Long-term Care in Massachusetts:

Problems, Causes and Solutions

Alan Sager, Ph.D.
Professor of Health Services
Boston University School of Public Health

Winchester Council on Aging

15 March 2003

Good morning! Thanks for inviting me to speak with you.

I bring good news. We are only 6 days from spring!

Introduction

Too often, discussions about long-term care are frustrating, almost futile. What comes to mind is the Carrie Fisher character in *When Harry Met Sally,* the friend who constantly complains that the man she's been dating will never leave his wife and marry her.

This is partly because we have been scurrying to find more money for long-term care. Because it's been very hard to find more money, we have made little progress. More money is certainly needed—but it may be easier to get that money if we can design and test ways to better deliver long-term care services.

In what follows, please think both about raising more money for long-term care and about improving how we deliver long-term care.

I. Problems and causes

A. General problems

1. Long-term care is the hardest problem to solve in health care, with the possible exception of mental health.

Why is that? When we and our families can no longer do things for ourselves, it becomes extraordinarily complicated and costly to substitute organized, paid services from outside the home and outside the family.

2. The population in need is growing. More of us are living longer—long enough to need more help from other people.

- Rise in over-85 share of population owing to better living standards and better medical care.

  The over-65 population grew from 5 percent of the nation in 1930 to 14 percent in 2000. It is projected to rise to 20 percent in 2030.

- Rise in disability owing to growing longevity—more of us are living long enough to need help from other people.

Still, we have plenty of time to get it right—the big population boom doesn't begin to hit long-term care for another 20 years or so.

And other nations have shown themselves able to address long-term care problems even though older people make up substantially greater shares of their populations.

- UK, France, Germany 16 percent > 65 now, versus our 14 percent
- Japan 17 percent
- Italy 18 percent

3. Families are less available, able, or—in some instances—willing to help.

- Physically available—living far apart—it's a long commute from Ohio to cook dinner for your parents in Phoenix.

  And just consider the matter of elders living alone. In only 25 years, from 1970 to 1995, the share of women older than 75 who were living alone grew from 37 to 53 percent—from over one-third to over one-half.

- Able—having the time—conflicting obligations of work outside the home, raising children

- Willing—confusion over who to care for—my children's grandparents, or my present husband's parents?

Families provide the most help, so a small drop in the share of needed care that's provided by families translates into a big rise in the share that must be financed publicly.

If families now provide 80 percent of the help given to disabled seniors who live at home, and if that share drops to 70 percent, the drop in family hours is 12.5 percent.

But if paid services pick up that drop in hours, their share of total help rises from 20 percent to 30 percent. That signals an increase in paid hours of 50 percent! Budgets must rise by 50 percent. And more paid workers must be found.

Government fears that a good public long-term care benefit will mean that higher public dollars will replace—not supplement—family help. So, how to design public support to complement, invigorate, and enhance family help?

B. Specific problems

1. Inadequate payment rates

Many nursing homes, home health agencies, and home care corporations complain that they are not being paid adequately.

A few years ago, visiting nurse agencies and other home health agencies were hit particularly hard by Medicare cuts under the 1997 Balanced Budget Act or BBA.

Some nursing homes were also hit by BBA, particularly homes that had been bought by national chains and had counted on earning substantial profits on Medicare patients.

Today, many nursing homes are greatly worried about Medicaid cuts. Medicaid sets payment rates for about 70 percent of the state's approximately 45,000

nursing home patients. And much of Medicaid's payment rate is keyed to median cost. But if Medicaid pays for care at the median cost, this means that half of the homes are being paid above cost and half are being paid below cost.

Unfortunately, Medicaid does not run a nursing home, so it does not have direct experience with how much it costs to actually deliver high-quality nursing home care.

Nursing home payments are embedded in Medicaid.

Medicaid payments are embedded in the state's deficits.

Besides, you have to be or become poor to qualify for Medicaid. So, for all these reasons, let's get some other program to pay for long-term care. Maybe Medicare. More on this shortly.

2. We spending enough to finance better long-term care services

Many citizens of the Commonwealth and their families complain that substantial public financing for long-term care is really available only to people who have essentially exhausted their own resources.

Today, in the United States and particularly in Massachusetts, huge sums are spent on health care.

- National problem

What do you think are the approximate sizes of total defense spending per year in the U.S. and of health care spending in the U.S.?

Health—almost $1.7 trillion in 2003--$1,656,000,000,000.
Defense—even after a 12% increase, $396 billion

So, health is 4.2 times as great as defense

- Massachusetts data

Consider this.

In 2003, health spending in Massachusetts will rise to $47.6 billion, or about $130 million per day. (During our three hours together, some $16 million will be spent.)

A day's spending of $130 million is almost exactly this fiscal year's budget for the state's home care program, I learned from Al Norman's Mass Home Care web site. What a coincidence.

Our 2003 spending will represent an increase of about $2.8 billion over last year.

If we spread this $2.8 billion increase over the 365 days of the year, total health care spending rises by almost $8 million each day. By another coincidence, this figure is very close to the $6.5 million in home care cuts that the state tried to take out of its budget under Gov. Swift.

In other words, the **annual cut in home care spending** just about equals ***one day's rise*** **in total health care spending**. One goes up. The other goes down.

In general, the vast share of the health care money is spent on acute care. This drains away dollars that might otherwise be available for long-term care.

We see something similar in Medicare's own short-term home health program, which pays for recuperative and rehabilitative care at home.

In 2003, Medicare home health spending of $9.8 billion will be about 3.6 percent of total Medicare spending.

But only five years ago, in 1998, home health spending was $11.7 billion in today's dollars, or 6.2 percent of Medicare's total. In real dollars, Medicare's home health spending has been cut by one-sixth in just five years.

Indeed, something else always seems more important than legislating an adequate long-term care program under Medicare. Not too many years ago, Congress was occasionally debating adding a new part to Medicare to cover long-term care—both long-term nursing home care and long-term in-home care. The subject was treated with some seriousness.

No one is taking a Medicare long-term care benefit seriously today. This is not just a matter of the growing federal deficit. No one was taking a Medicare long-term care benefit seriously during the second half of the 1990s, either—when the economy was booming and the deficit was shrinking.

The reason: the soaring cost of prescription drugs.

So, we have witnessed a major change. Instead of ineffectually debating a Medicare long-term care benefit, Congress has begun ineffectually debating a Medicare prescription drug benefit. Unless we can resolve the drug problem, the prospects are dismal for more fair, reasonable, and adequate public long-term care financing.

There has been far less political attention to long-term care than to other things that seniors care about, such as higher Social Security payments, prescription drug coverage.

- Fear
- Denial
- By the time you need long-term care, you're less likely to be an effective self-advocate, though your family is often still interested in advocating!
- Virtually all older people care about more adequate Social Security payments, and prescription drugs are a dreaded financial drain to more and more seniors, but neither Social Security nor medications has the frightfulness of becoming alone and helpless in an under-staffed nursing home bed.

3. Medicaid's institutional focus

The Massachusetts Medicaid program **does** spend a great deal of money on long-term care, probably over one-quarter of its $6 billion budget (half of which is federally financed). The great share of these dollars goes to nursing home care. But, in a democracy, how can we devote over 90 percent of long-term care dollars to nursing homes when over 80 percent of older people say they'd rather live out their lives at home?

- nursing home requires only one simple placement, not ongoing coordination of home health, homemaker, meals, transportation, and other services
- state probably sees its obligation to serve the most needful people first

- NH probably less costly than home care for very disabled, frail, or confused people, especially when an able family member is not available full-time
- still, nursing homes are very expensive, and tend to absorb available dollars
- state can limit eligibility by limiting how many beds are built
- state can limit use of long-term care by paying mainly for nursing homes, what is not most people's first choice, rather than home care
- sometimes, greater political power of nursing home industry

4. Moving the problem to a lower cost alternative

Medicaid originally started paying for skilled nursing facilities partly because these looked cheaper than hospitals.

Then, intermediate care facilities were covered by Medicaid partly because they looked cheaper than skilled nursing facilities.

Then, many people boosted home health services or assisted living or congregate living or continuing care retirement communities because these looked cheaper than intermediate care facilities.

Stop!

There are several problems with this approach.

First, we like to imagine that care we consider better is also cheaper. That argument certainly can be persuasive politically.

The trouble is that it is not usually true. What is better usually costs more. For example, when staff have time between emergencies, the ER is really a very cheap place to provide primary care. The trouble is that it is not good primary care. Good primary care is more costly.

Similarly, good home care for moderately or severely disabled people usually costs more than nursing home care, since one staff worker at the nursing home can care for many patients.

Second, we usually don't make a straight apples-apples comparison between costs of care at two sites. Rather, we take healthier people residing in an extended living facility or at home and compare their costs with those of a nursing home patient.

Third, we seldom substitute one form of care for another. Instead, we add a new form without reducing the old one. The result—more care (but also higher spending).

5. Quality of care problems

It is probably harder to provide good long-term care than it is to provide good MRI scans or good surgery. Yet the people who provide long-term care are paid substantially less than are surgeons or radiologists.

People who require long-term care are, by definition, dependent on others. They are often alone.

Psychologists sometimes define "anxiety" as being alone and feeling helpless in the presence of our human imaginations.

So it is not surprising that many people who need long-term care are anxious. People who are anxious sometimes forget to say thanks, and they are sometimes mistrustful, angry, or antagonistic toward those on whom they depend. Friction between dependent person and caregiver can sometimes be magnified by low pay, or by language/race/or other barriers between dependent person and caregiver. Especially when the caregiver is working a second shift or a second job to make ends meet.

At the organizational level, it can be hard to sustain high-quality nursing home care in the face of inadequate budgets, staff shortages, and gaps in management support or knowledge.

If quality is low, that can become part of a finger-pointing exercise between state agencies that set Medicaid rates for nursing homes and the nursing home industry—we need more money to provide high-quality care, say the homes; but why should we pay you more until you demonstrate that you can provide high-quality care, says the state. Neither party is accountable for remedying quality problems.

In home care, there can be problems of abuse or neglect of dependent persons by the helpers on whom they depend. We don't know how common these are.

II. Solutions

A. Public solutions—more public money

1. Federal dollars. Medicare should pay for nursing home and home care without means test or income limit. Once a hot topic for congressional debate, though never taken seriously politically.

Now not even a hot topic for congressional debate.

Prescription drugs problem has displaced it—a greater concern to more articulate elders who vote than is long-term care.

Unless Congress devises a way to win affordable prescription drugs for all Medicare patients, the chance of passing serious federal legislation to finance long-term care more generously is exactly zero.

Fortunately, if mental health and long-term care are the two toughest health care problems, prescription drugs are the easiest.

In the prescription drug field, as in most others, the choice must be among suffering more, paying more, and reform. Reform is to be preferred.

We suffer enough—more than enough.

And we certainly pay enough—more than enough.

This year, U.S. prescription drug spending will reach close to $220 billion. This means that we are paying almost one-half of the world's bill for prescription drugs—even though our 300 million people make up only 5 percent of the world's

population. And we provide far more than one-half of the world's drug makers' profits.

It is therefore clear that we do not reform enough.

Here are the bare bones of a way to win affordable medications for all Americans at a tiny rise in overall spending—while, at the same time, protecting prescription drug research and even drug makers' profits.

1. Channel all the streams of money that now pay for prescription drugs in one federal reservoir or in 50 state reservoirs. Employers would maintain their spending on prescription drugs, but their cost would be carved out of traditional insurance. It would probably be necessary to replace most of the out-of-pocket dollars with tax dollars.

2. Negotiate a treaty with the drug makers. Using the money in these reservoirs, we will pay you enough to assure your profits at today's levels just as long as you make enough medications to fill all prescriptions that doctors write.

3. Americans now fill about 3 billion prescriptions yearly. We need perhaps an additional 1 billion. Fortunately, the actual added cost of manufacturing, distributing, and dispensing the additional billion prescriptions is under $10 billion yearly. That's because once the research is done and the factories are built, the incremental cost of making more medications is very inexpensive.

4. This means we can obtain a one-third increase in prescriptions at an added cost of only about 5 percent of current spending—sales tax, more or less.

This is not alchemy. It is financial reality.

But it is not yet political reality. That's because the drug makers, understandably, don't trust government and want to be captains of their own fates. Sadly, for them—and for us—that captaincy leads them to try to double their incomes every five years—which also happens to double our costs. As a result, many of us are angry, and getting angrier.

If the drug makers keep pursuing more money for business as usual, they will bankrupt many of us, and infuriate the rest. We, in turn, will elect the angriest Congress in the history of the world. That Congress's first piece of business will be to slash drug makers' prices and profits. I'm not sure that would be good for anyone in the long term.

The sooner the drug makers decide to work with all of us to shape durably affordable medications, the sooner they will begin to protect themselves effectively.

And the sooner we will be able to turn to the really difficult job of financing and delivering safe, adequate, and dignified long-term care for all Americans.

2. Medicaid

Medicaid is the main program that pays for long-term care. As you know, the great share of Medicaid's long-term care dollars pay for nursing home care. And these payments are often not enough to finance safe, adequate, and dignified nursing home services.

Medicaid even pays hospitals and doctors at relatively low rates.

It is hard to imagine where our state will find enough Medicaid money to pay for safe, adequate, and dignified nursing home care, let alone money to pay for home care.

Massachusetts has greatly expanded its Medicaid program but not in durably affordably ways. We did not recession-proof Medicaid.

This is partly our fault, but it is mainly partly the fault of the federal government. As you know, Washington can run deficits during recessions, which states cannot really do. Medicaid needs money during good times and bad. Only Washington can find the money during bad times. It should therefore stand ready to pick up Medicaid deficits during recessions. The states could even be asked to repay the money in good years.

But even if we could improve Medicaid, it is available only to people with low incomes and few assets. This helps make it a good vehicle to pay for nursing home care—since a nursing home resident's own money goes fast at $150 or more per day. But Medicaid's income limit makes it a bad vehicle to pay for home care, which is needed by many people who actually have a little money saved up.

3. State dollars

With state government unable to find enough money for Medicaid—when the federal government pays one-half of the cost—it is even less likely to find the dollars for state programs—when the state pays 100 percent of the cost.

B. Private solutions—more private money

1. Private long-term care insurance

This is one of the most controversial areas of long-term care financing. Some people argue that private insurance will better protect some families and, at the same time, save dollars for the state and its Medicaid program.

The idea is to get people to save up for long-term care, whether they need it or not.

But since about one in three of us will need long-term care, and since that care is very costly when needed, the cost of the insurance premium is fairly high even if the policy is bought at a relatively young age—45 or 50. Think about it. Even crudely. A nursing home at $150 per day for two years costs $110,000. If we have a one-third chance of needing this, the average total premium needs to be about $36,500. Plus broker's commission, administration, and profit.

Very wealthy people don't need this protection and lots of us simply can't afford the premiums. It seems that no more than 15-20 percent of people can afford long-term care insurance.

But should those who can afford it buy it? The answer is far from clear. Several reasons:

Is a particular policy inflation-adjusted—is the benefit adjusted for inflation?

Is renewal guaranteed for life, at a premium known and specified in advance, though perhaps adjusted for ordinary inflation?

What will be the requirements for using the policy? If home care services look attractive to some of us as we become more frail or disabled, what tests will be made by the insurance company to make sure we really need the care we thought we were paying for?

And what is the expected care share (medical loss ratio)—the share of dollars actually paid out in benefits? For many individual health insurance plans, only 50-60 percent of income goes to benefits. The rest goes to agents, profits, and administration.

In other words, do the policies increase our sense of security? If we can afford the premiums, would we be better off putting the money aside in safe investments?

I don't know the answer. It requires very careful thought. One thing I do know is that sales of long-term care insurance have been very modest.

2. Reverse annuity mortgages

Many of us have accumulated substantial equity in our homes. But we sometimes don't want to have to sell and move out in order to unlock the equity even if we need it to pay for long-term care.

Reverse annuity mortgages have been designed to do this. You sell your home to a bank, and it pays you an annuitized sum, sometimes for at least a guaranteed minimum time, as long as you are alive. Subsequently, the bank sells the property and recoups its payments.

These arrangements have not appealed to many people. Some do not want to sell their home, because they expect that the equity will be needed to help their

children afford Boston-area home prices. Others may be concerned that the annuity payments may not fairly reflect the equity—that the bank is taking too much out of the deal up front.

3. Continuing care retirement communities

Here, we have a different form of private long-term care insurance. You enter a new community by renting or buying a home or apartment. The housing price plus other monthly payments cover the cost of one or more meals, some help managing the home, and sometimes personal care. In a few of these CCRCs, the housing price even includes the cost of nursing home care if you should need it. Clearly, you have to pay more to get more.

These used to be called life care communities, but some went broke in the stagflation of the 1970s. They were renamed to sound less durable. Continuing care, not life care.

These can be attractive to some seniors. The best offer rich social activities, substantial in-home support, and nursing home care also. The best seem fairly solid financially, with deep reserves. Others are less solid.

Shop carefully.

C. Diverting acute care dollars to long-term care

1. National health insurance

One-half of the vast sums we spend on health care each year is wasted. How?

Clinical waste—care that does not work, care that this patient did not really need, care that was not competently provided.

Administrative waste—the layers of paperwork and clerks who struggle and flail to make an inherently inefficient system function at all. So often, the bill is not right and we have a paperwork nightmare just to move the money around. We are trying to pump $1.7 trillion through a waterworks designed for only $100 billion.

Much of the administrative waste is deliberate—documentation required by a payer who does not trust a doctor or a hospital or a drug maker or a nursing home or a home health agency. And caregivers game the regulations, leading payers to adopt more rules. More administrative waste is a consequence of how we pay doctors and other caregivers. If, for example, we pay doctors fee-for-service, they have a financial incentive to give more care because that's how they make more money. So we then ask doctors to justify, prove that patients actually need the care that doctors give. More paperwork.

In addition to clinical and administrative waste is outright theft, fraud, abuse.

Wasting one-half of our $1.7 trillion in health spending this year disheartens all of us.

But it should also inspire each of us to find ways to cut the waste and spend our vast dollars more carefully, to take care of all of us.

Single payer, consolidated financing methods can save much administrative waste, but cutting all forms of waste will require that is far substantial than single payer alone. It will require better ways to raise the money to pay for care. It will require better ways to pay hospitals and doctors.

For example, we should identify each needed hospital and make sure that each is paid enough money to provide high quality care—as long as it is operated efficiently. This must be guaranteed. In a state that has allowed one-half of its hospitals to close in the past 40 years and one-half of its hospital beds to close in the past 20 years, we can't afford to lose even one more hospital—unless it can be proven in advance that that hospital is simply not needed—either today or tomorrow.

Tomorrow is particularly important. We should look ahead and make sure that we will have enough hospital beds in 5, 10, and 20 years, when we will need far more of them. A few years ago, when most people were sure that our state had too many hospital beds, my colleague and I warned that we would soon have too few. That day is here today, in many parts of the state. And we certainly do not have enough emergency room capacity.

And we need to pay doctors in ways that allow us to trust them to spend our money carefully—and to take care of all of us. This does not mean blaming doctors. They don't deserve blame. Rather, it means working with doctors to shape ways to pay for care that liberate doctors to weed out the waste and spend our vast but finite dollars carefully.

Immortality is not the goal. Right?

Medical care has never saved a single life. It has delayed countless deaths, and eased enormous pain, suffering, disability, and worry. And that is a blessing.

The aim of medical care is medical security—confidence that we will get the right care at the right time, regardless of ability to pay.

Medical security does not mean endless care, endless spending, to squeeze out tiny added benefits to health.

It means balanced and well-thought-out services that do as much good as possible with the dollars available. The sort of balance that leaves enough money available to finance long-term care.

Unless we successfully address the acute care side—the hospital/doctor/ prescription drug side—where some three-quarters of today's health care is given—we'll never find the dollars to finance the long-term care services we need. Or the mental health services. Or the care that today's uninsured people need and deserve.

2. S/HMO, On Lok, PACE—programs that promise a better balance of acute and long-term care

If we pool available health care dollars, long-term care might get a better shake, some people think. Imagine an HMO only for older people. Or only for people with serious medical problems or disabilities.

In one view, good routine care for diabetes or heart problems would prevent many hospitalizations. Good routines could include monitoring blood chemistry, making sure patients can afford their medications, and even ensuring that each person has enough good food to eat and a safe, warm place to sleep. For most people, friends and family, a pet, and even a little alcohol—in moderation—seem to offer valuable prevention of illness. For people who sometimes get dizzy or walk unsteadily, grab bars and other architectural modifications in the home would prevent many falls and resulting injuries.

In this view, investing in routine medical and social care pays substantial dividends by cutting hospital admissions.

They invest more in the quality of life than in the quantity of life.

Unfortunately, these programs do not generally seem to save money. They are hanging on but they have not grown very much.

This is partly because the costs of extending the quantity of life are growing so dramatically. Medicare, for example, has just approved a new heart assist device called HeartMate that could help 100,000 patients yearly at an annual cost of $6 billion.

3. Hospice

Medicare's hospice benefit is designed to offer comfort and care—not cure—to patients who are expected to live no more than six more months. Almost all are cancer patients.

This has worked reasonably well. Patients in hospices are seldom exposed to treatments that are often painful and usually futile.

D. New solutions

Innovation is at very low levels in long-term care. We have surprisingly few new ideas. There are two main reasons for this.

First, it's very hard to make money in long-term care, so private businesses have had little interest in innovating.

Second, the U.S. government, which could invest public dollars, is very cautious. They don't want to look bad, to seem to waste money on failed ideas that looked promising but turn out to have been hare-brained. But that's exactly the wrong approach. Innovations rarely succeed. What share of small businesses go broke each year?

The U.S. government should annually appropriate some $50 million to design, test, and evaluate innovative, speculative, and even seemingly silly methods of better addressing long-term care needs. The government should expect that three-fourths to 90 percent of the methods will fail. But if we identified one good new idea each year, that's an infinitely large improvement over our typical experience.

Time banking—one innovation. Americans volunteer to help older and disabled people all of the time. Why not recognize that time is the real medium of exchange in long-term care and therefore promote a parallel economy of time. This could mobilize much more voluntary aid. Individuals could volunteer when they have time available, bank their time, and then withdraw it when they need help from another volunteer. Time could even be used to pay insurance premiums, and it could be moved across space, just like money. Would this self-interested mechanism undermine pure altruism? I don't know, but I doubt it. Our motives are often hard to understand. Perhaps results matter more than motives.

Others—not one big solution, but 20 smaller ones, each of which fixes about 5 percent of the problem.

And more public money—like a stone bridge over a stream. Each half of the arch holds up the other half.

And in conclusion—

Long-term care is a tough problem. It will be hard to fix by adding money because that money is not available. Finding more money for long-term care requires addressing and reforming other large parts of U.S. health care—prescription drugs, hospitals, physicians, universal coverage, and the like.

And finding more money for long-term care, while essential, needs to be accompanied by improvements in the actual delivery of care. That will require serious innovation.