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## Back to the (Precarious) Future: Congress, Long-Term Care and the Pepper Commission Legacy

By HOWARD GLECKMAN

Twenty years ago, the Pepper Commission, chaired by the Florida Congressman Claude Pepper, issued a ringing call to “give Americans of all ages access to...necessary long-term care and adequate financial protection...that will assure quality care and choice of setting.” Now, after two decades, Congress finally may be about to adopt key changes in the way we both deliver and finance this critical assistance.

In my recent book, *Caring for Our Parents*, I had the opportunity to observe our deeply flawed system of long-term care through the eyes of some of the 10 million Americans who need this assistance and the family members and paid aides who help them.

I met Natalie Fenninger, who spent nearly \$600,000 of her own money on personal care before finally impoverishing herself. She spent her last months on Medi-caid, sharing a tiny room in a nursing home with a stranger. And I met Steve and Judy Dow, who struggled to care for Steve’s mom and Judy’s parents even as they raised two high school kids and tried to hold down full-time jobs.

### THE RIGHT STEPS TO CARE

Now, as the baby boom generation begins to face long-term care head-on, Congress may be about to make the lives of the frail elderly and younger adults with disabilities just a bit easier. The changes Congress is debating as part of health reform won’t solve our long-term care crisis, but they take big steps in the right direction.

The proposal getting the most attention is the Community Living Assistance Services and Supports (CLASS) Act, a voluntary national long-term care insurance program. First introduced by the late Senator Edward M. Kennedy, CLASS would provide a basic long-term care benefit for nearly all adults who want it.

While its exact benefits and premiums would be worked out by the Secretary of Health and Human Services, CLASS would probably provide a core cash benefit of around \$75 per day for life that could be supplemented with private insurance. Workers would be automatically enrolled in this coverage, although they could choose to decline the insurance.

A cash benefit, even if it is modest, would mean a significant change for consumers of long-term care and their families. This money could give families the flexibility to hire aides, retrofit a home for better accessibility or arrange for adult daycare. Funds could also be used to pay for a portion of care in an assisted living facility or nursing home.

Adopting a national long-term care insurance program would be a major change in the way the United States finances these services. Today, more than 40% of long-term care costs are paid by Medicaid, and less than 10% are financed with private insurance. The CLASS Act would begin to shift long-term care financing to an insurance-based system, a step that has been taken by most other countries in the developed world over the past two decades.

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#### QUESTIONS, POSSIBILITIES OF REFORM

However, many questions remain. While most developed countries have adopted a mandatory social insurance model, CLASS is voluntary. As a result, analysts don't know how many people would choose to participate and, thus, what the premiums would be.

CLASS is not the only item on Congress' long-term care agenda. Lawmakers may also expand home and community-based care under Medicaid. In recent years, states have gradually begun to provide these services, but unlike nursing home care, they are not a mandated benefit. While Congress won't require states to provide Medicaid homecare, it may give them additional funding to expand these programs.

Reform may also begin to better coordinate care for the "dual eligibles" who receive both Medicare and Medicaid benefits. Currently, except for some modest initiatives such as Special Needs Programs (SNPs) and the Program of All-inclusive Care for the Elderly (PACE), little is done to harmonize acute care services paid mostly by Medicare and the long-term care assistance funded by Medicaid. Proposed legislation would create a new government office to harmonize these benefits.

As I write this in late January, we don't know what will happen to either the overall health bill or these critical long-term care reforms. But both the frail elderly and younger people with disabilities, as well as their caregivers, deserve a better system of long-term care. And these issues will not go away, no matter what happens to the health bill. ♦

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*The following excerpt is from the chapter entitled "Solutions" from Caring for our Parents by Howard Gleckman. Copyright 2009 by the author and reprinted by permission of St. Martin's Press, LLC.*

## Solutions

So here is the challenge: Find a way to deliver and finance the long-term care future generations of aged and disabled need and deserve, but do it in a way that does not break the nation's fiscal bank.

To write this book, I spent more than two years studying long-term-care, learning from experts in the United States, England, Germany, and Japan. I talked to academics, government officials, owners and managers of nursing homes, assisted-living facilities, and home health agencies, as well as doctors, nurses, and aides. And I spent countless hours with the families who are living the long-term-care story. This is what I discovered: there is no easy or perfect solution. Each reform has its problems. But nearly everyone I spoke with agrees on one principle: The current system is failing. We can find better ways to deliver and pay for long-term-care. But we must do so quickly—before the Baby Boom generation begins to reach frail old age.

It will be easier to change the way we deliver this help than to fix the way we finance it. The problem is, unless we get the money right, we'll never really do a better job of providing assistance to those with disabilities and the frail elderly. We run the risk that long-term-care will become even more like our medical system, where an impenetrable tangle of inside-out financial incentives encourages poor but expensive treatment instead of good care.

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#### THE PERFECT AND THE GOOD

The eighteenth-century French philosopher Voltaire warned that "the perfect is the enemy

of the good.” He was not thinking about long-term-care. But his warning fits, nonetheless. In their zeal to find the perfect solution, long-term-care experts have been unable to come together on ways to improve the unsustainable mess we have today. Neither have long-term-care industry lobbyists, who are often driven by a self-serving search for the most profitable solution for their individual companies. Even advocates for the elderly and disabled have failed to agree among themselves on what to do. And politicians, terrified by the potential costs, baffled by the complexities, and unwilling to wade into these internecine wars, simply ignore the issue.

Individual families are terrible advocates for the long-term-care cause, in large part because they are so overwhelmed by their roles as caregivers that they have little time to lobby their representatives. And once their loved one dies, the last thing they want to do is relive their ordeal for some politician. All they want to do is get back to their lives.

But the Baby Boomers won't sit quietly for much longer. They are used to getting what they want, and soon they will begin to tell their elected officials that what they want is a way to care for their parents and themselves without facing financial ruin. And the politicians better be ready with an answer.