Why We Care About Long-Term Care

Transcript from Dr. Judy Feder's Presentation at the Long-Term Care Financing in Massachusetts: Current Challenges, Future Trends & Policy Options Forum on January 30th, 2009 at the Landmark Center in Boston.

Judy Feder:

Thank you, Phil. Thank you, everybody. It is a pleasure to be here. I didn't know it was FDR's birthday, but that feels auspicious, to be with so many old friends, and to be with a group who knows that the nation's well-being depends on the well-being of all its families. And who most particularly know that we can't achieve that well-being unless we provide the support to people whose impairments inhibit their abilities to manage their daily lives. And we know that today, that support is so sorely lacking.

Fortunately -- fortunately -- we gather at a time when our nation's leadership is committed to restoring prosperity to our entire nation. But I think we all know that it's our job to make sure that as we go about restoring that prosperity, that we make very sure that long-term care is part of the picture.

Now, I know it won't shock you if I point out that we did just have an election. And I do a lot of things where you're

supposed to be awfully non-partisan. I don't think it's partisan to point this out. Maybe partisan to smile as much as I am, but. (laughter) But we all know, I think, that the economy was the number one issue that voters were very, very concerned and driven by. Their fears about their future economic security. Concerns about health security and affordable healthcare were not far behind. But I would say that, as an honest woman, I don't think we heard a lot about long-term care and needs in the most recent election.

Just a minor digression, if you'll forgive me. Many of you know because you supported me, and I thank you for it, that I was running for Congress in Virginia, the other commonwealth. And I did hear frequently on the campaign trail from people. A well-to-do woman who lost her home because of her expenses with a disabled child. Usually women who were struggling. As we all know, women mostly do, between the problem of caring for their parents and managing their immediate families. And someone who always makes me proud, my 94-year-old supporter who remains a precinct captain in McLean, who was limited in the number of postcards she could write for me, because she was in and out of the hospital. And she and her husband, who were still in their home, are clearly needing support to stay there.

So we know that it's an issue, but it doesn't rise to the top of the list, unfortunately. And there are lots of reasons. And I'm sure lots of people in the room have views on why that it is. We know that it is hard to exert public leadership by an elected official, so thank you for it, on long-term care. It's an expensive issue. It's a frightening issue, to some. And I think, that a huge obstacle are the myths that abound about long-term care. And the most prominent, I think, is a widespread belief that the need for long-term care only happens when you get old. That it's going to happen to pretty much everybody. And so we should all just suck it up, be responsible, and plan ahead. Right? That seems to me -- I heard that from lots of people, many of whom should know better.

Now, we can take that myth apart pretty readily. The facts are that of the just over 10 million people estimated to need long-term care in 2005, about four in 10 were under the age of 65, children or working-aged adults, who plainly don't have the time to just plan ahead. And despite popular views to the contrary, even among the population over age 65, not everybody does develop a long-term care need. Estimates are -- and I think Peter [Kempro?], with my colleague Harry [Commisor?] did these estimates, so it's nice to have you in the room, Peter. But estimates are that among people turning age 65 today, three

in 10 will die without needing any long-term care. While one in five will need more than five years of care. And if we look at the financial picture, the estimate is that about half of the people turning age 65 today can expect to spend nothing on long-term care; a quarter to spend less than $10,0000; and at the other end of the spectrum, 6% are likely to have to spend over $100 thousand. So a very skewed distribution.

And when it comes to talking about whether families are doing their part and being responsible, it is almost a joke to talk about families not doing enough on long-term care. We know that 85% of the care that is provided to people at home is provided by family and friends, often at enormous cost to those caregivers. Given sacrificed economic opportunities and in sacrificed health and welfare. And so the problem -- and I am clearly speaking to the choir, but the choir ought to hear it said -- the problem is not that individuals and families aren't acting responsible or giving enough. It's that they don't have enough to give. Long-term care, the need for long-term care, is an unpredictable catastrophic risk.

And the answer, therefore, is not just to save up with each individual bearing the full cost when it happens to them. The answer in long-term financing is spreading the risk across all

of us to help the minority of us who have extensive and expensive needs. That means, as we all know, insurance.

Now, we've been talking about the financial risks of long-term care for a very long time. But I want to be really clear from the get-go, when we talk about having adequate insurance protection, it's not just so that people don't lose everything they have or have the resources they need to live, it's also to assure access to appropriate care. Especially for people at home, which is where we know people want to be. The last public survey of unmet long-term care need found one in five individuals at home in need of long-term care, yet not getting enough or reporting that they were not getting the care they needed. And people don't always take that report seriously. This study, this survey, went a step further and found that they were often more likely to suffer serious consequences as a result or associated with getting inadequate care. Consequences like falling, being unable to eat or bath, or soiling themselves as a result of not getting service. So while people sometimes minimize what people report, this is evidence that this is a serious, serious problem.

Now, we know that people want to stay home and be independent, and even if insurance is not the full answer to all

of the care needs and being sure that all needs are met, it sure as hell is not sufficient to achieving all our objectives, it is necessary to that end.

The case for insurance for long-term care is not new. And as I look in the faces of the people in the room, we've been making these arguments for many, many years, and yet engaged in what seem to be endless disputes about whether insurance should be primarily under public or private auspices. Well I, like many of you, am tired of those debates and would like to do what I can and what we all can, to somewhat shift that tone. Although, it is a challenge, there are major issues here. But I think it's about time that we recognize that we have a public-private partnership in long-term care financing and that we will always have a public-private partnership in long-term care financing. The question is whether we want one that's as lousy as the one that we've got, or we want one that really works.

In 2005, which is the year for which I have the data, we spent more than $200 billion in public and private funding on long-term care. Three-quarters of those dollars were public. About half in Medicaid, which we all know really does finance long-term care, and because it's the only way we can appropriately count the dollars, another quarter of those were

in Medicare which is sort of long-term care. But the private dollar contributions grossly understate the role that the private sector really plays in supporting care. Because the dollars don't count all of that informal family care, which I said is 85% of the care people receive at home. And it also, I think, ignores the fact that if you look at the effort, if you look at what people are spending as a percent of income on long-term care, it understates the burden people face because of the way we finance it.

The fact is, we've got lots of public and private investment in long-term care. But it's not insurance. What we've got on the private side is overwhelmingly out-of-pocket private financing, very little private long-term care insurance. And on the public side, with Medicaid, we've got last-resort financing, after you've exhausted everything else. I think we all know how valuable Medicaid is and how important it is to people who need long-term care. But insurance is supposed to protect us against catastrophe. Medicaid comes in only after catastrophe strikes.

And I think it's not fair to say that everybody hates this system. Individuals are paying enormous sums, don't get the care that they need, don't get the care where they want it.

People are very unhappy with the way the long-term care system works. States, Massachusetts and every other, are overwhelmed by the costs of long-term care. And the federal government is similarly appalled and reluctant to take on more responsibility.

Now, the good news is that we can build a better system than this. And I'd like to define it a little bit before I talk about how I think we ought to build it. A better public-private system can't just respond to this fiscal frustration at the state and federal levels and say, we're just going to limit the dollars we spend. That's not solving this problem or the healthcare problem or any other. An effective public-private partnership has to assure sufficient public and private resources to build a partnership that spreads risk, that supports access to quality care at home as well as in institutions, and that shares financial responsibility fairly across families and individuals and taxpayers. And that partnership has got to work for people who need long-term care of all ages, of all disabilities. And it's go to work for people who need long-term care now, as well as people in the future. We can't just ask them to hold on.

Now, simple tasks, right? I mean, it's a big one. But I urge us today, not to be daunted by the level of the task. When

we look at the changing demographics which people in this room know better than I, we know that we're going to see -- what is it, a tripling of the 85+ population, people over age 85, that portion of the population, over the next four decades. We know that younger people with disabilities are living longer. We know that the numbers of people who are going to be needing long-term care are likely to expand dramatically in the future. Being part of that older baby-boomer population, my view is, hey, this is a good thing, not a bad thing. And it is our population that we need to look to. And given that we're going to see so much growth in the population, I think that we can see ourselves as on the ground floor of building the system that we want, rather than feeling that we are stuck in the system that we've got. And it's just too much change coming for us to think that we're stuck.

The key financing question I would put forward in building that system is not whether insurance is public or private, it's what the appropriate role is of each. And now is the time when we are on the ground floor with all that demographic change coming, to make an explicit choice about the kind of financing that we want to have. Without an explicit choice, the implicit choice is to continue reliance on this current public-private financing partnership, which sucks. Over time, private

insurance is going to grow, I don't think we have any doubt about it. It's going to expand and improve protection for people with higher incomes. But alongside it, if we don't make any changes in our policy, the public safety net may well deteriorate, as Chris Bishop has argued. And under the pressure of this enormous and growing demand, the outcome of this path of least resistance, not choosing is clear. It means that things are going to keep getting worse for most American families. But it is hardly desirable. An explicit choice on future action means deciding whether the future long-term care financing partnership should have at its core, public or private financing.

Some argue, quite vehemently, that we ought to build a private foundation, a private insurance funding core, for our partnership. And even go so far as to argue that we ought to pull back the public safety net, Medicaid, so we make sure people go out and buy private long-term care insurance. That argument was behind the tightening of the asset rules for people going on Medicaid that we saw enacted in the last couple of years.

Now, analysis tells us, and I've done some myself with my colleagues Harry [Commisor] and Robert Friedland, analysis tells

us that we can make policy changes to improve and extend private long-term care insurance. And you know the primary proposals: tax credits to support the purchase of insurance; partnerships between private insurance and Medicaid; innovative and better long-term care policies to make them do a better job. And improving private long-term care insurance is all fine. But analysis also tells us that the benefits of this insurance will inevitably be limited to the top tier of the income distribution. It has little potential to spread risk for the rest, even if it is a company, as some have argued, by a universal public catastrophic benefit. Excuse me. A strategy that is grounded in private insurance, will primarily protect older people with higher incomes. It will leave most older people, and all younger people with disabilities, at considerable risk, or dependent on the safety net if they need substantial care.

I can't, for the life of me, figure out how a nation who talks about a crisis, in which it is, because have 16-17% of the population who lack health insurance, and then sets out to build a long-term care insurance system on not even as good a structure as we've got in health insurance. It never has and never will make any sense to me. Making private long-term care insurance policies better for those who can afford them makes

sense, but making it the centerpiece of the nation's long-term care policy just doesn't. If we wish to spread risk across the whole population, public insurance has got to be at the core of future policy. To make public insurance fiscally manageable, its benefits can be, let me call them, basic rather than comprehensive. And they can be phased in over time as future older people free-fund their own care, rather than shifting costs to their children. And strengthening the safety net in the shorter term.

Further, no matter how generous that insurance, it's important to recognize, although there are people who love to call everything socialism, and I thought was going to be good after we socialized the banks. But it still seems to be a problem in the fields we care about. So no matter how generous that insurance, it's never going to cover all service needs, it's never going to eliminate the importance of personal financial contributions, and it's never, ever going to eliminate the value and the desire to give family care. Planning for the future and caring for one's family members will, as they should, remain critical to an effective long-term care system. But private support will be built, if we proceed this way, around a predictable core that everybody can count. That's how we built our retirement and disability, our social security system, which

is not enough for people in retirement or facing disability. But it is an effective core around which private savings and private action have thrived.

Now, with a strong but limited public program, not only will there always be a private part of the public-private partnership in family care and personal resources, there will also always, always be a need for an adequate public safety net. No matter how thoughtfully we design our policy now and in the future, substantial numbers of younger and older people who need long-term care will simply not have the resources to fill inevitable gaps. Now, and in the future, policy must therefore place a very, very, I would say, top priority on improving that safety net. At the very least, in terms of assuring that everyone, regardless of the state in which they live, has access to services at home as well as in institutions, that assure a safe and decent quality of life.

Now, in just two years, the first of the baby-boomers will turn 65. With so much change ahead, we have a lot to gain and very little, in my view, to lose from building the right kind of public-private partnership, rather than accepting the one we have. It is up to us to make sure that long-term care is part of the discussion we are now beginning to engage in on health

reform, on entitlement reform, and in investments of all kinds in our future. If we don't speak up, it's not going to happen. Now is the time, with new leadership, new and powerful need to rebuild our nation, and new excitement about achieving our nation's and even our government's full potential to build a better society. Now is the time to confront the policy, political, and fiscal challenges of building a new long-term care system. We can do better and I look forward to building that system with all of you. Thanks.
[applause]

F1: We'll take question for Judy and then we'll do the reference panel (inaudible).

JF: Jean.

Jean: Well, that was great --

JF: But? (laughter)

Jean: We'll save that for later. (laughter) So you're talking to a state, here, who wants to support the national agenda too. But we're sitting here and launching, you know, a committee to look at the state opportunities today. What would

you say are the opportunities for innovation at the state level, knowing how often people say, if the feds don't move on long-term care, the opportunities of the states are so limited.

JF: I think being honest, and you know better than I, that you've got a row to hoe. And the first thing that has got to come to help you, to help every state, is we have got to got this stimulus passed and get money to the states in terms of the enhanced Medicaid match. The terrible problem that you know you face with the recession, is that the demand for care goes up, and the dollars go up, and states are left holding the bag. So it is my hope that these dollars are going to be forthcoming and give you some relief in the short-term.

I can't speak -- there are others here to speak to the particulars of Massachusetts, and I've regarded Massachusetts as being one of the leaders in doing the best that one can with the resources that we have. And I think that you all know what the answers are. That we need to have a tremendous leadership to move our system away from such a heavy reliance on institutional are, to supporting people at home. We make modest efforts in that regard, but we've got to push hard to do that.

I am not one who believes that we shouldn't have nursing homes. I think, for some people, that is what we do need. But for many people, we can do much better in terms of serving them at home. We can do better in terms of making the system friendlier to people. And I think, actually, a lot of the actions that states want to take, I would hope would be supported in a new administration and a new HHF. I think that whether we still call it -- I've been busy running for office -- one-stop shopping, where people can come into, and I don't know whether you do that already. But essentially to make the system very accessible to people, to have planning that is in advance of the need for care not just following when people are in a crisis state. Outside coming out of a hospital, but to be able to plan in advance and have the resources there. To have actual people, not telephone lines, do work. But you need people on the other end of them. But to have people who are actually engaged in helping families navigate the health and long-term care system that provides support. I don’t have any magic for you. I can't imagine that was tremendously innovative, but is there anything you want me to take back to Washington to tell those folks that they ought to do?

Jean: Approve my (inaudible).

JF: Approve your (laughter). Phil?

Phil: You know, I thought your comment about the fact that that 85% of the care that's delivered is delivered by family members is so important. And family members get the short end of the stick in this whole process. And we all know, those of us who have or who have had aging parents or disabled children or what have you, what the strains are on family members. Do you have any ideas about how the long-term care financing mechanisms, particularly in Medicaid, could be loosened up or made more flexible to help support families as they're going through these crises?

JF: I think that we have experience in some states in which we are actually paying family or caregivers to provide care. And I think that there is some promise in those. And I think that the supporting family caregivers is critical because you want them to stay in. That's often who people want and they want to do it. And you don't want them to burn out in the process.

There's also been talk in the past about tax credits, which I believe should go down the income state. Be refundable tax credits, if we're going to do it, for family caregivers. Even if what it does is just make their lives a little bit easier, in

terms of being able to spend on not necessarily long-term care services, but to support the family in an appropriate way.

I actually was kind of disappointed, although I think it was hard for us all to get our act together, but I think there was more room for this kind of support in the stimulus legislation. Along with support for training long-term care workers, which I think one could make the argument that that would be a very effective expenditure or investment of federal dollars in a stimulus environment. So I think there are a number of ways that we can do more to do better.

Debra: Yes, Debra Thomson from the [PAST?] group. I do a lot of work with attorneys who work on state planning issues for end-of-life care. And the population that I see is the most negatively impacted by our Medicaid policy is people who are not poor, such that the qualify for Medicaid, people that aren't well-to-do enough to buy long-term care insurance and have some assets set enough for their care. But it's really the person with $10 thousand in the bank and a house that gets impacted negatively by these policies. Can you speak a little bit about how we address those sort of lower- to middle-income populations?

JF: Yeah, the problem with any kind of means-tested approach, even if we make a much better safety net and a stronger safety net would help more of those people in dealing more appropriately with asset limits, are things that we can do to make it better for them. But wherever you draw that line, somebody falls off a cliff. And I think it's an inevitable outcome of a means-tested policy. Which is why I believe that we need to have a policy that gives some kind of core protection to everyone, because then you don't have it.

Now, you still will have some people who are not getting enough and stuck. And that's what social security does, it gives everybody something. And it has helped enormously in terms of enhancing the incomes of older people and people with disabilities. So, I think I would love for us to be pursuing a core benefit for everybody, and then working on how to build a safety net around. That's the best answer. And we can also and should work on making that safety net as fair and reasonable as we can.

(pause)

Thank you.

(applause)