of the benefit and includes a 150% FPL limit for certain individuals, but not uniformly. (LOC in most states is coupled with income eligibility of 300% of SSI or about 220% of FPL) CFC does not permit states to target the benefit based on diagnosis or other targeting criteria and states offering "k" services must provide them to all eligible beneficiaries.

Conversely, Section 1915(i), which offers states the option to provide HCBS previously only available through Section 1915(c) waivers, allows states to target the benefit to certain

populations and allows states to design a needs based eligibility criteria lower than the institutional level of care, unlinking eligibility from LOC requirements. For the first time, this allows states to significantly narrow their LOC requirements while simultaneously serving a broader “at-risk” population which they were unable to do under the traditional 1915 (c) waivers. This benefit is also limited to individuals under 150% FPL unless the state elects to cover a newly available eligibility group added to the 1915(i) benefit through the ACA which can reach 300% SSI FBR for individuals who would be eligible under a 1915(c) or similar waiver. States have been reluctant to elect this group given the open aspect of the benefit. Unlike CFC, 1915(i) brings no enhancement to the FMAP rate for the state.

Neither 1915(k) nor (i) allow the states to set limits on the numbers of individuals served or to limit the benefit geographically. While both of these options are attractive, many states still facing fiscal challenges are wary of adding state plan options where they cannot set enrollment caps. And states undergoing significant rebalancing efforts may not see it feasible to create expanded HCBS capacity to divert or re-locate individuals from institutions while simultaneously expanding and entitling access to HCBS for new or previously unserved populations.

Importantly, 1915(c) remains the standard bearer for HCBS, with more than 300 separate waivers operated nationally, not including 1915(c) replications covered through 1115 demonstration programs. An attractive feature for state fiscal concerns remains the ability to cap or limit HCBS enrollment growth which the (c) allows.

All of the options above have attractive features but each require completely different applications, protocols, regulations, timeframes, administrative and reporting requirements. It is challenging for a state to bundle and blend these options into a cohesive long-term strategy to completely reform and rebalance its LTSS system, especially since several of these options sunset within the next four years. Furthermore, despite the intentions to provide equal footing, these benefits remain options for the state while they are mandated to provide institutional services, and are largely unable to reduce their institutional licensed capacity and footprint in a manner that would facilitate a more meaningful tipping of the LTSS infrastructure. Finally, the different requirements and structures also serve to impede state efforts to design meaningful person-centered systems of care that integrate services.

**Proposal Features:**

This proposal would create a single HCBS state plan authority which unifies and bundles the best features of the options described above, and would make permanent the enhanced match incentives in the MFP and BIP programs. The key features would include:

- States can set needs-based functional eligibility less stringent than the institutional level of care
- Allows states to include any or all Medicaid eligibility groups with income standards up to 300% of SSI, with strategies incorporated to ensure the lowest income individuals receive coverage first

- Allows states to craft multiple programs or consolidate multiple programs across disability or other target groups, in a manner that adheres to applicable laws (ADA, etc.)
- Payments for HCBS services are 6% higher than the regular match rate subject to Secretarial approval. The Secretary will determine the specific HCBS services, settings and attributes that will be eligible for the enhanced FFP, including time periods for review of enhanced FMAP eligibility.
- Institutional services are held at the regular match rate
- Makes permanent the MFP feature of full FFP for HCBS costs for one year after relocation from a nursing home, hospital, ICF/DD or PRTF where a person has resided for more than 90 days and includes features of both MFP and the “K” to pay for certain start-up costs
- Adds PRTF as an allowable alternative for LOC determinations
- As a state plan option, states must serve all eligible individuals, however a state may negotiate enrollment growth targets tied to specific rebalancing benchmarks that permanently decrease the state’s institutional footprint. Allows a time-limited differential match for buy down of vacant institutional beds taken off line
- Allows a modest capped HCBS benefit on a cost-sharing basis for individuals who meet functional eligibility and are at high risk of Medicaid spend-down with income and assets no greater than 136 180 days of the average nursing home rate in that state
- Allows a state under this authority to create health homes to coordinate care for a sub-set of eligible individuals who are receiving HCBS services and have two or more chronic conditions, and the state can receive 90% FMAP for up to eight quarters as defined in the affordable care act
- Includes opportunities for easy linkage to tools for integration, such as health homes and managed care authorities, setting forth uniform expectations yet streamlined authority linkage quality and reporting structures
- Will create the possibility for a medically needy income level for community based services

The single state HCBS authority would also have uniform requirements including:

- Meets HCBS settings requirements
- Needs assessments include core elements for all populations but also address specific populations using valid and reliable population-specific assessments
- Person-centered planning requirements for all participants
- No Wrong Door for all intake and eligibility
- Requires a mitigation plan for potential conflicts of interests in the delivery of case management
- Participant direction, including hiring and firing authority over personal care staff and access to an individual budget must be an available option Specified quality measures
- Some level of cost neutrality

The provision will also “clean up” the statute to remove the various provisions (driftwood) to definitively provide a sleek option. However states may still elect to utilize the 1915(c) authority to fund HCBS services tied to an institutional level of care, subject to the periodic review by the Secretary to ensure that the services offered therein comport with established standards for HCBS.



**STATEMENT FOR THE RECORD  
SUBMITTED TO THE  
Special Committee on Aging  
United States Senate**

**on**

**“The Future of Long-Term Care Policy: Continuing  
the Conversation”**

**December 18, 2013**

**AARP  
601 E Street, N.W.  
WASHINGTON, DC 20049**

AARP appreciates Chairman Nelson and Ranking Member Collins convening this important hearing on the future of long-term care policy, and especially on continuing the conversation after the recent work of the federal Commission on Long-Term Care.

Long-term care is really about helping people live independently and supporting family caregivers who help their loved ones do just that. This critical issue affects millions of individuals of all ages and their families every day. Whether it is a 29 year-old man with a disability who needs supports to work and remain employed, an 89-year old woman who needs services to help her live independently in her home, or a 49-year old woman who works outside the home and spends nearly 20 hours per week providing unpaid care to her mother for nearly five years – the “average” US family caregiver – all these individuals rely on or provide services and supports to enable independent living. Right now, at kitchen tables across America, millions of real families are confronting the same question: how will we care for mom or dad, or another loved one, if something happens and they can’t care for themselves without assistance? And if and when the time comes, who will care for us?

About 12 million Americans need assistance to help them with regular daily activities, such as eating, bathing, dressing, and transportation. Almost half (44 percent) of these individuals are under age 65, and a little over half (56 percent) are age 65 and over. These 12 million people are projected to more than double to 27 million in 2050.<sup>1</sup> These individuals should receive the long-term care services they need as part of a person- and family-centered approach that is responsive, efficient, and integrated with health and other services to ensure people can access quality services in settings they choose.

### Family Caregiving

Family caregivers are the backbone of long-term care in this country and they are the first line of assistance for most people who need help to live independently. In 2009, about 42 million family caregivers in the United States provided care to an adult with limitations in daily activities at any given point in time. They provided unpaid care valued at \$450 billion that year, more than total Medicaid spending in 2009 and more than twice the total for paid services and supports, according to AARP’s Public Policy Institute.<sup>2</sup>

As the number of individuals needing services to help them live independently will grow in the coming decades, a recently released AARP Public Policy Institute report finds that the number of family caregivers available for older Americans will drop dramatically over this same time period. From 1990 to 2010, the Baby Boom generation entered their prime caregiving years; at the end of those two decades, there were 7.2 potential caregivers aged 45-64 for every person aged 80-plus. Over the next 20 years, as the Boomers become the population that will need the most care, the number of potential caregivers drops to 4:1. Looking even further out, between 2030 and 2050, the number plummets to

<sup>1</sup> Commission on Long-Term Care, *Report to the Congress 5* (September 30, 2013) available at <http://www.ltccommission.senate.gov/Commission%20on%20Long-Term%20Care-%20Final%20Report%209-26-13.pdf>.

<sup>2</sup> L. Feinberg, S. Reinhard, A. Houser & R. Choula, *Valuing the Invaluable: 2011 Update, The Growing Contributions and Costs of Family Caregiving* 1,3 (AARP PPI, 2011), available at <http://www.aarp.org/relationships/caregiving/info-07-2011/valuing-the-invaluable.html>.

2.9:1.<sup>3</sup> That means more people will be dependent on fewer family caregivers. We need better supports for family caregivers, a strong, stable paid workforce, and innovative solutions across sectors.

Many family caregivers take on care willingly and many find it a source of deep satisfaction and meaning. Yet family caregivers can also face physical, emotional, and financial challenges. Families often coordinate care and provide assistance with activities such as eating, bathing, toileting, meal preparation, transportation, managing finances, and household chores. A report released last year by AARP's Public Policy Institute and the United Hospital Fund also found that almost half of family caregivers perform medical/nursing tasks for care recipients, such as wound care, managing multiple medications, and helping with assistive devices for mobility.<sup>4</sup> Families generally do not receive training and other assistance to help them provide care. Such training and supports may also benefit the person receiving the assistance. Family caregivers should be given an assessment of their needs and then receive help based on the assessment, especially when a care or discharge plan depends on a family caregiver voluntarily providing services to an individual. Such assistance should include information, training, counseling, links to community resources, help locating services, respite care, or other supports. Family caregivers providing assistance to their loved ones at home can help delay or prevent these individuals from needing more costly care in a nursing home and help prevent unnecessary hospital readmissions.

#### **Paying for Services**

When families are not able to provide all the services that a loved one needs to live independently, individuals and their families turn to paid care. Often, they may be looking for someone to provide services in their local community or a long-distance family caregiver may be tracking down available services in her mother's community. Finding quality services and providers can be challenging. And, costs can quickly add up. The national median rate for home health aide services is over \$30,000 annually based on 30 hours per week. The national median cost for an assisted living facility is over \$41,000 annually, and the national median cost of a private room in a nursing home is almost \$84,000.<sup>5</sup> These costs can be overwhelming for individuals and their families. Financing options are currently limited. Private health insurance and Medicare do not cover these services and supports, even though many people believe they do.

<sup>3</sup> D. Redfoot, L. Feinberg, & A. Houser, *The Aging of the Baby Boom and the Growing Care Gap: A Look at Future Declines in the Availability of Family Caregivers* 3-6 (AARP PPI, 2013), available at [http://www.aarp.org/content/dam/aarp/research/public\\_policy\\_institute/ltc/2013/baby-boom-and-the-growing-care-gap-insight-AARP-ppi-ltc.pdf](http://www.aarp.org/content/dam/aarp/research/public_policy_institute/ltc/2013/baby-boom-and-the-growing-care-gap-insight-AARP-ppi-ltc.pdf).

<sup>4</sup> S. Reinhard, C. Levine & S. Samis, *Home Alone: Family Caregivers Providing Complex Chronic Care* 1 (AARP PPI and United Hospital Fund, 2012), available at [http://www.aarp.org/content/dam/aarp/research/public\\_policy\\_institute/health/home-alone-family-caregivers-providing-complex-chronic-care-rev-AARP-ppi-health.pdf](http://www.aarp.org/content/dam/aarp/research/public_policy_institute/health/home-alone-family-caregivers-providing-complex-chronic-care-rev-AARP-ppi-health.pdf).

<sup>5</sup> D. Redfoot & W. Fox-Grage, *Medicaid: A Program of Last Resort for People Who Need Long-Term Services and Supports* 3 (AARP PPI, 2013), available at <http://www.aarp.org/health/medicare-insurance/info-05-2013/medicaid-last-resort-AARP-ppi-health.html>.

A small percentage of the population has private long-term care insurance to help pay for services. However, private long-term care insurance is unaffordable for many, especially since many companies have dramatically raised premiums and introduced gender rating that has increased premiums for women. Most companies offering coverage a few years ago have left the market. Those still offering policies have often increased underwriting in recent years making it harder to purchase; many people are unable to obtain it due to pre-existing conditions, such as a disability. Products that combine long-term care insurance with life insurance or other products may help some individuals, but these products are relatively new and can be complicated, confusing, and even more expensive for consumers.

Given limited financing options, general denial about the potential need for help to live independently, the more immediate needs of paying a mortgage and other monthly bills, the need to save to send children to college, and inadequate savings for retirement generally – let alone help to live independently – many individuals and families struggle to pay for care when disability occurs. Many individuals spend down their life savings and end up relying on Medicaid to pay for services to help them live independently in their homes and communities or pay for nursing home care. Medicaid provides an important safety net for those with low incomes or those who have exhausted their retirement savings on the high costs of health care and the help needed to live independently. Clearly, more and better financing tools are needed.

### **Balancing**

Most people who need services and supports don't need or want to stay in expensive nursing homes. They want to live independently, and they could live in their homes if they have the right help with everyday tasks and other supports. Medicaid has an institutional bias that makes it more difficult to serve people in their homes and communities. Federal law requires Medicaid to cover institutional care, such as nursing homes, but home and community-based services (HCBS) are mostly "optional" services provided at state discretion. States provide these services, but they often have limitations, such as the number of people who can receive services, the types of services, and the amount of services. Most older Americans and persons with disabilities prefer to receive services in their homes and communities, and these services are cost effective, yet barriers to HCBS persist in the Medicaid program. On average, the Medicaid program can provide HCBS to roughly three older adults and adults with physical disabilities for the cost of serving one person in a nursing home.<sup>6</sup> Research shows that states that invest in HCBS, over time, slow their rate of Medicaid spending growth, compared to states that remain reliant on nursing homes. While states and the federal government have made gradual progress on

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<sup>6</sup> A. Houser, W. Fox-Grage, & K. Ujvari, *Across the States: Profiles of Long-Term Term Services and Supports 2012* 16 (AARP PPI, 2012), available at [http://www.aarp.org/content/dam/aarp/research/public\\_policy\\_institute/ltc/2012/across-the-states-2012-full-report-AARP-ppi-ltc.pdf](http://www.aarp.org/content/dam/aarp/research/public_policy_institute/ltc/2012/across-the-states-2012-full-report-AARP-ppi-ltc.pdf).

increasing access to HCBS, much remains to be done, especially for older individuals who have lagged behind younger people with disabilities in receiving HCBS.<sup>7</sup>

### **Quality and Workforce**

Individuals who need services and supports should receive both quality care and services that improve quality of life regardless of payer and where they are receiving services. A person- and family- centered approach to service delivery means providing quality services that meet the needs of the individual and their family caregivers, as appropriate. While there are quality providers across the array of services, the quality of services that help people live independently in their homes and communities or in nursing homes varies greatly. In addition, quality oversight is often insufficient, and quality measures in HCBS are lacking.

A vital part of providing quality services to older adults and persons with disabilities is having a strong, competent and stable workforce to provide these services. Too often, direct care workers (who provide most paid care) face difficult jobs, inadequate compensation, high turnover rates, limited opportunities for career advancement, and other challenges. Given the current and future demand for services, especially for individuals living independently in their homes and communities, and the declining number of family caregivers in the coming decades, it is important to recruit and retain a strong and stable paid workforce with better career opportunities. Direct care workers, as well as family caregivers and individuals receiving services, are critical members of interdisciplinary teams providing services to individuals.

### **Recent Developments**

In September, a federally appointed Commission on Long-Term Care released a report with important bipartisan recommendations to help build a better system to support individuals and their family caregivers nationwide. Congress and the Administration should seriously consider these recommendations in developing legislative and administrative steps to improve options to help people live independently. Importantly, the Commission called for a national strategy to address the needs of family caregivers. The Commission also specifically recommended assessing family caregivers and their needs in the care planning process, including family caregivers in patients' health records and as members of care teams, ensuring family caregivers have access to relevant information technology and, importantly, encouraging family caregiver interventions, including respite, training, and other supportive services and volunteer support.

In addition to providing support to family caregivers, the Commission endorsed the broader ideas that people should have greater choice about care setting and that HCBS should be sufficiently robust to meet the needs of older Americans and people with disabilities who

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<sup>7</sup> D. Rowland, Testimony before the Commission on Long-Term Care on *What Would Strengthen Medicaid Long-Term Services and Supports?* 4 (August 1, 2013), available at <http://www.ltccommission.senate.gov/DRowland%20Testimony.pdf>.



wish to remain in their homes and communities. However, we wish the Commission had gone farther in calling for enhancements to the social safety net.

The Commission also made some important recommendations relating to service delivery and care coordination, among others, and to help address the needs of individuals with disabilities who need services and supports to enable them to work.

While these recommendations are a good start, they are only one step in what must become an ongoing constructive national conversation that looks at the whole picture. The Commission had limited time and regrettably did not reach agreement on comprehensive financing. Solutions in these and other areas are important.

No one silver bullet will address all the challenges outlined in these comments. A continued dialogue and action among individuals, stakeholders, and the public and private sectors is essential to address these issues in our country. There are some important steps Congress could take in the short-term, such as requiring the development of a national strategy to support family caregivers.

Again, AARP thanks the Senate Special Committee on Aging for today's hearing. We encourage those on both sides of the aisle to continue engaging to help find solutions on this vital issue to millions of individuals of all ages and their families. We have an opportunity to seize the moment to raise the visibility on this issue – and to build on the Commission's bipartisan recommendations for a better system to support individuals and their family caregivers nationwide. AARP looks forward to working with Congress, the Administration, and a diverse array of stakeholders to successfully address these issues.

PROTECTING THE RIGHTS OF LOW-INCOME OLDER ADULTS

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**Statement for the Record Submitted to the Senate Special Committee on Aging on  
“The Future of Long-Term Care Policy: Continuing the Conversation”**

The Commission on Long-Term Care accomplished an important goal: elevating the conversation in Washington about the need to improve long-term care. The Commission report and the alternative report call attention to the urgent need to enhance the long term services and supports (LTSS) system to support families across the country.

The National Senior Citizens Law Center (NSCLC) believes the first step in improving LTSS is addressing the imbalance that exists in LTSS financing. Unfortunately, Medicaid, the nation's largest LTSS payer, continues to give preference to providing LTSS in institutions such as nursing homes instead of at home and in the community. As a result, many low-income older adults who could be receiving care at home are unnecessarily moved into institutions.

There was widespread agreement by the Commission that a high quality, accessible network of home and community-based services that supports individuals so that they may live with dignity and independence in the setting of their choice is an important component of long-term care reform. As Congress addresses the recommendations of the Commission, we urge them to seize the opportunity to correct Medicaid's imbalance and finally shift the delivery of Medicaid-funded long-term services and supports away from institutions and into the community.

NSCLC commends Chairman Nelson and Ranking Member Collins for convening this hearing. The Committee is continuing an important conversation that parents, children and caregivers have every day: what can be done to support individuals and families who feel the impact of a fragmented long-term care system?

A Policy Issue Brief of the recommendations we shared with the Commission can be found on our website.

*The National Senior Citizens Law Center is the only national non-profit whose principal mission is to protect the rights of low income older adults. Through advocacy, litigation, and the education and counseling of local advocates, we ensure their health, economic security and access to the courts. NSCLC has offices in Washington, DC, Oakland and Los Angeles, CA. For more information, visit [www.nslc.org](http://www.nslc.org).*



**THE SENATE SPECIAL COMMITTEE ON AGING  
The Future of Long Term Care Policy:  
Continuing the Conversation  
December 18, 2013**

**Statement of Richard P. Grimes | President & CEO  
ASSISTED LIVING FEDERATION OF AMERICA**

**"The Future of Long-Term Care Policy: Continuing the Conversation"**

Hearing before the Senate Special Committee on Aging  
Dec. 18, 2013

Statement for the Record  
Submitted by Richard P. Grimes, President/CEO  
Assisted Living Federation of America

Chairman Nelson, Ranking Member Collins and Members of the Committee, we are grateful for this opportunity to address the future of long-term care policy in the United States.

The Assisted Living Federation of America (ALFA) is the largest national association exclusively dedicated to companies operating professionally managed, resident-centered senior living communities and the seniors and families they serve. Since 1990, ALFA has advocated for choice, accessibility, independence, dignity and quality of life for all seniors.

As the majority of the U.S. population trends older, the future of long-term care policy is a pressing issue for ALFA and the nation. *We believe assisted living is part of the solution.*

Our member companies operate senior living communities offering assisted living, independent living and memory care services to seniors and their families. Assisted living and memory care communities are licensed and regulated by each of the 50 states and provide 24-hour supervision, meals, activities, medication management and assistance as needed with activities of daily living such as dressing and bathing.

Until the 1980s, seniors who could not live safely in their own home or with family had very few alternatives to institutional care. Today, more than 730,000 seniors live in assisted living communities where they get the assistance they need when they need it while maintaining their privacy, dignity and respect with the assistance of a caring professional staff.

A 2010 national survey of residential care conducted by the Centers for Disease Control and Prevention revealed that *a typical assisted living resident is female, widowed, 85 years old and needs assistance with activities of daily living such as bathing and dressing.* Additionally, the study indicated that 42% of residents in assisted living have some degree of Alzheimer's or a related dementia.

The statistical profile of the typical resident in assisted living is important because a common assumption is that assisted living is serving a younger, independent and healthy population of retirees. Because the majority of assisted living residents are

among the oldest old, they often require considerable help with their activities of daily living and a safe living environment but don't require the 24/7 nursing care provided by skilled nursing facilities.

Assisted living is home for our residents, most of whom pay out of their own pockets from their own private resources. There are many assisted living options available at a range of price points including large or small, urban or rural, high-rise or single level to name a few.

**Assisted Living Is Part of the Solution**

In 2010, 40.3 million or 12% of the total U.S. population was age 65 or older with the fastest growing segment of America's population consisting of those who are age 85 and up. In 2010, there were 5.8 million people aged 85 or older and by 2050, it's projected that there will be 19 million people in that age group, according to the U.S. Census Bureau.

Additionally, many assisted living communities offer special care and services for residents with Alzheimer's or related dementia. While today 5.4 million people suffer from Alzheimer's, it is estimated that 16 million U.S. residents will have the disease by 2050.

Alzheimer's disease, the most common form of dementia, almost always results in a need for long-term services and supports. It affects more than 42% of Americans over the age of 85, according to the Alzheimer's Study Group, part of the U.S. National Alzheimer's Strategic Plan.

Today, many of our elderly citizens are under the care of family members. Family caregivers have a noble and critical role in caring for individuals, providing the majority of long-term support and services for their loved ones throughout the United States. However, care giving "often places a financial, physical, and emotional hardship on the caregivers" who often have little advance knowledge or training in the activities they have to perform, according to the Commission on Long-Term Care's Report to Congress.

Many seniors and their family caregivers turn to assisted living when they can no longer perform complex medical or nursing tasks or have the necessary supports they need to continue caring for their loved one. For example, they may be wary of, lack the training or be too emotionally connected to perform complex medical tasks, wound care or medication management.

Finding a way to pay for long-term care services is a growing concern for older adults, persons with disabilities and their families. Recent estimates for the amount spent annually on all long-term care services reach up to \$306 billion, according to a 2012 report from Genworth Financial cited in a new Centers for Disease Control and Prevention report on long-term care services.

Assisted living is financially competitive. Average rates in 2012 for a private room in a nursing home were \$7,543 per month compared to a private room in assisted living at \$3,550 per month, according to MetLife Mature Market Institute. Annually, this means assisted living is about 50 percent less expensive than skilled nursing facilities — \$42,600 versus \$90,520.

**Assisted Living Is Working**

Occupancy in assisted living is averaging 90.9% nationwide. While anecdotally we have known that consumers are extremely satisfied living in assisted living, a 2013 poll conducted by Public Opinion Strategies and Frederick Polls showed that 94% of assisted living residents say they are *satisfied or very satisfied* with the overall quality of life in their community, and 99% say they feel *safe or very safe* living in their community.

ALFA's goal is to continue to explore ways for consumers to plan and prepare for their own long-term care needs.

**ALFA Supports Many Commission on Long-Term Care Recommendations**

The Commission on Long-Term Care made a set of important recommendations in its Sept. 18, 2013 Report to Congress.

We at ALFA strongly support many of the recommendations, including:

**Service Delivery**

We agree that the process of accessing and navigating long-term services and supports can be challenging. We also support that individuals should be able to receive the needed services and supports in the least restrictive setting possible and that these options should be available regardless of income and age. Because the network of long term services and supports varies state by state, we believe the states would be in a better position to inform consumers of state options. As Assisted Living providers, we voluntarily embrace consumer disclosure to ensure that prospective residents are adequately informed of our services and fees to help them make an informed choice on whether or not assisted living is the best option.

**Paid Workforce**

ALFA strongly supports the Commission recommendation enabling nurses to delegate to appropriately trained direct care workers to perform tasks typically performed by nurses, such as the administration of medications and injections. We agree with the commission - and our members have seen firsthand - that this has a positive impact on the workforce who now has a career path and increased job satisfaction. Additionally, studies show that safety of medication administration is not compromised with adequately trained and supervised direct care staff.

ALFA strongly supports the recommendation that the federal government work with states to enable national criminal background checks for all members of the long-term services and supports workforce. ALFA members have a zero tolerance for elder abuse, neglect and exploitation, but we are well aware of the horror stories we read about where vulnerable populations are victimized mainly in their own homes but other settings as well.

While assisted living providers are mandated in almost every state to conduct criminal background checks, consumer protections could be improved through a more integrated, comprehensive and efficient background check system. In addition there are conflicting recommendations such as the Equal Employment Opportunity Guidance on Criminal Background Checks that has the philosophy that background checks can be discriminatory and should not be used in all situations, even when mandated by state law.

ALFA believes that when caring for vulnerable populations receiving long term services and supports, a comprehensive criminal background check process must be in place. We support the Commission recommendation that Congress direct the Department of Justice to examine barriers to sharing interstate criminal background data for health care workers in every setting and accelerate the effort to develop solutions.

Additionally, ALFA completely agrees that there is a shortage of professionals and direct care workers to work in this field. Students are unaware of the career path and opportunities they can have in the field of aging and long-term care. We need to work with universities and high schools to educate students about this career path.

#### **Finance**

ALFA completely agrees with the Commission that Americans are not aware of or adequately prepared for the costs of long-term services and supports. ALFA absolutely believes that Medicaid needs to be the safety net for low income Americans who through no fault of their own cannot pay for their long-term care needs. However, we believe consumers should also bear some personal responsibility for future long-term care needs. ALFA supports the Commission principle stating: "Public policy toward the financing of LTSS must reflect a comprehensive and balanced approach to public and private responsibility. It must encourage and enable individuals to prepare adequately to finance their own needs while providing a strong safety net for those who simply cannot do so."

Commission recommendations to "create a comprehensive, understandable and affordable LTSS financing system with both public and private components that work together effectively to enable individuals to plan for their LTSS needs."

ALFA applauds the Commission's suggestion that such a system include:

- A public insurance program to spread risk and help individuals pay for LTSS;

- Expansion of private savings incentives and access to workplace saving options;
- Reforms and improvements in the private long term care insurance market; and
- Information, education and other resources to help individual understand different financing options and make the right choice

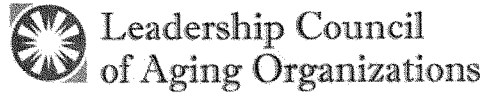
**Next Steps**

We commend the Commission for making tremendous progress in a very short period of time. We believe this is a great start and the report should not languish on an office shelf. For too long, elected officials and the public have tried to avoid talking about long term care. The discussion can no longer be pushed aside and we are grateful that the Senate Special Committee on Aging has taken on this topic wholeheartedly.

We support the recommendation to create a national advisory committee to continue the work of the Commission. We support the recommendation that this national committee include governmental, private sector stakeholders as well as family caregiver representatives.

Assisted living communities have become an integral part of neighborhoods across the country and of our daily lives, providing a valuable service to seniors and families in a residential environment that enriches their lives and wellness.





December 18, 2013

Chairman Bill Nelson  
Senate Special Committee on Aging  
Dirksen G31  
Washington, DC 20510

Ranking Member Susan Collins  
Senate Special Committee on Aging  
Dirksen G31  
Washington, DC 20510

Dear Chairman Nelson and Ranking Member Collins:

Thank you for holding this very timely hearing on the future of long-term care policy. The Leadership Council of Aging Organizations (LCAO) and the Consortium for Citizens with Disabilities (CCD) offer the following set of consensus principles for reform that we hope provide a framework on essential elements to a reformed system, from the consumer, family and long-term services and supports (LTSS) worker perspective.

Together, LCAO and CCD include over 150 organizations representing older adults, people with disabilities, and providers of health, housing and supportive services. Our consensus on a new direction for financing and delivering these services puts millions of Americans behind the push for reform.

An estimated 11 million Americans currently have needs for LTSS. The number of individuals needing LTSS is projected to increase to 27 million by 2050. However, the nation lacks a coordinated, national public-private system for delivering LTSS. Nearly half of all funding for these services is now provided through Medicaid, which is a growing burden on states and requires individuals to become and remain poor to receive the help they need. While the situation has improved, the institutional bias in Medicaid persists whereby the majority of LTSS funding is directed toward nursing homes and other institutions instead of preferred community-based services and supports.

The principles adopted by CCD and LCAO call for national solutions. Consumers should have access to a broad array of affordable, quality support options, including a range of home and community-based supportive services. The financing system(s) should facilitate universal access so that individuals of all ages and disabilities can obtain LTSS. The financing system should promote independence and dignity across the lifespan by ensuring individuals the right to control and choose what services they receive, how and where they are delivered, and who provides them. Any system must also put in place strategies for supporting the central role of family caregivers and attracting and retaining an adequate number of direct care workers to deliver high quality services.

We look forward to working with you to advance this discussion and develop policies to improve LTSS in this country. Please do not hesitate to contact us if we can be of assistance.

Sincerely,

Richard J. Fiesta  
Chair  
LCAO

Katy Beh Neas  
Chair  
CCD

### **Principles for Long-Term Services and Supports**

For too long, our nation has ignored the urgent need to address in a bipartisan fiscally responsible manner the emerging long-term services and supports (LTSS) crisis facing older adults, baby boomers, people of all ages with disabilities, and family caregivers. LTSS should offer consumers access to a broad array of support options, including an array of home and community-based supportive services, as well as residential options, as needed. Our current system forces people into institutions, requires many to spend-down into poverty before receiving the help they need, fails to provide realistic opportunities for personal planning, and fails to support family caregivers adequately. America can and must do better.

The following principles for LTSS are intended to provide a framework for focusing attention, generating discussion and crafting solutions to the problem in the near future. In the interim, the members of the Leadership Council of Aging Organizations (LCAO) and the Consortium for Citizens with Disabilities (CCD) will work toward a strong Medicaid program and advocate for additional resources and opportunities for home and community-based services and individual planning.

#### ***Financing***

**National Problem, National Solutions** – Recognize that financing for LTSS is a national problem that requires national solutions, although states, communities, families, and individuals have important roles to play.

**Universal Access** – Facilitate universal access so that individuals of all ages and disabilities can obtain LTSS. Create a system that does not exclude individuals or groups.

**System Organization and Integration** – Develop a well-organized system that aligns payment and services to promote optimal care and service delivery. Community-based long-term services and supports should be seamlessly integrated with acute, ambulatory, advanced and palliative care to ensure efficient and effective coordination of care across the continuum.

**Affordability**– Make costs affordable by using tools such as broad pooling of risk and appropriate low-income subsidies so that all people, regardless of income, age, gender, disability and health status, have access to LTSS. Ensure that any new system(s) protects the financial security of individuals and families and does not force people to impoverish themselves to get the services and supports they need.

**Public/Private Partnership** – Promote personal planning and private sector options with a strong foundation of consumer protection. Support both public and private insurance options, including new alternatives to Medicaid, and enhance the feasibility of private LTSS solutions.

**Fiscal Responsibility** – Provide actuarially sound funding for LTSS that builds reserves over time sufficient to pay for future needs in a way that is affordable to individuals and to society as a whole.

**Relieve Pressure on Medicaid** – Provide additional LTSS funding mechanisms that will help take the pressure off future Medicaid expenditures, while preserving and enhancing the guaranteed safety net.

**Housing, Transportation and Technology** –Include a strategy to meet the housing and

transportation needs of older adults and people with disabilities, as well as to finance technological supports that enable independence.

#### **Consumers and Family Caregivers**

**Consumer Choice** – Promote independence and dignity across the broad array of services and supports by ensuring individuals the right to control and choose which services they use, how and where those services are delivered and who provides them including education about and the use of advance directives, and individual care planning.

**Consumer Control** – Ensure consumer services and supports are flexible, consumer driven, person-centered and tailored to the individual's needs and preferences. Develop mechanisms to connect consumers who want to hire their own direct care professionals with available candidates. Improve the ability of consumers, caregivers, and healthcare professionals to plan for and understand the full array of long-term services and supports including advanced care and end-of-life planning through education and other supports.

**Support Family Caregivers** – Recognize and support the central role family caregivers play in planning for and providing LTSS. Develop strategies to support caregivers who are otherwise employed to maintain their financial security. Assess the needs of family caregivers and provide information, training, counseling, respite and other supports to address their needs. Guard against designing a system that relies too heavily on family caregivers in lieu of developing a viable system of long term services and supports.

#### **Quality of Life, Quality of Care**

**Invest in Quality** – Provide adequate funding to support quality care, including sufficient training, protections, and compensation for the LTSS workforce. Invest in the development of quality standards for home and community-based services and supports. Provide additional funding to strengthen oversight, enforcement, and advocacy programs that ensure quality of life and improve quality of care in all settings.

**Quality Standards** – Support strong quality standards that include quality measures and assessment of the consumer experience including oversight, enforcement, and robust advocacy programs.

**Quality of Life** – Promote community inclusion and engagement that allows individuals to participate in activities, events and work to the extent they desire throughout their lives, including the end of life. Acknowledge that disability, chronic disease and advanced illness bring their own set of criteria for quality of life, including psychosocial support, pain relief, and person-centered planning.

#### **Workforce**

**Professionals in LTSS** – Recommend strategies to bolster the professional long-term services and supports workforce through recruitment, opportunities for professional education and training for those specializing in aging or disability work, including loan forgiveness and grants; competitive compensation; and practice-based research.

**Stabilize and Strengthen the Direct-Care Workforce** – Recognize the essential role of direct-care workers in providing LTSS, promote a plan for attracting an adequate number of workers to direct-care positions to meet consumer demand, as well as for addressing the causes of high-rates of turnover. Recommend mechanisms for stabilizing and strengthening the direct-care workforce through training and credentialing, data collection, and improved compensation.



## **NCOA Applauds Senate Aging Committee Hearing and Calls for Congressional Action on Long-Term Care**

**Statement of Howard Bedlin,  
NCOA Vice President for Public Policy & Advocacy**

*Washington, DC (Dec. 18, 2013)* – The [National Council on Aging](#) (NCOA) applauds Senate Aging Committee Chairman Nelson and Ranking Member Collins for convening a hearing today to advance solutions to the long-term care challenges facing millions of seniors, people with disabilities, and their families.

Over 12 million Americans and their families require long-term assistance to perform activities of daily living. This number is projected to more than double to 26 million by 2050. Families provide the vast majority of long-term care with little or no support. Medicare does not cover long-term care, and private insurance is unaffordable or unavailable to the vast majority of Americans, forcing most individuals and families to spend-down their life savings into poverty before getting help from Medicaid. Even then, they struggle to get community-based services to stay at home instead of going into a more costly nursing home.

Earlier this year, Congress formed a bipartisan Federal Commission to advise Congress on how long-term care can be better financed and provided. While the Commission did not adequately address the critical issue of financing, it reached strong bipartisan agreement on a number of positive, modest recommendations in the areas of family caregiving, the direct care workforce, rebalancing from institutional to community-based services, and quality measures for home and community-based services.

It is now time for Congress to follow up on these common-sense recommendations to assist millions of struggling middle-class families. It is also long overdue for Congress to take action on the issue of financing, which was the central reason the Commission was formed.

NCOA believes that the best solution is to create a new national long-term care insurance program that allows all people, including individuals with disabilities and those near retirement, the opportunity to contribute to, and prepare for, the costs of long-term services and supports. We must work together on a bipartisan basis to establish a national program that:

- Is actuarially sound
- Is largely self-funded
- Increases affordable options for working Americans

- Does not exclude purchasers based on pre-existing health conditions
- Improves market opportunities for private insurance options
- Produces significant savings to Medicaid

We hope this hearing is the catalyst for Congressional champions to rise up and demonstrate leadership by taking action on the Long-Term Care Commission recommendations and the establishment of a national long-term care insurance program.

NCOA will continue to work with Congress, the White House, and other organizations—including those representing seniors, people with disabilities, providers, and insurers—to craft solutions to help millions of American families afford the long-term care they need to age with dignity and independence.

NCOA's detailed recommendations to the Long-Term Care Commission are available at [www.ncoa.org/LTCC](http://www.ncoa.org/LTCC).

**About NCOA**

The National Council on Aging (NCOA) is the nation's leading nonprofit service and advocacy organization representing older adults and the community organizations that serve them. Our goal is to improve the health, independence, and economic security of 10 million older adults by 2020. For more than 60 years, NCOA has been a trusted voice and innovative problem-solver helping seniors navigate the challenges of aging in America. We work with local and national partners to give older adults tools and information to stay healthy and secure, and we advocate for programs and policies to improve the lives of all seniors, especially the most vulnerable. For more information, please visit [www.ncoa.org](http://www.ncoa.org).



December 18, 2013

Chairman Bill Nelson Ranking  
Senate Special Committee on Aging  
Dirksen G31  
Washington, DC 20510

Member Susan Collins  
Senate Special Committee on Aging  
Dirksen G31  
Washington, DC 20510

Dear Chairman Nelson and Ranking Member Collins:

The Visiting Nurse Associations of America (VNAA) thanks the Senate Special Committee on Aging for continuing the conversation on reform of the delivery of long-term supports and services today and for future generations. Listed below is a profile of VNAA's non-profit members and the many ways they support the delivery of long term supports and services to homebound beneficiaries including those with serious and/or multiple chronic conditions.

At the end of this memo are VNAA's principles for long-term care reform, also offered to the Long Term Care Commission earlier this year. The principles promote policies that provide access to vital needed care for vulnerable beneficiaries. These principles are particularly timely as, earlier this month, CMS finalized a damaging rule that cuts payments to the home health industry and endangers access for homebound patients could lose the option of receiving skilled care at home.

#### **About VNAA**

VNAA represents community-based nonprofit home health and hospice providers throughout the United States. Its members care for homebound patients with serious and often chronic conditions by providing a full array of healthcare services along with care coordination, management and prevention. VNAA members provide a vital link between patients, physicians and acute care settings and serve all patients without regard to their ability to pay or the severity of their illness. VNAA members are a necessary part of the solution to improve quality and health outcomes and reduce costs in the nation's health system.

#### **VNAA Members Drive Innovation**

VNAA members' experience in providing care to people in their own homes and communities predates both the Medicare and Medicaid programs. VNAA's nonprofit agency members have a proven record of accomplishment of furnishing high quality, patient-centered care at home as well as supporting family caregivers who assist homebound patients.

Today, VNAA members are engines of innovation, actively engaged in Accountable Care Organizations (ACOs), bundled payment demonstration projects and innovations designed to resolve breakdowns in care for patients with multiple chronic conditions. In addition, many

VNAA member agencies devote already stretched resources to incorporate health information technology into their practice.

Home health care providers are key partners in transforming the delivery of long-term supports and services, and in keeping patients in their homes. Home health care providers are critical partners in teams that include physicians, nurses, therapists and home health aids. Home health providers:

- Ensure high-quality care for homebound patients;
- Provide critical care coordination for patients with chronic conditions;
- Deliver high-tech care including infusion therapy and home monitoring;
- Furnish skilled care for complex patients following an illness or surgery;
- Reduce costs across systems of healthcare; and
- Keep vulnerable patients at home and out of expensive acute care settings.

The Medicare Payment Advisory Commission (MedPAC) reports that 3.4 million, or 9.5 percent, of traditional fee-for-service Medicare beneficiaries used home health in 2011. CMS data shows that approximately 86 percent of home health users are age 65 or older, 63 percent are 75 or older and nearly 30 percent are 85 or older. Women make up a majority of home health users at 63 percent, and more than 35 percent of home health users live alone. Of the patients who received home health care in 2011, 83.2 percent have three or more chronic conditions. Roughly, 28 percent of home health users have two or more limitations in activities of daily living. Finally, 45.8 percent report fair to poor health.

Home health care services can play a critical role in achieving current health care policy goals to enhance care coordination among providers to extend care beyond the four walls of the physician office, to prevent initial hospitalizations and to avoid or prevent re-hospitalization of post-acute care patients. However, service providers cannot meet these goals without the support and intervention of skilled, high quality, community-based home health providers.

Reductions in hospital readmission rates and improved management of patients with chronic illness in their own homes are two of the most significant challenges in health care delivery today. Home health plays a critical role in coordinating care for vulnerable patients and provides medically necessary care to vulnerable patients to prevent a hospitalization as well as after a hospitalization. Home health providers work with physicians and hospitals and play an important role in helping keep patients in their homes longer. Home health also helps extend the reach of primary care practitioners, particularly in rural and underserved communities. All of these activities help support seniors and people with disabilities to receive care at home rather than in more costly institutional settings.

VNAA urges policymakers to “deem” home health care as the recommended site of care unless an assessment by the patient’s provider indicates that home health is not appropriate. This is consistent with the MedPAC recommendation in the March 2013 Report to Congress. VNAA strongly supports these goals and recommends that home health care be the recommended site of care unless an assessment determines otherwise and patient choice is maintained.

#### **Impact of Recent Rebasing Cuts on Home Health Delivery**

In a November 22, 2013 final rule, CMS cut funding for the Medicare home health benefit by \$200 million starting Jan. 1, 2014. This "rebasing" rule reduces base payments for home health services 3.5 percent annually for 2014- 2017 despite CMS's claims that reductions are only 1.05 percent in 2014. CMS finalized this rule despite substantive arguments and significant concerns about the impact on patient accessibility to home health services from VNAA and other home health industry organizations, patient advocacy groups, providers and a bi-partisan group of over 193 members of Congress. Fifty-one senators and 142 representatives signed on to two letters to CMS raising serious concerns about the home health benefit and its proposed implementation of the rebasing provision. These payment reductions most definitely will curtail access to the benefit.

CMS cuts in the Medicare home health mean that many homebound patients will lose the option of receiving skilled care at home and instead receive admission to high cost acute care, institutional settings, which is an outcome in direct conflict with the goal of reducing unnecessary care and costs. Cuts will affect elderly and disabled patients with multiple chronic conditions the hardest. VNAA's mission-driven nonprofit agencies serve all who need care but are often the only agencies that take high-cost, low reimbursement patients avoided by other providers.

#### **Principles for Long Term Care Reform**

In addition to our specific recommendations on transforming the delivery of post-acute care, VNAA offers the following principles for reforming long-term care, focusing on access and patient choice.

**ACCESS:** Beneficiaries should have access to the full range of home care and hospice services. Medicare and Medicaid each offer important benefits that are necessary to the care and management of the complex conditions; and these benefits should continue. It is important to retain these benefits in full including the levels of hospice care and the interdisciplinary team as well as skilled nursing and therapy for home health services.

**COMPREHENSIVE BENEFITS:** The benefits provided to beneficiaries should be comprehensive and include all necessary long-term services and supports needed for their care, including the care they receive in their home. Financial incentives should focus on providing care in home and community settings to the extent possible and as desired by the individual.

**CHOICE:** Beneficiaries should be able to choose their own providers for their care, as well as their preferred setting, and receive appropriate education about their options.

**QUALITY AND EFFICIENCY:** Coverage should emphasize quality, coordinated care provided in the most efficient setting and offer incentives to provide this type of care. Policies should not incentivize denials of, or stinting of, care. Home health provides a cost effective alternative to other traditional long-term care settings, and allows beneficiaries to receive their care at home.

**NO COST SHIFTS TO BENEFICIARIES:** Costs should not shift to beneficiaries in the form of new or additional copays.



**MANAGED CARE:** Prior authorizations, utilizations reviews and other managed care tools must be reasonable and not barriers to care. Payment systems should be seamless and focus on covering the care that beneficiaries need. Providers should not have to be at financial jeopardy when providing covered services and should instead focus on caring for beneficiaries. Beneficiaries should receive their benefits without worrying about benefit coverage by Medicare, Medicaid or by private insurance.

**FAIR REIMBURSEMENT:** Provider reimbursement must be fair and appropriate to ensure patients can maintain access to high-quality care. In order to ensure that payments reflect the complex needs of individual beneficiaries, the risk adjustment methodology must reflect the characteristics and functional capacity of the patients.

**NO INTERRUPTIONS OF TREATMENT:** Care should be continuous with access to current providers, services, treatments and prescriptions during any transitions.

**CARE COORDINATION:** Coverage should maximize care coordination, including early intervention. Home health plays an important role in the daily coordination of care for vulnerable patients.

**STREAMLINE PAPERWORK:** Avoid duplication of effort in all aspects of delivering care. Coordinated care should lead to reduced paperwork – not more. For example, patients and providers should not complete the OASIS as well as another assessment document. Prior to awarding contracts, an agreement must exist on universal format for submission of claims. Further, these systems should be set up in advance and based on electronic submission to prevent additional administrative burdens on providers. If for any reason the decision not to use the OASIS in lieu of another tool happens then waive the OASIS completion requirement to prevent duplication of efforts.

**WORKFORCE:** Implement workforce policies that expand and sustain the direct-care workforce.

VNAA members commit to serving all people who need our services, including beneficiaries eligible for both Medicare and Medicaid. Home health services are critical for coordinating and ensuring high quality care to these complex patients. Our principles seek to preserve beneficiary choice and preference, and access to the full range of needed long-term care services and supports.

Sincerely,



Tracey Morehead  
President and CEO  
VNAA



Ph: 202.332.2275  
 Fax: 202.332.2949  
 www.theconsumervoice.org

December 23, 2013

**Statement for the Record**

**“The Future of Long-Term Care Policy: Continuing the Conversation”  
 Senate Special Committee on Aging  
 December 18, 2013**

The National Consumer Voice for Quality Long-Term Care (Consumer Voice) is pleased to submit these comments to the Senate Special Committee on Aging concerning the future of long-term care policy in our nation. Consumer Voice is a national non-profit organization that advocates on behalf of long-term care consumers across care settings. Our membership consists primarily of consumers of long-term care and services, their families, long-term care ombudsmen, individual advocates, and citizen advocacy groups. Consumer Voice has over 38 years experience advocating for quality care.

We thank the Committee for holding this hearing to examine ways to improve access to and the affordability of long-term care in the United States. The federal Commission on Long-Term Care’s report to Congress serves as a wake-up call to the urgent need to improve the delivery and financing of long-term services and supports (LTSS) in our nation. The Consumer Voice supports the broad recommendations made by this body and commends the work of the commissioners in putting forth a final report. However, we are concerned that the recommendations fail to include a concrete plan for the reform of America’s inadequate long-term care system. This result is not surprising since Congress rushed the development of a commission that had only 100 days to discuss numerous concerns surrounding the payment and provision of long-term care in our nation and come to agreement upon recommendations.

Despite the obvious limitations of the final report, such as the lack of any prospective structure that would allow consumers to better finance long-term services and supports and very little attention given to quality of life and quality of care concerns, Consumer Voice supports many of the Commission’s proposals, such as:

- The better inclusion of family caregivers in LTSS systems
- The establishment of a competent and adequately sized LTSS workforce through career ladders
- The requirement of criminal background checks for all long-term care workers

- Elimination of the 3-day hospital stay requirement for skilled nursing facility coverage under Medicare
- Reconsideration of the requirement for receiving home health services under Medicare that the individual be "homebound."

Many of these recommendations would be important steps towards improving long-term care in our nation.

Consumer Voice also expresses particular support for the minority report released by Judy Feder, Judith Stein, Laphonza Butler, Henry Claypool, and Lynnae Ruttledge of the commission. We agree that a public social insurance program that can be easily understood and navigated by consumers should serve as the core of any effective long-term care system.

We urge members of the Committee to advocate for the creation of a permanent advisory committee or council to build on the momentum created by the Commission's work. An ongoing committee is needed to delve deeper into long-term care issues and build a system that is affordable and ensures that each consumer reaches his or her highest level of well-being in a setting of his/her choice. We believe that at a minimum such a system must include the following elements:

- Standards supporting quality of life and quality of care
- Strong consumer rights and protections
- Consumer choice and direction; accommodation of needs and preferences
- Well-trained, well-supervised and adequate numbers of direct care workers
- An independent, effective ombudsman program across all long-term care settings

We hope today's hearing will serve as a call to action. It is time for Congress to make affordable, quality long-term services and supports a financial and political priority.

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*The National Consumer Voice for Quality Long-Term Care (formerly NCCNHR) is a 501(c)(3) nonprofit membership organization founded in 1975 by Elma L. Holder that advocates for quality care and quality of life for consumers in all long-term-care settings.*

1001 Connecticut Avenue, NW • Suite 425 • Washington, DC 20036

## Bloomberg

### At 61 She Lives in Basement While 87-Year-Old Dad Travels

*By Carol Hymowitz - Dec 18, 2013*

Eighty-seven-year-old Lew Manchester has just returned from a three-week trip touring Buddhist temples in Laos and cruising the Mekong Delta in Vietnam. His 61-year-old daughter Lee lives year-round in the basement of her friend's Cape Cod cottage, venturing into the winter cold to get to the bathroom.

Lew is making the most of his old age. Lee is paring back and lightening her load as she looks ahead to her later years. Both worked all their lives, both saved what they could. Yet Lew, a son of the Great Depression and former company man, and Lee, a baby boomer who has pursued careers as an entrepreneur and a mid-level manager, are winding up in two very different economic strata.

"Timing is everything and my dad's timing with jobs, real estate and retirement benefits was better," said Lee.

While plenty of baby boomers, born from 1946 to 1964, have become affluent and many elderly around the U.S. face financial hardship, the wealth disparity of this father and daughter is emblematic of a broad shift occurring around the country. A rising tide of graying baby boomers is less secure financially and has a lower standard of living than their aged parents.

The median net worth for U.S. households headed by boomers aged 55 to 64 was almost 8 percent lower, at \$143,964, than those 75 and older in 2011, according to Census Bureau data. Boomers lost more than other groups in the stock market and housing bust of 2008, and many also lost their jobs in the aftermath at a critical point in their productive years.

#### Worse Off

That's left many ill prepared to provide for themselves as they approach old age, even as they are likely to live longer than their parents. For the first time in generations, the next wave of retirees will probably be worse off than the current elderly. More than half of those aged 50 to 64 think their standard of living in retirement will be somewhat or much worse than their parents, according to a [2011 survey](#) by the AARP Public Policy Institute.

"Baby boomers are the first generation without the safety net of pensions and other benefits their parents have," said [Alicia Munnell](#), director of the Center for Retirement Research at Boston College. "They're facing a much more challenging old age."

Lee Manchester knows she'll have a more austere old age than her father's. She made a choice early on, seeking to become an entrepreneur rather than work for a large company with benefits, as he did. After running a real estate business with her Cape Cod friend, Brita Tate, she started a commercial construction company when she was 34. Instead of saving for retirement, she borrowed and spent money on her venture.

## Work Ethic

To be sure, many parents have had more financial success than their children and Lee conceded that she's made a mistake or two along the way. Still, like many of her generation, Lee pursued a steady path, forging ahead in the wake of economic headwinds and career setbacks.

Lee said she harbors no resentment for her dad, who she credits with instilling her with a strong work ethic. As teenagers, she, her older sister and her younger brother, all in their 60s now, each paid 5 cents a mile whenever they used their dad's car. After graduating from University of Wisconsin, she married her high school boyfriend and followed him to Arizona, where he was training to be an Air Force pilot. She worked as a substitute teacher until the couple returned to Hartford, Connecticut, where they'd both grown up.

"I was never allowed to dream," she said. "My parents and then my husband expected me to work, and I couldn't really think about what I most wanted to do."

## New Company

Lee got the courage to stretch when she started a commercial construction company in 1986 with \$150,000 from her divorce settlement. She hired a dozen employees and succeeded in landing contracts supplying steel parts for buildings, until the construction industry slumped in 1989.

"When the company went down, my father was likely shaking his head and thinking, 'Holy mackerel, what is she doing?'" she said.

Her father, in fact, has never blamed Lee. "She did her best and tried to make it work," he said.

Bouncing back, Lee became a sales manager in the airport parking business. Still, she didn't start saving for retirement until she was in her late 40s, when her employer established a 401(k) account.

## Median Savings

Lee is hardly the only baby boomer who didn't save enough, worked for companies without 401(k) accounts or lost significant amounts in the financial crisis. Today, her retirement savings of \$120,000 are right at the median 401(k) balance for households headed by baby boomers, according to 2011 data from the Center for Retirement Research at Boston College.

That will provide just \$4,800 a year to boomers when they turn 65, assuming they take out 4 percent annually, the limit financial planners say should be withdrawn to assure retirees don't run out of money in their lifetimes.

Her father said both he and Lee's mother worried about her finances and helped her raise her sons. They baby-sat regularly, and Lew took his grandsons camping. And they reduced the rent on the apartment Lee rented from them so she could send her younger son, who was having trouble in junior high, to a boarding school in ninth and 10th grades.

"It was our privilege to help raise our grandsons, and we thought of a way to help with their education that wasn't just writing a check to the school," her father said.

### **Fewer Pensions**

Had boomers like Lee been thriftier, they would have still been hurt by a shift to 401(k) accounts from pensions in the 1980s. Thirty-seven percent of the elderly in the U.S. collect pensions, which provide some guaranteed income until they die. Fewer than 10 percent of boomers collect pensions, and that number is quickly shrinking.

Lee thought her finances were improving in 2008 when she was recruited as the business development manager at Parking Co. of America for \$70,000 a year, a 25 percent jump over her previous salary. Then the economy tanked. After one year she was laid off, just a few months before her employer filed for bankruptcy.

During the next two years Lee took whatever part-time jobs she could find, including telemarketing from home. She was remarried by then and her spouse's modest income helped cover living expenses. She resisted dipping into her depleted retirement account.

"I sold my silver, but didn't touch my savings, even when the value fell to \$35,000, from \$80,000, at one point," she said.

### **Mounting Costs**

Although she found a new job in 2010 as manager of the customer service department at Holo-Krome Co., a manufacturer of metal fasteners, with an annual salary of \$52,000, it lasted only two years. She was laid off again just as her second marriage ended. Lee could no longer afford to cover the costs of her four-bedroom house, which she purchased for \$225,000 at the height of the housing bubble. Her health insurance costs rose to more than \$400 a month.

She asked her father for a loan to cover the legal costs for her divorce last year. He sent her a check within days.

"She has never complained to me about not having enough money," he said. "But if she needs it, I'll advance it."

Lee, who has repaid the money she borrowed, avoids dwelling on her difficulties during her weekly calls to her dad.

"I know he'll help me if I fall off the ledge, but he taught me to be self-sufficient," she said.

When she told him she'd have to either sell or rent her house in West Hartford, he suggested she move close to his assisted living residence in Sonoma, California, where she could rent an apartment for about \$1,300 a month.

"That was more than I was earning," said Lee.

## **Housing Plan**

Instead, she came up with a plan she thought would help both her and her former real estate partner and friend. Brita Tate, 70, had spent summers at Lee's house while renting her one-bedroom cottage in Wellfleet, Massachusetts, an artsy coastal enclave near the tip of Cape Cod much coveted by summer vacationers.

"I asked, 'How do you feel about me coming to you now?'" said Lee, who offered to pay \$400 a month to rent Brita's basement. That would be enough to cover her friend's real estate taxes and other costs so she would no longer need summer renters.

"She's a very caring woman who has helped me so many times," said Tate. "I said, 'Move in as soon as you're ready.'"

## **'Breathing Room'**

The arrangement, Lee figured, would also allow her to hold on to her house in Hartford by renting it for \$1,600 a month, enough to cover her mortgage and taxes. Though the house is still worth less than she paid for it, Lee is hoping that if she holds on to it long enough, she'll be able to one day recoup her investment.

Her father was relieved.

"She would have a place with an old friend and some breathing room before she found another job," he said.

Lee moved to Wellfleet last February when the town's population, which quintuples in the summer, was less than 3,000 and most stores and restaurants were shuttered. Before leaving Hartford, she sold jewelry she'd inherited from her mother and grandmothers, gave her best furniture and household items to her sons, now 33 and 31, and donated or discarded the rest.

She arrived with a bed, a dresser, a hope chest, a small desk, a small amount of clothing, photos and artwork, and her two cats. That was plenty for the 250-square-foot finished basement space adjacent to the laundry room.

## Less Stuff

“It’s liberating finally getting to a point in my life where I don’t need a lot of stuff,” she said. “I felt like I was getting rid of the baggage of life that I’d kept dragging behind me and which was just weighing me down.”

Within a month, she found a job managing the spa at Crowne Pointe Historic Inn in nearby Provincetown. It’s a year-round position, hard to find on Cape Cod. She earns \$13.50 an hour, working as a combination hostess, receptionist, fixer of gym equipment and laundress.

“Everyone here is on vacation, so no one is ever complaining,” said Lee.

After work, she fixes a salad for dinner and chats with Brita. Before heading to the basement, she makes sure to use the bathroom. There’s only one in the house and getting to it from her bedroom requires going outside and climbing the patio steps.

## Trimming Expenses

Lee has cut her expenses by more than a half and is living on about \$2,000 month. She spends less than \$100 a month in Massachusetts for health insurance, a big incentive for her move. Gasoline is 30 cents a gallon cheaper in Wellfleet than Hartford and her car insurance is \$700 a year instead of \$1,200. She takes lunch to work instead of spending \$8 for a sandwich and gave up diet Coke to save a few more dollars each week.

Lew Manchester doesn’t worry about how much he spends on lunch, nor has he ever since retiring 23 years ago when he was 64. Every month, in addition to his \$1,750 Social Security payment, he gets two pension checks: \$1,000 from Marsh & McLennan Cos., the last insurance company where he worked, and \$783 from the military for serving in the Army Reserve for 20 years.

He also has more than \$800,000 in savings, close to \$400,000 of which he cleared from the sale of his Hartford home in 2005, when he and his then ailing wife moved to an assisted living residence in northern California, three years before the housing market crash. During the next five years, while caring for his wife, who died in 2010, he was able to save more. A long-term care policy he’d purchased years earlier for \$500 a month over 10 years paid out more than \$275,000, covering most of their living expenses, and it’s still available for him to use if he needs it.

## Medical Complications

Lee could use a policy like that. She has multiple sclerosis, a disease she has controlled with medication and exercise for 27 years. Given her medical history, she doesn’t think she’d be eligible for long-term care insurance, although she can’t afford even a modest policy.

“I can’t worry about what I don’t have,” she said. “I have to focus on what is.”



That puts Lee among the swelling ranks of older Americans vulnerable to soaring medical costs. Hospital, doctor and medicine expenses for a 65-year-old couple retiring this year are expected to be \$220,000 over the course of their lives, as company-paid retiree health benefits disappear and the cost of Medicare rises, according to Fidelity Investments.

Lee hasn't discussed her health coverage with her father, who said he hopes she has "enough for her needs."

Her dad also knows he is fortunate to have had a working spouse. Lee's mother started a real estate business when the couple's children were teenagers. She saved some of her income in a Roth IRA that has grown to about \$250,000.

### **'Happy Money'**

"I call that fund my happy money," he said. He uses it to pay for his travel, a pursuit he's loved since the Army stationed him in Japan shortly after World War II.

He's planning another trip to Hawaii this February with his new girlfriend, who's 77. In the spring he'll visit Lee for the first time in Wellfleet and then fly to Portugal.

Lee told him on a recent phone call that she's glad he's healthy enough to travel and that she likes his girlfriend.

"After taking care of mom for 10 years, you deserve to have fun," she said.

Lew has done careful estate planning and expects to leave money to each of his children and five grandchildren. Every Christmas he writes them each a check for several hundred dollars and this year plans to be more generous.

"The farther I go along, the less I need, so I'm loosening the purse strings," he said.

### **Looking Back**

Lee sometimes can't help dreaming about the trips she'd be planning if she'd invested the \$150,000 she spent to start a construction company.

"If I'd done that, I wouldn't be where I am now," she said. Still, "launching the business was the most fun I ever had and my way to fight a frightening medical diagnosis."

Lee doesn't regret downsizing her life. She has more time than ever to enjoy the outdoors, read and spend time with her friends.

"There's so much pressure to keep up, to keep buying things, to stay on the treadmill always hoping to have more," she said. "Well, less can be better."