

Testimony
by Susan M Daniels

Good morning, Senators. Thank you for the opportunity to talk to you about the situation of long-term-care across the age span and to set out some ideas for how the system can be saved and improved.

The long-term care delivery system is a mess. The Census Bureau estimates that in 2050 there will be two and a half times more people age 65 or over. At the same time, societal trends such as the mobility of families and the growing rate of working women reduce the previously available family caregivers. Paid/professional caregivers are poorly paid, receive few benefits including insurance for their own health care, received inadequate training, all resulting in personnel shortages that will only worsen with time.

Principles for Long-Term Care Reform

As a first step in addressing the current problems in the long-term care system, the CMS's Policy Council¹ developed a set of principles for long-term care reform. These principles include:

- Increase consumer choice and control for older individuals, persons with disabilities and chronic illnesses of any age, their family members and caregivers
- Ensure access to an appropriate array of institutional and home and community-based long-term supports;
- Reverse the institutional bias in long-term care services.

On a similar track, The National Academy of Social Insurance (NASI) is calling for fundamental reforms in financing long-term care². The panel's report finds a high level of public concern about paying for long-term care and widespread discontent with the current system of financing.

“Members of the panel feel strongly that a better long-term care system is essential to enable all Americans, regardless of age or disability, to participate fully in our society. The current long-term care system falls far short of meeting reasonable expectations. Achieving a system that meets individual needs and distributes costs equitably will require greater federal involvement and financing.”- Sheila P. Burke, the panel's co-chair

Shortcomings of the Current Long-Term Care System

The current long-term care system falls far short of meeting reasonable expectations in several ways:

- *Unmet Needs.* Many people receive inadequate care. Nationally, 20 percent of people living in the community and needing services get less help than they need. As a result they are more likely to fall, soil themselves, or be unable to bathe or eat.
- *Burden on Caregivers.* Unpaid caregivers play a critical role in the system but often pay an economic, physical, and emotional toll. Workers in the formal long-term care system labor under difficult conditions and low wages, frequently without fringe benefits.
- *Financial Jeopardy.* The cost of long-term care can impose financial hardship or even spell financial catastrophe for many families. Few people have any type of insurance against the expense of long-term care, which can reach \$26,000 a year at home and more than twice that amount in an institution.
- *Limitations in Medicaid.* The federal-state Medicaid program finances long-term care only for those who are or have become impoverished. Its benefits vary widely from state to state, and it requires some people who need help to move to institutions, when they would much rather live in their communities.
- *Quality Problems.* Serious quality problems persist in some nursing homes, partly as a result of inadequate staffing. Quality in non-institutional settings is also a concern.
- *Demographic Challenges.* The long-term care system is unprepared to meet the demands that the large baby boom generation will impose upon it. The coming demographic shift will also exacerbate staffing shortages.

Because the need for long-term care is a risk, not a certainty, the panel recommended that it should be handled through insurance, like other unpredictable and potentially catastrophic events. The study panel did not endorse one particular solution but I do: a payroll based universal access to a basic, limited long-term care benefit.

The Panel recommended three tenets to guide the long-term care system of the future:

- *Meeting Individual Needs.* The needs of individuals should determine the kinds of services available.
- *Preserving Autonomy.* Service delivery should preserve the autonomy of the people receiving services.

- *Promoting Equity.* The costs of services should be shared equitably among individuals, families, and the society in which we live, and services should be similarly available and affordable regardless of the state in which a person lives.

Nearly 10 million Americans need help with basic tasks of living, such as bathing, eating, dressing, or walking, or help with other activities that maintain their independence, such as shopping, cooking, or cleaning. More than 80 percent of those who need care live in their communities, not in nursing homes, and nearly 40 percent of them are under age 65.

You are taking up the cause of long-term care, building coalitions for change, and taking advantage of opportunities for action. We all acknowledge fiscal pressures facing federal and state governments. The impending retirement of the baby-boom generation will add to already large demands on the major federal entitlement programs. As you grapple with these budgetary issues, meeting the needs of the elderly and the disabled for long-term care should have an important place on the agenda and we should not shrink from providing the innovations that will be required.

Thank you.

¹ Policy Council Document September 28, 2006 Long-Term Care Reform Plan

² Developing a Better Long-Term Care Policy: A Vision and Strategy for America's Future November 2005 Report of the Long-Term Care Study Panel National Academy of Social Insurance Study Panel on Long-Term Care, *Co-Chairs* Sheila P. Burke and Judith Feder