

Long-term care and the policy agenda

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On May 21, 2003, the Georgetown University Long-Term Care Financing Project hosted a conference on The 21st Century Challenge: Providing and Paying for Long-Term Care (more information about the conference is available at <http://ltc.georgetown.edu>). What follows is an edited version of conference remarks made by William Scanlon, long-term care policy expert and Director, Health Care Issues, U.S. General Accounting Office. In his remarks, Dr. Scanlon first offered his views on long-term care's place on the policy agenda, then presented his perspective on ways to think about long-term care financing in the future.

Having spent many years working on long-term care issues, I feel a sense of frustration. Why is it that an issue that seems so important to people never becomes urgent to policymakers? The importance of the issue to people is apparent whenever individuals with disabilities describe their difficulties getting care—as they did at the opening of this conference. And the problems they described are by no means limited to a few people. Each example is likely multiplied manyfold around the country. Why are these problems so persistent and receiving so little policy attention?

I've come to believe that the necessary policy attention is lacking because we—that is, the policy community—have not been able to turn stories like these into a convincing “face” on what it means to go without needed long-term care. I hope to motivate you by describing why I feel that I, like other long-term care researchers, keep coming up short.

Many years ago I did an analysis of a seriously disabled population whom unarguably needed long-term care. I focused on a group of people who were old (over age 75), single, dependent in every activity of daily liv-

ing, and poor—expecting to find that the vast majority of this population resided in nursing homes. In states like Minnesota, Wisconsin, and other states with a lot of nursing home beds, 90 percent of these people were indeed in nursing homes. But in the ten states with the fewest nursing home beds, only half this population was in nursing homes. The question that I immediately asked myself and have kept asking myself since is: what happened to the 50 percent that weren't in nursing homes? How were their care needs being met? Why don't we hear about their plight?

I think the amazing silence is testament to two things. One is the incredible role that families have played in providing services to individuals within their homes, sometimes doing heroic things to meet their needs. But the other factor—which is tragic—is that we, the researchers, haven't identified the consequences of unmet needs and identified how many individuals are actually suffering those consequences.

Harriet Komisar, Marlene Niefeld, and Gloria Eldridge have done some of that work, looking at the problems of individuals who've reported on the National Health Interview Survey on Disability that they didn't get all the services they need. And the results are powerful. In that survey, about 20 percent of those who needed assistance with activities of daily living or instrumental activities of daily living reported not getting the services they needed. For people who needed help toileting, not getting the help they needed meant they would often wet or soil themselves. For people who needed help to eat, it meant they couldn't eat when they were hungry. These are real consequences that we can all relate to. If we genuinely had them in our consciousness, I believe we would have a very different perspective on the urgency of improving our long-term care system.

Let me now turn to the financing necessary to improve that system. To me, that means having a system that can ensure better access to services for individuals with disabilities and promote a more equitable distribution of the burden of providing and paying for services. We can do better than have the burden fall so disproportionately on the families or individuals who have the disabilities. And, with the aging of the baby boom generation, we can do better than have it fall so disproportionately on their children or, more precisely, their grandchildren—those who will be the working-aged when the baby boomers are in need of long-term care.

Accurately describing the long-term care risk

In thinking about financing, we should first remember that long-term care is a risk, not a certainty. As we've tried to promote attention to long-term care, and to the importance of individuals purchasing insurance to protect themselves, we've described this risk as large—all of us facing a 50 percent probability of entering a nursing home before we die. That may be true; it's the result of analysis by good researchers and I don't dispute it. But a statistic like that exaggerates the risk of financially catastrophic long-term care. The reality is that many people likely to use nursing homes are not going to be in them for very long. Furthermore, they are going to be in a nursing home following a hospital stay and financing for their care often comes from a Medicare post-acute benefit that does cover up to one hundred days of nursing home care following a hospitalization. For many of the 50 percent who will use a nursing home, that's the only kind of nursing home care that they're going to use before they die—and Medicare pays for it. To use the risk of short-term nursing home care to motivate the purchase of private long-term care insurance is to mislead and exaggerate the real risk people face.

Another example of exaggeration has come from efforts to promote the Office of Personnel Management's Federal Long Term Care Insurance Program. They noted that 40 percent of the people needing long-term care are between the ages of 18 and 64. Again that's true. But this is not the group of people to whom this plan is being marketed. These are people who, for the most part, were born with a developmental disability or had an unfortunate disabling occurrence early in life. People who are going to need a lifetime of care are not the people whom private long-term care insurance policies are designed for or are aiming to reach. This is not the risk we should be focusing on as we try to promote expanded financing.

Exaggeration and inaccurate understanding of the risk also increase the probability that we will look to the wrong solution. As a risk (not a certainty), long term care should be insured against, not saved for. To expect people to save for long-term care would be to adopt the attitude of the pre-Medicare period, when people saved for their hospitalizations. For some, that meant opportunities foregone. For others, it meant the inability to put together the funds that were needed. As we've learned from health insurance, insurance, not savings, is a far fairer and more effective way to assure access and spread burdens.

Reshaping discussion of insuring against the long-term care risk

If a focus on insurance makes sense, why haven't we seen the market for private long-term care insurance develop? Promotion of long-term care insurance began in the early 1980s, about the same time that personal computers were introduced to the world. For a while, they were very similar products, with new and cheaper models emerging every year or so. But then the two products diverged. Personal computers have had a very good sales history. Long-term care insurance has not. Why have we been unable to convince individuals that buying long-term care insurance is the right way to prepare for the future?

I think it's because: (1) it's not always the right answer; (2) the available products are not always appropriate or of good value for individuals; and (3), the point I want to focus on, trying to promote private insurance as the only answer is likely not the best way to advance better protection. Discussions of how to improve long-term care financing and provide individuals with better risk protection have too often become polarized—with one side advocating ways to improve the private insurance market and the other advocating ways to adopt social insurance. Rather than continue the contentious discussion we've been having for more than 20 years, which does not aid individuals to prepare, it may be time to shift from thinking about these approaches as alternatives to thinking about them as complements.

A new way of thinking about financing begins with rethinking long-term care itself. We typically discuss long-term care as if the only problem with its financing is that it wasn't put on the list of services covered by existing forms of health insurance. I think that's too narrow a view—one that is unlikely to move us toward the improved system we ought to have. Delivery of long-term care differs from the delivery of health care. Health services are generally guided by accepted norms of efficacy and benefit. They aim at cure or maintenance of health and, even if not always applied, there is generally professional consensus on what's appropriate. By contrast, though long-term care is also about maintaining health in the face of a disability, its services affect how you live your life—the nature of your living situation, the degree of comfort you have, the burden that's imposed upon your family. I think it's a mistake to think that a private insurance policy or a public program is ever going to

be the panacea to satisfy all people's individual interests in what kind of long-term care they have.

Instead of thinking about long-term care financing as analogous to health insurance, I think we should think about it as analogous to retirement security. We'd then recognize that there's a need for multiple sources of funding, as well as a role for individuals to contribute to meeting their own needs in the way they prefer. With that perspective, I think we will have a better chance of moving this discussion forward and finding models that may have some traction for the future. And as we do so, we need to do more than think about how to develop the private insurance market, though that's important. We need to recognize that there is already an extraordinary amount of public financing for long-term care, with which we can do better. In the year 2000, public financing for long-term care was about \$85 billion or 62 percent of total long-term care spending. When we consider the public sector's role, we ought to be asking not just what investment is needed but whether we are leveraging current public dollars in a way that's most effective in satisfying people's long-term care needs—and in promoting the complement of private resources that will also be necessary to satisfy those needs.

Government's role in insurance protection

In my view, there are two potentially critical roles for government financing in long-term care. One is government support for an adequate safety net. There are individuals—and we've talked about and heard from them today—who are not able to avail themselves of private long-term care insurance, particularly if they are disabled at young ages and will need services over decades. They need an adequate safety net. There are also individuals who may develop a need for long-term care in old age who are not going to have the economic wherewithal within their lifetimes to be able to purchase insurance—that is to forego other necessities in order to have insurance when the need for services develops. They need an adequate safety net.

Is today's Medicaid that safety net? When it comes to needing long-term care today, the good news is that you're on Medicaid and the bad news is that you're on Medicaid. More precisely, once on Medicaid, you do receive financial support for services but they are only the services that Medicaid “prescribes” or is willing to offer in your particular state, or even in your particular community. We at GAO reported a year ago on

case managers' actual service "prescriptions." We prepared that report by contacting Medicaid case managers, giving them the description of an individual's needs, and asking what would you prescribe? The prescriptions were all over the map—from very modest to very generous services for the same individual. Indeed for one of the prototype individuals, the prescriptions ranged from 24-7 assistance to no home care (only the option of entering an institution). That tells us that what you get from Medicaid is very much the luck of the draw—and no guarantee of adequate services.

It's government's job to assure a good safety net—better than we have today. But the attractiveness of that safety net should not be so strong that it discourages thinking about each individual's own role in meeting future long-term care needs. Private insurance should be an important component of long-term care financing. And government's second potentially critical role is to ensure consumers are adequately protected when purchasing insurance. Others at this conference have emphasized the confusion consumers face in navigating the health, let alone the long-term care, system. We're experts and we have trouble understanding the system. Expecting individuals to navigate a very complicated and confusing set of choices and tradeoffs may be expecting much too much.

The role of government in assuring that the long-term care insurance products on the market are of reasonable value to consumers is therefore critical. The National Association of Insurance Commissioners (NAIC) played a critical role in promoting that assurance during the '80s and '90s, as long-term care insurance was first introduced—when there was little in the way of standards. The NAIC's effort in establishing model legislation and model regulations helped increase the value to consumers of the policies being offered. This role of consumer protector remains critical as innovations emerge to make long-term care insurance more affordable. Innovations appear all the time, as they should. Today, we hear of opportunities to convert some of your life insurance into long-term care insurance, and people are talking about opportunities to convert pensions. We hear of opportunities for reverse annuity mortgages to generate funds to pay the premiums for long-term care insurance. Every one of these innovations has potential. But every one of them also adds to the complexity, adds to the confusion and leaves consumers vulnerable to not getting value for their dollar.

To me, some of these options are a little like deciding to get a new car and asking yourself—should I lease or should I buy? Boy! That lease payment looks really low and attractive...until you hear there's a mileage charge, there's a dent charge, and there's the fact that you don't have the car at the end of the lease. Those elements change the equation dramatically. Government really needs to play a role in assuring that consumers know about the whole range of elements, that they are well-informed about the products they're going to buy.

Besides these critical roles, government also has the potential for a powerful role in serving as a catalyst for changing and improving our long-term care system. We've already directed government to play that role, through the tax subsidies that exist to subsidize the purchase of long-term care insurance. It's common when we feel a market needs a push to provide subsidies through the tax system—lowering the price of something and hoping that people will buy more of it or invest more in it. But, with respect to long-term care insurance, government can and does play a more positive role—going beyond the subsidy and making sure that better policies are available in the market. We've done that by linking tax subsidies to “qualifying policies.” Government can do even more than it's done if it also plays an active role in consumer education. We really need to provide people accurate information on the nature of risk, the limits of current protections, and the values of their options. Although it's very, very easy for me to set out this goal, I have no sense of how we're going to accomplish it. But I think we must figure it out as we're thinking about the future.

Social insurance as a catalyst for change

Finally, I want to suggest that we should think about how to use social insurance as a catalyst for changing the long-term care system. Some of you may think that I've lost a little touch with reality here—since social insurance is typically regarded less as a catalyst than as a poison pill that will kill private long-term care insurance and leave us with a totally public system instead. But I think we need to take a creative perspective—something akin to that taken by The Robert Wood Johnson Foundation's Partnership for Long-Term Care. The idea there was to partner private long-term care insurance at the front end with public insurance—specifically, Medicaid—at the back end. That partnership aimed to make private insurance more affordable, by having public insurance pick up the back end of the costs. It may be worthwhile to con-

sider reversing this approach—that is, to think about social insurance at the front end or a continuing base of support, with private resources providing a supplement. Public and private resources would complement one another in assisting individuals throughout the course of their disabilities. This arrangement would reduce the cost of both public and private insurance—neither would do the whole job. And it would give people options in terms of how they would like to finance their possible needs. I don't have specific proposals to offer. But I do think that after 20-some years of no progress in the area of financing, we'd do well to think creatively and to develop some. This may be an act of desperation—but I'd rate the progress we've made over the last twenty years as being at a snail's pace. With only seven years and 224 days until the first baby boomer will turn 65, I think we need to start moving today.

About the Project

The *Georgetown University Long-Term Care Financing Project* pursues analysis designed to stimulate public policy discussion about current long-term care financing and ways to improve it. The project is funded by a grant from The Robert Wood Johnson Foundation. More information about the project and other publications can be found at <http://ltc.georgetown.edu>



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