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**THE ROLE OF LONG-TERM CARE
IN HEALTH REFORM**

HEARING
BEFORE THE
SUBCOMMITTEE ON HEALTH CARE
OF THE
COMMITTEE ON FINANCE
UNITED STATES SENATE
ONE HUNDRED ELEVENTH CONGRESS
FIRST SESSION

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MARCH 25, 2009
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CONTENTS

OPENING STATEMENT

	Page
Rockefeller, Hon. John D., IV, a U.S. Senator from West Virginia, chairman, Subcommittee on Health, Committee on Finance	1

WITNESSES

Feder, Judy, Ph.D., senior fellow, Center for American Progress Action Fund, Washington, DC	4
Scheppach, Raymond C., Ph.D., executive director, National Governors Association, Washington, DC	6
Smith, Dennis G., senior research fellow in health care reform, The Heritage Foundation, Washington, DC	8
Wiener, Joshua M., Ph.D., senior fellow, RTI International, Washington, DC ..	10

ALPHABETICAL LISTING AND APPENDIX MATERIAL

Enzi, Hon. Michael B.: Prepared statement	31
Feder, Judy, Ph.D.: Testimony	4
Prepared statement	32
Hatch, Hon. Orrin G.: Prepared statement	43
Rockefeller, Hon. John D., IV: Opening statement	1
Prepared statement	45
Scheppach, Raymond C., Ph.D.: Testimony	6
Prepared statement	48
Smith, Dennis G.: Testimony	8
Prepared statement	51
Wiener, Joshua M., Ph.D.: Testimony	10
Prepared statement	62

COMMUNICATIONS

Assisted Living Federation of America	83
Deland, Jennifer A.	86
Kapp, Marshall B., J.D., M.P.H.	88

THE ROLE OF LONG-TERM CARE IN HEALTH REFORM

WEDNESDAY, MARCH 25, 2009

U.S. SENATE,
SUBCOMMITTEE ON HEALTH CARE,
COMMITTEE ON FINANCE,
Washington, DC.

The hearing was convened, pursuant to notice, at 2:35 p.m., in room SD-215, Dirksen Senate Office Building, Hon. John D. Rockefeller IV (chairman of the subcommittee) presiding.

Present: Senators Wyden and Cantwell.

Also present: Democratic Staff: Jocelyn Moore, Legislative Assistant, Health; Brian Hensel, Fellow, Health; David Schwartz, Health Counsel; and Kate Gross, Legislative Assistant. Republican Staff: Patricia Deloatche, Health Policy Director; and Kelly Whitener, Fellow.

Also present: Chris Hildebrant, ADAPT.

OPENING STATEMENT OF HON. JOHN D. ROCKEFELLER IV, A U.S. SENATOR FROM WEST VIRGINIA, CHAIRMAN, SUB- COMMITTEE ON HEALTH, COMMITTEE ON FINANCE

Senator ROCKEFELLER. Welcome, everybody.

The attendance today is actually the fullest that I have seen it in 24 years. That was a joke. [Laughter.] We are all here, all of us, for exactly the same purpose. Just as a point of mild pique, a statement, I have either been chairman or vice chairman of the Health Subcommittee for 14, 15, 16 years, something of this sort, and this is the second committee meeting we have had, which tells you, sometimes, how things do not work the way they should. Because we have the whole health care thing before us and we want to do it all, then long-term care has to be a part of it or else it does not work.

The President wants to do the budget and everything—environment, energy, health care, education, everything—all at once. And he is exactly right: you have to do them all at once. No matter what it costs, you have to do it because, if you do not, you fail in the future. You can fail because you cannot pay your debts, or you can fail because you just never get there.

So again, I do welcome all of you. I am just trying to find my opening statement; it is prosaic, but it is passionate.

A long time ago, somebody by the name of Dr. Judy Feder had this thing called the Pepper Commission—and it had a much longer name than that. Unfortunately, Claude Pepper died, and they had all of the sort of “bigs” in the Senate on it, except for me.

But I cared. So nobody wanted to be chairman. I said, well, I do, because I figured that was my way to learn health care. This was in 1989 and 1990. We produced the only comprehensive health care bill that has ever been produced by the U.S. Congress. It did all of acute care and all of long-term care, and we won both. We won quite closely.

But the long-term care we passed rather easily, 11:4, and it was declared by those who did not like it “dead on arrival,” because health care’s time had not arrived, evidently. So this is now, as we launch into the Obama—and that is not to be political. This is because he is President, and one sort of recognizes presidents. He wants to do health care, and he wants to do the whole thing. I really like that. Judy Feder became my mentor. Well, you did. I do not think you have any particular reason to be proud of that, but I am.

Dr. FEDER. I am.

Senator ROCKEFELLER. And we have expert witnesses who will not get similar praise, which is not fair, because I worked with Ray Scheppach for years, and others. The actual name of that commission was the U.S. Bipartisan Commission on Comprehensive Health Care. Why do we name things that are important with such awful names as that? So we just called it the Pepper Commission.

Anyway, in the 20 years since we made those recommendations, we have done nothing. Congress has done nothing, the administration has done nothing. If they have done something, it has not been with any intensity. To me, the whole business of achieving anything in health care, whether it is acute care or long-term care, is intensity, is just voracious intensity, moral outrage that does not stop.

To get health care, that is what you have to have. Benefits are severely limited. I can remember, we used to talk—as we still have to—if you are going to fit into long-term care now under Medicaid, you have to spend yourself into poverty. I remember we started talking about that back in those days, and we are still talking about that, because that is still the only way you can do it. Except that the numbers on long-term care have jumped so enormously—so enormously—and the baby boomers are 2 years away, I think—am I right, my four panelists?—before they all qualify for getting this. A lot of long-term care is not for people who are older, it is for people who are between the ages of 16 and 60. A lot of it, something like 46 percent.

So they make the mistake—I am going to an Alzheimer’s dinner tonight. My mother had Alzheimer’s, and my wife Sharon’s father has Alzheimer’s, and we are going to get an award, with a lot of other people, from Sargent Shriver, who is one of my ultimate heroes, one of the five great people in American life, as far as I am concerned, who himself has Alzheimer’s. His daughter, Maria, is going to present it to us. I think back to when my mother had Alzheimer’s.

Our family could afford to get her all the care that she needed, which was endless numbers of oxygen tanks and fights with doctors over this, that, and the other thing, and biting down on feeding tubes and advanced directives. We just went through endless, endless fury to keep somebody alive who did not want to be kept alive, and who finally made that clear by biting down on her feed-

ing tube. That was her signal. All of her children were around, all of her children agreed. If one of the children had not agreed, then we would not have been able to do it under New York State law. So we took her home, and she died 3 weeks later, but very peacefully, with morphine and Bach, Mozart, and Handel. That was the way she wanted to go, and that is the way she went. The way that she would have wanted to go.

Payments for long-term care are so disjointed. Why is that? Because we do not focus on it, because we do not talk about it. Young people, a lot of people, just do not think long-term care is obtainable. People do not offer it, or, if they do, it is too expensive.

We have all these silos. I mean, in the intelligence community they talk about, the CIA would not—after 9/11, we had to pass a bill saying that it was all right for the FBI and the CIA to talk to each other. Well, that is kind of the way it is in health care, and particularly in long-term care. Insurance companies, of course, do their best to stay away from being a part of anything to do with this.

So, when long-term supports and services are available, they are always extremely expensive. In 1988—this is interesting to me; that is when we were doing our work—a short stay in a nursing home cost more than \$2,500 a month, on average, and exceeded most Americans' incomes. In 2008—20 years later—the average annual rate for a private nursing home was \$76,000. That is more than \$6,300 a month, on average.

So in 1988 we spent \$53 billion on long-term care. What does it get us? We are not sure. Does it have anything that anybody can depend upon? No. Does anybody really understand it? No. Does anybody have the political will to undertake it? No. The chairman of this committee has what is called a white paper, which is meant to be very good, but it has no long-term care in it. It is not mentioned. It is not mentioned. Long-term care is the one thing every single person will face. Every single person faces. Nobody does not do long-term care unless they die in a head-on crash. I mean, that is the way I look at it.

So we are trying to do better. This is our first hearing on this subject. I will stop talking and we will have questions, and some people will come, hopefully. If they do not, that is fine with me. Then I will get to ask all the questions.

First, we have Dr. Judy Feder, who is senior fellow at the Center for American Progress Action Fund. I keep saying you are dean at Georgetown.

Dr. FEDER. I am a former dean.

Senator ROCKEFELLER. I know you are a former dean.

Dr. FEDER. But I am still a professor of Public Policy at Georgetown.

Senator ROCKEFELLER. All right. Well, that helps a lot.

Then we have Dr. Raymond Scheppach, whom I knew when I was Governor. He is executive director of the National Governors Association. He has been working on this problem.

Then we have Mr. Dennis Smith, who is number three, who is the senior fellow in health care reform at The Heritage Foundation Center for Health Care Policy Studies, where he is working on

ways to improve the Medicaid program, including the future of long-term care.

Then, fourth, Joshua Wiener. He is a senior fellow at Research Triangle Institute International. I guess that is, if you take Duke and North Carolina University, incorporate them, and then internationalize them. Is that what that is? It is kind of a limited partnership. Something like that. Anyway, he is the program director there of Aging, Disability, and Long-Term Care at RTI international.

So I look forward to statements and conversation. We will start, amazingly enough, with Dr. Judy Feder.

STATEMENT OF JUDY FEDER, Ph.D., SENIOR FELLOW, CENTER FOR AMERICAN PROGRESS ACTION FUND, WASHINGTON, DC

Dr. FEDER. Thank you, Mr. Chairman. It is a great pleasure to be with you today and to continue the effort that you have been championing for a long 20 years, to have health reform include long-term care reform so that everybody, the people who need both, can get both. You called for that 20 years ago, said the time was “now” then, but the time is clearly “now” now. So I am sure many in the room join me in thanking you for this hearing.

Sadly, the mythology about long-term care that the Pepper Commission report sought to counter still inhibits our ability to move forward. As you have said, the facts are that young, as well as older, people need long-term care. It is true that many, many people will need long-term care if they live long lives. But actually, even among older people, there is tremendous variability in the likelihood of needing long-term care, extensive care. It remains an unpredictable catastrophic risk. Despite claims to the contrary, families are giving their all in caring for their loved ones who need long-term care.

Senator ROCKEFELLER. And I totally forgot to mention that. Thank you.

Dr. FEDER. Well, I think you demonstrated it with your comments on your own family, and I thank you for that.

I think that you know the problem with today’s long-term care system is not that individuals and families are not giving enough, it is that they do not have enough to give. That is why we so desperately need public support that actually spreads the risk and the burden of needing long-term care rather than leaving it concentrated and such a heavy burden on just those families who experience it.

Fortunately, we have ways we can go. We proposed some 20 years ago—and I have a few proposals that I wanted to lay out for you today, because we definitely have options. I am going to give you four examples. Two focus on the low-income population—on improving Medicaid while slowing the growth in its costs—and the other two, a phase-in broad public long-term care insurance for the future so that people do not remain underserved and at risk of losing everything.

So, first on my list for consideration is to assure broader Medicaid support for care at home, where people want to be, rather than in nursing homes. Home care was a focus of the report 20 years ago. Different proposals do that in different ways. I think we

have a lot of advocates for the Community Choice Act with us. [Applause.]

So you know I hate to modify your eloquent statement, but I do believe that Senator Baucus, in the white paper, does have a mention of improving Medicaid for long-term care for home- and community-based services, so we will look at that.

Senator ROCKEFELLER. Good.

Dr. FEDER. Good. And if supported by Federal dollars and changes in Medicaid, we really can make a significant difference in assuring that people, no matter where they live, no matter what State they live in or within States, that they have access to services.

Now, a second proposal that affects both Medicaid and Medicare beneficiaries is to better integrate acute and long-term care for the Medicare/Medicaid, or as you know, dual eligibles, who need both. Now, dual eligibles are really the poster children for the population who can benefit from what we are talking about in better coordinated and better chronic care.

There are many models that exist. There is sometimes a quick move to just changing payment for services, but I would urge us, as we move toward that model, to make sure that we are focused on what we are actually delivering and on supporting a delivery system that works. But I believe there is promise in that regard.

Now, for the future. That is what I would like to see us do this minute. Well, I would like to see us do it all this minute, but that takes care of the low-income populations. I believe that what we can do is start today to take care of all of us in the future by phasing in public insurance protection across the income scale.

One option that we received, developed for our Robert Wood Johnson long-term care financing project, was to develop a Medicare benefit that would be phased in, so today, not available to people who are currently 60 years of age or older, but pre-funded, so that contributions are made today, and we are essentially paying for ourselves when we get older.

A second option, the CLASS Act, would create a new long-term care benefit, again, starting with the working-aged population and financed through a voluntary deduction from payroll, and, unlike Medicare, providing a cash benefit. Again, although available to people in nursing homes, it's focused on people at home, just as the social insurance recommendations of the Pepper Commission report did years ago.

Now, you know better than anybody how challenging it is to move forward. But as you wrote, and I wanted to quote what you wrote 20 years ago, after the Pepper Commission reported out, you said the following: "The President and the Congress have a choice. We can continue to duck our heads and hope this issue will not bring the Nation to its knees, or we can use the Commission's recommendations as the rallying point for building the political consensus that can make universal coverage for health and long-term care a reality. I—you—opt for the latter course, not just because it can work, but because it is the only responsible means to take action that we know is imperative."

Mr. Chairman, now is the time. With new presidential leadership, a powerful necessity to invest in rebuilding our Nation's pros-

perity, and new excitement about our Nation's and our government's potential to build a better future, now is the time to confront those policy, political, and fiscal challenges you know so well, to build a better long-term care system. I look forward to continuing to work with you to do just that.

Senator ROCKEFELLER. See, we are breaking all rules today, all right? Because I am the only person here, so I cannot be voted out of order. The fascinating thing to me is that the President understands better than anybody else that you cannot have a recovered economy unless you have done health care, that the two are just like this.

Dr. FEDER. Absolutely.

Senator ROCKEFELLER. Excuse me.

Dr. FEDER. Thank you.

Senator ROCKEFELLER. You are not finished?

Dr. FEDER. I am finished.

Senator ROCKEFELLER. You did not say that.

Dr. FEDER. I said I looked forward to continuing to work with you. [Laughter.] That was meant to be—so I am now finished with this statement and look forward to continuing to work with you. [Laughter.]

Senator ROCKEFELLER. I see. I see. I have never heard you short before, Judy.

Dr. FEDER. Well, I was trying to do the 5 minutes, Senator.

Senator ROCKEFELLER. Well, we could be relaxed about that.

Dr. FEDER. All right.

[The prepared statement of Dr. Feder appears in the appendix.]

Senator ROCKEFELLER. Dr. Scheppach?

STATEMENT OF RAYMOND C. SCHEPPACH, Ph.D., EXECUTIVE DIRECTOR, NATIONAL GOVERNORS ASSOCIATION, WASHINGTON, DC

Dr. SCHEPPACH. I am beginning now. [Laughter.]

Mr. Chairman, I appreciate the opportunity to appear before you today on behalf of the Nation's Governors to discuss the critical issue of long-term care and the need to include this issue as part of general health care reform.

To put it simply, failure to reform the under-funded, uncoordinated patchwork of long-term care supports and services is a failure to truly reform health care. This is an opportunity and a responsibility to do so now as part of the general health care discussions under way. On behalf of the Nation's Governors, I urge you to give equal attention to this critical component of the Nation's health care system.

The broader reform discussion so far has focused on improving the coverage, cost, and quality aspects of primary and acute care services, with an emphasis on prevention. These are the exact same issues with respect to reforming long-term care, and thus make it both a moral and fiscal imperative to undertake both simultaneously.

Mr. Chairman, I would like to make three primary arguments in favor of including long-term care with general health care reform. First, if we were starting anew to build a national long-term care public program, it would not look anything like the current pro-

gram. Currently, as elderly individuals' health status and income deteriorate, they get services from two different programs, State-administered Medicaid and federally administered Medicare, with very little coordination and little ability for the individual to understand which level of government is providing which services and which one should be held accountable.

This is further complicated by the fact that there are often limited incentives for cost containment, since the action by one level of government often accrues only savings to the other level of government. The bottom line is that, from a quality, efficiency, and accountability standpoint, the structure of the existing system gets very poor grades.

The second point is that, unfortunately, the wrong level of government has financial responsibility for most of long-term care. From a federalism standpoint, a national division of responsibilities has emerged in the Nation, starting with Social Security in 1935, and then through enactment of Medicare and Medicaid in 1965, to the present.

Essentially, the Federal Government took 100 percent of the responsibility, both administratively and financially, for the elderly, for those over 65. This is seen in both Social Security and Medicare.

This has been a distinct advantage in that it allowed the Federal Government, through its taxing and spending authorities, to redistribute funds for a mobile program so that no State that had an unusually high level of elderly would be held responsible. That seems to be a traditional role of the Federal Government.

States, on the other hand, took administrative, and to a large extent financial, responsibility for working Americans and their children through education, job training, nutrition, welfare, and other programs. When Medicaid was essentially a health care program for low-income women and children, this was a rational division of responsibilities, as States could coordinate health care with other similar programs for that population.

Long-term care, however, with substantial State financing is inconsistent with this basic federalism division of responsibilities. Long-term care, which is mostly—at least a majority of it—for the elderly, should be a Federal responsibility.

Third, not only is it the wrong level of government—meaning States—that has the major financial responsibility, but also States cannot sustain this program financially. I know States have made this point a number of times, but we all know the demographics in long-term care. It is the fastest-growing component and is likely to accelerate in the foreseeable future.

Unfortunately, both the short- and long-run fiscal viability for the current arrangement has eroded substantially for States over the last couple of years. My best estimate is, even after you factor in the recovery plan that you just enacted, States still face short-falls of well over \$200 billion over the next 3 years. Even after that period, I suspect the U.S. economy will emerge in a very different form than we entered this recession. Unfortunately, I suspect slower growth is probably highly likely.

This means States probably, going forward, cannot even fund the current level. Unfortunately, I would argue that, from this point

on, expansions, or just the normal growth in level of care, will be paid for by cuts in elementary, secondary, and higher education.

The bottom line, Mr. Chairman, is that the structure of our long-term care system in this country is broken. It does not deliver quality service, and it is uncoordinated. Not only is it inefficient, but it has perverse incentives. It is financed by the wrong level of government, which is unable to sustain it.

Our fear is that, if the Congress does not include meaningful long-term care reform at this time, it will be 20, 30, or 40 years before it is on the table again. It would be unfair to the Nation's most vulnerable citizens and irresponsible to the Nation to not incorporate it at this time.

Thank you, and I am finished. [Laughter.]

[The prepared statement of Dr. Scheppach appears in the appendix.]

Senator ROCKEFELLER. All right. Thank you, Ray. And I do not agree with you that it will be another 20 or 30 years. I think we are going to be on this until we have done it. It is like climate change, it is like giving veterans the health care they deserve, this kind of thing. I just think it is with us until we get it done, no matter how much it costs. And incidentally, on the States and Medicaid, I am a big non-believer in Medicaid waivers, which either you do or do not agree with, but I know Judy does.

You cannot hold States harmless. Everything changes. Everything changes. EPA has come out with some administrative announcement about Mountaintop removing West Virginia, which I am not unsupportive of. I think the coal industry has not changed in 150 years. There has been no reason to. Everything has been profitable. Now everything is different. Everything is different, everywhere. States are going to be run differently. The Federal Government is going to be run differently. We are going to be living under debt, deficit. So I do not hold anybody harmless on anything. I do not think we can at this point. We may come to that point.

Dr. SCHEPPACH. That is fair.

Senator ROCKEFELLER. All right.

Mr. Smith?

STATEMENT OF DENNIS G. SMITH, SENIOR RESEARCH FELLOW IN HEALTH CARE REFORM, THE HERITAGE FOUNDATION, WASHINGTON, DC

Mr. SMITH. Thank you, Mr. Chairman. It is great to be with you again. First, let me say that my testimony reflects the views of only myself, not of my current employer, and not of my previous employer, the Federal Government. So you all posed four great questions, and I have tried to come up with four, what I hope will be recommendations for serious consideration to reflect the changes there have been.

First, I would like to say there has been some progress for which I think that we can be proud of, part of it attained through waivers. Quite frankly, I think the greatest credit goes to the families themselves, very much so when you look at the increase in the percentage of Medicaid spending on long-term care for people with disabilities. That has now shifted to where a majority for that popu-

lation is spent in home- and community-based care rather than institutional care.

In the year 2000, of total long-term care spending, 72 percent went to institutions. In 2007, that had dropped to 58 percent. So, we have made progress. But I think it is very interesting to note that 63 percent of the Medicaid spending on long-term care is now in the community rather than in institutions. But for the elderly, 69 percent of their long-term care spending under Medicaid continues to be in the institutions. I think for a large part, people with disabilities, it is the families who demanded the change and who I think really led the way.

In terms of recommendations, first, I would say Medicaid needs to be reorganized, in itself. That should start by leveling the playing field between institutional and community-based care. It makes no sense to me why an institution is a mandatory service under Medicaid, but to live in your own home and in your own community is an option for which you have to go to the Federal Government, saying, may I please? We have now had over 25 years of experience with home- and community-based waivers. I think it is time that the statute itself keep pace with the people that it serves.

People with disabilities account for 51 percent of the Medicaid long-term spending. I think you need an agency that is prepared to lead the way for the future. In all due respect to my former colleagues at CMS, I believe that CMS is too big and too slow to lead the change.

Picking up on your opening remarks, I believe there should be a consolidation of functions in an entirely new agency that is focused on the needs of people with disabilities, to provide them with the assistance that you need. If you asked a person with a disability, what type of assistance do you need from the Federal Government, chances are pretty good the answer would be "a job." They want to become taxpayers. They want to work.

If we change our institutions at the State and Federal level for them to attain what they want, then they will not only become more satisfied with the way government is serving them, they will also become taxpayers as well, reducing the cost of Medicaid, SSI, food stamps, et cetera. But I think you do need a new agency to lead the way.

I would not, though, distinguish policies in terms of people with disabilities versus our elderly, because I think they basically want the same thing, which is person-centered, money-follows-the-person types of arrangements, even though there might be different selections. A young person with a disability, for example, is much more likely to choose employment-supported type of activities than perhaps an elderly person, but then they would have an equal choice of what type of services that they want.

Our current programs' basic message to people with disabilities is, do not work, do not become independent, do not plan for the future. For that remedy, I would recommend that we create what we called previously Living with Independence, Freedom, and Equality Accounts, or LIFE Accounts, which would be tax-exempt special accounts where people can build assets to plan for the future. Under current law, if you build assets, you lose your health insurance. I

think that is exactly the wrong message to send people with disabilities.

My final point—I see my time is expiring—is to look specifically at the models that I think are very successful out there that achieve two principal things that we are trying to achieve, which is to give people the choices they want, but also to make it more cost-effective. I would encourage the committee to look at Washington and Oregon, which have long been considered the leaders in home- and community-based services, and yet they also spend considerably less on a per capita amount. Washington spends 30 percent less than the U.S. per capita for people with disabilities; Oregon spends 21 percent less per capita than the U.S. average.

I think what we also need, at the final round, though, is to change Medicaid financing. I saved financing for the last, because, if you talked about financing first, you tend not to get to the other issues. But I think we need to recognize (A) the current financing system is not working for States to begin with, and (B) it also actually becomes a barrier to move to home- and community-based services, because institutional providers themselves have an advantage under the current financing situation. Institutions can put up a non-Federal share of the match.

Institutions can pay what are called provider taxes, or assessments, so they become part of the financing solution, so they have an advantage over community-based care. There are good reasons to want to change the reimbursement structures. Again, over the past, it has been considered good public policy not to pay for an empty bed in a nursing home, for example. But in a movement towards home- and community-based services, though, in order to maintain quality of care while a facility is down-sized and taken offline, there are very good reasons to want to change the reimbursement system. To be able to do that in a more cost-neutral way, you then are also going to have to change the financing.

I am well over time. I look forward to your questions.

Senator ROCKEFELLER. Do you see any blinking red lights? We turned them off. [Laughter.]

Mr. SMITH. Oh, you are very kind. Thank you.

Senator ROCKEFELLER. Thank you very much.

[The prepared statement of Mr. Smith appears in the appendix.]

Senator ROCKEFELLER. Dr. Wiener?

**STATEMENT OF JOSHUA M. WIENER, Ph.D., SENIOR FELLOW,
RTI INTERNATIONAL, WASHINGTON, DC**

Dr. WIENER. Thank you, Mr. Chairman. I appreciate this opportunity to testify today on financing reform and long-term care.

During my time today I would like to make five points. First, long-term care should be part of health reform for four reasons. First, with the aging of the population, the number of people with disabilities is sure to grow substantially. The number of older people with disabilities will approximately double between 2000 and 2030. Second, the Federal and State governments spend substantial amounts of money on long-term care. In 2006, the public sector spent about \$150 billion on long-term care for people of all ages, primarily through Medicare and Medicaid. The government's fiduciary responsibility requires it to spend its money wisely. Third,

not only do older people and younger persons with disabilities use expensive long-term care services, they have high medical care costs related to their underlying chronic illnesses. Addressing chronic illnesses solely through the medical care system is certain to fail in terms of controlling those costs. Finally, the current system is broken and needs to be fixed. The system is biased towards institutional care, the financing system forces people onto welfare in the form of Medicaid, it is the leading cause of catastrophic out-of-pocket health care costs, and all too often the quality of care is poor.

Second, the aging of the baby boom generation will increase spending for long-term care, but these higher expenditures will be manageable. We can afford to improve the long-term care system. Too often, people have viewed the potential increase in demand for long-term care—

Senator ROCKEFELLER. Dr. Wiener, why do you say that they will be manageable?

Dr. WIENER. That is exactly the point I am getting to now.

Too often, people have viewed the potential increase in demand for long-term care in apocalyptic terms and used that as a reason to avoid the problem. They say we cannot afford what we are doing now, so obviously we cannot afford any improvements. But total public and private long-term care expenditures were about 1.5 percent of Gross Domestic Product in 2005. Projections done before the current economic downturn suggest that they are likely to increase to about 3 percent of GDP in 2040, assuming that we have modest, but positive, economic growth. If we do not return to positive economic growth, then I am sure this committee will be concerned about many other things.

Third, many other countries, such as Sweden, Japan, Germany, and England, already have populations that are much older than ours, without dire results. Sweden, which has over 17 percent of its population over the age of 65, compared to our 12 percent, spends 3 percent of the Gross Domestic Product for long-term care. So my point here is not that we should not be concerned, because we should. My point is that it is a substantial problem, but one that we can, in fact, afford to fix.

Third, long-term care financing reform should be designed to shift the service delivery system towards home- and community-based services. The vast majority of older and younger people with disabilities live in the community and want to be there. Only about 17 percent of people with disabilities live in nursing homes.

Yet, in 2002, only 37 percent of older people who needed assistance with the activities of daily living received any paid home care. As Dennis alluded to, although Medicaid home- and community-based services for older people and younger persons with physical disabilities have been increasing, only 31 percent of Medicaid long-term care expenditures were for non-institutional services in 2007.

Fourth, private sector initiatives can do more, but they are not likely to be a major source of financing without large public subsidies. A private long-term care insurance market has existed since about the mid-1980s, but in 2005 only about 7 million policies were in force, covering between 8 to 10 percent of older people and much less than 1 percent of the non-elderly population. The major barrier

is cost. A good-quality policy purchased at age 65 costs more than \$2,800 per year, too expensive for most older people.

There are many options to reduce price, but unless they radically—and I underline the word radically—reduce the costs, they are unlikely to substantially increase the number of insurance purchasers.

The qualities of policies have improved over the years, but far too many policies still provide no inflation projection, and almost none have non-forfeiture benefits. More regulation is needed, and that can be accomplished here in this committee.

Fifth, and finally, the limitations of private initiatives means that long-term care financing is likely to continue to be dominated by public programs. Three-quarters of people in nursing homes have their care paid for by either Medicaid or Medicare, and much of the private payment is, in fact, Social Security and other public programs.

According to the Organization for Economic Cooperation and Development, public programs dominate long-term care financing in virtually all developed countries. There are a wide range of possible options. We could start minimally with demonstration programs that include initiatives that provide integrated care, including long-term care for people with disabilities. I would recommend breaking out of the budget neutrality requirements that have hampered many demonstrations under the Medicare and Medicaid program.

We can increase funding for appropriated programs such as title 20, or the Older Americans Act, to fund home- and community-based services. We can expand Medicaid by requiring States to cover more home- and community-based services, and easing financial eligibility requirements such as proposed in the Community Choice Act. [Applause.]

Senator ROCKEFELLER. Dr. Wiener, are you willing to—

Dr. WIENER. I am almost done.

And finally, we can establish a social insurance program for the long-term care, as has been done in Germany, Japan, and the Netherlands, and as is proposed by Senator Kennedy's, and others', CLASS Act.

Senator ROCKEFELLER. All right.

[The prepared statement of Dr. Wiener appears in the appendix.]

Senator ROCKEFELLER. I am embarrassed, but I have 5 minutes left on a vote. It will take me 5 minutes to get there. These days, you just do not miss votes. We are debating community service all this week, and at least I want to send the President, when he goes abroad, let him be able to sign a bill increasing the Peace Corps, Vista, Americorps, Teach for America, every type of community service available, working with everybody here. That is what I think the vote is on, and I want to go vote.

So Senator Hatch will be coming, but in the meantime, with your permission, I would like to recess the hearing, and I will be right back. I am not a fast runner. I will be back as fast as I can. Thank you.

[Whereupon, at 3:17 p.m., the hearing was recessed, reconvening at 3:34 p.m.]

Senator ROCKEFELLER. Just for your information, Senator Hatch actually is doing a very important thing. He is managing, for the

Republicans, on the floor, this community service bill. That is what he should be doing. It is so important that that pass.

For Dr. Feder and Dr. Wiener, paying for long-term care. We sort of figured out a way to do that, did we not?

Dr. FEDER. There are ways in which we could do it.

Senator ROCKEFELLER. Well, that sounds like maybe we did not, then. We put forward a lot of options.

Dr. FEDER. Some said that we did not do it. It was said at the time, we did not make a choice. But I think that with the proposals, what is interesting about the proposals, the two social insurance proposals that I offered in my testimony, both of them are talking about, in many ways, pre-funding.

So the Medicare option that I talked about has contributions today, whether from general revenues or some other mechanisms, that go into a trust fund so that you prepay, and separates it from government so it is not like the way we do the Medicare trust fund. So that is one proposal about paying in advance.

The CLASS Act is talking about, or proposes that, the voluntary reductions from payroll, that those be made 4 or 5 years before any services are available under the program. So, there is the concept of essentially paying for the benefits in advance.

Senator ROCKEFELLER. Do you remember, we had the big dispute about activities of daily living, and at one point there was an argument, should it be four ADLs or three ADLs, and we decided on three ADLs. I forget how that worked out. I apologize to the rest of you. I just see Judy, and I reminisce.

Dr. FEDER. I would have to double-check what we actually chose.

Senator ROCKEFELLER. You do not remember, Dr. Feder?

Dr. FEDER. It is horrifying.

Senator ROCKEFELLER. I love that.

Dr. FEDER. It is horrifying, but that is true.

Senator ROCKEFELLER. Yes.

Dr. FEDER. But I think that there are specifications in both proposals I put before you, and I would have to check. Although I know there are many in the audience who know, and Josh may know, or others on the panel may know what the specifications are. The concern is that limitations in three activities of daily living is really pretty severely disabled, and that the desire is, of course, to get services to people while they are in the community, so that you can keep them in the community. So our desire is to go down from that high a level of severity.

Dr. WIENER. Clearly it is just a question of how much money you are willing to put on the table. There are more people who have two or more problems with activities of daily living than three. So depending on how much money the committee is willing to spend, then you can kind of slice it and dice it to meet that level of need.

Senator ROCKEFELLER. Yes. And it is not a casual process, because each ADL is a humongous task.

Dr. FEDER. Right.

Senator ROCKEFELLER. Whether it is toileting, or bathing.

Dr. FEDER. Right. And the concern actually with some of the Medicaid rules currently is that, if you only give home- and community-based services to people who are nursing home-eligible, you are not able to help them remain at home, which is what you

want to do. So it is both a goal for people's quality of life, as well as for properly using our resources.

Senator ROCKEFELLER. Let me ask—look, we are just here talking, all right? I remember a couple of times in West Virginia, when I was Governor, we had these huge floods. Since only 4 percent of the land is flat and all the rest is mountain, you can imagine what a flood does and what it wipes out.

So I opened up all the national guard armories, at least in the affected areas. Nobody came. Nobody came. Why did nobody come? Because everybody took everybody from their neighborhood in or they moved up 50 feet on a mountainside, and moved in somebody's house. And it was not just a question of your relatives, it was a question of belonging to a community and the community acting to protect you. This is what you were talking about, Mr. Smith.

That is the whole concept of personal responsibility, which liberals here say, well, that is avoiding giving the service, or it is not. In West Virginia, which is a very, very value-oriented mountainous, and therefore very close—all the communities are very small and very close and tucked into mountains. The sun does not come up until noon in some places. People are close and they do take care of each other, and there is a sense of community responsibility that really works.

But then as the economy begins to go sour, you can make two arguments. One is that people have more time to do that and therefore they can exercise their nature, or you can argue people become deeply frustrated out of their own situation, they are trying to find jobs, and are less inclined to do that because they have to be self-interested to protect any chance they have of a future.

I am kind of wondering what you think about that and the idea of—because I saw all kinds of examples, and we used to talk about this—of families that would move back from Ohio to take care of their mother or their father who had Alzheimer's or some other debilitating long-term disease. Then they would go broke. They would spend down. It was not a question of qualifying for Medicaid, they would just spend down.

What would happen is, their children could not go to college and all of their dreams went right out the window because they were doing what children in Appalachia and the Midwest, et cetera, tend to do, and that is, be good to their families, take care of their families. But then there comes a point at which that becomes counter-productive.

So my question to you all, sort of philosophically, what is the relationship between the downturn in the economy, do you think, and the willingness now of people to participate in community caregiving, family caregiving, exercising personal and community responsibility? What do you predict?

Dr. WIENER. Well, I think the fundamental thing is what you have underlined, which is that people do not abandon their relatives. I think that basically happens. People have that commitment in good times and bad times because that is what families do. If you look historically at survey data, people have continued to provide substantial amounts of help to disabled relatives for as far

back as we have data. It always comes out as the overwhelming amount.

People do, as you noted, move back or they move the relatives closer in. About two-thirds of older people with disabilities have a relative within 20 miles of where they live. But it, as you pointed out, can be an unfair burden on the family in terms of what it means for their future and their ability to live a life, and especially for younger people with disabilities. It means living a life in which you are perhaps dependent on a family caregiver, when other people your age are independent and able to live on their own and free from having to answer to their parents or those kinds of things. Not every family gets along perfectly all the time.

Senator ROCKEFELLER. And that is correct. This can undo family relationships as well as it can bond family relationships. It just depends. I mean, for example, when my mother got Alzheimer's, I am of that generation when my father simply felt he could not tell his children that our mother had Alzheimer's. We found out 2 years after she had it. That was just the way it worked back then. I was not very happy about it, but I was not going to blame him, because that is what happened.

But another question I have is, being a community caregiver, being a family caregiver is not just a question of loving somebody and helping somebody or moving somebody from place to place. It also has to do with a good deal of medical knowledge, when you get to the use of oxygen and knowing what medications are to be used. That is not a casual event, and people are not trained for that, as far as I know.

Dr. FEDER. No. Also, what it raises, I was going to share with you that the most recent survey we have had of people who have long-term care needs in the community and whether they are getting their needs met is that 1 in 5 are reporting that they are not getting the care that they need and are more likely to report that they are suffering serious consequences as a result, such as not being able to eat, or to bathe, or soiling themselves, or falling.

So independent of the medical, but even in the services, the support services, even if the families are doing a great deal, it is not sufficient to meet the needs of the people who need the care. That is a very real problem. We had some evidence that, in States where there is greater paid care, there is a lesser level of unmet need. So it matters to be able to draw on people who are paid to be there—

Senator ROCKEFELLER. Or trained.

Dr. FEDER [continuing]. And have the skills to be there.

Senator ROCKEFELLER. Yes.

Dr. WIENER. In general, in the United States—

Senator ROCKEFELLER. Josh, let me just call on Mr. Smith and Ray Scheppach, how you would answer that. I do not mean to be rude.

Dr. SCHEPPACH. It is interesting. There has been a fair amount of research on what happens to communities when a major manufacturer or other plant tends to move out, and what are the impacts. A lot of times what you find is that there is great stickiness originally—that the community holds together. They try to, in fact, find other firms to come in. They do not, in fact, move away. But

as the situation continues to deteriorate, then it breaks loose and people abandon a particular area. So I think, up to a point, economic hardship can be a plus in terms of bringing community together, but further deterioration from that begins to break it apart.

Mr. SMITH. I think this is an area where we have to really change our entire outlook from the current rules that we have in the program from the Federal level that spill on down. A large part of long-term care has to deal not only with the individual, what is happening to the individual, but also to somebody else. Whether you still have a living spouse who can help take care of the spouse who has a disability—your family arrangement is extremely important in determining what is happening to you.

I think part of a lot of this, and again, from your earlier question about trying to move away from the current standards about meeting an institutional level of care, or how many ADLs do you need—you may have only two ADLs, but have a greater need because you have no family or no support system. You may have three or four ADLs, but being in a large family with a large support group, your needs are being better taken care of.

So I think we need to move to a truly different model, where we are talking about a needs assessment, a comprehensive needs assessment. Housing is maybe a huge factor in what happens to the individual. So I truly think we just need to have an entirely different model.

In terms of the economy, actually, it works somewhat backwards. When I ran Virginia Medicaid, and looking at long-term care in Northern Virginia, the likelihood was that your nurse's aides, your home health aides, et cetera, were going to have very high turnover within a year because there was a lot of competition for your work. You move from a home health aide in an agency to a nursing home, to a hospital, because you had competition for your services: good for the individual, but very high turnover, which also affects quality.

We generally did not have that problem in Southwest Virginia, though, where a nursing home, in fact, was one of the best and most stable employers. So you have a lot of economic dynamics that go into the workforce itself. As I said right now, it actually is helping to stabilize the status quo when, again, in my estimation, we need to move beyond the status quo.

Senator ROCKEFELLER. Yes.

We have been joined by Senator Cantwell, who has a great interest in this subject. We welcome you.

Senator CANTWELL. Thank you, Mr. Chairman. I am sorry I was not able to get here earlier, because I was chairing a subcommittee in the Energy Committee. But I do very much appreciate you holding this very important hearing on this subject. I think there is lots of opportunity for us to continue to make investments that will help deliver better care, and at more effective rates.

I wanted to mention that my State, Washington, has been working to improve the long-term care system for a couple of decades now. I was in the legislature when we made some of those reforms, but we are really, I think, a leader now in providing high-quality, cost-effective alternatives to nursing home care, because I think we do a good job at the education benefits of keeping people in their

homes longer. Nursing home care is almost 70 percent more expensive than the home care approach. We now, in Washington State, provide almost twice as many people as we would have been able to cover if we had not reformed our long-term care system.

So, unfortunately, as Dr. Feder was mentioning in her testimony, these States almost get penalized for that effectiveness, and the national programs have not evolved to that point.

So we certainly want to work with the committee on how we might be able to take some steps at the Federal level that would support these kinds of reforms, similar to what Washington State made, and that we do a better job on the Medicaid/Medicare dual eligibility population.

But I know, Dr. Wiener, you discussed in your testimony the role that aging and disability resources play in the resource center, and that is a program obviously that provides a great deal of support to anybody, but it really does help them avoid that nursing home care.

So I was wondering, if we help increase that role of the Aging and Disability Resource Center, how that can help us in actually saving dollars and how we can make that clear to people, as we have this population that is reaching retirement that is going to demand more for these services, how critical it is that we reform the system and get a program in place where we are giving the right information to people to really actually keep them out of these long-term care facilities.

Dr. WIENER. Well, I think one of the key factors in long-term financing is that the financing is fragmented. There are a variety of State programs, as well as Medicaid, as well as a number of private organizations providing services. So one of the things that the Aging and Disability Resource Centers try to do is to be a single point of entry into the overall long-term care system so that people can see the complete range of options that are available to them and put together a package of services that makes sense for them. As you alluded to, most people want to stay in the community if it is possible. It is not possible for everyone, but certainly Washington State is a State that has done a great deal to try to make home- and community-based services available.

The Centers for Medicare and Medicaid Services and the Administration on Aging have had a grant program that provides funds to 43 States to try to start to develop these Aging and Disability Resource Centers, but in most cases they are operating only in a couple of counties in each State. I think Federal funds, infrastructure funds for this to help the States go to scale, go to State-wide status, would be a big help and I think would help to provide consumers with the information they need to choose the services that make the most sense for them.

Senator CANTWELL. Dr. Feder, do you have any comments on the reforms that we have had in long-term care in Washington State and how they might be applied?

Dr. FEDER. Oh, absolutely. In the testimony earlier, I think that Dr. Wiener talked about Washington State as an example of, just as you have said, shifting from institutions to home- and community-based services. What I advocated in my testimony was that we make changes in Medicaid law and rules, as well as support with

Federal dollars—so both the dollars and the regulations—so that other States are more likely and better able to move in your direction. I think, without the Federal changes, we are always going to have States that do far more than others. What matters is that, no matter where people live, that they have the opportunity to get the services they need, ideally, at home where they want to be.

Senator CANTWELL. But if this can save at least a billion, if not billions, why have we not implemented it sooner?

Dr. FEDER. Well, I think the challenge is, and we do have some recent research that shows that—and I am sure that Washington is one of the States that is being looked at—when programs are mature, the home- and community-based service programs are mature, and they are accompanied by other policies to limit the use of nursing homes and the development of nursing homes, that the growth in total spending is slower than it would otherwise be.

The initial investment, however, appears to cost in the first instance as we, as you said, serve more people. Sometimes we serve them with the same dollars, sometimes initially we will serve them and we will take more dollars if it takes a while to get the system in balance. I think what history tells us is that it depends on how aggressive States are in accompanying the new availability of home- and community-based services with restrictions on the use of nursing homes.

Senator CANTWELL. But in this case we know we are going to have a growing population demand. We know that, so this is almost prevented if we are looking at that increase in the number of people who are going to be demanding services, and say, how can you provide them at a more cost-effective—

Dr. FEDER. I think you are absolutely right.

Senator CANTWELL. Thank you.

Thank you, Mr. Chairman.

Senator ROCKEFELLER. Thank you very much for being here. I am honored.

The whole problem is people available to provide services, community-based, nursing home. I sort of think of all the geriatricians who are trained in this country, and then they practice geriatrics for a couple of years, and then there is some other specialty that pays a lot more money, and they go into that and they leave geriatrics. I think that is the case. That is a very unfortunate statement.

You go back to the Hippocratic oath. There is nothing in it about curing people, it is about not doing harm, which means taking care of people, responding to their needs. You would think that, with the present economic downturn, people having to depend upon each other more, that there would be a greater instinct, and maybe just the theory that America works in cycles, that people would feel a responsibility to help each other. But I am not sure that is going to be true.

In other words, we have agreed, as Mr. Smith said, people in Appalachia do have that obligation, they do feel that, and they do elsewhere in the country. But they have to be trained. They have to know what they are doing, which means they have to take a course, which means they have to pay money and they cannot learn on the job.

I think I can remember, Dr. Feder—I have to call you Dr. Feder—that we talked 20 years ago about the fact that there were, across America at that time, some 9 million seniors living in completely inappropriate 2- or 3-story old housing on the tops of hills. There had to be sort of a check-in system. People would call every other day to find out, how are you doing? That was their form of community service, that they would just call. And, of course, if there was no answer, the question was, they would then go and check it out. That is a pretty shoddy system.

I am just trying to think, what does the fact of the training that people have to get in order to provide this service at a time that I hope, and I think Senator Cantwell hopes, there is a new sort of sense of obligation to each other, to our families, to each other as we go through this really horrible period—that people do have to get trained to do this stuff.

Dr. FEDER. Yes. People do have to get trained. People have to want to go into this field.

Senator ROCKEFELLER. Right.

Dr. FEDER. It is across the spectrum of professions. So you are starting with geriatricians. I would take us back to the purpose of your hearing, which is to make long-term care reform a part of health reform.

Senator ROCKEFELLER. Yes. Right.

Dr. FEDER. And there is a concern, a medical concern, and it affects very much people who need long-term care, that we have an insufficient emphasis on primary care and prevention, and much too great an emphasis on specialty services and specialists. So, I think that, in part, as we look at changing that balance in the medical field, that we are doing a service, which I think we will do as part of health reform. We will be looking at what we can do, or that those efforts can be very beneficial to people who need long-term care. It is not just the geriatricians, but doctors trained in primary care.

Senator ROCKEFELLER. No, I understand that.

Dr. FEDER. I was going to go down the—

Senator ROCKEFELLER. I was just trying to make the point with them.

Dr. FEDER. Yes. Absolutely. Which is why I take back my language. I would go to other people and professions. We could involve more nurses and physician's assistants in care, and the direct service workers who, in many cases, are earning subminimum wage and get no health insurance benefits. How can we expect them to be good caregivers if they are not adequately taken care of? So even those who are dedicated to service need to live quality lives, so we need to look across the spectrum of the workforce. It is a very, very important issue.

You will remember that Robyn Stone was on the staff of the Pepper Commission and is now doing a great deal of work that I am happy to share with your staff, but I am sure they have already seen, in that area. I think there is a lot we can do.

Senator ROCKEFELLER. So it is a problem. It is a problem.

I made a statement earlier which you corrected, and that is that everybody at some point in their life is going to need long-term care. I tend to continue to believe that, in spite of what you said,

which is an amazing statement in and of itself. You were not so sure about that. I am very interested in why.

Dr. FEDER. Yes. You had—

Senator ROCKEFELLER. I mean, if you have a head-on crash and two people die immediately, obviously that is—

Dr. FEDER. The reality is, it is much more than head-on crashes that lead people to die without needing long-term care.

Senator ROCKEFELLER. Yes.

Dr. FEDER. I was just looking for the numbers, which are in my testimony; I will find them in a second.

Dr. WIENER. Sixty-nine percent.

Dr. FEDER. Thank you. Go ahead, Josh. You give the Senator numbers. Oh, here it is. I found it. Never mind. [Laughter.] You can do it, too. But 3 in 10 people turning age 65 today—so even looking just at older people—are expected to die without needing any long-term care. If you die of a heart attack, you may need no long-term care.

Senator ROCKEFELLER. Of course. Of course.

Dr. FEDER. There are other illnesses where you do not need those services.

Senator ROCKEFELLER. Of course.

Dr. FEDER. And then at the other end of the spectrum, we have 1 in 5 who need 5 or more years of care. So, there is variability, even among people who are turning age 65 now, which is why we say the need for extensive long-term care is an unpredictable catastrophic event.

Dr. WIENER. I think the key point, though, is that it is not a rare instance. Somehow the American people think it is, that it is something that happens to somebody else in some rare instance, when, as the figures that Judy was citing clearly indicate, it is a normal life risk and one that most of us will have to deal with. Most people do not believe that. Most people do not know that, and certainly most people do not prepare for that or arrange their life around that.

Dr. FEDER. It is why, Senator, the variability. I mean, it is something that can happen to any of us. When you live to a very old age, it is very likely to happen to you.

Senator ROCKEFELLER. I think the major problem on long-term care is that somehow the Congress and the press and the American people think that it is just unaffordable, and somehow acute care, to them, because it is around them and visible a lot, is affordable. It does not necessarily last, so there is an end point in long-term care, though the end point may be some point off.

I can remember Dick Darman—I think we have talked about this—when he was President Reagan's Director of Office of Management and Budget, an absolutely brilliant person. He had testified before the Finance Committee, and he just disappeared for a week or 10 days, nobody could find him. He was just completely learning health care. He said—this was back in, I guess, what, the 1980s—that we were going to go up to 36 percent of Gross Domestic Product, and that was unsustainable. Where are we now? I would ask somebody other than Dr. Feder.

Dr. WIENER. We are at 18.

Mr. SMITH. Going up to 20 percent on health care. I think this is one of the areas that is unsustainable. I think Senator Moynihan used to say, actually, we could spend everything on health care because the demand is so insatiable. We could spend everything. Obviously that cannot happen from an economic standpoint. I think it is well short.

When you look at what families can afford as a percentage of their family income, when you look at what States can afford as a percentage of their budget, they cannot go beyond what is currently being spent. We had two States in the past, Missouri and Tennessee, that got up to as much as 30 percent of their entire State budget being spent on Medicaid. They found that that was unsustainable, and they had to take very dramatic action to reduce that.

So I think we are very close to the tipping point now. But I think part of the problem for long-term care is in the existing model. When CBO and OMB put their baselines together, they assume increased costs, for example, due to flexibility. The budgeteers tend to score flexibility as costing money versus the flexibility that I talk about in terms of training family members, having people be able to self-direct. Those things save money in the longer term.

If you can delay an individual's going into a nursing home or if you can shorten that length of stay in a nursing home, you can save money, as States like Washington, for example, have demonstrated. Vermont has a very interesting experiment going on right now, again, where they have leveled the playing field between services. They have actually moved to a model to help prevent going into a need for a higher level of care.

The current system is based on, we are going to wait until you are as sick as possible, until you have the absolutely highest need, then we will step in and help you, versus a more, helping you through the continuum. Much of long-term care has a medical element to it if, for example, you need to learn how to help care for a catheter. But so much of long-term care is a social service and helping families just know who to call, giving them peace of mind, helping them to understand that there are people out there just like them who want to support them, giving them the skills, training them to help deal with some of these conditions.

Again, this is very much a family issue. The rates of divorce among families with a disabled child are extraordinarily high. So the more we can do to help support them in staying together as a family—again, those are things that will save money and lead to higher quality of care, much higher.

The satisfaction rates among people who self-direct are extraordinarily high. So, these are things that we can do, but it does mean changing. Just adding on to the system as we now have it, yes, is going to cost an extraordinary amount of money, so you have to change the underlying structures of the current system.

Dr. SCHEPPACH. And I might argue, Mr. Chairman, that this industry is very unique, largely because productivity change is negative. There is almost no other industry, in America where productivity change is negative. That is a double-edged sword. When you talk about creating jobs and employment, I suspect that, when we

look back at this year, 2009, there will be only one industry that has created jobs.

The flip side of that is, we are not able to bring capital to make productivity changes in this industry, and ultimately that is the problem. It is so labor-intensive. Capital investment is cost-increasing as opposed to cost-decreasing. It is partly inherent, I think, in the industry. But until we get to a point where we can use capital and have a positive productivity change, we are stuck. Dick Darman will eventually be right.

So what Dennis talks about, I tend to agree with. I would probably define the model somewhat differently. We have to find a way of using capital intensely to get the cost controls that are necessary. Otherwise it is going to increase as a share of GNP. That may be the right thing to do as a Nation, but the cost is ultimately going to be lower productivity for the Nation. The only increase in real wages we have as a Nation is increases in productivity.

Senator ROCKEFELLER. Judy, just before you say what you were going to say, there are four parts to the President's program. One of them, obviously, is cost containment, another of them is early intervention. Now, it is pretty well known, whether it is early childhood education, or whether it is Early Periodic Screening, Diagnosis, and Treatment—which was not in the first Children's Health Insurance Program bill, and which, happily, is in the second. I mean, it was shocking that it was not for 5, 6 years.

You have to make a balance between what you spend early and, if you take life into two sections, you take long-term care and you take acute care, when you are taking acute care you tend often to be getting to young people, and you are talking about immunizations and all the rest of it. Then there is a distinct relationship between what you do now and what you save later because of what you do now. That is a little more complicated, I would think, in long-term care. Help me understand.

Dr. FEDER. Well, I think some of it is similar. If you can invest to prevent falls, for example, or to manage chronic conditions, then it is very similar to what you are thinking in terms of seeing a payoff to immunizations. You really can prevent people from suffering circumstances that are going to make their health decline.

The reality of long-term care for an elderly person toward the end is that conditions are going to deteriorate. You can help them deteriorate more slowly perhaps, you can keep them in more comfortable circumstances, but you cannot prevent the ultimate ending. Your mother died, right? So you cannot prevent that.

Senator ROCKEFELLER. Let me ask one more question, and then I have to adjourn. I went through a big, long spine operation several years ago at Johns Hopkins, and I was under anesthesia for 11 hours, for which I am still mad because I have no idea what they do. I mean, you put your chin on a thing, and I have still got a scar from that, and then in 11 hours you wake up and you have absolutely no idea what is in you, what it does to you. That is actually something that needs to be understood by the American people. Anesthesiologists have to tell you that, and they do not. And they make a lot of money in doing what they do and not telling you about what they are doing to you. But in any event, not falling was a huge part of my early rehabilitation.

Dr. FEDER. Yes.

Senator ROCKEFELLER. A huge part.

Dr. FEDER. Yes.

Senator ROCKEFELLER. Because they put this massive amount of titanium in my back, which actually gave me a lot of confidence. But it had to graft with the bone. So now I sort of feel impregnable on that front. On the other hand, there is the whole question of, you have to keep physically healthy.

Dr. FEDER. That is right.

Senator ROCKEFELLER. So 6 days out of 7, I go out and walk for an hour. I call it "Rockefeller at midnight," just because I like the sound of that, rather than "Lincoln at midnight." It is when I like to walk. I just go out, and I climb hills and come back and sweat, and then go to bed and show up for work, and I am happy and I am in condition. That is one thing, as you are growing up or go through what I went through. It is quite another thing if you have lost a limb, or you are suffering paralysis, as some of our ADAPT members. The whole question is, how do you handle staying physically fit in order to compensate for the other acts of care that you are taking or are being helped with? Physical fitness is important.

Dr. FEDER. Absolutely.

Senator ROCKEFELLER. Maybe somebody from ADAPT wants to answer that.

Mr. HILDEBRANT. Always being shy, I will speak up. As far as health, you certainly have a point.

Senator ROCKEFELLER. I have been watching you. You have been going up and down like this.

Mr. HILDEBRANT. Distracting you with my fidgets.

Senator ROCKEFELLER. No, not at all. Educating me.

Mr. HILDEBRANT. I am Chris Hildebrant. I am with ADAPT. I am out of Rochester, NY. Obviously with the shirts, we are here primarily supporting the Community Choice Act. But in particular, I am a person who has lived with spinal cord injury for 19 years now. I am 33, and physical fitness is something that I do not do very well. I move around a lot, as you are identifying. I am an incomplete injury; I have some of my sensation, but not a lot of motor control. So I feel my butt—and let us be honest—being uncomfortable, and I do my lift and get up. As we have kind of been talking about, it is preventative.

Senator ROCKEFELLER. So that is not just discomfort, that is a deliberate act.

Mr. HILDEBRANT. Right. Folks with that loss of sensation, that loss of movement, one of the very real risks—whether you are in the community or, I mean, there is a prevalence of it in nursing homes—is pressure sores. If you do not move enough, whether you are in bed, or whether you are in a wheelchair, if you do not move enough, your skin dies, and a sore, necrotic flesh will just eat away inside. It is a very real and very dangerous risk for folks.

So, that physical well-being is important, but also having the supports to help you do that, so some of our folks can use their attendant services, whether consumer-directed or otherwise, to do like PT-type exercises. I know Terry who works with us has her attendants help her do those shifts because she is not as physically mobile as I am, but she can use her community supports to help

her relieve that pressure so that she stays healthy and so that she does not have to go to the hospital for that expensive acute care, or go to the nursing home, ultimately, which some of our people get stuck doing because they do not have those supports in the community.

Senator ROCKEFELLER. All right. I appreciate that. Thank you very much.

Mr. HILDEBRANT. Absolutely. Thank you, sir.

Senator ROCKEFELLER. Let me ask you one final question. I am a big believer in hospice. That has been slow to get off the ground in West Virginia, but we are getting it off the ground. This is a delicate question, but how does a health care professional describe when it is that somebody decides to go to hospice who would also have other choices, but decides to go to hospice because that is the best thing to do medically, or for the condition, and in so doing, what does one give up if one decided not to do that, but to continue in another path? I mean, that is complicated phrasing, but you understand my question. Or you do not? Nobody understood it. I could try again.

Dr. FEDER. When you choose—and I am going to need help from others on the panel—what I think what you value about hospice, and you hear it from many people, is that there is a focus on what is called palliative care, making you feel better and comfortable and not over-providing care when you know that the course of an illness is going to end in death. I think that we all can imagine, if we have not seen directly, what that choice means. You described it: you brought your mother home so she could listen to Bach and Handel and have her family around her rather than having her feeding tubes, and all of her tubes.

So those are the alternatives. I think what we want for people, and need to do better with, is for people to truly have the choice of doing it their way and not simply, because of ignorance, not being offered opportunities, ending up dying in a way that is lacking in dignity, is inconsistent with what they would choose, and involves also a lot of costs—you would call them costs, not value.

Senator ROCKEFELLER. Well, who makes that judgment, that it is time now to go to hospice? What if the doctor does? The doctor made the decision that my mother should not go home, and we just told him, you know what, and took her home. That was when she bit down on her feeding tube. Now, that was not a medical decision, that was her decision. There was some kind of a reaction that just came from deep inside of her, what was left of her. But there was nothing medical about it. It was a choice. But could you say it was an informed or uninformed choice? I do not know. So who makes that decision?

Dr. SCHEPPACH. I just happened to go through this personally with my mother. Basically, it is a discussion among the person, the family, and the doctor. My experience was, it was a pretty good discussion, that most doctors are comfortable with it. It is also true that you do not necessarily have to go to hospice. You can have hospice come to you, either in your nursing home that you are in or in your home itself.

Senator ROCKEFELLER. All right.

Dr. SCHEPPACH. Mother's situation was, she was in a nursing home. It ended up a very positive thing because we did not have to worry about the nursing home calling emergency and taking her to the hospital, making her very uncomfortable for 48 hours, sending her back to the nursing home, and 30 days later doing it again. It forced them to call me, and we jointly made a decision of whether she went there or, if she decided to go to the hospital, they had a special hospice care wing on it. So I think it is, from my personal experience, very supportive. It made a lot of sense. The decision-making was a lot of counseling.

Senator ROCKEFELLER. But if there were, in my case, four of us who made the decision to take her home, and therefore could, to the great displeasure of the New York hospital, and the doctor visited and had beads of sweat on him—and I am not sure why, whether he thought we were going to sue him, or what. I never really figured that out. But he was terribly nervous because we were going to make her comfortable, i.e., use morphine. They did not love that. So we did that.

But it always stuck to my brain that if any one of the four of us had objected, she would have stayed in the hospital. Now, that strikes me as—now, I will not say amoral or immoral, but if you have a child who has a particular grudge—oh, my heavens. Ron, I apologize. It is the purple tie that caught my attention, and your handsome profile. I will shut up in a minute. But that rule, that if one child objects, that therefore determines the future of your mother, is very strange to me.

Dr. FEDER. But you know circumstances where I could imagine, independent of thinking about my siblings, that I knew what was right, and they were all wrong. If they wanted to do something different from what I did, I could understand that it is difficult to get agreement. You want to get agreement, because what is right can be controversial. Not everybody has the best interests of the sick individual at heart. So, I understand that.

Dr. WIENER. I think that underlines why it is important for people to make clear what their preferences are before they get into that kind of circumstance.

Dr. FEDER. In advance.

Dr. WIENER. The other point I just would like to make is that, because of reimbursement for Medicare versus other things, we have drawn this line between hospice and long-term care. But hospice is just good, long-term care and good, long-term care is good hospice care. It is one and the same thing. There are lots of people in nursing homes and home care who die all the time, and somehow we have to bring the lessons of hospice into those other settings so that we can get those advantages and have good long-term care and hospice care in both settings.

Senator ROCKEFELLER. Senator Wyden? My apologies to you.

Senator WYDEN. Not at all, Mr. Chairman. And thank you, first of all, for doing this hearing. I think we both know that long-term care has essentially been the forgotten stepchild in this whole debate, and you have consistently been prosecuting this cause. I know that on your watch we are not going to have a health reform bill in this session of Congress that leaves long-term care behind, and I just want you to know that I am going to be your ally in this

fight, because you have been at it year after year after year. I also want to join in welcoming all the folks from Community Choice. [Applause.]

They have been great advocates. The reality, as they know lots better than any member of Congress could know, is we are spending \$2.6 trillion on health care in our country this year, and more ought to go into community-based services.

Too much of it is going into institutional care. I am going to be Chairman Rockefeller's advocate in this cause to kind of balance the scale.

Just a couple of questions, if I might. Mr. Scheppach, you have been doing good work in these fields for a long time. I want to ask you a little bit about Medicaid, because what is so striking about Medicaid today is that, if you are poor, you have to go out and try to squeeze yourself into one of these boxes in order to get covered. Every time something changes in your life, you have to go off and reapply, and redo it, and all the rest. It just seems so degrading to vulnerable folks. I have always thought it is not in the taxpayers' interests, either.

What do the Governors think in terms of Medicaid reform and how it fits into the agenda of Chairman Rockefeller?

Dr. SCHEPPACH. Well, I think that the focus here, of course, was on long-term care. I think they do believe that that ought to be a Federal responsibility. We think we cut a deal with the Federal Government a long time ago, that States sort of took responsibility for working poor and children, and the Federal Government took responsibility for the elderly population. This is the case with respect to Medicare and Social Security, but it does not work for long-term care.

So I think that, now, obviously it is difficult to do, but over some long transition, it seems to me it should be phased into Medicare. Having two levels of government provide services is really an awful system—no accountability, poor quality, and so on.

On the other components of it, I think in that case the Governors would probably be open to at least discussing taking over some more of the acute care if the Federal Government were willing to take over more of the long-term care. I think it is a difficult conversation because, as you know, Medicaid has evolved into 50 different State programs, and therefore getting equity, I think, between 50 States in the transferring of programs is, in fact, difficult.

We would probably agree that the categorical nature of the program is pretty obsolete, that one should move over time, perhaps, to some income-based program. Although, again, I think they worry about the ability to fiscally sustain the program even if the Federal Government were to take over more of long-term care, because I think we are really getting to a position now of—I mentioned previously, just over the next 2 to 3 years, the State deficits, this is after the stimulus—are clearly over \$200 billion. We are very fearful that economic growth is going to be slower, going forward. So the fiscal problems, I think, are very significant.

Senator WYDEN. Let me move on to Josh Wiener. He has been doing yeoman work over the years, and particularly looking at some of the financing options. What do you think, Josh? What are the best ways and tough financial circumstances to try to finance

this public/private partnership that is going to be so important to long-term care?

Dr. WIENER. Well, I think it really depends on how much money you are willing to spend. There is a very broad range of options, from simply increasing funding for appropriated programs, such as title 20, or Older Americans Act programs. Clearly, the Community Choice Act would do a lot to expand home- and community-based services. We could go towards a social insurance program, and that is an affordable thing to do. Japan has done that, Germany has done that, the Netherlands has done that. That would increase expenditures. It would increase the role of government in the program, but it would have the advantage of covering everybody.

As Dr. Feder has often pointed out, private insurance can do a substantial amount, but at the end of the day maybe 20 or 30 percent of the population will have private insurance, if we are lucky, and that would only come after very substantial subsidies.

So, if we are serious about doing something about long-term care, then I think we have to start with thinking about what we want our public programs to be, fixing Medicaid in a variety of ways and trying to move into some ways that recognize that long-term care is a normal life risk, and that you should not have to impoverish yourself in order to get the services you need.

Senator WYDEN. I certainly am interested in that kind of approach. I also hope that we will put more effort in long-term care, and generally in health reform, in looking at trying to spend the existing dollars in the system more efficiently. As you know, on any given day something like 10 percent of the population in this country uses more than 50 percent of the health care dollar, and a lot of those folks are people with chronic conditions—heart, stroke, diabetes—and often end up needing long-term care.

Yet, we have not done much to boost doctors and health care providers in terms of the coordination of those chronic cases. You have been a master over the years at coming up with innovative ways to address financing. I hope, whether it is chronic care or some of the other options in long-term care, you can give us some more of those creative Josh Wiener ideas as we go forward.

Let me ask you one question, Dr. Feder, if I could, because you have been out in these fields doing good work for a lot of years, and that is your thinking about consumer protection. My sense is that a lot of the private long-term care insurance, not unlike what we were dealing with back in the Medigap days—and Chairman Rockefeller remembers that we would find seniors with a shoebox full of health insurance policies, and a lot of them were not worth the paper they were written on. A lot of these private long-term care insurance policies, because they do not have inflation protection, basically do not give seniors much of a benefit. So what is the latest thinking in the field about consumer protection in this whole area?

Dr. FEDER. Senator Wyden, actually, I think Josh may know that better than I. Josh, you want to go?

Dr. WIENER. Well, I have testified before this committee and the House Ways and Means Committee on numerous occasions, recommending that the two highest priorities are to make mandatory inflation adjustments a requirement for private long-term care insur-

ance policies, because there is no circumstance in which it makes sense to have your best financial protection now right after you have bought a policy, after you have been medically underwritten and are healthy.

Inflation, especially in private long-term care insurance, is very important because you are buying a policy 20 or 30 years in advance of using it, so, without inflation protection, the policy is nearly worthless. I have recommended that. The industry has resisted it because it usually roughly doubles the premium, so it reduces sales, and they would rather have the sale and hope that people will buy additional coverage over time. But to me, that is the single most important thing that needs to be done.

The other is establishing some kind of non-forfeiture benefit, again, because people are buying policies 20 or 30 years in advance. Even if you have relatively low lapse rates, compounded over 20 or 30 years, that gets to be a very large number, and it means that people will have overpaid for the protection that they have received. They ought to be able to get something back.

The industry says it would cost too much to do it, but at the same time they say lapse rates are not a problem. Those two things cannot go together. If it is not a problem, then it should not cost much to put in the benefit.

Senator WYDEN. Sensible ideas.

Dr. Feder, did you want to add anything?

Dr. FEDER. Yes. I just wanted to comment and to thank Josh. But what Josh is describing to you are improvements in these policies that likely limit the number of sales because they are going to raise the price, and even when the inflation protection goes in, it is an estimated amount of inflation. It is not guaranteed to actually be what the price is. We are all trying to slow cost growth, but you are not guaranteed.

So even when you improve these policies, the limitations to them remain substantial and, most important, the number of people who will be able to take advantage of them remains relatively modest and at the upper end of the income scale, which is why it is so important to move forward with a public insurance or public program so that we really do protect everybody.

Senator WYDEN. It is a fair comment. The National Association of Insurance Commissioners has raised a lot of the same concerns that Dr. Wiener and Dr. Feder have raised, too.

The only other point I wanted to make, Mr. Chairman, is I am so glad that you also brought up hospice, at least during the part that I was here. One of the things that, for the life of me, I cannot figure out is why in the world someone would have to give up curative care in order to get hospice care under the Medicare law. I have actually put that into the legislation I have that we talked about, and you are going to be our champion on the hospice and the long-term care issue. I would like to work with you to make sure that we do not put Americans in this ridiculous Hobson's choice, where they have to literally give up the prospect of curative care to get the hospice benefit. The hospice advocates are very much in favor of that, and I would like to work with you on it. But I feel badly about coming in late, and just look forward to working with you, Mr. Chairman.

Senator ROCKEFELLER. You are wearing your Alzheimer's tie, so all is forgiven. [Laughter.] And I think that point is one that I was trying to make earlier: what is that point? Is there that point or is it just a non-point?

Dr. FEDER. My recollection of the rules is that there has to be a presumption of death within a certain period.

Senator ROCKEFELLER. Made by?

Dr. FEDER. Made by the doctor.

Senator ROCKEFELLER. A doctor?

Dr. FEDER. I believe it has to be certified. I assume it is by a physician, but I would have to check that for you. I am getting nods.

Dr. WIENER. That is correct. You have to have 6 months to live or less.

Senator ROCKEFELLER. Yes. All right.

Well, look. This has been terrific. I thank all of you. I thank ADAPT for being here. I thank everybody for being so patient. This went on longer than I thought, but not longer than I wanted. I am grateful to you, Senator Wyden and Senator Cantwell, for being here.

It is my conclusion, it is like the stimulus package. We may have to do another one, the President says, and everybody blanches. We basically barely got the first one through, and that was, as you know, by one vote, or two votes. Maybe it was not enough. Now there is the question of the banks. People say, well, you cannot do banks because they have AIG on their mind. But the banks have something to do with housing and, if they do, is that not something that you have to do?

Then what do you do about energy? There is a particular technology that takes the carbon release from burning coal from 70 percent immediately down to 5 percent, which is where nuclear power is, which is considered a clean source of energy. So, that is going to cost money. Everything is going to cost money. Health care is going to cost money. If we do long-term care, that is going to cost money.

People talk about cost containment, and in a funny way it is an oxymoron, because you cannot do what you need to do to have a health care system which keeps, overall, people healthier, therefore more productive and all the rest of it, and does early screening and prevention and advanced directives, and all of those things. You cannot have that without spending more money. Yet, we always think we can do things by somehow saving, and we cannot. We cannot. That is a fundamental decision that Americans are going to have to face.

Then they look at their long-term grandchildren and great-grandchildren. Then I look at climate change. I think, well, if we have not done anything about climate change by the year 2060, all of my children are going to be under water, so they are not going to have to worry so much about debt. So, I mean, everything is relative. I think this is our opportunity to strike at all of it to make a whole solution, and I think it is the only way to be done. I think the President is right about that, not because I am a Democrat, but because I think he is right. A lot of my colleagues do not, so we will

see what happens. But you have certainly made your contribution,
and your passion is well known. I thank you all.

This hearing is adjourned.

[Whereupon, at 4:40 p.m., the hearing was concluded.]

A P P E N D I X

ADDITIONAL MATERIAL SUBMITTED FOR THE RECORD

Statement of Michael B. Enzi

Subcommittee on Health Care of the Committee on Finance

“The Role of Long-Term Care in Health Reform”

March 25, 2009

Today, many Americans are not able to pay for long-term care services. According to the Congressional Budget Office, fewer than 7 percent of seniors have annual incomes equal to or greater than the annual cost of a nursing home stay. As we all know, Medicaid and Medicare are the largest payers of long term care. We will not be able to continue providing long-term care for baby boomers with the financing mechanisms that are insolvent. Long term care should be a part of any solution we propose involving the solvency of Medicare and Medicaid. But there is also an element of personal responsibility here. Saving for retirement and purchasing long term care insurance helps people avoid burdening their families and taxpayers when they can no longer support themselves. We need to create incentives for individuals to access coverage before they need it.

In providing access to health care, I believe it is important to envision where we would like to provide that care. Community- and home-based care is often preferred by the beneficiary, less costly, and proven to increase quality of life. For example, programs funded by the Administration on Aging help consumers make informed decisions about and easily access existing health and long-term care options. In short, the goal is to empower people to live with dignity in their own homes rather than in an institution. I think it is critical that we give seniors even more options to receive care in their homes and communities. Community- and home-based care is often much preferred, less costly, and proven to increase quality of life.

We need to think creatively and figure out ways in which all Americans will be able to access the community services and supports they need at a price that will fit their budgets.

Testimony of

Judith Feder, Ph.D.

**Professor of Public Policy, Georgetown University
Senior Fellow, Center for American Progress Action Fund
and**

Harriet L. Komisar, Ph.D.

Research Professor, Georgetown University

on

The Role of Long-Term Care in Health Reform

before the

Subcommittee on Health Care

of the

Committee on Finance

U.S. Senate

March 25, 2009

Chairman Rockefeller, Senator Hatch, and members of the committee, I am pleased to testify before you today on the need for public action to improve long-term care services and supports. I know you share my view that the nation's economic stability depends on the well-being of its families and that support for people impaired in the tasks of daily life is key to that well-being. Sadly, that support is sorely lacking under current policies.

Both during the presidential campaign and since the election of President Obama, we've heard much about the need for health reform as critical to restoring prosperity for families and the nation's economic and fiscal health. Health reform is not only essential to assuring all of us affordable health care; it is also essential to slowing cost growth in our health entitlement programs, Medicare and Medicaid.

But we cannot achieve health or fiscal security unless health and entitlement reform address the need for affordable long-term care. Mr. Chairman, you alerted the Congress and the nation to the importance of long-term care reform as well as health reform when you chaired the U.S. Bipartisan Commission on Health and Long-term Care Reform (the Pepper Commission) twenty years ago. And since then, families' problems have only gotten worse.

People with health problems that create both acute and long-term care needs do not distinguish between the two when it comes to finding or paying for care. Both threaten their health and financial well-being. Our current entitlement programs serve people who need both sets of services. About 16 percent of Medicare beneficiaries are eligible for both Medicare and Medicaid ("dual eligibles"), more than half of whom need long-term care.¹ More than a third of Medicaid expenditures are devoted to long-term care services—at home and in the community as well as in nursing homes.² We cannot effectively address the needs of people served by these entitlement programs—or their costs—without addressing responsibility for financing long-term care.

Sadly, the mythology about long-term care that the Pepper Commission report sought to counter has continued to impede effective long-term care policy. We still hear claims that the need for long-term care only arises when people get old, that it happens to just about everybody, and that it is the responsibility of individuals and families simply to "plan ahead" and take care of themselves or their family members "when the time comes."

Such claims egregiously misrepresent the reality of long-term care needs and the extraordinary commitments families make to address them.

- The need for long-term care is not limited to older people. Of the just over 10 million people estimated to need long-term care in 2005, about four in ten were working-aged

¹ Kaiser Commission on Medicaid and the Uninsured, *Dual Eligibles: Medicaid's Role for Low-Income Medicare Beneficiaries*, February 2009; and Centers for Medicare and Medicaid Services, "2003 Section 8. Medicare Dually Eligible Population," *The Characteristics and Perceptions of the Medicare Population*, 2003, http://www.cms.hhs.gov/MCBS/Downloads/CNP_2003_dhsec8.pdf.

² Kaiser Commission on Medicaid and the Uninsured, *The Medicaid Program at a Glance*, November 2008.

adults or children.³ Simply telling families to “plan ahead” is useless for the millions of people who experience disability at a young age.

- Even among older people, the need for extensive long-term care varies considerably. Among the population turning age 65 today, three in ten are expected to die without needing any long-term care.⁴ By contrast, one in five will need five or more years of care. Looked at in terms of expenditures, half the people turning age 65 today can be expected to live their lives without spending anything on long-term care; another quarter are expected to spend less than \$10,000 (in present discounted value). At the other end of the spectrum, 6 percent can expect to face over \$100,000 (in present discounted value) in long-term care expenditures.⁵
- Far from avoiding responsibility for long-term care, it is families whom most people who need long-term care count on for support. Unpaid care provided by family and friends accounts for an estimated 85 percent of the care people are receiving at home.⁶ That care comes at enormous cost to overtaxed caregivers, both in economic opportunities foregone and in health burdens associated with caregiving.

And, despite substantial effort, even extensive family care too often leaves significant needs unmet. The last public survey of unmet need for long-term care found one of every five individuals at home and in need of care going without care they needed—and facing increased risk of serious health consequences as a result: falling, being unable to eat, bathe, or dress, or soiling themselves.⁷

The problem with today’s long-term care system is not that individuals and families fail to take enough responsibility. Rather, they simply do not have enough to give. The need for extensive long-term care is an unpredictable and catastrophic risk. Typically, as, for example, in health care, we rely on insurance to “spread” such risks—having a large population contribute to a fund that is then distributed to the minority for whom catastrophic risk becomes a reality. For long-term care, however, instead of insurance, costs are concentrated on the individuals and families of those who use service, backed only by a public program (Medicaid) that finances care—primarily nursing home care—as a “last resort”—only after they have spent virtually all they have.

Despite considerable recognition among experts of the need for better insurance against the risk of extensive long-term care needs, policy action to develop better insurance has been

³ Judith Feder, Harriet L. Komisar, and Robert B. Friedland, *Long-Term Care Financing: Policy Options for the Future* (Washington, DC: Georgetown University Long-Term Care Financing Project, 2007), <http://ltc.georgetown.edu/papers.html>.

⁴ Peter Kemper, Harriet L. Komisar, and Lisa Alecxih, “Long-Term Care Over an Uncertain Future: What Can Current Retirees Expect?” *Inquiry* 42, no. 4 (winter 2005/2006):335-350.

⁵ *Ibid.*

⁶ Mitchell P. LaPlante, Charlene Harrington, and Taewoon Kang, “Estimating Paid and Unpaid Hours of Personal Assistance Services in Activities of Daily Living Provided to Adults Living at Home,” *Health Services Research* 37, no. 2 (2002):397-415.

⁷ Judith Feder, Harriet L. Komisar, and Robert B. Friedland, *Long-Term Care Financing: Policy Options for the Future* (Washington, DC: Georgetown University Long-Term Care Financing Project, 2007).

stymied by endless debate about whether our long-term care financing system should be “public” or “private”. Such ideological rhetoric obscures the facts. The reality is that we already have a mixed public-private long-term care financing system and that we will always have a mixed public-private long-term care financing system. The real policy choice is whether we want a public-private system that works, or we want to retain today’s dysfunctional combination.

We currently dedicate substantial public and private resources to long-term care—but we do not use our resources effectively. Instead of insurance we have a combination of out-of-pocket private financing (very little private long-term care insurance) and last resort public financing (mostly through Medicaid).

In 2005, we spent over \$200 billion in public and private dollars on long-term care supports and services.⁸ Three quarters of those dollars were public—about half through Medicaid, which explicitly covers long-term care, and about another quarter through Medicare, which covers long-term care-like services, but for relatively short periods, typically associated with acute illness. But private financial contributions grossly understate the private role in today’s financing system—in part because of the enormous contribution of unpaid family care and in part because of the enormous contribution—as a share of income—made by affected families.

No one likes this system. Individuals in need face financial catastrophe, too often do not get care at home where they want it, and, even when they do, too often get inadequate care. Families face overwhelming care-giving burdens. State and federal governments face growing fiscal burdens, leading them to focus more on how to limit what they spend—simply shifting burdens to individuals and families—than on how to build a system that works.

We can and must do better. With current leadership committed to investment in our future, now is the time to exert public leadership to build an effective public-private long-term care system—one that assures sufficient public and private resources to spread risk for people of all ages, supports access to quality care at home as well as in institutions, protects people who need care now as well as in the future, and shares financial responsibility fairly across taxpayers and affected individuals and families.

A better system will require a clearer, more effective public role. Fortunately, we have many ways to move forward. Today I will outline four—drawing on some of the proposals experts developed for our Robert Wood Johnson-funded Georgetown University Long-term Care Financing Project (<http://www.ltc.georgetown.edu/>), as well as proposals under discussion in the Congress.

The first two options focus on better long-term care services for people least able to protect themselves—low income people eligible for Medicaid. By extending Medicaid support for home and community-based care and improving services for low income Medicare/Medicaid beneficiaries (“dual eligibles”), policy can promote better access to services at potentially lower

⁸ Judith Feder, Harriet L. Komisar, and Robert B. Friedland, *Long-Term Care Financing: Policy Options for the Future* (Washington, DC: Georgetown University Long-Term Care Financing Project, 2007).

costs than the current system. Such policy changes are an obvious target for immediate action in the current fiscal environment.

But our current fiscal problems should not obscure the importance of building a long-term care system that goes beyond the low-income population. Now and into the future, as the Pepper Commission recognized, reliance on a means-tested program will continue to leave modest and even better-off people of all ages at risk of impoverishment and under-service if they need extensive long-term care.

The third and fourth options therefore look at proposals for phasing-in broad public long-term care insurance that will spread the risk of needing long-term care across a broad population, assuring access to better support for people who need care.

MORE EFFECTIVE, EFFICIENT MEDICAID LONG-TERM CARE

Extending Medicaid Support for Home and Community-Based Care

First on the list is a proposal to broaden Medicaid coverage of long-term care supports and services at home. We start here for two reasons: first, because as a safety net, Medicaid focuses on people least able to protect themselves, because of limited resources, and second, because evidence suggests that expanding home care in Medicaid can efficiently improve access to needed care where people prefer to receive it—at home, rather than in nursing homes.

Despite its enormous value to people who need help, Medicaid is frequently and legitimately criticized for inadequate support for long-term care outside of nursing homes. Medicaid gives states the primary role in defining the scope of both eligibility and benefits. States vary substantially in their investment in all long-term care services, but particularly in investment in home and community-based care. In 2005, spending per low-income resident in the five highest-spending states (\$1,137) was nearly three times the national average (\$383) and nearly eight times the average spent in the five lowest spending states (\$145).⁹ Research at Georgetown shows that differences in state policies have enormous consequences for people who need long-term care. A person who is financially eligible and sufficiently disabled to receive Medicaid services in one state might not be eligible for Medicaid in another and—even if eligible—may receive a very different mix or frequency of services.¹⁰ Further, research on unmet need indicates that states with a broader use of home-based services had a lower incidence of unmet need than states with narrower use.¹¹ This result is consistent with a large body of research showing that use of paid services eases the burdens of, but does not replace, family caregivers.

⁹ Judith Feder, Harriet L. Komisar, and Robert B. Friedland, *Long-Term Care Financing: Policy Options for the Future* (Washington, DC: Georgetown University Long-Term Care Financing Project, 2007).

¹⁰ Laura Summer, *Choices and Consequences: The Availability of Community-Based Long-Term Care Services to the Low-Income Population* (Washington, DC: Georgetown University Long-Term Care Financing Project, 2003)

¹¹ Harriet L. Komisar, Judith Feder, and Judith D. Kasper, "Unmet Long-Term Care Needs: An Analysis of Medicare-Medicaid Dual Eligibles," *Inquiry* 42, no. 2 (summer 2005):171-182.

While Medicaid's support for home and community-based care has been growing, nursing homes still absorb the bulk of Medicaid's long-term care spending in most states.¹² Medicaid's emphasis on institutions flies in the face of the desire expressed by people of all ages who need long-term care: they would far prefer to remain at home or in the community. Research also suggests that investing resources in home and community-based care not only can provide services that people prefer but over time actually slow the growth in total long-term care spending by reducing reliance on costly institutional care.

In an analysis of Medicaid long-term care spending from 1995-2005, researchers at the University of California San Francisco found that overall long-term care spending grew more slowly in states with extensive, well-established home and community-based care than in states with few such services—actually reducing total inflation-adjusted “non-MR/DD” long-term care spending over time.¹³ While support for home and community-based care initially boosted total spending (and served more people), the researchers argue, over time the availability of care at home and policies to control nursing home use actually reduced reliance on costly nursing home care.

Different approaches would expand the availability of home and community-based services in Medicaid in different ways. For example, the *Community Choice Act*, S. 799, introduced in the 110th Congress, would require all states to make home and community-based personal attendant services available as an option to people eligible for Medicaid nursing home services. States would receive enhanced federal matching rate for attendant care services during an initial period, as they developed these programs.

Another approach, proposed in the *Empowered at Home Act*, S.3327, in the 110th Congress, would allow states to extend income eligibility standards for home and community-based care to nursing home and home and community-based services waiver levels (that is, income up to 300 percent of the supplemental security income, SSI, benefit level) and allow people to retain more assets, so they could actually afford to stay in their homes. States could also extend disability-based eligibility for home and community-based care to people whose conditions have not yet deteriorated to a nursing-home-equivalent level of need so they are actually able to manage in their homes.

These changes would overcome restrictions that have limited states' interest in amending their state Medicaid plans (as allowed under the Deficit Reduction Act of 2005) to broaden long-term care services in the community. For states that choose to expand in these ways, the bill would also eliminate states' ability to cap enrollment and waive state-wideness requirements. If

¹² Enid Kassner et al., *A Balancing Act: State Long-Term Care Reform* (Washington DC: AARP Public Policy Institute, 2008).

¹³ “Non-MR/DD” long-term care spending does not include spending for services specifically aimed at people with mental retardation and other developmental disabilities (MR/DD). In the analysis, “non-MR/DD” spending consists of nursing home, personal care, home health, and non-MR/DD waiver spending. Stephen Kaye, Mitchell P. LaPlante and Charlene Harrington. “Do Noninstitutional Long-Term Care Services Reduce Medicaid Spending?” *Health Affairs* 28, no. 1 (January/February 2009):262-272.

states take up the option, these changes could assure far broader availability of home and community-based care in many states. If made mandatory, or funded more extensively by the federal government, people in need of long-term care could be better and more efficiently served in all states.

Improving Service Delivery for Medicare-Medicaid “Dual Eligibles”

A second proposal, similarly aimed at the population least able to protect themselves, focuses on measures to promote more efficient service delivery for acute as well as long-term care for low income older and disabled people who are beneficiaries not only of the Medicaid but also of the Medicare program.

Approximately 8.8 million Medicare beneficiaries, poor enough to qualify for Medicaid, have their acute care services financed by Medicare.¹⁴ Medicaid pays the cost-sharing associated with their Medicare benefits and, if they need long-term care, it is Medicaid that pays for their services. Although together the two programs provide a broad set of benefits, except for some state demonstration programs, neither program bears responsibility for coordinating services within or across programs. Neither program, for example, assumes responsibility for assuring support services following a Medicare-financed hospitalization that might prevent a Medicaid-financed admission to the nursing home. And, if Medicaid were to invest in such support and prevent a hospital admission, its administrators often point out it is Medicare and the federal government that would reap the savings from lower hospital spending, while Medicaid and the state would bear the expense for in-home care.

Coordination of acute and long-term care services for dual eligibles has the potential to promote both more efficient use of resources and better quality care. Some models currently exist that use a single delivery system to provide the full range of Medicare and Medicare-covered services, in return for payment from both programs.¹⁵

For example, in Wisconsin, The Family Care Partnership Program is a voluntary program, available in some regions of the state, for dual eligibles who have a nursing home level of long-term care need. Participants receive integrated care from a health plan that has contracts with both Medicaid and Medicare. The plan receives monthly per-person payments from Medicaid and Medicare for each participant to pay for all services its enrollees receive.¹⁶

Payment based on capitation, rather than fee-for-service, can encourage efficiency and enable a delivery system to use savings from reduced hospitalizations or other acute-care services to offset costs of coordination and long-term care. However, capitation also can reward an organization that delivers too little service—delivering less but not better care and simply

¹⁴ Kaiser Commission on Medicaid and the Uninsured, *Dual Eligibles: Medicaid's Role for Low-Income Medicare Beneficiaries*, Fact Sheet (Washington, DC: Kaiser Family Foundation, February 2009).

¹⁵ Center for Health Care Strategies, Inc., “States with Fully-Integrated Care Programs for Dual Eligibles,” http://www.chcs.org/usr_doc/ICP_State-by-State_Dashboard.pdf; and David C. Grabowski, “Special Needs Plans and the Coordination of Benefits and Services for Dual Eligibles,” *Health Affairs* 28, no.1 (2009): 136-146.

¹⁶ Wisconsin Department of Health Services, “Program Overview,” Family Care Partnership Program, <http://dhs.wisconsin.gov/wipartnership/2pgsum.HTM>.

reaping greater profits. Use of capitation rates on the assumption that the result will be greater efficiency can risk harming the very disabled patients coordination is aiming to help.

Efforts to encourage coordinated care must therefore begin with the development and assurance of effective delivery arrangements—not with payment of a capitation rate. Providers and plans can be encouraged to develop those mechanisms through demonstrations and rewarded for reducing unnecessary services with mechanisms that pose less risk than full capitation—for example, the opportunity to share in and reallocate “savings” from lower than projected use of hospital care. Even for a sophisticated organization, payment based on fixed budgets, which depend on the actual delivery of services (of whatever mix), may be preferable to payment of capitation payments, which are made whether or not services are delivered. Finally, quality monitoring and beneficiary choice can help assure that delivery systems are actually delivering better value, not simply lower costs.

PUBLIC CORE OF INSURANCE FOR LONG-TERM CARE

Adding a Long-term Care Benefit to Medicare

Medicare’s health insurance protection is of enormous value to the seniors and people with disabilities who are its beneficiaries. But Medicare’s gaps—especially in financing for long-term care—leave even its beneficiaries at risk of financial catastrophe and inadequate care when their illnesses or impairments create the need for long-term care services and supports.

As we look at reforming our entitlement programs—Social Security, Medicare, and Medicaid—in the face of an aging population, it is essential that we look at the full range of people’s financial and health care needs and equitable, efficient ways to support them. Adding a long-term care benefit to Medicare—with a financing stream to support it—is therefore worthy of our attention.

One such proposal was developed for our Robert Wood Johnson-funded Long-Term Care Project by Leonard E. Burman and Richard W. Johnson.¹⁷ The proposal would provide long-term care benefits alongside health benefits through a pre-funded, phased-in, progressively-financed program—in which resources are accumulated in advance of service needs and individuals who earn more, contribute more. The proposal is aimed at the working-aged population, should they become disabled and eligible for Medicare, and the future older population when they become eligible for Medicare.

The proposed Medicare benefit would cover nursing home services and up to 100 hours per month of home care for persons meeting specified disability criteria. Cost-sharing and deductibles would be required, up to a maximum out-of-pocket ceiling and would be subsidized for low-income beneficiaries. In order to allow revenues to accumulate to support the benefit, the new Medicare benefit would not apply to current Medicare beneficiaries aged 60 or older. All

¹⁷ Leonard E. Burman and Richard W. Johnson, “A Proposal to Finance Long-Term Care Services Through Medicare with an Income Tax Surcharge,” working paper no. 8, Georgetown University Long-Term Care Financing Project, 2007, <http://ltc.georgetown.edu/forum/3burmanjohnson061107.pdf>.

individuals under the age of 55 would participate, with individuals aged 55-59 given the option of participating by paying an additional lifetime surcharge. Five years after the program begins, participating Medicare enrollees would be eligible for benefits, and Medicaid would cover the cost-sharing and deductibles for low-income beneficiaries.

The proposal's financing would be designed to replicate the current distribution of long-term care financing across income groups, but to spread it across the full population, rather than concentrate it on users. General revenues currently support Medicaid; the new Medicare benefit would replace most of Medicaid and rely on equivalent general revenues for part of its financing. Current private long-term care spending, the authors show, increases with income, whether through Medicaid spend-down for people with low and modest incomes or through self-financing for the better-off. The new Medicare benefit, which would replace the bulk of that spending, would be financed with a surtax on the income tax that similarly varies with income.

The financing mechanisms used to support the proposal stand out in their attention to pre-funding and progressivity. To assure pre-funding, dedicated revenues would be placed in a trust fund, as currently in Medicare. But unlike Medicare, contribution rates would be designed and the trust fund structured to pre-fund future expenses by investing in nongovernmental securities, "so that", in the authors words, "revenues raised would be exactly offset by outlays and could thus not be used to mask budget deficits." The financing mechanism is not only promoted as a mechanism for more equitably and adequately supporting long-term care but also as a means to raise national savings—or to pre-fund future expenses. By establishing and investing the trust fund, it is designed to "improve the nation's ability to cope with the long-run fiscal imbalances that will start with the retirement of the baby boom generation." Essentially, this proposal allows future generations to finance their own benefits—paying now to support future needs.

Adding a long-term care benefit to Medicare builds on and strengthens our existing universal public program for health insurance, and is therefore designed to accommodate an American system. But it is interesting to note that other industrialized nations are moving toward universal public protection for long-term care financing. According to analysis of 19 Organization for Economic Cooperation and Development (OECD) countries this movement does not imply the absence of private obligations (cost-sharing and other out-of-pocket spending) nor does it imply unlimited service or exploding costs.¹⁸ Rather, in general, it reflects an effort to balance public and private financing in a way that relates personal contributions to ability-to-pay and targets benefits to the population with the greatest need for care. Because so many of these nations already have the larger elderly populations that the U.S. is moving toward, their experience can provide important lessons for our design of a more effective long-term care system.

Establishing a Voluntary Public Long-term Care Insurance Program

Another option for broad public insurance protection for long-term care is to create a new program, specifically designed for this purpose. One such proposal is the *Community Living*

¹⁸ Organization for Economic Cooperation and Development (OECD), *Long-Term Care for Older People*, OECD Health Project, 2005.

Assistance Services and Supports Act (CLASS Act), S. 1758 introduced by Senator Kennedy in the 110th Congress. This proposal is similar to the proposal for a new Medicare benefit in promoting a broad (if not universal) spreading of risk and in phasing in coverage as its participants age, rather than covering those who are currently elderly or disabled. It differs from the Medicare proposal not simply in creating a new administrative mechanism but in its financing structure and in its offer of a specified cash benefit, rather than the coverage of a defined set of services.

As introduced in 2007, the *CLASS Act* would provide an initial cash benefit of \$50 or \$100 per day, depending on disability level, for people to use on non-medical services and supports. Dollar amounts would increase with inflation.

The primary focus of a cash benefit is on people with long-term needs living at home or in the community. This population was also the primary focus of the Pepper Commission's social insurance recommendations. A cash benefit has been advocated—particularly by the working aged disability community—as providing greater flexibility for beneficiaries to tailor services and other purchases to suit their particular needs—including the ability to pay family caregivers, make home modifications, or make other eligible expenditures on non-medical services and supports that make life easier in ways that a pre-specified benefit package might not accommodate. Demonstrations using cash or vouchers within Medicaid suggest the importance of accompanying a cash benefit with information and counseling to help people identify and arrange their hiring or purchases, as well as with arrangements to assure that workers are both qualified and paid adequate benefits.

All employed individuals and their spouses would be eligible to participate in the new benefit, contingent on the payment of a monthly premium (subsidized for low-income participants)—and people who had previously joined could continue to participate if no longer employed. The goal would be to have a person's premium remain constant over time. But the commitment to self-funding would allow premiums to rise if necessary to assure program solvency.

Participants would first become eligible for benefits ("vested") after 5 years of payment. Premiums would be voluntary but deducted from workers' paychecks—with workers' of participating employers automatically enrolled—unless they explicitly opted out. This "opt out" approach has also been applied to employment-based savings programs, and produced substantial, albeit not universal, participation rates.¹⁹

The cash benefit and voluntary participation of the *CLASS Act*, illustrate the potential for creating an optional, self-funded, phased in, limited long-term care benefit—starting with the working aged population among whom the need for long-term care is relatively rare. Over time the benefit would apply to the very old, who are most likely to need long-term care. Providing a substantial portion of the population, younger and ultimately older, a core of financial protection against long-term care needs, this approach has the potential to spread the risk of long-term needs and assure better access to care.

¹⁹ The Retirement Security Project, *Automatic IRAs: Extending Savings Opportunities to 75 Million More Workers* (Washington, DC: The Retirement Security Project, February 2007).

THE IMPORTANCE OF ACTING NOW

At this time of economic hardship and fiscal stress, many will argue that improving our long-term care financing system is a low priority—that we cannot afford to address financing for long-term care. Indeed, Mr. Chairman, in 1990, when the Pepper Commission issued its report, you observed that “For some, it has become far easier to bemoan our inability to act than to tackle the problems we all face.” You rejected that approach, arguing

The President and the Congress have a choice. We can continue to duck our heads and hope this issue will not bring the nation to its knees, or we can use the Commission’s recommendations as the rallying point for building the political consensus that can make universal coverage for health and long-term care a reality. I opt for the latter course – not just because it can work, but because it is the only responsible means to take action we know is imperative.²⁰

The facts are that long-term care costs, like health care costs, undermine families’ financial security, and that the costs of dual eligibles—especially those who need long-term care—are driving up federal and state expenditures for existing entitlement programs, Medicare and Medicaid. Assuring efficient, adequate, and equitable long-term care financing is part and parcel of building our nation’s economic future.

The need to address this problem will only grow as our nation ages. In the next forty years, the population over age 65 will roughly double—growing from 39 million and 13 percent of the population to 80 million and 21 percent of the population. The proportion aged 85 or over, who are most likely to need long-term care, will more than double—from 2 percent to 5 percent—and from 6 million to 21 million people. At the same time, people under age 65 who need long-term care are living longer, with their numbers expected to grow from 4 million to 13 million over the same period.²¹

This is not bad news—having more people living longer is a major accomplishment for our society. We must match that accomplishment with policies that enhance the quality as well as the duration of life. And, given the scope of the demographic changes before us, we do not have to consider ourselves stuck with the inadequate long-term care system we have; we should consider ourselves on the ground floor of the long-term care system we want to build.

Now is the time—with new leadership, a powerful necessity to invest in rebuilding our nation’s prosperity, and a new excitement about our nation’s and our government’s potential to build a better future—to confront the policy, political, and fiscal challenges of building a better long-term care system. I look forward to continuing to work with you to do just that.

²⁰ Senator John D. Rockefeller IV, “The Pepper Commission Report on Comprehensive Health Care,” *New England Journal of Medicine*, Vol. 323, No. 14, October 4, 1990, p. 1005.

²¹ Judith Feder, Harriet L. Komisar, and Robert B. Friedland, *Long-Term Care Financing: Policy Options for the Future* (Washington, DC: Georgetown University Long-Term Care Financing Project, 2007).

The Honorable Orrin G. Hatch
Senate Finance Committee's Subcommittee on Health
Hearing on
The Role of Long-Term Care in Health Reform

March 25, 2009

Mr. Chairman,

First, and most important, I want to thank you for holding this important hearing today. Long-term care is an extremely important issue, especially as the baby boomer population starts to retire. In fact, over the next 30 years, the number of Americans 60 years or older will drastically increase as more than 76 million baby boomers approach retirement and old age.

Additionally, the disabled community has long-term care needs. Today, 47% of adults receiving long-term care assistance and living in the community are disabled. Most care received by those with disabilities is provided by family and friends who give care without compensation. Due to my interest in issues facing the disabled community, I created a Disability Issues Advisory committee in Utah back in 1981. Since then, members of the Utah Advisory Committee have been advising me and my staff on legislative matters related to those with disabilities. Over the years, the committee's counsel has been very helpful to me – we have worked together on the Americans With Disabilities Act, the ADA Restoration Act, and many other important bills before Congress.

Long-term care is difficult to define because it not only includes health care services, it also includes social services and support needed by those who are unable to care for themselves. Individuals of all ages and varying health conditions may have long-term care needs. Children born with disabling health conditions such as Down's syndrome, Cerebral Palsy or Cystic Fibrosis may have long term care needs that are different from the elderly who develop dementia or suffer the long-term effects of diabetes. In addition, there are middle age adults who are diagnosed with cancer or ALS who also may have long-term care needs. All of these individuals would benefit from long-term care but need different types of services. And we all know that these services are extremely expensive.

Caregivers are getting older themselves. It is not uncommon for people in their sixties to be caring for elderly parents. Some of these older *children* have chronic diseases themselves and may even have disabilities that inhibit their ability to care for their older relatives.

While federal, state and local government provide some long-term care services to our citizens, it is clear to me that there are limits. In order for children, middle aged adults, or

the elderly to receive assistance with long-term care services, they have to be extremely poor, disabled or spend down their assets in order to receive benefits.

Our challenge will be figuring out whether or not long-term care should be included in health care reform legislation being considered by Congress. And the other challenge is how do we pay for it? What additional steps should the federal government take to improve long-term care in our country? In addition, what are states doing to address the looming long-term care crisis? What are local communities considering? How do individuals decide which long-term care insurance policy is best for them?

I want to thank our witnesses for taking time out of their busy schedules to join us today. It is my hope that our witnesses will be able to help us answer some of these important questions.

**Senator John D. Rockefeller
Senate Finance Health Subcommittee Hearing
“The Role of Long-Term Care in Health Reform”
Oral Statement for the Record
Wednesday, March 25, 2008
2:30 PM**

Good afternoon. I am pleased to be here today with my friend, Senator Hatch, in this second Subcommittee hearing on health reform. Today's topic is one that is very important to me – long-term care.

I would like to thank each of our expert witnesses for being here today for what I know will be informative testimony. I will introduce each of them shortly.

Nearly two decades have passed since Congress seriously considered long-term care reform.

The U.S. Bipartisan Commission on Comprehensive Health Care – also known as the Pepper Commission – released its “Call for Action” blueprint for health reform in September 1990.

In the 20 years since we made those recommendations, which Congress has never acted on, the long-term care provided to our nation's elderly and disabled has not improved. In fact, for many, it has gotten far worse.

Benefits and services are severely limited. There is no long-term care insurance system in the U.S. – private or public. Instead, the elderly and disabled have a patchwork of services, across public and private programs that are not coordinated.

Contrary to what most Americans believe and expect, Medicare does not provide meaningful coverage for long-term care. And, help through Medicaid – the largest payer of long-term care – requires individuals to spend down their income and assets to a level of impoverishment.

Payment for long-term care is also disjointed. To an even greater extent than payment for acute care, payment for long-term care comes from a number of reimbursement silos between and within Medicare and Medicaid. These silos create gaps in coverage, provider payment, and quality.

Just as there are opportunities to align provider payment with better patient health outcomes for acute care, there are also significant opportunities to improve quality in long-term care. In many respects, and largely because of the dual eligibles, the opportunities in long-term care are much greater.

When long-term supports and services are available, they are often very expensive – for individuals and for our health care system. In 1988, a short stay in a nursing home cost more than \$2,500 a month, on average, and exceeded most Americans' incomes.

In 2008, the average annual rate for a private nursing home room was \$76,460 – more than \$6,300 a month, on average. The demand and costs for home and community-based services are on the rise.

In 1988, the U.S. spent \$53 billion on long-term care. In 2007, this number more than quadrupled to an estimated \$233.4 billion – or 10.6% of the \$2.2 trillion spent on personal health care in 2007. And, we face a caregiver shortage that could drive costs even higher.

As we embark on comprehensive health reform, it is imperative that long-term care be a part of the solution. Expanding coverage, improving quality, and reducing costs must not be the goals of acute care alone.

Instead, we must create a 21st Century health care system that responds to the health care needs of all Americans – regardless of their age or level of ability.

We have four very knowledgeable witnesses with us today to help us understand the role of long-term care in comprehensive health reform and the options for moving forward:

First, we have Dr. Judy Feder, who is a Senior Fellow at the Center for American Progress Action Fund. Dr. Feder is one of our nation's leading experts in health policy, and she also served as my distinguished staff director on the Pepper Commission. Welcome, Judy.

Second, we have Dr. Raymond Scheppach, Executive Director of the National Governors Association. Dr. Scheppach is knowledgeable about the challenges states face, including the significant obstacles to providing and paying for long-term care. Thank you for being here.

Third, we have Mr. Dennis G. Smith who is the Senior Fellow in Health Care Reform at The Heritage Foundation's Center for Health Policy Studies where he researches ways to improve the Medicaid program, including the future of long-term care. Before joining Heritage in May 2008, Mr. Smith was the former director of the Center for Medicaid and State Operations at CMS. Welcome back, Mr. Smith. Good to have you.

And fourth, we have Dr. Joshua Wiener, Senior Fellow at Research Triangle Institute International. Dr. Wiener is program director of aging, disability, and long-term care at RTI International. He is currently involved in studies of Medicaid home and community-based services, the long-term care workforce, quality assurance for long-term care, and projection and simulation models for long-term care. Thank you for joining us.

I look forward to the thoughtful testimony of all our witnesses and now would like to turn it over to Senator Hatch for his opening statement.



Edward G. Rendell
Governor of Pennsylvania
Chair

James H. Douglas
Governor of Vermont
Vice Chair

Raymond C. Scheppach
Executive Director

Written Testimony for the Subcommittee on Health of the Senate Finance Committee
“The Role of Long-Term Care in Health Reform”
Presented by the National Governors Association Executive Director Ray Scheppach
March 25, 2009

Mr. Chairman and members of the committee, my name is Ray Scheppach, and I am the Executive Director of the National Governors Association. I appreciate the opportunity to appear before you today on behalf of the nation's Governors to discuss the critical issue of long-term care and the need to include this issue as part of health reform.

To put it simply, failure to reform the underfunded, uncoordinated patchwork of long term care supports and services is a failure to truly reform health care. There is an opportunity and a responsibility to do so now as part of the health reform discussions underway, and on behalf of the nation's governors, I urge you to give equal attention to this critical component of the nation's health care system.

The broader reform discussions thus far have focused on improving the coverage, cost, and quality aspects of primary and acute care services and emphasized the value of prevention. These are the exact same issues with respect to reforming long term care, and further reason why reform of both needs to occur simultaneously.

Just as we take steps to plan for our financial health and future, we – as a nation and as individuals – must take steps to plan for the entire lifespan of our physical health needs. To do so, the health care delivery system should be regarded as a continuum that provides services to meet needs across an individual's lifetime. In fact, it is usually a question of not whether an individual will utilize some type of long-term care insurance, but rather when along this continuum the services are needed.

The people of this country deserve a health care delivery system that is designed to allow individuals to remain healthy as they age, that delivers quality care that meets the needs of the elderly population, and that provides appropriate services and support to persons with disabilities.

Reform also must consider the diversity of those who will access long-term care services. This includes elderly individuals as well as persons with disabilities. Through the management of Medicaid and other public programs, states have learned that the needs and capacity of these populations can be strikingly different and therefore require different options within the long-term care system.

There are three fundamental aspects of long-term care reform: coverage and financing, coordination of care, and quality. These largely mirror the issues prevalent in the broader health reform discussions.

Financing: Medicaid

First, with respect to financing, there is a pressing need to create sustainable mechanisms for funding long-term care services.

The primary problem is that the Medicaid program has become the nation's de facto long-term care provider. This was never the intended purpose of the program, and it is not a purpose that can be sustained. In part, Governors have contributed to the status quo. They seek pragmatic, immediate solutions to pressing problems, and have used Medicaid to temporarily solve the critical long-term care needs of their most

vulnerable citizens. This has lessened the pressure on Medicare, and other payers to adapt to meet these needs, despite the fact that most seniors still think that Medicare will pay for their long-term care needs. This has also taken the pressure off of Congress to address this growing crisis, as evidenced by the need for today's hearing.

Medicaid now accounts for approximately 40 percent of all long-term care expenditures compared to 23 percent for Medicare, 22 percent for out-of-pocket expenditures, and nine percent for private insurance. With respect to nursing home coverage, the most intensive and expensive type of services, Medicaid pays an even greater share. The relationship between these various payers is fraught with tension as each tries to shift responsibility and cost to the others.

Since the elderly and persons with disabilities have significant health needs, they are among the most costly of Medicaid beneficiaries. In 2007, long-term care services, including nursing home intermediate care facilities, home health and personal care services, and home and community based services, accounted for about 32 percent of all Medicaid expenditures. Given the trends in both health care costs and the aging of the population, this is a tremendous strain on state budgets that simply is not sustainable.

States will continue to use the levers at their disposal to facilitate reform in the long-term care systems and to foster the full integration of persons with disabilities into society. For example, many individuals prefer to receive long-term care services in a community-based setting. States have made tremendous progress in strengthening the system of home and community-based services. However, the fact remains that Medicaid remains an institutional-biased purchaser of long-term and primarily non-medical services for persons with severe disabilities and elderly individuals.

While improving access to Medicaid home and community-based services is essential, it is NOT a solution to the long-term care challenge confronting us. Unfortunately, from a state budget perspective, states have now reached the point where additional funding for health care will come only at the expense of additional funding for education and other priority issues important to our citizens. The current fiscal crisis makes this problem all the more acute.

Financing: Other Options

There are a number of steps that could help further reduce reliance on Medicaid as a long-term care provider. In recent years, there has been growth in the availability of private long-term care insurance. Although the growth of this market has been slow, for those who have access to and can afford such coverage, it is a reasonable alternative to Medicaid and other sources of public financing.

Medicare must be at the table for these discussions as well, as efforts to restrict Medicare's home health care benefit usually serve only to shift costs to Medicaid. Medicare must, at the very least, embrace more of the nation's long-term care needs, primarily due to the overlapping – but currently uncoordinated – sets of services.

Other solutions could include the creation of a separate federal program devoted solely to the provision of long-term care services, or fundamental changes in tax and insurance policy to allow for universal access to a comprehensive set of long-term care benefits.

Again, the bottom line is that Medicaid cannot be the vehicle for long-term care reform. It must be a combination of individuals' resources, Medicare, Medicaid, and other revenue streams.

Coordination of Care

Although financing reform is critically needed, system reform maybe even more important. Entry into the long-term care system should involve a needs assessment followed by effectively planning, arranging, coordinating and monitoring the services that most appropriately meet the identified needs of the client.

The existing approach to long-term care is unfortunately disjointed and inefficient largely because there is little to no coordination between the various payers, providers, and those who use or need long-term care

services. The lack of financial incentives – and in some cases technical capacity – are barriers to integrating and coordinating care.

In addition to the particular implications for state health reform initiatives, the existing system is an acute problem for individuals insured by Medicare and Medicaid – known as the dual eligibles. There are more than seven million dual eligibles which represents 18 percent of all Medicaid beneficiaries. They are responsible for over 42 percent of all Medicaid expenditures and 24 percent of Medicare expenditures (\$250 billion in federal fiscal year 2008). Yet nearly all receive uncoordinated care because the systems are not integrated. Despite recent efforts such as the creation of Medicare Advantage Special Needs Plans, there remain misaligned benefit structures, opportunities for cost-shifting, and unresolved tensions between the federal and state governments as well as an uncoordinated system of care for beneficiaries.

In addition, regardless of where the patient lives, the focus should be on management and treatment of chronic conditions. This means managing the flow of information and perhaps bundling services to streamline our system of care. In fact, many states are working on preventing the need for long-term care services through the use of aggressive care coordination programs and disease management strategies.

Quality

Finally, as with the committee's ongoing discussions on other aspects of health reform, health reform is an opportunity to improve the quality of long-term care services. Medicare and some states have begun to do this but more needs to be done to support and coordinate efforts to measure improvements in quality, in patient satisfaction, and to have better outcomes for the investment the federal and state governments make on long-term care services.

Standards are needed to enhance quality measurement. Together, measurements, standards and processes to coordinate care can drive development of different reimbursement models that more effectively and efficiently reward provision of high quality long-term care that is most appropriate for an individual's needs. When combined with transparency initiatives, measurements also serve to better inform consumers about their options. The federal and state initiatives to develop and adopt interoperable systems for health information technology and exchange will be essential in realizing this goal.

Health Reform and Federalism

As the Congress begins to think through broad health care reform, including long-term care, it is important to continue the existing federalism principles that were established when first Social Security was created in 1935, and then later with Medicare and Medicaid in 1965. At these times, the federal government took both financial and administrative responsibility for programs for individuals over age 65 (Social Security and Medicare). States, on the other hand, took administrative responsibility and partial financial responsibility for Medicaid, which at that time focused essentially on women and children. There were substantial efficiencies in this approach as states could coordinate with other state administered programs such as food stamps, welfare, and job training which focused on the same population.

This federal responsibility is also important as the elderly are distributed across states differently than the rest of the population. A federal redistribution, through the tax system and federal spending, can ultimately "hold harmless" southern and western states that have a high percentage of the elderly. In regard to long-term care, this federalism principle indicates that the elderly should become a full federal responsibility.

Conclusion

Postponing the discussion on long-term care perpetuates the fragmented system of care that exists today. Efforts to improve the financing mechanisms, care coordination and quality of long-term care services can be complementary and very important in the efforts related to strengthening the rest of our health care system.

Thank you Mr. Chairman and members of the Committee for this opportunity to speak about the place for long-term care in health reform. On behalf of the nation's governors, we look forward to working with you on meaningful reform legislation. I would be happy to answer any questions you may have.



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CONGRESSIONAL TESTIMONY

**The Role of Long-Term Care in
Health Reform**

**Testimony before
Committee on Finance
United States Senate**

March 25, 2009

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The Heritage Foundation**

My name is Dennis Smith. I am a Senior Research Fellow in Health Care Reform at The Heritage Foundation. The views I express in this testimony are my own, and should not be construed as representing any official position of The Heritage Foundation.

Long-term care is an important but all too often overlooked component of health care reform. The great challenges we face because of population changes between now and 2030 are well known and will require bold solutions. As the Committee's statement points out, "... Medicaid continues to be overwhelmed as the sole solution for long-term care ...".¹ All too often, Medicaid is called upon to fill missing pieces. Yet the federal government and the states are facing the reality that Medicaid in its current form is unaffordable and unsustainable.

About one-third of Medicaid spending, or about \$100 billion in FY 2007 went to long-term care.² Over the next 10 years, Medicaid long-term care spending is projected to grow at an average rate of 8.6 percent per year.³ At this rate, Medicaid will spend a cumulative total of \$1.7 trillion on long-term care between 2008 and 2017. Within Medicaid, there has been some shift in where long-term care dollars are spent. In FY 2000, 72 percent of Medicaid long-term care expenditures went to institutional care and just 28 percent to community based services.⁴ The overall distribution of FY 2007 expenditures had changed to 58 percent institutional and 42 percent community-based.⁵

The Committee's has asked the panel to address four questions which should help lead to the formulation of policies to create a system that is adequately prepared to meet the challenges of the 21st century. I will address them, however, in a different order as the policy decisions should lead sequentially from one to the next, ending with the financing question. From past experience, the financing is where consensus tends to fall apart. If you start with financing, chances are good that enthusiasm will wane before you discuss the policies of change. If agreement on policy can be reached, financing should follow.

How would better long-term care coverage affect overall health care access, quality and costs?

Long-term care coverage includes a mix of private and government sources. Better coverage should include the promotion of private sector options. Research from the National Bureau of Economic Research demonstrates that Medicaid has a large "crowd out" effect on private long-term care insurance.⁶

¹ Committee on Finance, hearing notice, March 20, 2008.

² Office of the Actuary, Centers for Medicare and Medicaid Services, 2008 Actuarial Report on the Financial Outlook for Medicaid, October 17, 2008, p. 10.

³ OACT, p. 17.

⁴ Suzanne Crisp, Steve Eiken, Kerstin Gerst, Diane Justice, Medstat, *Money Follows the Person and Balancing Long-Term Care Systems: State Examples*, prepared for the Centers for Medicare and Medicaid Services, September 29, 2003, Appendix 1, p. 15.

⁵ Brian Burwell, Kate Sredl, and Steve Eikern, Thomson Reuters, *Medicaid Long-Term Care Expenditures in FY 2007*, September 26, 2008, p.1.

⁶ www.nber.org/digest/jul05/v10989.html

We certainly see every day how poor quality increases costs. The journey into the long-term care system often begins with a senior who is on too many prescription drugs becomes disoriented, falls and breaks a hip. A person with a disability who did not get the properly equipped wheelchair is at risk for skin problems that can lead to pressure ulcers and hospitalization. In one study, the actuarial firm Milliman, Inc. estimated that 25 percent of hospitalizations for Wyoming's long-term care population were avoidable.⁷

More money does not mean better quality. Last month, the Nelson Rockefeller Institute of Government issued a report, *Medicaid and Long-Term Care: New York Compared to 18 Other States*. It concludes, "[u]nfortunately, New York's broad range of services and higher spending have not produced a higher quality of care. The state is about average or slightly above average on measures of quality. The comparisons in this report show that New York has room to improve quality and lower costs."⁸

The AARP Public Policy Institute has recently published its *2009 Across the States: Profiles of Long-Term Care and Independent Living*. Among its ten key findings, AARP estimates that, "[o]n average, Medicaid dollars can support nearly three older people and adults with physical disabilities in home and community-based settings for every person in a nursing home."⁹

Reform should offer more alternatives to Medicaid in order to divert people from needing Medicaid in the first place and Medicaid itself must be rebalanced. In this respect, Vermont provides a model for serious consideration. Patrick Flood, Deputy Secretary of the Vermont Agency of Human Services, has described how Vermont has abandoned the out-dated Medicaid structure of long-term care, and leveled the playing field between institutional and home care with the option of self-direction:

In 2005, Vermont received approval from CMS for an 1115 Waiver to re-design our Medicaid long term care system. The goals for the Waiver were to:

- Provide equal access to either a nursing home or home based care services
- Serve more people
- Manage the overall costs of long term care.

Three years later, it is clear that the Waiver has succeeded beyond what Vermont hoped for. We are serving many more people than we could have under the old system. The number of new persons we can admit each year to our home based alternative programs has grown 2-3 times over what we could in the old system.

⁷ Bruce Pyeson, Kathryn Fitch, and Susan Panteley, *Medicaid Program Redesign: The Long Term Care and Developmentally Disabled Programs*, Milliman, Inc., September 15, 2006, p. 12.

⁸ The New York Health Policy Research Center, *Medicaid and Long-Term Care: New York Compared to 18 Other States*, prepared for the New York State Department of Health, February 2009, p. 14.

⁹ Ari Houser, Wendy Fox-Grage, and Mary Jo Gibson, *AARP, Across the States: Profiles of Long-Term Care and Independent Living*, 8th Edition, p.17.

Nursing home use continues to decline gradually. Overall costs of the system have remained manageable.¹⁰

Flood summarized the Vermont experience: “The beauty of Vermont’s approach is that it turns out our theory is correct: more people, given the choice, will choose home based care, and less money will be spent on nursing homes. Thus we can shift money from the nursing home side of the ledger to the home based side and not spend more than was planned, but still serve more people overall.”¹¹

Millions of Americans served by Medicaid are also clients of other government programs such as the Supplemental Security Income (SSI) program, Food Stamps, housing assistance, mental health, aging, and even transportation programs. All of these programs are part of the long-term care continuum and we should view them as a cohesive system rather than individual, unconnected parts which is the way these programs are currently organized. Better coordination of current coverage would certainly increase access, improve quality, and lower costs. Milliman observes that, “[m]uch of the data collected and information reported about the LTC and DD programs are intended to demonstrate compliance with entitlement rules rather than support care management. A future that provides more efficient, better quality care will have strong capabilities to manage care processes.”¹²

In July 2008, the AARP Public Policy Institute published *A Balancing Act: State Long-Term Care Reform* which provides a good roadmap to reform. “Policy makers and researchers have attempted to identify successful practices. A review of the literature reveals several studies that analyze and identify key determinants that contribute to more balanced LTSS (long term services and supports) systems. But there is no magic formula that will accomplish system change without strong leadership and the political will to do so. ‘Success’ cannot be measured only by look at the allocation of state’s Medicaid dollars. An analysis of the hallmarks of a balanced system identified the components of an ideal LTSS system ...”¹³

The report describes 12 components of an “ideal” system as philosophy, array of services, state organization of responsibilities, coordinated funding sources, single appropriation (also called “global budgeting”), timely eligibility, standardized assessment tool, single entry point, consumer direction, nursing home relocation, quality improvement (which includes patient-defined measures of success), and integrating health and long-term care services.

These 12 ideal components suggest that from an organizational perspective, the current federal structure is out-dated and deficient. Reform should include a new

¹⁰ Statement of Patrick Flood at The Heritage Foundation, “Workable Solutions for Long-Term Care,” September 24, 2008.

¹¹ Ibid.

¹² Pyenson et. al., p.2.

¹³ Enid Kassner, Susan Reinhard, Wendy Fox-Grage, Ari Houser, Jean Accius, AARP Public Policy Institute, *A Balancing Act: State Long-Term Care Reform*, July 2008, p. 12.

organization at the federal level to lead such change. The Centers for Medicare and Medicaid Services (CMS) is too big and too slow to make the changes that are needed. While people with disabilities want to self-direct, CMS is still arguing with itself over the “homebound rule” dealing with wheelchairs.

To support a system that can meet the challenges of the 21st century, the federal government should lead by example. A new federal agency would be created and agencies dealing with people with disabilities and the elderly would be consolidated under one roof. Experts from Medicaid, the Administration on Aging, vocational rehabilitation and other agencies and programs would be brought together to focus on the common mission. Various federal long-term care programs currently administered by the Social Security Administration and the Departments of Agriculture, Education, Health and Human Services, Housing and Urban Development, and Labor would also be consolidated and added to the new agency with a renewed emphasis on helping individuals with disabilities to achieve or maintain independence.

The current fragmentation across agencies leaves individuals with disabilities trying to navigate the system frustrated and dilutes efforts to serve them. Fragmentation and duplication among dozens of different programs that each serves the same populations also drive up the costs of government, hidden from public view. This consolidation will reduce the size of the federal bureaucracy as duplicative support staff can be eliminated. To ensure savings, Congress should reduce funding for program operations for the effected agencies from current levels as part of consolidation. It will be a more nimble agency as well and return the focus of the various welfare programs to the most vulnerable populations. Decisions will be more timely and consistent and a new structure will provide a greater level of accountability.

The new agency would contain new centers for excellence for the populations to be served:

- Center for Excellence in Long-term Care and Supportive Service—Physical Disabilities
- Center for Excellence in Long-term Care and Supportive Services—Developmental Disabilities
- Center for Excellence in Long-term Care and Supportive Services—Behavior Health
- Center for Excellence in Long-term Care and Supportive Services—Seniors

Some will argue that Medicare and Medicaid must be kept together because of the “dual eligibles,” the 8 million low-income senior citizens and individuals with disabilities who are eligible for both Medicare and Medicaid. Some may think the missions of the two agencies are too intertwined to be separated. But the same argument was made in the past to keep Medicare and Social Security together and was ultimately put to rest. Although the programs were separated more than 30 years ago, the Social Security Administration (SSA) continues to administer major parts of the Medicare program including determining eligibility, collecting Medicare premiums, and explaining benefits.

Though there is overlap between the two programs, they can be neatly separated. Most people on Medicare will never cross over into Medicaid. Medicare does not provide long term care services. The role of Medicaid, for most seniors, is to pay bills, not make policy or deliver Medicare covered benefits.

Medicare is not the only program that has links to Medicaid. Development of Medicaid information systems requires interaction not with Medicare but with federal, state, and local officials who run other welfare programs--Food Stamps and the Temporary Assistance for Needy Families (TANF) program. The cost of eligibility workers and information systems are allocated among Medicaid, Food Stamps, and TANF. There are as many "dual eligibles" between Medicaid, Food Stamps, TANF and the Supplemental Security Income (SSI) program as there are between Medicaid and Medicare. Because Medicaid, TANF, SSI, and Food Stamps are means-tested programs, there are more eligibility policy issues among these programs than between Medicare and Medicaid.

Consolidation and reorganization will benefit recipients and taxpayers alike by focusing resources on services rather than bureaucracy, coordinating policies across programs that have the same mission, shrinking the size of the federal bureaucracy, reinvigorating federalism, and measuring results rather than process. It is not sufficient to engage in wishful thinking that by coordinating with greater intensity, frequency, or passion, significant improvements in outcomes will be achieved under the current organizational structures. The concentrated efforts will emphasize a person-centered approach rather than an institutional or provider-driven approach. Nor should taxpayers accept the current "watered-down" versions of performance measurements. Reorganization of the management at the federal level would be an important message about how serious the Medicaid problem is and how far the federal government is willing to go to solve it.

Are there different policy options for improving long-term care for the elderly in comparison to the disabled?

There clearly are differences between the elderly and people with disabilities in the use of long-term services and supports when we examine the length of time the two populations use LTSS and the array of services. However, policies for both populations should be the same: they should be person-centered and money should follow the person. Young adults with disabilities are more likely than seniors to be interested in supports that will lead to employment, for example. But at the federal level, we should avoid making artificial policy distinctions that could impede the choices and preferences of either population. Some current federal policies unnecessarily complicate the delivery of services to those who rely on them. For example, a person's benefits can change solely because he had a birthday.

Community care for the developmentally disabled has progressed more rapidly than for the elderly and physically disabled. Community based care for the developmentally disabled now accounts for 63 percent of Medicaid long-term

expenditures on their behalf while 69 percent of long-term care expenditures for the elderly and physically disabled still go to institutions.¹⁴

Why has community care progressed more rapidly for the people with developmental disabilities than for our seniors? A better understanding of these changes and differences will assist in identifying how current policies should be changed.

First, the overwhelming credit goes to families. The shift from institutional care to community services reflects their preferences and demands. Families spoke and states responded, though some states faster than others. Long-term care should be properly viewed as a matter of personal liberty and freedom, a family issue, and a social issue as well as a health care issue. They have moved their loved ones out of institutions and, in many cases, on to self-direction. When long-term care is still viewed as a medical model, the progress has been slower. Choice and self-direction improves access and quality while lowering the cost. That is a successful formula that families embrace.

Second, the financial relationships are different. Government needs to acknowledge that its own fragmentation of programs and philosophy of dependency in which providers, rather than people themselves are the decision-makers may be contributing factors as to why the majority of funding for the elderly and physically disabled still goes to institutional care. The institutional bias of Medicaid in which a nursing home bed is an entitlement but supports at home are optional are reinforced by financing advantages of institutions and relationships between institutions. In many states, institutions themselves help finance the cost of Medicaid through upper payment limits and provider taxes. Because they can be a source of the nonfederal share of the cost of Medicaid, they have an advantage when it comes to making budgetary decisions at the state level. Furthermore, institutions, especially in many rural areas in particular, nursing homes are major sources of employment, giving the mutual business interests of owners and workers a powerful political voice.

A third reason is the professionalization of community based services within the developmentally disabled community. Organizations have moved out of someone's basement or the church daycare into sophisticated operations. There are other reasons as well, but whatever the reason is, the central focus should be on leveling the playing field between institutional and non-institutional care. To achieve this, Title XIX itself will need to be amended and reorganized. Long-term care should have its own distinct part within Title XIX. The current distinctions between "mandatory" long term care services and "optional" long term care services should be eliminated. After more than 25 years of experience with home and community based waivers, it is time to recognize the obvious. Home and community based care works and states should not have to rely on waivers from Washington to provide it. However, the budget scorekeepers at the Congressional Budget Office (CBO) and the Office of Management and Budget (OMB) generally view

¹⁴ Burwell et. al., Table, "Distribution of Medicaid Long Term Care Expenditures for DD services, Institutional vs. Community-Based Services, FY 2007" and Table, Distribution of Medicaid Long Term Care Expenditures for A/D services, Institutional vs. Community-Based Services, FY 2007.

greater state flexibility in Medicaid will increase costs. Thus, flexibility will need to be coupled with financing reform as well.

How do we best achieve broad-based long-term care coverage, and why is this important for health reform?

Broad-based solutions will require improvement in all of the current efforts in long-term Medicaid, our retirement systems, and private long-term care coverage. Part of the solution to easing the pressures on Medicaid is for Americans to better prepare for their own retirement needs.

There is great attention to the aging of the “baby boomers” and to the rapidly growing population over the age of 75 where the need for long-term care increases. The age and functional abilities of the person are not the only determinant in whether a person will seek long-term care services and supports. What happens to someone else also matters. That is, family members are the greatest source of support, typically, one spouse caring for the other or an adult child caring for her parent. Broad based solutions should focus on keeping families together for as long as possible.

Better transition planning can lower costs. System redesigns should focus on delaying entry into institutional care or reducing the length of stay in an institutional setting. We should also help ensure a sense of security for families by helping a person with disabilities build assets for their future needs. Today, the message from Medicaid and SSI to individuals and families is don’t work, don’t build assets, don’t plan because if you do, you will lose eligibility. We should reverse this by creating special accounts for people with disabilities to build assets. The Bush Administration proposed such accounts called Living with Freedom, Independence, and Equality (LIFE) Accounts. LIFE accounts would be tax exempt and would not be counted in determining eligibility for Medicaid or SSI. Families could draw some funding out of the Account for incidental items, perhaps 10 percent annually, without penalty. The Account would then be used for future cost of care if the person needs to go into an institutional setting.

What is the range of distinct policy options for financing long-term care? What are the pros and cons of each?

Option 1: Expansion of Medicare Benefits to include LTC. Various interests have proposed that long-term care be added as a benefit to Medicare and that an increase in the payroll tax be added to finance the cost.

Adding new benefits to Medicare when the current program is already stressed does not make sense. Medicare will soon be liquidating assets in order to pay current benefits. The insolvency date of the Hospital Insurance Trust Fund is likely to be moved up when the Trustees report next month. Raising taxes on low-income workers for a benefit 50 years away makes no sense in the current economy. Small businesses would likely reject this as a threat to recovery and jobs and so should Congress.

Option 2: Federalization of LTC Under Medicaid. Federalization of Medicaid long-term care costs has been an official position of the National Governors' Association (NGA) for a number of years. The increased cost to the federal government has been an obvious impediment to the idea.

Option 1 and Option 2 suffer from similar deficiencies. First, the nature of long-term services and supports do not comport with Medicare. Medicare is a medical model and provider-driven entitlement model. Neither one of these is compatible with long-term services and supports which should be flexible and person-centered. Long-term care services and supports are as much social services as they are health care services. Housing is often a critical issue that needs to be addressed. Yet that is not an issue that can be equitably reduced to an actuarial value. While seniors typically use high cost long-term care for a relatively short period of time, many people with disabilities will rely on long-term care services and supports for a lifetime. What has been accepted as sound public policy for years may actually be counterproductive. For example, requiring a nursing home stay of some length has been viewed as a deterrent against the so-called "woodwork effect." But a person's ties to the community breaks down over time. Policies that protect the Medicare trust funds do not always work in the best interest of the individual.

Second, the cost of long-term care would increase substantially. The political pressure to increase provider reimbursement to the highest reimbursement levels possible would be significant. States also play an important role in the supply side of long-term care through the certificate of need process. Under Medicare or federalization of Medicaid, the cost of long-term care could double without any increase in real value. Finally, the federal government lacks the expertise to develop, support, and sustain a community based delivery system. Long-term services and supports are local and personal.

Option 3: LTSS Grant Under New Part B of Medicaid. I recommend that a third option be considered that will assist in the transformation of long-term care from institutional to person-centered supports and services. The current mandatory/optional services for long term care should be replaced by a new Part B of Medicaid under which long term services and supports (LTSS) are offered on an equal basis as under the Vermont model. States should be allowed to move away from the institutional level of care to a functional needs assessment system based on prevention, low, intermediate, and high needs. States should be required to offer families the opportunity to self-direct their long term services and supports. Federal rules on important policies such as spousal impoverishment protections, eligibility, and nursing home quality standards would be preserved to continue to hold providers and states accountable.

Medicaid long-term services and supports would be funded through a dedicated but capped LTSS grant that is stable, predictable, indexed, and guaranteed. States would have the incentive to adopt new delivery options through the conversion of the current

matching system to a maintenance of effort requirement (MOE). States therefore could improve service delivery and save state dollars without losing federal dollars.

States need a more flexible financing arrangement within existing funding levels to be able to level the playing field that also provides them with the ability to work outside the lines of current federal law and regulations. There can be good reasons to want to deviate from the current payment rules. For example, government generally does not want to pay providers for an empty bed. But to shift to community care while maintaining quality within institutions, a state would benefit from flexibility which would allow it to offer a funding stream that puts some nursing homes on a glide path to closure. The federal government would be more favorable to states experimentation with “pay for performance” if it did not have to take the risks connected with open-ended funding commitment.

The current match system works against the interests of what we should be trying to accomplish—greater value at lower costs. States are under tremendous pressure to maximize federal dollars. Medicaid needs a neutral approach in which states can reform their long term services and supports system but maintain a guaranteed stable and predictable source of financing from the federal government.

As part of this transformation, the federal government should create a new agency as previously suggested and increase, if necessary, support for discretionary programs that can divert or delay the need for long term care. The LTSS grant approach combined with the recommended federal reorganization will fulfill the AARP’s 12 “ideal” LTSS system. Investment in information and education will provide families with greater emotional security that there will be a continuum of care that supports the health, security, dignity, and individuality of their loved ones.

Funding for Medicaid acute medical care benefits for eligible individuals would continue under the current benefit structure under a new Part A in Medicaid. A child with a disability, for example, would remain eligible for the Medicaid early periodic, screening, diagnosis, and treatment (EPSDT) services.

Response to Concerns over Capped Funding. Over the years, criticism of and opposition to funding caps in Medicaid have generally focused on three areas:

1. states would be handicapped to respond to unforeseen events that would increase eligibility. Hurricane Katrina, SARS, and HIV/AIDS have been offered as reasons to oppose capped funding.
2. there could be medical breakthroughs that could be very expensive, putting states at risk for high cost technology.
3. states have little control over the cost drivers of health care making capped funding an unacceptable risk.

None of these objections particularly apply to the area of long-term care. These three reasons pose little risk in long-term care in which populations are stable and

predictable. Long-term care is more high touch than high tech. And in the area of long-term care, states have considerable control over how long-term care is delivered, which is why there are such great differences among the states in per capita spending and the distribution between institutional and community-based care.

Summary. The current Medicaid financing and benefit structure is an impediment to transformation of long-term care from an institution-based, provider-driven medical model to a person-centered, consumer-directed model. Reform should be focused on policies that can keep families together which will result in making Medicaid more sustainable and affordable. The current program costs taxpaying families approximately \$5,000 each. Promises to lower the cost of health care for the average American family should include modernizing Medicaid so they get the greatest value for government programs they support with their taxes.

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INTRODUCTION

As President Barack Obama and Congress debate health care reform, it is important that long-term care be included.¹ While not central to providing basic health insurance to all Americans, long-term care should be part of efforts to improve health care for all Americans. Contrary to widespread belief that long-term care affects only a small minority of the population, 69 percent of people turning age 65 will need long-term care before they die and a third of the population will spend some time in a nursing home (Kemper, Komisar and Alexih, 2005/2006).

In thinking about the place of long-term care in the health reform debate, four factors are important:

- With the aging of the population, the number of older people with disabilities is sure to grow substantially. According to one estimate, the number of older people with disabilities will approximately double between 2000 and 2030 (Johnson, Toomey, and Wiener, 2007). As a result, the relative financial and other burdens of long-term care will be greater in the future than they are now. Comprehensive reform will need to take into account both the number of people needing long-term care in the future and their characteristics, which may be very different than today.
- Federal and state governments spend substantial amounts of money on long-term care. In 2006, the public sector spent \$150 billion on long-term care for people of all ages (Tumlinson and Aguiar, 2008). With the aging of the baby boom generation, it is highly likely that public spending for long-term care will increase significantly over the next 30–40 years. In addition, no other part of the health care system is as dependent on public financing as long-term care. In 2008, for example, 77 percent of nursing home residents had their care covered by either Medicare or Medicaid (American Health Care Association, 2008). As a result, government policy is especially important for long-term care providers and consumers.
- Not only do older people and younger adults with disabilities use expensive long-term care services, they have high acute care expenses related to their underlying chronic diseases. An analysis of the Medicare Current Beneficiary Survey by Avalere Health suggests that, in 2005, older people with problems performing at least one activity of daily living had average Medicare costs of \$14,775 compared with \$4,289 for beneficiaries with no problems with the activities of daily living (Tumlinson and Aguiar, 2008). One study estimated that disability-associated health and long-term care expenditures were \$398 billion in 2006 (Anderson, Wiener, Finkelstein, and Armour, 2008).
- The current long-term care financing and delivery system is broken. The United States does not have, either in the public or private sectors, satisfactory mechanisms for helping people anticipate and pay for their long-term care. As a result of the lack of insurance coverage, long-term care expenses are the leading cause of catastrophic health care costs among older people. The disabled elderly and their families find, often to their surprise, that neither Medicare nor their private insurance covers the costs of nursing home care or home and

¹ This testimony primarily addresses long-term care for older people and younger adults with physical disabilities. The important topic of long-term care for people with intellectual disabilities or mental illness is not the main focus of the paper.

community-based services. Instead, people needing long-term care must rely on their own resources, or when those have been exhausted, must turn to welfare in the form of Medicaid. Despite the strong preference of people with disabilities for home and community-based services, the available financing is highly skewed toward institutional care. Moreover, the home and community-based services that are available do not necessarily meet the preferences of people with disabilities. Quality of care is often deficient and the workforce needed for high-quality care is lacking.

PROBLEMS OF THE CURRENT SYSTEM AND GOALS OF REFORM

The current system of financing and organizing long-term care satisfies almost no one. There are at least five goals that should be addressed by long-term care reform:

Treating the Risk of Long-Term Care as a Normal Life Risk

Although not often discussed, perhaps the most important goal of reform should be to treat long-term care as a normal risk of living and growing old. Fully 69 percent of people who turned age 65 in 2005 will have some long-term care needs before they die; among the 35 percent of older people who will spend some time in a nursing home before they die, about half will reside there for a year or longer (Kemper, Komisar, and Alecxih, 2005/2006). Mechanisms should be established so that people will know how they will pay for services should they need them. The large expenses of long-term care should not come as an unpleasant surprise that causes severe financial distress to individuals and their families. Currently, the problem of coping with disabilities is compounded by worries about paying for care. Older people and others fear that if they need long-term care, they will become a burden on their family.

Protecting Against Catastrophic Out-of-Pocket Costs

With very little public or private insurance coverage against the high costs of long-term care, it is not surprising that users of long-term care services often incur very high out-of-pocket costs. The average private pay cost for a year in a nursing home in the top 31 metropolitan markets was \$78,475 as of the second quarter of 2007 (National Investment Center, 2007), but the median income of older people with disabilities was \$18,480 in 2001 (Johnson and Wiener, 2006). Among current retirees who will have long-term care out-of-pocket costs during their lifetime, 36 percent will have expenditures that exceed \$25,000 and 10 percent will have expenditures that exceed \$100,000 (Kemper, Komisar, and Alecxih, 2005/2006).

Preventing Dependence on Welfare

A separate but related concern is to prevent people who have been financially independent all their lives from depending on welfare—Medicaid—at the end of their lives. Two thirds of all nursing home residents depend on Medicaid to pay for their nursing home care (American Health Care Association, 2008), and a substantial portion of residents were not eligible spent down to Medicaid because of the high cost of services (Wiener, Sullivan, and Skaggs, 1996).

Changing the Balance of Institutional and Home and Community-Based Services by Maximizing Consumer Choice

Reform of the financing system should also aim to create a more balanced delivery system by expanding paid home and community-based services. The overwhelming majority of people with disabilities are at home and want to stay there (AARP, 2003). Despite these preferences, public expenditures for long-term care for older people are overwhelmingly for nursing home rather than home care. In 2004, only about 32 percent of total long-term care expenditures for older people were for home and community-based services (U.S. Congressional Budget Office, 2004). Of total home care expenditures, 25 percent was financed by Medicaid, 42 percent by Medicare, and the remaining 33 percent by out-of-pocket payments, private insurance, and other government programs.

Designing an Affordable System

Political reality dictates that any reform system be “affordable” to both users and governments. Although there is little consensus as to what constitutes society’s willingness to pay for long-term care services, there is little doubt that raising taxes to pay for a public program is always difficult, even for popular programs like Social Security and Medicare. Total (public and private) long-term care expenditures for older people are projected to be 2.1 percent of the gross domestic product (GDP) in 2048, compared with 1.21 percent in 1993 (Wiener, Illston, and Hanley, 1994). While this change is a big increase in percentage terms, it is a relatively modest change in absolute terms, given the aging of the population. On the other hand, long-term care will be needed primarily by older people, who will also require much larger Medicare and Social Security spending.

SETTING THE STAGE ON FINANCING

The debate over long-term care financing is primarily an argument over the relative merits of private versus public sector approaches. Some people believe that the primary responsibility for care of older people and younger adults with disabilities belongs with individuals and families and that government should act only as a payer of last resort for those unable to provide for themselves. Policymakers who hold this view generally advocate private sector initiatives, such as private long-term care insurance and using reverse mortgages to pay for long-term care services and insurance, and may advocate tightening eligibility for public programs to prod people to plan for their own long-term care needs. The long-term care financing systems of the United Kingdom, New Zealand, and the United States largely reflect this view (Organization for Economic Co-operation and Development, 2006).

The opposite view is that the government should take the lead in ensuring that all people with disabilities, regardless of financial status, are eligible for the long-term care services they need. The long-term care financing systems of Germany, Japan, the Netherlands, and Sweden reflects this view. U.S. policymakers who hold this view generally favor expansions of Medicaid, Medicare, the Older Americans Act, and other public programs and advocate a social insurance program for long-term care. Between these polar positions, many variations are possible.

Cutting across political ideology is the question of whether the current system of long-term care financing will be affordable in the future because of increased demand associated with the aging of the baby boom generation. Surprisingly, recent projections to assess this issue are

lacking, but Wiener, Illston, and Hanley (1994) projected that total long-term care for older people would increase from about 1.4 percent of GDP in 2008 to about 2.1 percent of GDP in 2048; public spending would account for about half those amounts. In the view of the author, new projections might put the total spending percentage at about 3.0 percent for 2048, roughly doubling the percent of GDP for long-term care. Projections of this type depend on a number of factors, including assumptions about the growth of the economy. Under a “slow” growth scenario, total long-term care expenditures for older people were projected to be 3.7 percent of GDP in the earlier projections (Wiener, Illston, and Hanley, 1994).

Moreover, long-term care for persons of all ages accounted for about a third of total Medicaid expenditures. As a result, Medicaid long-term care for persons of all ages accounted for 4.6 percent of state-revenue expenditures in 2004, and might, therefore, account for roughly 10 percent of state revenue expenditures in 2048 (author’s calculation based on Scott, 2005). States, in particular, are worried about the long-range impact of an aging population on their budgets.

Countries such as Germany, the Netherlands, and the United Kingdom that have populations older than the United States spent between 1.35 and 1.44 percent of GDP for long-term care for older people in 2000; Sweden, where 17 percent of the population was elderly, was the outlier, spending a little under 3.0 percent of GDP for long-term care for older people (Organization for Economic Co-operation and Development, 2006).

How policymakers view these projections heavily determines what type of financing reform they propose. Advocates for private sector initiatives view these increases and their implications for public spending to be unacceptably high and worry that they will crowd out other worthwhile public spending, especially for younger people. In addition, they note that long-term care expenditure increases would be on top of huge projected increase spending for Social Security and Medicare, programs that serve the same population. Because of these fiscal burdens, they argue that it is imperative to shift as much long-term care cost to the private sector as possible.

On the other hand, the implicit assumption of advocates for a greater role for the public sector is that these costs are affordable. From their perspective, long-term care is a small portion of the total health care system and even if its proportion doubled, it would remain a small portion of the health care system. Indeed, overall national health expenditures increased by more than 2 full percentage points of GDP between 2000 and 2006 (Catlin et al., 2008) with relatively little notice and modest economic consequences. Moreover, from a macroeconomic perspective, it may matter little in terms of the burden to the economy whether services are financed by the public or private sector (Wiener, Illston, and Hanley, 1994).

In addition to these ideological and value choices, the choice of emphasis between public and private programs also depends on who would benefit and whether they meet specified policy goals. For example, if a large majority of citizens were to purchase private long-term care insurance, then many people would see less need for expanding government programs. Conversely, if private insurance were to prove widely unaffordable or otherwise encounter barriers that prevent people from voluntarily purchasing policies, then the case for an expanded public role would be stronger.

PRIVATE SECTOR INITIATIVES

Private sector approaches are appealing because they reflect the American tradition of individuals taking responsibility for their own lives and those of their families. Moreover, problems of the economy, the huge budget deficit, resistance to new taxes, and the aging of the baby boom generation make large-scale expansions of public programs difficult. In the case of long-term care, advocates contend that private sector initiatives might hold down public spending by preventing the middle class from spending down to Medicaid, although most previous research suggests that this is unlikely (Rivlin and Wiener, 1988; Wiener, Illston, and Hanley, 1994). Over the last decade, most national policy debate on financing reform has focused on private initiatives. Private sector initiatives fall into two broad categories—individual asset accumulation and use and various forms of private risk pooling, principally long-term care insurance. These options are summarized in *Exhibit 1*, along with their strengths and weaknesses.

Individual Asset Use: Reverse Mortgages

Motivated by the historically large amount of home equity among older people and, up to recently, the substantial increases in housing prices, there has been interest in finding ways to use reverse mortgages to finance long-term care (Merlis, 2005). Typically, reverse mortgages are home equity loans that do not have to be paid off until the borrower dies or moves from the house. These loans can be used for long-term care or anything else. They can either provide a regular stream of income or a line of credit. In 2007, there were approximately 100,000 older people with reverse mortgages (National Council on the Aging, 2009).

Reverse mortgages raise a number of issues: First, home prices are falling rapidly. Thus, like everyone else, older people are likely to have much less home equity than just a few years ago and mortgage lenders may be more reluctant to offer reverse mortgages, which are riskier than conventional mortgages. Second, even before the housing crash, home equity by older people with disabilities was not as high as it is for people without disabilities. In 2002, median home equity among older persons with disabilities (including those with no home equity) was only \$56,956, and \$35,640 for persons with severe disabilities (Johnson and Wiener, 2006). Third, restrictions on the amount of home equity that can be obtained, closing costs, and interest costs substantially erode the amount of money available to pay for long-term care directly (Merlis, 2005). Finally, the home has a near mythic quality in the United States, and it is uncertain how many older people would be willing to deplete their major asset, especially if home values are not rising.²

² Some analysts have suggested using home equity conversions to purchase private long-term care insurance, which provides more coverage than may be available through direct use of home equity to purchase long-term care services. While the use of home equity would marginally increase the proportion of older people who can afford private long-term care insurance, it seems unreasonable to expect that people will partly deplete their major asset to purchase a product, one of whose major purposes is to protect their major asset. Moreover, individually sold private long-term care insurance has high overhead, because of substantial marketing, commission, and profit costs. Most private long-term care insurance policies have long-term loss ratios of 60 percent, which roughly means that 60 percent of the premiums are used for benefits (U.S. Government Accountability Office, 2006). Thus, the use of home equity (with a “loss ratio” of 66 percent) to purchase a private long-term care insurance policy (with a “loss ratio” of 60 percent) would result in only about one in three home equity dollars providing long-term care benefits (Merlis, 2005).

Exhibit 1: Principal Private Long-Term Care Financing Options

Option	Pros	Cons
Reverse mortgages	<ul style="list-style-type: none"> • Older people have substantial home equity, although older people with disabilities have much less 	<ul style="list-style-type: none"> • Various restrictions, fees, and interest payments reduce the amount of money available for long-term care • Older people may resist using home equity for long-term care costs • Recent drop in home prices may reduce demand by older people and lenders
Employer-sponsored long-term care insurance policies	<ul style="list-style-type: none"> • Reduces premium costs and medical underwriting • Encourages private responsibility 	<ul style="list-style-type: none"> • Employer and employee market take-up has been low • Policies still relatively expensive • Selling to younger people means predicting what will happen far into the future • More employers may offer policies, but few help pay for them
Tax incentives for private long-term care insurance	<ul style="list-style-type: none"> • Reduces net cost of policies, making them more affordable • Encourages individual responsibility 	<ul style="list-style-type: none"> • Results in loss of federal revenue • May be inefficient, providing benefits mostly to people who would have purchased policies without the incentive • Tax deductions are regressive, providing greater benefits to upper-income persons • Most people would receive relatively small tax benefits, not solving affordability problem
Public-private partnership, whereby people who purchase state-approved long-term care policies can become eligible for Medicaid while retaining much higher level of financial assets	<ul style="list-style-type: none"> • Brings together public and private sectors • Makes policies more affordable to middle class 	<ul style="list-style-type: none"> • Previous partnerships have had limited market penetration • Asset protection and easier access to Medicaid may not motivate many purchasers • Inflation protection provided in the Deficit Reduction Act is weak
Hybrids of long-term care insurance with other types of insurance (e.g., disability insurance)	<ul style="list-style-type: none"> • Allow people to buy one policy to protect against two or more risks 	<ul style="list-style-type: none"> • Products are complicated and difficult to understand • Offer only small premium savings by combining products

Risk Pooling: Private Long-Term Care Insurance

A viable private long-term care insurance market, primarily sold on an individual basis, has existed since the mid-1980s. In 2005, approximately 7 million policies were in force, covering about 3 percent of the total American population aged 20 and older; about 10 percent of older people, but only 0.2 percent of people aged 20–49, have private long-term care insurance (Feder, Komisar, and Friedland, 2007). Most policies have substantial limitations in terms of length of covered benefits, inflation adjustments, and benefits in case of lapse.

Among the reasons that relatively few people have private long-term care insurance are that people think that Medicare covers long-term care services, failure to recognize the potential risk, medical underwriting of policies which excludes many applicants, and the existence of a public safety net in Medicaid. Especially in the current economic environment, questions about the financial stability of insurance companies may deter people from buying policies.

Perhaps the greatest obstacle to purchase is that private long-term care insurance is expensive, especially for older people on relatively fixed incomes (Feder, Komisar, and Friedland, 2007; Wiener, Illston, and Hanley, 1994). The average premium in 2002 for private long-term care insurance policies providing \$150 daily benefit amount, 4 years of coverage, a 90-day elimination period, 5 percent compound inflation protection, and a nonforfeiture benefit was \$2,862 per year if purchased at age 65, meaning that married couples would face premiums exceeding \$5,000 a year (Coronel, 2004). However, the median income for households headed by persons aged 65–74 was \$34,243 in 2004, and declines sharply with increasing age (U.S. Census Bureau, 2006). Thus, even with generous assumptions about the willingness of people to pay, private long-term care insurance is expensive for most older people. It is also expensive for many working-age adults, who may lack health, life, and disability insurance. In addition, insurers are generally unwilling to sell insurance to people with health problems, eliminating them from the market.

The limitations of the unsubsidized, individual private long-term care insurance market has led to a number of proposals and initiatives to “jump start” the private long-term care insurance market, primarily by finding ways to make policies more affordable. These initiatives or proposals include encouraging employer-sponsored policies so that people will buy policies when they are younger when policies are less expensive, federal and state tax deductions or credits for the purchase of private long-term care insurance so that the net cost to the purchaser would be lower, public-private partnerships that apply less stringent Medicaid financial eligibility requirements to persons who purchase a state-approved private long-term care policy, and combining long-term care insurance with other types of insurance (such as life insurance) to provide value to people with other types of financial products.

PUBLIC SECTOR INITIATIVES

Private sector initiatives can play a bigger role than they do today, but none of the options described above is likely to result in private long-term care insurance or similar initiatives replacing public financing of long-term care without very substantial federal subsidies. An alternative approach would rely more heavily on the public sector. For advocates of a greater role for public sector programs, five factors are important:

First, long-term care services are already heavily financed by the public sector. In 2004, 56 percent of long-term care spending for older people was by Medicare, Medicaid, the Older Americans Act, state home care programs, and the Department of Veterans Affairs (U.S. Congressional Budget Office, 2004). In addition, a large portion of out-of-pocket payments are, in fact, contributions toward the cost of care required of Medicaid beneficiaries in nursing homes and not purchases of services by private payers. A substantial but unknown proportion of the out-of-pocket payments for long-term care is paid for with Social Security payments to individuals. A heavy role by the public sector in financing long-term care is typical of virtually all developed countries (Organization for Economic Co-operation and Development, 2006).

Second, the public sector originated or played an important role in many innovations in long-term care, including consumer-directed home care, cash and counseling, money follows the person, case management, capitated approaches to integrating acute and long-term care, and third-party funding for residential care facilities such as assisted living.

Third, the public sector is more likely to be able to address the needs of younger people with disabilities, who accounted for 36 percent of people with long-term care needs in 2000 (Rogers and Komisar, 2003). Medical underwriting for private long-term care insurance products excludes people with existing disabilities and working-age adults are less likely to purchase private long-term care insurance because the risk seems small and far away.

Fourth, because they require substantial discretionary income to be affordable, private sector initiatives are likely to be regressive or at least not to target working class and lower-middle class families. On the other hand, Medicaid targets a relatively low-income population and Medicare covers virtually all older people regardless of financial status. The relatively low incomes and assets of people with substantial disabilities (Johnson and Wiener, 2006) means that most additional spending, even under social insurance programs, would be spent primarily on lower- and moderate-income people with disabilities (Wiener, Illston, and Hanley, 1994).

Fifth, public programs have much lower administrative overhead and other nonbenefit costs than does private insurance. Most private long-term care insurance policies budget 40 percent of the revenue for administrative overhead, profits, marketing, and so on.

At least three broad strategies exist for expanding the role of the public sector—increasing funding for the Older Americans Act or similar appropriated programs, expanding Medicaid eligibility and covered services, and establishing a social insurance program. These options are summarized in *Exhibit 2*. While increasing funding for the Older Americans Act or similar programs and expanding Medicaid are incremental approaches that could have relatively modest costs, establishing a new social insurance program would be a major departure for the existing financing system and would require large additional investment of federal funds, now and in the future.

Increase Funding for the Older Americans Act or Similar Programs

Apart from Medicare and Medicaid, the federal government funds long-term care through a number of appropriated programs, including the Older Americans Act, the Social Services Block Grant, and the Department of Veterans Affairs. Compared with Medicare and Medicaid, these programs are very small and have been relatively flatly funded in recent years. As a result, their role in the direct funding of long-term care services has declined over time (Rabiner et al., 2007).

Exhibit 2: Principal Public Sector Long-Term Care Financing Options

Option	Pros	Cons
Increase funding for Older Americans Act and similar programs	<ul style="list-style-type: none"> • Provides funding for people not eligible for Medicaid, but not high income • Focuses on home and community-based services • Could provide funding to build infrastructure through Aging Network 	<ul style="list-style-type: none"> • Might increase fragmentation of financing system • Funding for appropriated programs less likely to increase over time than entitlement programs • Would require additional government spending
Expand the Medicaid program	<ul style="list-style-type: none"> • Easy to implement because it builds on existing system, which dominates long-term care financing • Targets people in greatest financial need 	<ul style="list-style-type: none"> • Does not prevent people from incurring catastrophic out-of-pocket costs • Higher Medicaid spending may squeeze other priorities at state level • States will resist additional mandates • Increases number of people dependent on public means-tested system • Would require additional government funding
Expand Medicare nursing home and home health benefits	<ul style="list-style-type: none"> • Builds on already existing program • Administrative structures already in place • Provides near universal coverage for older people and some younger persons with disabilities 	<ul style="list-style-type: none"> • Would require substantially greater government funding • Medical model would likely dominate • Program could be rigid and bureaucratic • Limited range of services • Does not make use of state expertise
Social insurance for long-term care	<ul style="list-style-type: none"> • Treats needs of people with disabilities the same as acute care • Provides universal coverage • Recognizes that vast majority of people cannot afford long-term care • Spreads risk over largest possible group 	<ul style="list-style-type: none"> • Would require substantially greater government funding • Some funding would support services to upper-income and wealthy individuals • Program could be rigid and bureaucratic

Through programs funded by the Older Americans Act, the U.S. Administration on Aging funds three types of activities. First, the Older Americans Act funds a nationwide system of 655 Area Agencies on Aging and 56 State Units on Aging, which provide information and referral, advocacy, and services to the older population. Many State Units on Aging and Area Agencies on Aging are involved in administering Medicaid home and community-based services waivers. Second, the Administration on Aging funds a variety of home and community-based services to people aged 60 and over, including supportive services, senior centers, congregational and home-delivered meals, disease prevention and health promotion services, and caregiver support services. Third, the Administration on Aging funds long-term care infrastructure development grants to states and Area Agencies on Aging on improving Alzheimer's disease services, establishing health promotion and disease prevention services, implementing nursing home diversion programs, and creating Aging and Disability Resource Centers, which are "one-stop shops" for information and referral on long-term care.

Expand the Medicaid Program

Medicaid, a means-tested welfare program, has strict requirements on income and assets and home care coverage that vary greatly by state. For example, the \$2,000 limit on financial assets that single Medicaid beneficiaries may retain has not increased since 1984. The Deficit Reduction Act of 2005 restricted Medicaid eligibility for long-term care by reducing the amount of home equity that beneficiaries may retain and by tightening the rules against transfer of assets. Most states allow nursing home residents to retain only \$40 per month or less in income as a personal needs allowance, only about \$1 a day (Bruen, Wiener, and Thomas, 2003). In 2007, while almost all states provided home and community-based services through Medicaid waiver programs, only 34 states and the District of Columbia covered personal care services as part of their regular Medicaid program (Burwell, Sredl, and Eiken, 2008).

An incremental approach to long-term care reform would be to expand the Medicaid program. This approach targets public expenditures to people in greatest financial need. Possible changes could be establishing more lenient financial eligibility standards—raising the level of protected assets and increasing the amount of income that nursing home and community-based beneficiaries can retain for personal needs—and expanding home care coverage either by providing financial incentives to states or by mandating coverage. The Community Choice Act is an example of a proposal that would expand home and community-based services by mandating more home and community-based services and by liberalizing financial eligibility standards. Another example would be to repeal the requirement that states recover the cost of home and community-based services from the estates of Medicaid beneficiaries, a requirement widely believed to deter some people from receiving needed services. Without the federal government providing all or almost all of the funds for any expansion, states are likely to resist any new requirements as unfunded mandates.

It should be noted that some observers contend that the existence of Medicaid as a safety net for long-term care and the possibility of transfer of assets to qualify for Medicaid lead middle class people to forego private insurance (Moses, 2005). The provisions in the Deficit Reduction Act of 2005 that tightened transfer of assets restrictions and lowered the level of protected home equity were heavily influenced by the argument that it is too easy for middle-class persons to obtain Medicaid long-term care services. However, given the widespread misunderstanding of Medicare coverage, the denial of the risk of needing long-term care, and the lack of knowledge about Medicaid eligibility rules, it is unlikely that Medicaid eligibility rules are a major reason that people in their 50s and early 60s do not buy long-term care insurance. Moreover, despite the conventional wisdom that transfer of assets to obtain Medicaid eligibility is widespread, there is a large, rigorous research literature that finds that transfer of assets is relatively infrequent and usually involves quite small amounts of funds when it occurs (Bassett, 2004; Lee, Kim, and Tanenbaum, 2006; O'Brien, 2005; Waidmann and Liu, 2006). The maximum amount of asset transfer is probably no more than about 1 percent of Medicaid nursing home expenditures (Bassett, 2004; Waidmann and Liu, 2006).

Augment the Post-Acute Care Benefits under Medicare

The Medicare program already provides some coverage for skilled nursing facility care and home health on a non-means-tested basis. However, this coverage is oriented toward short-term, medically oriented services; Medicare does not cover nursing home or home health care

over an extended period and does not cover services such as assisted living. For beneficiaries with at least a 3-day hospital stay, Medicare covers up to 100 days of care in a skilled nursing facility for beneficiaries requiring skilled nursing or rehabilitation services on a daily basis. The average length of a Medicare covered stay is only about 26 days (U.S. Centers for Medicare & Medicaid Services [CMS], 2008). In addition, Medicare covers home health care, but it is limited to people who need part-time or intermittent skilled nursing care or physical, speech-language, or occupational therapy. Although no hospital stay is required, beneficiaries must be homebound. During the 1990s, the Medicare home health benefit was used by many beneficiaries with largely long-term care needs, but this practice ended abruptly with passage of the Balanced Budget Act of 1997. Thus, one option would be to expand Medicare coverage, perhaps by eliminating the 3-day hospitalization requirement for skilled nursing facility care or by removing the homebound requirement for home health.

New Social Insurance Program for Long-Term Care

A much more ambitious approach to reform would be to establish a new social insurance program for long-term care. This strategy offers coverage to all persons who need it, regardless of their financial need. While not much discussed in the United States in recent years, a number of other countries, including Japan, Germany, the Netherlands, and some parts of Canada and Scandinavia, have financing systems that are based on a universal coverage approach (Organization for Economic Co-operation and Development, 2006). One example of a social insurance proposal is the Community Living Assistance Services and Supports (CLASS) Act, introduced by Senator Edward Kennedy. The CLASS Act would create a nationwide voluntary long-term care insurance program financed through voluntary payroll deductions of \$30 per month, with an option to opt out for those who choose not to participate. This legislation would provide a \$50–\$100 per day cash benefit to those individuals who need long-term care for a limited period of time.

MOVING FORWARD: FIRST STEPS

The long-term care financing and delivery systems in the United States need a dramatic overhaul. Although long-term care affects people of all ages, the increase in the elderly population over the next 40 years, and with it the growth in the number of older people with long-term care needs, inevitably will force long-term care onto the policy agenda. Some observers worry about whether the current Medicaid-dominated system can be sustained, although it seems likely that America can muddle through, albeit in a less than optimal fashion. While the costs and other demands of long-term care are almost certain to be greater in the future than they are today, long-term care in the future does not have to look like the long-term care of today. We have the opportunity and the responsibility to build a better system than the one we have today.

Common Understanding of the Problems

While there are strong disagreements among long-term care stakeholders on many issues, most observers would agree with the following observations on financing:

- Because each state has its own coverage and eligibility rules, the heavy emphasis on Medicaid financing results in great variation across the country in what services older and younger persons needing long-term care have available to them.
- States are not fiscally structured to address the large long-run increase in demand for long-term care.
- Addressing the problem of long-term care financing is likely to require a combination of public and private initiatives and will need to address both older people and younger persons with disabilities.
- While private sector financing is likely to increase, it will not become a major source of financing without much greater financial incentives, which would be costly to federal and state governments.
- Although substantial progress has been made over the last 10 years, the long-term care financing and delivery system continues to be tilted toward institutional care rather than to home and community-based services.
- The split between acute and long-term care financing and delivery results in suboptimal care for older and younger people with long-term care needs.

Agreements and Disagreements on Policy Directions

Long-term care stakeholders agree on some policy directions and disagree about others. In terms of financing, policymakers face a fundamental choice on whether they wish to devote the resources necessary to substantially change the existing system. Significant changes from the status quo—be it a large expansion of private long-term care insurance, modifying Medicaid, expanding Older Americans Act programs, or enacting a new public insurance program or expanding Medicare—will require substantial additional government spending either as direct government expenditures or as tax losses through deductions or credits for private long-term care insurance or other private financing mechanisms. As with the stimulus package and health care for the uninsured, sharp disagreements exist among policymakers over whether expansion of public or private programs is desirable or possible.

In contrast to the disagreements about long-term care financing, there is broad policy consensus to expand and reform home and community-based services. Most, but not all, stakeholders would strongly prefer that this expansion be accompanied by a decline in the use of nursing homes. The Medicaid funds to attain this goal are lacking in most states, but the direction is clear. Moreover, a number of initiatives are underway to expand participant-directed care, the use of residential care facilities, nursing facility transition programs and money-follows-the-person initiatives, and single points of entry to the long-term care system. This policy direction enjoys remarkable consensus across the political spectrum—liberals view these initiatives as a way of empowering a disadvantaged underclass and conservatives view these initiatives as a way of promoting market solutions.

Starting the Conversation

While major reform would be costly, there are many initiatives that are fairly widely agreed upon that could be implemented at relatively low cost, especially in the context of

significant health care reform. Presented below is a list of initiatives that in the opinion of the author represent the “low-hanging fruit” of long-term care reform. As such, they represent a fairly minimalist set of recommendations, but they represent a starting point, and are not inconsistent with other likely initiatives. Under the proper circumstances, much more ambitious initiatives could be adopted. These initiatives, which are summarized in *Exhibit 3*, include the following:

Educating the American People

Although an increasing number of people have experience with long-term care either directly or through relatives, most Americans know little about long-term care. For example, despite the fact that Medicare covers only short-term skilled nursing facility and home health care, most Americans continue to believe that Medicare covers long-term care (GfK NOP Roper Public Affairs & Media, 2006). Building on the existing *Own Your Future Campaign*, the federal government could mount a major campaign to educate Americans on the long-term care financing and delivery system, with a major focus on eligibility and coverage of government programs and options within the public sector.³ The campaign should also educate the public about the range of long-term care services.

A National Commission on Long-Term Care

A national commission on long-term care, modeled on the Pepper Commission of the late 1980s, could be a useful way to create a consensus on long-term care reform. Mandated by the Medicare Catastrophic Coverage Act of 1987, the Pepper Commission was a bipartisan group composed primarily of members of Congress, charged with addressing health care for the uninsured and long-term care. Despite lopsided majorities on the Commission for major long-term care initiatives, they were not enacted. However, the Commission did educate Congress and the public on the problems of long-term care and its potential solutions, and was a touchstone for the long-term care debate over the next several years. While establishing a commission is likely to have significant support, some observers might object to this proposal because they see it as a way for politicians to avoid dealing with the issue, or as the British say, “kicking the ball into the long grass.”

Federal Funding for State Long-Term Care Infrastructure Initiatives

The federal government currently operates a number of small programs that provide grants to the states to improve the long-term care infrastructure. For example, these grants have funded state initiatives to develop single points of entry to the long-term care system, improve quality management systems, develop nursing home transition and participant-direction programs, establish workforce initiatives, and improve services for people with Alzheimer’s

³ The Own Your Future Campaign is a project, started in January 2005, to increase consumer awareness about, and planning ahead for, long-term care. The project’s core activities are state-based direct mail campaigns supported by each participating state’s Governor, and targeted to households with members between the ages of 45 and 70. Campaign materials include a Long-Term Care Planning Kit and state-specific information and resources. The Own Your Future Campaign is a collaboration of CMS, the Office of the Assistant Secretary for Planning & Evaluation, and the U.S. Administration on Aging, and has support from the National Governors Association.

Exhibit 3: The Beginning Elements of a Reform Agenda

Proposal	Description
Educate the American people on long-term care	<ul style="list-style-type: none"> Public education campaign to increase public understanding of the long-term care financing and delivery system
National Commission on Long-Term Care	<ul style="list-style-type: none"> High-level, bipartisan commission, including appointees by the President, the House and Senate, to recommend a comprehensive strategy for long-term care reform
Increase federal funding for state long-term care infrastructure initiatives	<ul style="list-style-type: none"> Substantially increase funding for existing or new grants to states to help states establish infrastructure, such as Aging and Disability Resource Centers, Alzheimer's disease programs, participant-directed home care programs, quality assurance systems for home and community-based services, and nursing facility transition programs
Ease Medicaid spend-down requirements for beneficiaries receiving home and community-based services	<ul style="list-style-type: none"> Allow states to establish higher Medicaid income and asset spend down limits for people receiving home and community-based services
Increase funding for Administration on Aging and other appropriated long-term care programs	<ul style="list-style-type: none"> Increase funding for infrastructure development and for home and community-based services for people of all ages
Increase support for a variety of relatively low-cost initiatives related to quality of care	<ul style="list-style-type: none"> Increase funding for the Administration on Aging Ombudsman program Increase research funding on quality of care of home and community-based services Amend Medicaid to more clearly require states to establish standards for and monitor the quality of Medicaid home and community-based services Establish Medicaid pay-for-performance demonstrations for nursing homes Continue financial support for integrated data systems that cut across provider settings, such as the CARE tool
Establish grant program to states, providers, and consumers to improve direct care workforce	<ul style="list-style-type: none"> Establish grant program to promote training programs, organizational change, worker registries, and other workforce initiatives
Research and development	<ul style="list-style-type: none"> Increase funding for long-term care research and policy analysis. Conduct demonstrations of innovative approaches to long-term care, including ways to coordinate and integrate with acute care.

disease. However, the size of many of these grants has been only a few hundred thousand dollars, limiting their impact; many projects have had difficulty going statewide or becoming permanently integrated into ongoing programs. In this proposal, funding for existing infrastructure programs would be increased or a new program that would consolidate and increase funding for these grants would be established. These infrastructure grants would address entry to the long-term care system, expansion and reform of home and community-based services, and workforce and quality of care initiatives.

Ease Medicaid Spend-Down Requirements and Other Improvements

Medicaid beneficiaries eligible for home and community-based services waivers may have incomes up to 300 percent of the federal Supplemental Security level (over 200 percent of the federal poverty level), but beneficiaries receiving other home and community-based services (such as personal care under the regular Medicaid state plan) must meet normal Medicaid eligibility rules. Many states use the “medically needy” option to provide Medicaid eligibility to people who incur substantial medical expenses. However, people who “spend down” to the medically needy income level must incur expenses, which, when subtracted from their income, leave them little income on which to live. Under federal law, the maximum level of protected income is only 133 percent of each state’s old Aid to Families with Dependent Children level (the Aid to Families with Dependent Children program was replaced a decade ago by the Temporary Assistance to Needy Families program). These income levels are extremely low, well below the federal poverty level and the Supplemental Security Income payment level. In this proposal, states would have the option to set higher levels of protected income and assets for persons receiving Medicaid home and community-based services outside of waivers.

Funding for Administration on Aging and Other Appropriated Programs

Federal funding for Administration on Aging and other appropriated programs providing home and community-based services could be increased without committing the federal government to large and possibly unknown increases in Medicaid and Medicare. For example, the entire budget for the Administration on Aging was only \$1.4 billion in FY2008 (U.S. Administration on Aging, 2008), so significant percentage increases could be obtained at relatively low cost. Funding could be increased for Administration on Aging service programs, such as the supportive services program, the National Family Caregiver Support Program, and the Ombudsman program and for the administrative costs of State Units on Aging and the Area Agencies on Aging.

Workforce Grant Program

Options to improve the direct care workforce that involve increasing wages and fringe benefits will require significant investment of funds, which may or may not be available. Health insurance coverage for these workers is likely to be addressed as part of other health care reform initiatives. Progress on a number of other initiatives could be promoted by establishing a grant program to states, providers, and consumers to implement training programs, promote organizational change, develop worker registries, and a variety of other workforce initiatives.

Quality of Care Initiatives

While many proposals to improve quality of care, such as raising staffing levels in nursing homes, carry high price tags, other initiatives are less expensive. These initiatives include (1) increasing funding for the Administration on Aging Ombudsman program; (2) funding research on quality of care of home and community-based services; (3) amending Medicaid to more clearly require states to establish standards for and monitor the quality of Medicaid home and community-based services (Institute of Medicine, 2008); (4) establishing Medicaid pay-for-performance demonstrations for nursing homes; and (5) increasing support for integrated data systems that cut across provider settings, such as the CARE tool.

Research and Development

Despite the aging of the population, federal funding for research and development in long-term care has been modest at best. Moreover, in recent years, several private foundations have reduced or narrowed their funding of long-term care research and policy analysis. Ironically, as the need for long-term care has increased, research funding has declined. Broad health services research funding earmarked for long-term care could be increased in the Office of the Secretary, CMS, the National Institute on Aging, the Administration on Aging, and the Agency for Healthcare Research & Quality. Beyond health services research, increased biomedical research on Alzheimer's disease would target one of the main causes of disability and use of long-term care services and increase the likelihood that interventions that prevent or treat this disease would be discovered, thus potentially reducing the need for long-term care services.

Closely allied to increasing the research base would be sponsoring new demonstrations of innovative long-term care programs, including those that better coordinate acute and long-term care services, including those that integrate these two systems. In addition, recognizing the high health care costs of people with long-term care needs, including long-term care and older and younger persons with disabilities in future Medicare chronic disease demonstrations is critical to meeting the needs of this population and finding ways to reduce costs. These demonstrations should include rigorous evaluation of their impacts.

CONCLUSIONS

Despite the fact that long-term care is the third main pillar of retirement security along with health care and income support, it has not received the policy attention it deserves. There is no doubt that when the baby boom generation is age 80 or 85, long-term care will be at the center of public policy debates, but those days are still quite far away (although not as far as they used to be). However, we are now at a time when the parents of the baby boom generation are now elderly; some of these parents are quite old and in need of long-term care. It may be the combination of the baby boomers and their parents that put long-term care on the national political agenda sooner rather than later. The health reform debate that is about to begin is a vehicle to begin to achieve the needed reforms.

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COMMUNICATIONS

US Senate Committee on Finance Subcommittee on Health Care “The Role of Long Term Care in Health Reform” Hearing March 25, 2009

Testimony submitted by Richard Grimes, President and CEO, Assisted Living Federation of America (www.alfa.org), 1650 King Street, Suite 602, Alexandria, Va. 22314

Sen. Rockefeller and committee members,

My name is Richard Grimes, the President and CEO of the Assisted Living Federation of America (www.alfa.org). Thank you for giving me the opportunity to submit testimony on the role of long term care in health reform and thank you for highlighting the need to include long term care in the health reform debate.

I would encourage you and the committee members to take the broadest possible view of long term care. It was not so long ago, in our own childhoods, when the only real option for long term care was a skilled nursing home. In the past 25 years, much has changed. The private assisted living industry has exploded in popularity in the United States and is now the fastest growing long term option in the nation.

The nature of aging has changed in the United States and it will continue to evolve as the baby boomers move through their senior years. When lawmakers sitting in your seats passed the Social Security Act, the average life span in this country barely reached 60 years of age. Now 60 is the new 40 and seniors are living into their 80's, 90's and beyond. The number of Americans living beyond the century mark is at a record high and promises to only grow with time.

I was struck that all of your expert witnesses at the hearing agreed that home and community based care, which includes assisted living, is far more desirable than institutionalization. Even though most public long-term care funds go to institutions, a consensus in favor of other options has clearly emerged among both consumers and government officials. Not only is home and community based care far less expensive than hospital or skilled nursing care but every study shows that disabled and senior consumers and their families prefer it. No senior asks to go into a nursing home or hospital. Circumstances sometimes make it unavoidable but in many instances, the needs of the individual can be met in a less rigid setting.

None of your witnesses spoke specifically about assisted living. I would like to offer some thoughts as to why assisted living provides a desirable and more cost effective model for long term care in the future.

Assisted living is the resident-centered alternative to institutional care. More than one million seniors call assisted living communities home at tens of thousands of communities located in every state. Our residents

are frail seniors who need some assistance with activities of daily living and can no longer (or choose not to) live in their family home—but do not need round the clock nursing care. Our typical resident is an 85 year old widow. She takes eight to 10 different drugs each day, almost as many medications as a nursing home resident, but her medications enable her to manage chronic health conditions . She usually lives in her own room or apartment. The community provides her meals and a variety of social and recreational activities from card games to movies to book clubs. A van takes her to her doctor's office, to local entertainment events, and to the local mall for shopping trips. She lives surrounded by caring staff and friends and maintains control over her own life, deciding when to go to bed, when to get up, when to bathe and when to eat. In other words, she has independence and choice.

Assisted living is a *philosophy of care* that embraces choice, independence and the opportunity for seniors to live enriching lives with dignity, respect and privacy.

We are convinced that assisted living is popular because of the bedrock principle of choice. Assisted living supports the resident's decision on how and where a person should live. Many of you are grappling with the challenge of caring for aging parents and grandparents. Senator Rockefeller's moving description of caring for his own mother who suffered from Alzheimer's disease in her final days is an experience many Americans share. I , too, am one of the 74 million baby boomers with aging parents who need care.

The decision for someone to leave the family home where children were raised and she spent many happy years is never an easy one. But when a loved one realizes it simply is not safe to live alone, nor does she want the responsibility of living in her own home, assisted living is a terrific option. Many seniors grow isolated and depressed living alone as their spouses and peers die. In assisted living, we see men and women truly gain a new lease on life. Consumer surveys, including those conducted by state regulatory agencies repeatedly show an astonishing satisfaction rate of more than 90 percent.

The issue for most seniors and their families is finding quality care that is affordable. The assisted living alternative is available everywhere in the United States. Because it is resident-centered and affordable, it has grown to become the consumer preference. Assisted living costs about half as much as skilled nursing home care. Medicaid saves between 50 and 66 percent for each resident cared for in an assisted living community instead of a nursing home. (More than 40 states have sought or obtained waivers to use Medicaid funds for assisted living for qualified residents. This population amounts to less than 10 percent of the residents in private assisted living communities.) Any form of long term care is labor intensive. A tiny fraction of Americans purchase long term care insurance now and with the recent stock market decline, many have seen their savings dwindle or disappear.

To us, the public policy challenge you face as you consider long-term care needs is helping Americans save for retirement and afford the type of housing and care they need and want as they age. ALFA strongly supports the Community Living Assistance Services and Supports (CLASS) Act which would create a

nationwide public insurance program to help pay for Americans with significant functional needs. The CLASS act keeps control in the hands of the individual and guarantees choice in long term care options.

The growth of assisted living shows that the long term care industry is no longer monolithic and nursing homes are not the only option. All of you know that an institutional bias in government programs lingers against home and community based settings. That is because Medicaid and Medicare, the twin safety net programs for the poor and aging, were created by Congress long before the private assisted living industry existed in the United States. Indeed, when the prescription drug benefit was added to the Medicare program, it inadvertently charged a co-payment for low incomer seniors who live in assisted living communities, so called dual eligible recipients of both Medicare and Medicaid. We are pleased that lawmakers are trying to correct that inequity this year.

There is a risk to over-medicalizing the federal government's approach to aging. Aging is not a disease even though the US Census Bureau tells us a majority of seniors suffer from two or more chronic health conditions. Yet millions of seniors live busy and happy lives for decades with chronic diabetes, heart disease, arthritis and other serious illnesses because of modern drugs. Just a generation ago, that would have been unthinkable.

We are fortunate to live in a time when the average lifespan is steadily growing longer and the quality of life for older Americans is improving. As you grapple with health care reform, we urge you to make certain your plans give maximum flexibility and choice to aging Americans.

ALFA and its members welcome the opportunity to provide more information to the committee as it considers this challenging topic. We are grateful for the chance to submit this testimony and look forward to working with committee members.

The Assisted Living Federation of American is the largest national association serving companies operating professionally managed assisted living communities for seniors. ALFA is the voice for senior living and advocates for informed choice, quality care and accessibility for all Americans needing assistance with long term care. For more information go to www.alfa.org.

Jennifer A. Deland
Counselor-at-Law



TOTAL ESTATE PLANNING

March 30, 2009

Senate Committee on Finance
Editorial and Document Section
Rm SD-219
Dickson Senate Office Bldg.
Washington, DC 20510-6200

Re: March 25, 2009 Hearing: Subcommittee on Health Care of the Committee of Finance on the Role of Long-Term Care in Health Reform

The attached Article appeared under my by-line in the Metrowest Daily News, Sunday, March 8, 2009. The purport of the article is that long-term care is best addressed as an insurance issue, like health care, so that middle class families are not required to liquidate their savings in order to provide for care.

I can be reached at 508-429-8888

Or by mail at

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My e-mail address is Jennifer@jenniferdelandlaw.com
My website is www.jenniferdelandlaw.com

I am a member of the National Academy of Elder Law Attorneys. I do provide help for families who wish to use trusts to protect their assets from "spend down" requirements. I believe that such trusts are effective, legitimate tools under the law as it now stands. However, putting such an arrangement in place only works for people who plan ahead, the same kind of people who voluntarily buy long-term care insurance. Many families come to my office when it is too late for such help.

Truly yours,

Jennifer A. Deland

SUNDAY

AMERICAN NIGHTMARE

Nursing home costs force choice between welfare and impoverishment

Suppose you are living the American Dream: you own a house and you have saved enough for a comfortable retirement. You have children and your children have children. Then a bad thing happens - you have a heart attack, and die suddenly. Your children are the beneficiaries of



Jennifer Deland
Local columnist

your will. They and their children will benefit from your hard work and careful saving. Your grandchildren will be able to attend better schools. That is as it should be; part of the American Dream is being able to leave your children better off than you were.

Now, let's consider another scenario, call it the American Nightmare - instead of dying from that heart attack, you recover and go on to live a long time. The accumulation of the ills of old age make life harder and harder for you. Your bones become more fragile, your memory more fickle. You come to need help just to get out of bed, dress, even eat. Your children, much as they love you, have their own lives to lead. They cannot give you the full time nursing care you need. Reluctantly, you and your family decide you must go into a nursing home.

Up until this point in your retirement, your Medicare, a federal program that provides health insurance to people over the age of 65. Medicare will pay for nursing home care, but only if you enter the nursing home from a hospital and only for a short period of time, if you need long-term care in a nursing home, you must pay for it on your own.

There is a safety net. Called "Medicaid," it is a federal program, administered by the states. In Massachusetts, it is administered by the Division of Medical Insurance under the name, MassHealth.

Medicaid is not insurance. Insurance pays if something happens that you insured against. If your house burns down, your insurance company can't get out of paying by claiming that you have plenty of money, you don't need the benefit. You paid for the insurance; the

DELAND, Page E2

Nursing home costs force tough choice

DELAND, From E1

DELAND, From E1
billion you insured against happened; therefore, the insurance company has to pay. Health insurance works the same way. It doesn't matter whether you can afford to pay for care or not. If you need medical care, and you have medical insurance, the insurer has to pay.

Medicare is health insurance. All working people pay for it, along with Social Security, through payroll deductions. It is insurance that we are required to pay for. Fire insurance on your house (if you have a mortgage), car insurance, and, now in Massachusetts, health insurance, are all required. But we are not required to pay for long-term care insurance.

Instead, most of us will rely upon Medicaid if we ever come to needing long-term nursing home care. Unlike Medicare, Medicaid is not insurance; it is welfare. It only pays the bills of the needy. What does it mean to be needy? Long-term care can run close to \$100,000 a year. If your investments, retirement, and social security, combined, yield that kind of income, you obviously don't need Medicaid.

But what if you have income of "only" \$50,000 a year? Will Medicaid pay the difference? It will not. Medicaid will pay nothing until you have spent your assets. A single person is allowed to keep \$2,000. You don't have to sell your house until it becomes real-ly clear that you are not coming back to it. But, when that happens, the house must be sold and the money used for nursing care. If you die still owning it, the house must be sold and the proceeds used to reimburse the state for the money that has been spent to care for you. There may be nothing left for your children or your grandchildren.

To many, this seems an unfair result. If you can afford to pay for nursing home care out of your own pocket, you

can pass on all your assets to your children. If you are not wealthy enough to pay a nursing home out of your income, you must liquidate your assets in order to pay. So the children of the rich stand to inherit more of their parents' assets than the children of the middle class. This is a mechanism for increasing the gap between the rich and the not-so-rich.

The question is, who should pay. If we all shared the burden, the burden would be lighter.

The truly poor have nothing to worry about. They are taken care of, as they should be, by this system. But if you have something put away, whether or not you can leave the benefits of your hard work and careful saving to your family depends on how you die. If you die suddenly, your family benefits. If you stay alive for a long time, you will have to spend your children's inheritance.

A decision has been made in this country, that nursing home care, unlike most other kinds of medical care, should be a "pay as you go" proposition. We have decided not to require people to insure against it. At the same time, we have decided that we cannot let helpless elders be thrown into the street because they cannot pay for care. These decisions have had some odd results.

One of those odd results is a niche market for lawyers. By placing your savings and your house in an irrevocable trust, you can avoid having the property in your own name when you die. Because the state can only recover

the cost of your care from the property that was in your own name when you died, you can use a trust to pass assets on to your children.

There is one catch, however: the state will refuse to pay for the period of time that the property in the trust would have served to pay for your care if it had been available. However, if you manage to stay out of the nursing home for five years after setting up the trust, the transfer to the trust will be ignored, regardless of the property's value. The use of such a trust is perfectly legitimate. However, setting one up does require forethought and cost money. So, among the "not-so-rich," people who plan ahead, by insuring against the need for long-term care or by taking legal steps to protect their property, will leave their families better off.

But what about someone who is struck by unforeseeable illness or accident and has had no time to plan? What about someone who owns a house but has low income, who feels that they cannot afford either insurance or legal fees? What about those who are too proud to plan to take advantage of a form of welfare, and choose to simply hope that they will die quickly?

The reason that Medicare does not cover long-term care insurance is that it was thought to be too expensive. However, the question is not, should we have long-term care insurance. The question is, who should pay. If we all shared the burden, the burden would be lighter. As things now stand, the burden falls heavily on a certain group of people: those who have worked hard and saved carefully all their working lives and who live a long time. These people, our virtuous elders, deserve better.

Jennifer Deland of Holliston is an attorney.

www.metrowestdailynews.com

SUNDAY, MARCH 8, 2009

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March 30, 2009

Senate Committee on Finance
Attn: Editorial and Document Section
Rm. SD-219
Dirksen Senate Office Bldg.
Washington, DC 20510-6200b

Dear Finance Committee:

I enclose my recently published article in *Marquette Elder's Advisor* for inclusion in the record of the March 25 hearing on The Role of Long-Term Care in Health Reform conducted by the Subcommittee on Health Care Reform. Thank you for your consideration.

Sincerely,

A handwritten signature in black ink that reads "Marshall B. Kapp".

Marshall B. Kapp, J.D., M.P.H.

Enclosure

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THE ROLE OF PRIVATE RESPONSIBILITY IN CLOSING THE GAP BETWEEN KNOWLEDGE AND PRACTICE IN LONG-TERM CARE

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INTRODUCTION

My friend and nationally respected aging policy analyst Dr. Larry Polivka is absolutely correct about the very important goal of closing the gap between knowledge and practice in the United States long-term care financing and delivery system.¹ He is also correct about many of the challenges that must be surmounted if we are to reasonably achieve this paramount objective in time to avert social and political disaster. Dr. Polivka offers a straightforward public policy prescription for overcoming the current challenges; although I concur with certain aspects of his policy prescription, it is his overwhelming emphasis on the public sector while substantially minimizing private sector potential with which I must find fault.

I briefly enumerate in the next section some basic points of congruence between Dr. Polivka's viewpoint and my own. I then offer, in response to his policy recommendations, my own ideas about the significance of personal responsibility as a vital

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1. Larry Polivka, *Closing the Gap Between Knowledge and Practice in the U.S. Long-Term Care System*, 10 *ELDER'S ADVISOR* (forthcoming Jan. 2008). Dr. Polivka uses the word "system" to describe the long-term care picture in the United States, although that word is not really an accurate descriptor for the present situation. See generally Martin Kitchener & Charlene Harrington, *U.S. Long-Term Care: A Dialectic Analysis of Institutional Dynamics*, 45 *J. HEALTH & SOC. BEHAV.* 87 (2004). For reasons made clear below, I prefer to characterize the long-term care picture as a "marketplace" rather than a "system".

component of any appropriate strategy for moving the United States away from our present long-term care practice, toward a financing and delivery paradigm that is more attuned to the kinds of care we should be making available to older and disabled individuals needing help in navigating the inevitable vicissitudes of daily living.²

WHAT WE KNOW: POINTS OF AGREEMENT

There is probably little serious dispute, even by the professional representatives of the American nursing home industry,³ that—as thoroughly documented by Dr. Polivka⁴—we know by now that it is better for most people needing long-term care to receive that care in home and community-based settings rather than in nursing homes.⁵ In other words, it is best in terms of individual and family desires,⁶ as well as considerations of quality and economic efficiency,⁷ to minimize (and ideally eliminate altogether) premature or unnecessary admissions to

2. “The estimated 10 million Americans with long-term care needs today are not all alike. Indeed, there are many different ‘paths’ to dependency and the services such dependency requires.” EDWARD ALAN MILLER & VINCENT MOR, *OUT OF THE SHADOWS: ENVISIONING A BRIGHTER FUTURE FOR LONG-TERM CARE IN AMERICA, A Brown University Report for the National Commission for Quality Long-Term Care* 14 (2006), http://qualitylongtermcarecommission.org/pdf/out_of_isolation.pdf.

3. The primary national trade associations advocating the positions of the American nursing home industry are the American Health Care Association (AHCA), <http://www.ahcancal.org> (last visited August 26, 2008), and the American Association of Homes and Services for the Aging (AAHSA), <http://www.aahsa.org> (last visited August 26, 2008). AHCA represents both for-profit and not-for-profit nursing homes. AAHSA represents only not-for-profit entities.

4. See Polivka, *supra* note 1.

5. See Kevin Eckert et al., *Preferences for Receipt of Care Among Community-Dwelling Adults*, 16 J. AGING & SOC. POL’Y 49 (2004); Michelle Doty et al., *Health Care Opinion Leaders’ Views on the Future of Long-Term Care*, Commonwealth Fund Data Brief, Pub. 1157, Vol. 10, 3 (July 2008). Even AHCA now includes as members, besides its nursing home core, assisted living and subacute care providers. See http://www.ahca.org/about_ahca (last visited August 26, 2008). AAHSA, in addition to its nursing home base, also represents adult day care providers, home health agencies, assisted living facilities, continuing care retirement communities, senior housing providers, and adult community centers.

6. See Eckert et al., *supra* note 5, at 60.

7. See generally Glenn Mitchell et al., *The Relative Benefits and Cost of Medicaid Home and Community-Based Services in Florida*, 46 GERONTOLOGIST 483 (2006).

nursing homes and to reduce the lengths of stay following necessary admissions as much as possible.

We also know, albeit unhappily, that too many public and private dollars being used to purchase long-term care today continue to go toward paying for nursing home care⁸ despite the largely successful efforts of the American aging enterprise⁹ to keep, or move, many extremely disabled persons out of nursing homes and to care (quite adequately for those clients) in home and community-based settings.¹⁰ Put differently, perhaps the major gap between knowledge and practice is the disparity between long-term care service delivery, on one hand, and the allocation and expenditure of financial resources devoted to buying long-term care, on the other; succinctly, the money has not followed the clients.¹¹

Unless this gap (which in many states is really more of a chasm)¹² is addressed effectively and expeditiously, American society runs the substantial risk of repeating many of the same mistakes that were made as part of the concerted, largely litigation-assisted, deeply flawed movement to deinstitutionalize huge state mental illness institutions in the late 1960s and the 1970s.¹³ It was a social movement in which the

8. In fiscal year 2005, the national Medicaid spending for home and community-based long-term care amounted to just 37% of total Medicaid spending for long-term care, even though fewer than 5% of Americans over age 65 are nursing home residents at any particular moment. ARI HOUSER ET AL., *ACROSS THE STATES: PROFILES OF LONG-TERM CARE AND INDEPENDENT LIVING* 11, AARP Pub. Pol'y Inst. 10 (7th ed. 2006).

9. This phrase is borrowed from CAROLL L. ESTES, *THE AGING ENTERPRISE* (1979).

10. See Martin Kitchener et al., *Medicaid Home and Community-Based Services: National Program Trends*, 24 *HEALTH AFF.* 206, 207 (2005).

11. See generally ENID KASSNER ET AL., *A BALANCING ACT: STATE LONG-TERM CARE REFORM*, AARP Public Pol'y Inst. #2008-10 (July 2008) (examining Medicaid long-term care spending for older people with physical disabilities).

12. For example, in fiscal year 2005, Mississippi Medicaid spending for home and community based long-term care amounted to only 13% of its total Medicaid long-term care spending. For the District of Columbia, the figure was just 16%. HOUSER ET AL., *supra* note 8, at 11. But see generally Tracy Bach, *Choices for Care: Consumer Choice and State Policymaking Courage Amid Medicaid's Shifting Entitlement to Long-Term Care*, 9 *ELDER'S ADVISOR* 269 (2008) (describing the Vermont Medicaid waiver success story).

13. See generally DEINSTITUTIONALIZING LONG-TERM CARE: MAKING LEGAL

failure of sufficient public dollars to accompany the people who were swept or kept out of the public institutions resulted not in would-be institutionalized mental patients becoming happily and productively integrated into a welcoming community environment, but rather in *de facto* trans-institutionalization of the erstwhile mental institution population into homeless shelters, the criminal justice system, or nursing homes.¹⁴

Dr. Polivka is on the mark in identifying and lamenting this gap in the current long-term care context. Nonetheless, a couple of cautions ought to be considered by those who might be too intent on quickly and aggressively eliminating the disequilibrium between long-term care client need and the funding to address that need. First, despite enormous progress in the capacity of home and community-based long-term care providers to serve very disabled individuals outside of nursing homes, it is inevitable that there will always be some people—because of a combination of chronic, severe disabling conditions and the lack of an adequate family and community support structure—who will need nursing home care for some period of time during their lives.¹⁵ We must be careful to fund surviving nursing homes sufficiently well so that they can provide decent care for the residents who need to be cared for there on either a short-term or lengthy basis.¹⁶

Second, we should not be overly optimistic about the likely impact of the United States Supreme Court's 1999 decision in

STRIDES, AVOIDING POLICY ERRORS (Marshall B. Kapp ed. 2005) (examining the challenges entailed in substituting home and community-based long-term care for nursing home admission as long as possible for severely disabled older people).

14. See, e.g., PAUL S. APPELBAUM, ALMOST A REVOLUTION: MENTAL HEALTH LAW AND THE LIMITS OF CHANGE 49-52, 217 (1994); RAEI JEAN ISAAC & VIRGINIA C. ARMAT, MADNESS IN THE STREETS: HOW PSYCHIATRY AND THE LAW ABANDONED THE MENTALLY ILL 7 (1990).

15. Judith Kasper, *Who Stays and Who Goes Home: Using National Data on Nursing Home Discharges and Long-Stay Residents to Draw Implications for Nursing Home Transition Programs*, Kaiser Commission on Medicaid and the Uninsured, Rpt. #7386, available at <http://www.kff.org> (last visited August 26, 2008).

16. Joshua M. Wiener, *An Assessment of Strategies for Improving Quality of Care in Nursing Homes*, 43 Special Issue, GERONTOLOGIST 19, 24 (2003) ("The nursing home industry has warned that Medicaid reimbursement rates are already too low and that further reductions would adversely affect the quality of care.").

Olmstead v. L.C. ex rel. Zimring on radically transforming the American long-term care financing scenario.¹⁷ The Court majority interpreted Title II of the Americans With Disabilities Act and its implementing regulations to require that, when the government finances services for a disabled person (such as states do when they subsidize long-term care through their respective Medicaid programs), the purchased services must be provided in the most integrated, least restrictive available setting consistent with the disabled person's needs.¹⁸ This judicial decision has spawned significant activity at both the national and state levels aimed at exploring alternatives to nursing home placements for many chronically disabled individuals.¹⁹ Nevertheless, as earlier social activists in other contexts ultimately came to learn when they sought to use litigation as an instrument to reform institutions such as schools, prisons, and hospitals for the mental ill and developmentally disabled, the judicial branch of government lacks any legal power to authorize or appropriate the expenditure of funds; that spending function is solely the province of the politically accountable legislative branch of government.²⁰ Thus, in light of the American constitutional concept of separation of powers,²¹ the judiciary may proclaim ambitious constitutional or statutory rights and responsibilities, but only the legislature has the power to spend whatever money is necessary to actually effectuate those judicially enunciated rights and responsibilities.²² Consequently, the potential for bold systemic or marketplace change embodied in the *Olmstead* precedent is not self-executing.

17. *Olmstead v. L.C. ex rel. Zimring*, 527 U.S. 581, 604 (1999).

18. *See id.* at 587-601.

19. U.S. DEPT HEALTH & HUMAN SERV., OFF. CIVIL RIGHTS, PREVENTING DISCRIMINATION AGAINST PEOPLE WITH DISABILITIES IN HEALTH CARE AND SOCIAL SERVICES: SERVING PEOPLE WITH DISABILITIES IN THE MOST INTEGRATED SETTING--OLMSTEAD AND THE NEW FREEDOM INITIATIVE, available at <http://www.hhs.gov/ocr/mis.htm> (last visited Sept. 2, 2008).

20. GERALD N. ROSENBERG, *THE HOLLOW HOPE* 1-3 (1991).

21. JESSE H. CHOPER ET AL., *CONSTITUTIONAL LAW: CASES, COMMENTS, QUESTIONS* 151-220 (10th ed. 2006).

22. ROSENBERG, *supra* note 20.

With those caveats in mind, then, I endorse Dr. Polivka's call for a hearty (and thus far largely absent outside the boundaries of academic journals and conferences)²³ national conversation regarding the optimal mix of public and private responsibility²⁴ for correcting the gap between what we know about where long-term care should be provided (and where it increasingly is being provided), on one hand, and our continued tangible spending patterns skewed toward institutional providers, on the other. Dr. Polivka and I diverge somewhat, however, in our respective views about the specific policies toward which that needed national conversation ultimately ought to lead.

POLICY CHOICES: LEVERAGING PUBLIC AND PRIVATE RESPONSIBILITY

The broad policy alternatives available for addressing the gap between knowledge and practice in United States long-term care, that is, for addressing the problem of dollars not following the clients in need, are rather limited. I presume that Dr. Polivka and I would concur, as would virtually everyone else except the most extreme libertarian thinkers,²⁵ that simply abandoning older disabled individuals totally to their own luck in weathering the contingencies of life—as those contingencies of health and wealth might apply to long-term care needs—is not a viable ethical and political option. Eliminating the survival-of-

23. David G. Stevenson, *Planning for the Future--Long-Term Care and the 2008 Election*, 358 N. ENG. J. MED. 1985, 1985 (2008) (“[T]he candidates in the 2008 presidential race have been virtually silent about long-term care policy. Health care received substantial attention during the 35 Democratic and Republican [primary] debates (garnering more than 1000 mentions), but almost nothing has been said about long-term care.”).

24. A mixture of public and private responsibility for long-term care builds upon a rich precedent demonstrated in the history of American health care policy. See, e.g., ROSEMARY STEVENS, *THE PUBLIC-PRIVATE HEALTH CARE STATE: ESSAYS ON THE HISTORY OF AMERICAN HEALTH CARE POLICY* (2007).

25. For a libertarian approach to health care, see, e.g., RICHARD A. EPSTEIN, *MORTAL PERIL: OUR INALIENABLE RIGHT TO HEALTH CARE?* (1999).

the-fittest approach of social Darwinism²⁶ from the conversation essentially leaves three possibilities on the policymaking table: “enhancing private long-term care insurance, replacing the current welfare-based system with a public social insurance program, and introducing a hybrid public-private system.”²⁷

I present public and private responsibility here in a basically dyadic, either/or way, but of course in this arena they are not mutually exclusive. Rather, these approaches need to be symbiotic and mutually reinforcing.²⁸

Any solution will require shared responsibility among individuals, families, and government. However, the mechanisms that would be needed to extend the Medicaid safety net or to create a new benefit under Medicare, as well as the trade-offs inherent in such moves, differ substantially from those that would be needed to expand incentives for private long-term care insurance or to offer greater support to informal caregivers. The former strategies emphasize government’s role in targeting a defined set of services to those in need, whereas the latter strategies primarily subsidize the ability of individuals and families to meet their own current or future care needs.²⁹

PUBLIC RESPONSIBILITY

Dr. Polivka argues in favor of establishing a universal, non-means tested social insurance program as a primary vehicle to finance long-term care in the United States.³⁰ As a first (rather than a last or catastrophic) resort, this proposal is seriously flawed. A broadly expanded entitlement program of the sort advocated would impose an enormous financial burden on

26. See e.g. DAVID P. CROOK, *DARWIN’S COAT-TAILS: ESSAYS ON SOCIAL DARWINISM* (2007).

27. Howard Gleckman, *How Can We Improve Long-Term Care Financing?* Boston College Center for Retirement Research, Number 8-8, 1 (June 2008).

28. Doty et al., *supra* note 5, at 3 (“[T]he most endorsed approach among leaders from all sectors is that government and individuals should share the responsibility for paying for long-term care.”).

29. Stevenson, *supra* note 23, at 1987.

30. Polivka, *supra* note 1.

future generations, on top of all the other suffocating financial burdens³¹ that the Baby Boomers have already heaped upon those who will follow us.³² Even putting aside fundamental moral principles of social justice as they apply to those who contribute the most resources to society,³³ basic considerations of fiscal prudence and political accommodation counsel against such an intrusive approach. Yet another permanent, uncontrollable assault on the federal and state budgets—and thus on the taxpaying segment of the American public—would threaten, perhaps beyond repair, the delicate intergenerational balance that is increasingly strained by the insatiable entitlement obligations of Medicare and Social Security.³⁴

The common response to these concerns, that any potential intergenerational inequity problem could be avoided or substantially mitigated if only current federal budget priorities were wholly rearranged (i.e., if funds were diverted from the Departments of Defense and Homeland Security to expanded social welfare programs), is unconvincing. Although budget priorities are a legitimate topic for robust, continuing public

31. See PHILLIP LONGMAN, *BORN TO PAY: THE NEW POLITICS OF AGING IN AMERICA* (1987).

32. I say "us" because, as a matter of full disclosure, I am a member of the Baby Boom generation and quickly approaching an age category placing me at increased risk of needing long-term care.

33. See generally JUSTICE ACROSS GENERATIONS: WHAT DOES IT MEAN? (Lee M. Cohen ed., 1993).

34. See SOCIAL SECURITY AND MEDICARE BOARDS OF TRUSTEES, STATUS OF THE SOCIAL SECURITY AND MEDICARE PROGRAMS (2008), available at <http://www.ssa.gov/OACT/TRSUM/index.html> (last visited Aug. 31, 2008) (detailing the precarious financial positions of these programs). See generally PHILLIP LONGMAN, *THE RETURN OF THRIFT: HOW THE COMING COLLAPSE OF THE MIDDLE-CLASS WELFARE STATE WILL REAWAKEN VALUES IN AMERICA* (1996); MILLER & MOR, *supra* note 2, at 33:

Fundamental to these discussions [about long-term care financing] will be the level of inter- versus intra-generational transfer. Social Security, Medicare, and Medicaid are all "pay-as-you-go" programs, with current generations of workers paying the benefits of today's elderly and disabled. To add long-term care to these existing entitlements as a largely inter-generationally financed program might be particularly difficult for the majority of workers whose wages have not grown substantially in the past decade and who need to continue to purchase health insurance for their own families.

debate, altering those priorities—even radically—would hardly eliminate the reality of finite (albeit more abundant) resources available to be spent on long-term care for an aging population; consequently, there will be a need at some juncture for difficult choices—put bluntly, for rationing decisions. In the final analysis, demand always will exceed supply, even if there were a much greater supply of resources than current budgetary priorities now make available.³⁵

Moreover, a universal social insurance entitlement program for long-term care would eliminate or greatly discourage private responsibility even more than the current combination of Medicaid availability and learned public complacency has already exerted a “crowding out” effect.³⁶ The crowding out impact of a completely government financed program on the willingness of individuals to shoulder any personal responsibility to save or invest money or purchase private insurance policies to prepare for their future needs would be inevitable,³⁷ unless the guaranteed public benefit coverage turns out to be so deficient that consumers feel the need to escape or supplement the public system.³⁸ Given the enormous, and

35. Regarding rationing of care in the long-term care context, *see, e.g.*, Jane Aronson, *Silenced Complaints, Suppressed Explanations: The Cumulative Effects of Home Care Rationing*, 36 INT'L J. HEALTH SERV. 535, 536-37 (2006); Diane Morin & Nancy Leblanc, *Less Money, Less Care: How Nurses in Long-Term Care Allocate Hours of Needed Care in a Context of Chronic Shortage*, 11 INT'L J. NURS. PRAC. 214, 215 (2005); William Weissert et al., *Titrating Versus Targeting Home Care Services to Frail Elderly Clients: An Application of Agency Theory and Cost-Benefit Analysis to Home Care Policy*, 15 J. AGING HEALTH 99, 99-101 (2003).

36. Regarding the “crowding out” effect, *see generally* Cong. Budget Off., FINANCING LONG-TERM CARE FOR THE ELDERLY xi (2004); *cf.* David Baer, *Establishing a Moral Duty to Obey the Law Through a Jurisprudence of Law and Economics*, 34 FLA. ST. U. L. REV. 491, 500 (2007) (“[E]ven when benefits are directly and voluntarily received, because the government has monopolized the market by crowding out all other alternatives, there is no choice for individuals but to accept its services.”).

37. *Cf.* Colin Brown, *Minister Rules Out Free Care for Elderly*, THE INDEPENDENT, May 13, 2008, <http://www.independent.co.uk/news/uk/politics> (last visited Sept. 14, 2008) (quoting the British Prime Minister, in the context of rejecting total government funding of social care for older persons, stating that it was essential that those people who worked hard and saved for retirement be treated fairly).

38. We have certainly seen such opting out of a universal entitlement system because of the perceived deficiency of the public benefit package in other contexts, such as primary and secondary education. *See, e.g.*, Kimberly A. Yuracko, *Education Off the Grid: Constitutional Constraints on Homeschooling*, 96 CAL. L. REV. 123, 123

indeed ultimately unsustainable, financial burden that a universal social insurance entitlement program for long-term care would place on the involuntary backs of taxpaying members of future generations, crowding out the private sector—an objective explicitly embraced by Dr. Polivka and other universal entitlement advocates—seems to be the last, not the first, result we should be seeking.

PRIVATE RESPONSIBILITY

Thus, excessive reliance on public responsibility is highly problematic. The alternative, preferable policy direction is to encourage and facilitate more individual responsibility for advance planning, through various savings and investment vehicles (including Health Savings Accounts (HSAs))³⁹ and the purchase of private long-term care insurance,⁴⁰ in anticipation of eventual long-term care expenses.

When we target Medicaid's scarce resources to the genuinely needy, those needy will get better care across a wider spectrum of services. When more people pay privately for long-term care, they will command red-carpet to top-quality care at the most appropriate level of care. When people with money have to pay for their own long-term care, they will buy long-term care insurance and use their home equity, which means those businesses will boom, provide more jobs, and pay more taxes. When long-term care providers have more private payers, nursing homes, assisted living facilities, and all other caregivers will be more financially solvent. Debt and equity capital, which are desperately

(2008).

39. See GOV'T ACCOUNTABILITY OFF., HEALTH SAVINGS ACCOUNTS: PARTICIPATION INCREASED AND WAS MORE COMMON AMONG INDIVIDUALS WITH HIGHER INCOMES, GAO-08-474R (2008); J.M. Razor, *Health Savings Accounts: Increasing Health Care Access in America*, 17 LOY. CONSUMER L. REV. 419, 434-35 (2005). But see Amy B. Monahan, *The Promise and Peril of Ownership Society Health Care Policy*, 80 TUL. L. REV. 777, 836-37 (2006) (contending that HSAs and other components of consumer-driven health care will fail to achieve meaningful health care reform).

40. Stephen A. Moses, *The Brave New World of Long-Term Care*, 21 NOTRE DAME J.L. ETHICS & PUB. POL'Y 561, 567 (2007).

needed to finance the construction and operation of long-term care facilities, will return to the marketplace.⁴¹

There are a number of strategies that might be employed to move more individuals toward planning responsibly and timely for their own future long-term care financial needs, including the provision of individual or employer tax incentives (deductions or direct credits) to create incentives for those individuals who save money⁴² and/or purchase private insurance policies.⁴³ Certainly, it would be unfair to drastically curtail public spending for long-term care too quickly. That action would seriously and unjustly disadvantage a current older age cohort that has miserably failed to plan adequately for its own long-term care contingencies largely because of repeated “don’t worry, be happy” assurances by public officials and academic commentators that the government could be depended upon to generously fulfill all their needs (if not all their desires).⁴⁴ There is no good reason, though, that—if given sufficient advance notice, incentive, and opportunity—today’s younger population, with many likely healthy and economically productive years ahead of them in which to make and effect sound financial planning choices, should not be expected—indeed required—to make and effect choices that direct a reasonable amount of private resources toward the long-term care needs of the individual saver/insurance policy purchaser.

Contrary populist claims notwithstanding, policy initiatives emphasizing and encouraging more private responsibility for anticipating and preparing for long-term care expenses do not

41. *Id.*

42. See, e.g., GOV’T ACCOUNTABILITY OFF., *supra* note 39; Edward A. Zelinsky, *The Defined Contribution Paradigm*, 114 YALE L.J. 451 (2004).

43. See LAWRENCE A. FROLIK & RICHARD L. KAPLAN, *ELDER LAW IN A NUTSHELL* 146-49 (3rd ed. 2003) (discussing “tax qualified” long-term care insurance policies).

44. As Alexis de Toqueville warned several hundred years ago, “The American Republic will endure until the day Congress discovers that it can bribe the public with the public’s money.” Brainy Quote, http://www.brainyquote.com/quotes/authors/a/alexis_de_tocqueville.html (last visited Nov. 6, 2008).

equal the abandonment of poor people. The autonomy and dignity of individuals—regardless of their current⁴⁵ financial status—is served, not hindered, by making long-term care financing alternatives available to them that reduce their reliance on the vagaries and risks⁴⁶ of government safety net programs. As a matter of fact, instead of equating the absence of complete government hegemony with a calculated neglect of the less fortunate, society's commitment to the general welfare could be optimized by using public dollars to leverage private dollars to economically empower people who otherwise would lack sufficient personal resources to control their own long-term care destinies.

Public dollars could be employed to subsidize (or, in a more extreme version, mandate)⁴⁷ individuals to purchase private long-term care insurance, thereby overcoming one of the chief, obvious current barriers to purchase: high premium costs. Public dollars can also work to leverage private resources if they are used to provide objective, comprehensive information and counseling to prospective long-term care insurance purchasers, thereby eliminating or reducing the impediment to private responsibility now imposed by consumers' perceptions of

45. In the United States, there is opportunity for the movement of individuals from one economic stratum to another. See generally DOWELL MYERS, *IMMIGRANTS AND BOOMERS: FORGING A NEW SOCIAL CONTRACT FOR THE FUTURE OF AMERICA* (2007). Commentators (representing the overwhelming majority of the academic community) who prefer to keep individuals permanently dependent on government largess rather than to empower them tend to disparage the possibilities of upward mobility. See, e.g., Richard Delgado, *The Myth of Upward Mobility*, 68 U. PITT. L. REV. 879, 883 (2007).

46. See generally DAVID A. MOSS, *WHEN ALL ELSE FAILS: GOVERNMENT AS THE ULTIMATE RISK MANAGER* 294-95 (2002) (discussing government's weaknesses as a risk manager).

47. Lawrence A. Frolik, *An Essay on the Need for Subsidized, Mandatory Long-Term Care Insurance*, 21 NOTRE DAME J.L. ETHICS & PUB. POL'Y 517, 533-35 (2007); Diane L. Dick, *Tax and Economic Policy Responses to the Medicaid Long-Term Care Financing Crisis: A Behavioral Economics Approach*, 5 CARDOZO PUB. L. POL'Y & ETHICS J. 379, 387 (2007) (advocating "that federal and state governments work together to develop a universal compulsory [long-term care insurance] program, so that consumers are obligated to make a relatively small present-day sacrifice to provide benefits for the future incapacitated self."); *id.* at 420-21 ("When consumer choice cannot be sufficiently modified to achieve the desired governmental outcome, a compulsory program may be necessary.").

insufficient unbiased information available to enable intelligent comparisons among competing investment and long-term care insurance products.

The United States will continue to need, as Dr. Polivka convincingly emphasizes, a social safety net regarding long-term care. However, the safety net concept implies a fallback last resort, to be relied upon only when other alternatives have failed.⁴⁸ Dependence upon the government *qua* protective intrusive nanny⁴⁹ may be minimized by treating individuals who legitimately need public subsidies as consumers to be empowered with prodding and support, but not coercion, to plan and act in a timely fashion, rather than by relegating them to the diminished status of public wards eager to be infantilized.

An important problem with the personal responsibility argument, as Dr. Polivka forcefully notes and I readily but reluctantly acknowledge, is that thus far the private sector—and especially the private long-term care insurance industry—has not shown itself to be up to the formidable but important task outlined above. For several reasons, the available private long-term care insurance products marketed have not been very attractive heretofore to a significant percentage of potential consumers.⁵⁰ For one thing, premium prices have been very expensive, in large part because of an adverse selection problem consisting of insurance policies being bought primarily by those who are most likely to file claims for benefits;⁵¹ insurers have, quite literally, priced themselves out of the market.⁵² Second,

48. See MOSS, *supra* note 46, at 294-95 (the government is weak as a risk manager, and risk-management policies could unleash moral hazard).

49. See Jonathan Garthwaite, ABC News, *Nanny State, USA: We should expect more from ourselves and our government officials*, available at <http://abcnews.go.com/US/Story?id=2995594&page=1> (last visited Sept. 22, 2008) ("If you want a dictionary definition, 'A government perceived as having excessive interest in or control over the welfare of its citizens, especially in the enforcement of extensive public health and safety regulations.' A shorter version might be: Government acting like your mommy -- like a nanny.").

50. Leslie A. Curry et al., *Individual Decisionmaking in the Non-Purchase of Long-Term Care Insurance*, 49 GERONTOLOGIST (forthcoming May 2009).

51. Frolik, *supra* note 47, at 529-30.

52. "Pricing out of the market" is an idiom meaning "to eliminate the demand

long-term care insurance is unavailable to many potential consumers at any price (or at the least, at *nearly* any price) because insurers have imposed extremely stringent medical eligibility standards for underwriting individual policies. The coverage limits contained in many policies offered for sale are too limited in the typical consumer's eye to make the probable benefits of owning a policy worth the certain costs.

For private responsibility to succeed as a reasonable, indeed desirable, alternative to a totally public long-term care financing system, it will be incumbent upon the American insurance industry to develop and offer an array of desirable quality products at an affordable price to enough customers, along with sufficient, comprehensible, accurate information to enable intelligent, voluntary shopping within the long-term care financing marketplace by those potential customers. If the private sector can rise to this challenge and public policy supports (as it should)⁵³ the private options thus made available,⁵⁴ those private initiatives will succeed. If, however, the private long-term care insurance industry finds that the challenges of adverse selection, high care costs,⁵⁵ and objective information needs are insurmountable in the face of the industry's legitimate profit objectives, then the private portion of the private/public partnership will fail—as well it should in a properly functioning free enterprise system that punishes the

for goods or services by setting prices too high." The Free Dictionary, <http://www.thefreedictionary.com/pricing+out+of+the+market> (last visited Nov. 6, 2008).

53. One of the ancillary benefits of a combined private/public long-term care insurance marketplace is "that partnerships of this type also present an opportunity for consumer-protective regulation of the insurance industry if certain conditions are met." Note, *Public-Private Partnerships and Insurance Regulation*, 121 HARV. L. REV. 1367, 1368 (2008).

54. Besides using tax policy to create incentives for the purchase of private products, "[f]or long-term care insurance to play an important role, government needs to foster genuine price competition and better informed consumers." Richard L. Kaplan, *Retirement Planning's Greatest Gap: Funding Long-Term Care*, 11 LEWIS & CLARK L. REV. 407, 449 (2007).

55. "The cost of providing long-term care to all those who require it is immense." Alissa E. Halperin et al., *Medicare Advantage Special Needs Plans for "Institutionalized Individuals": What Advantage to Enrollment?*, 1 ST. LOUIS U. J. HEALTH L. & POL'Y 175, 175 (2007).

failure to satisfy consumer demands effectively, efficiently, and affordably.

CONCLUSION

There is a rapidly growing need in the United States for long-term care services of various types for an expanding population of older and younger disabled individuals. This situation presents many difficult questions, not the least of which concerns how the needed services will be financed. There is substantial public sentiment for some sort of private/public collaborative effort to respond to the financing challenge. The threshold unresolved issue is the shape and contours of that collaboration.

Proponents of a broad, first-resort governmental financing role—articulately represented by Dr. Polivka—portray the future of long-term care as a set of social needs in danger of otherwise going unfulfilled because of massive, preordained private sector failure. This perspective might ultimately turn out to be correct. Certain vital social needs (such as national defense) require exclusive or nearly exclusive public sector responses. Before we resign ourselves to an excessive governmental role in long-term care financing, however, with all the problems attendant upon such a policy course, the private sector should be afforded a fair, even chance to offer alternatives that—when done correctly—economically empower people to exercise optimal control over the concluding segment of their aging journeys.