Submitted Testimony of the Honorable David F. Durenberger
Chairman, Citizens For Long Term Care
To the United States Special Committee on Aging
June 28, 2001

Many of life's most critical hazards are those that unexpectedly reduce the sources of income, significantly strain one's financial security or greatly affect one's health. Saving for retirement or protecting one's financial security during working or younger years is subject to all kinds of events or risks. Many events, like the cost of college tuition, can be planned for. But some risks like an accident or a birth related impairment or the onset of a chronic disease, which can necessitate years of costly care, are not expected nor very often planned for. During retirement, events such as higher than expected inflation, longer than expected life or the need for long term care can impede the best of plans and threaten financial and retirement security.

What has emerged to help families protect financial security is a base of social insurance, upon which private insurance and publicly encouraged deferred compensation arrangements have been built. For most people, financial security is principally derived from earnings and then Social Security, Medicare, employer-provided pensions and benefits, and savings, all of which seek to help protect individuals and families from unexpected risks associated with health care or loss of income.

There is a safety net of public assistance both for those workers who were unable to adequately save or acquire insurance and for those who did not or could not work.

Public assistance is a traditional state and local government response to financial need. In the middle of the last century our national government began to fund the safety new as well. Over time, as our less advantaged grew in number, and the cost of meeting their needs expanded, national government financing, especially Title 19 and other provisions of the Social Security Act became critical. Today, it is impossible to determine where responsibility and accountability begin or end.

As the numbers of people who are elderly or disabled increase, more people will face greater risks to their financial security from long term care costs. This gaping hole in our system of ensuring financial security needs to be addressed.

What is long term care and how is it delivered?

Long term care services and support encompasses a broad range of assistance to people who need ongoing help to function on a daily basis. These services may range from assistance with daily activities such as bathing, dressing and eating to more complex services such as meal preparation, shopping, money management, medication management, and transportation. Long term care cannot be relegated to specific hours, days of the week or to fixed settings.

For the twelve million people who need help now and for the millions of family members who are their caregivers, there is no national, cohesive or uniform long term care system. Long term care is provided in a range of settings encompassing home, community and facility based settings depending on the recipient's needs and preferences, the availability of formal and informal support, and the type of reimbursement. In essence, we have a patchwork of programs that vary from state to state and community to community. Each program has its own standards for eligibility and provides different services. This patchwork of efforts is inefficient, inequitable and often ineffective. The lack of a cohesive national policy to assure access to long term care has left people with disabilities and the elderly without a consistently dependable and predictable system of support for their long term care needs.

Why we need financing reform

Long term care is an essential component of individual and family financial security. To disregard the financial impact of long term disabilities on individuals and on society leaves a gaping hole in our nation's economic security. The current system for enhancing economic security is principally derived from earnings, Social Security, Medicare, employer-provided pensions and benefits, and savings, none of which adequately address long term care for a majority of Americans.

Everyone is at risk not only of having a family member in need of long term care, but also of needing assistance themselves. About 45 percent of the long term care population is under the age of 65. Yet, although the need for health insurance to cover a patient's medical expenses in case of catastrophic illness is widely recognized, few people are insured against the costs of providing long term support services for that same person. This lack of insurance coverage jeopardizes the financial security of families and diminishes the economic security of the country.
At more than $4,500 a month, the cost of even a short stay in a nursing home or other facility has the potential to exceed the financial resources of many Americans, especially those no longer able to work. A long stay in a nursing home or extensive use of home and community-based services can easily (and quite often does) consume a lifetime of financial resources. Upon exhausting their own private resources, individuals and families must turn to the federal-state Medicaid program as the payer of last resort. The current Medicaid based financing system, which is the largest single payer of long term care, dictates that people must effectively impoverish themselves in order to receive government assistance.

The federal-state design of the Medicaid system is a product of its times-the early 1960s. It divides financing between the states and federal government. As a result reimbursement and service delivery vary widely from state to state. Moreover, although most people prefer to be cared for at home, Medicaid's preference towards institutional care has left Americans with few alternatives and tremendous confusion over how best to arrange the options that are available to them. Families are often forced to balance a loved one's needs and desires with financial realities.

Demographic change, including the 77 million aging Baby Boomers, increased longevity due to medical advances, and declining family size, not only calls attention to the inefficiency and inequity of our current system, but also raises a clear alarm about the future. The costs of long term care, which are already economically devastating to most families, will only become more expensive as the population ages. Other demographic changes, including families living farther apart, two-wage earner families, and smaller families indicate there will be relatively fewer adult children upon which elderly parents or siblings in need of long term care will be able to depend.

As the pool of potential unpaid caregivers shrinks due to demographic and economic trends, paid professionals will play an increasingly greater role in delivering long term care. However, the relative size of the paid long term care workforce is not likely to increase with the anticipated demand for paid long term care. Under funded staffing levels, unrealistic workloads, insufficient government reimbursement rates, along with the need for additional training and support, as well as labor shortages have resulted in high staff turnover. Recruitment and retention problems create an unstable workforce and are a barrier to high-quality care. In addition, our current financing system does not support today's wages, and therefore raises serous questions about the ability to recruit future paid caregivers.

The fragmented services and supports available to people with disabilities is the result of how long term care has been funded in the past. Changing long term care financing will change how long term care is organized and delivered. A rational approach to financing will improve the efficiency and equity of the system, it will recognize people's desire to receive care where and when they need it, and it will improve the quality of the care.

Pillars of reform

Citizens For Long Term Care's members have agreed upon a set of core beliefs that are fundamental to beginning of any discussion on long term care and long term care financing reform. We called them the Eight Pillars of Financing Reform. They are:

- Every American must be assured access to needed long term care services.
- A wholly new, stand-alone, comprehensive financing system for long term care is neither practical nor likely at this time and hence long term care financing reform should be initiated on existing structures.
- The social commitment to long term care must be in the form of a public/private system built on the principles of social insurance and private insurance.
- Eligibility for the social insurance benefit should be based on functional limitations as an entitlement benefit.

- Private and public policies should be developed to educate and encourage individuals and families to plan for the financing of care prior to the onset of disability.

- Professionals, paraprofessionals, and direct support professionals are critical to quality care and must be recognized and valued by the system.

- Public assistance must be maintained and improved to provide a full range of services and supports to those who are not otherwise covered.

- The financing system must support choices across the continuum of care and help maximize personal independence, self determination, dignity and fulfillment.

An American approach to pooling risk

The need for long term care is an insurable risk. This means that the risks are relatively low, but the financial consequences are not. As an insurable risk, the most efficient way for individuals to finance long term care is to pool the risks relative to the expected costs. That is, saving for this contingency is not efficient either for the individual or for society as a whole. Reliance on public assistance as the primary source of financing long term care should be reserved for those whose asset levels necessitate such public assistance.

Nevertheless, government has a critical role in ensuring that every American has access to long term care and that the service infrastructure be adequate to the need. Universal access to care must be maintained by a social commitment expressed through a combination of social insurance and tax subsidized incentives to support and encourage private insurance; a Medicare program that adequately addresses chronic illness, preventive medicine, acute and episodic care needs; and publicly financed safety net protections for those who are not supported by these other means.

Based on lessons from the national debate on health care reform, Henry Aaron suggests "…reform will have to build on existing U.S. institutional arrangements – modifying, improving, and extending them, but not scrapping them in favor of some entirely new system." This statement reflects the American approach to pooling risk and ensuring financial security. It also acknowledges that it would be difficult to create a wholly new, separate long term care system. Instead we must build upon existing institutions and programs.

The American approach to pooling insurable risks has been a combination of social insurance and tax-encouraged private insurance, both of which are tied to earnings. Social Security, including the life and disability insurance, and Part A of Medicare are earned rights derived from employment for the worker or the worker's dependent. Most private insurance is organized through group purchases made by employees or by employers on behalf of their employees and their dependents. Relatively common employer-provided benefits include health insurance, disability insurance, and life insurance. Retirement income is also enhanced through employer-provided pensions and deferred compensation plans such as 401(k) type arrangements. These employee benefits as well as many individual savings plans are encouraged by preferential tax treatment.

Clearly, there are gaps in these arrangements as well as gaps between these arrangements. Savings are used to bridge those gaps. But in the absence of sufficient savings, public assistance is often available. Public assistance benefits are targeted to those in specific categories with the least financial means.

Building on the foundation these polices have laid but shifting the emphasis from public assistance to earnings and insurance provides the opportunity and means to guarantee all Americans access to needed long term care. It is upon this system that we must build better options to help people secure access to long term care services.

Towards reform

The pillars of reform developed by Citizens For Long Term Care, taken in concert with our established American system of pooling risk, provide a basis for discussing reform options. Citizens For Long Term Care agrees that there must be a new social insurance benefit that finances a minimum floor of financial protection combined with a program of incentives for the early acquisition of private insurance. The social insurance component would provide a new floor of protection based on functional need with appropriate eligibility and benefit level qualification standards. Public assistance must be available to ensure that those whose needs exceed all other public and private resources are helped. There must be a clear national commitment to finance long-term care based on principles of social and private insurance. Without specifying the details of this framework, there are areas of clear agreement that must be a part of reform proposals. These include:

The New Social Insurance Benefit

- A new social insurance benefit with appropriate eligibility and benefit level qualification standards must be based on the level of functional need and provide a minimum floor of protection in a way that is sufficiently flexible to best help disabled individuals and families meet their unique circumstances.

- The financing system should be as flexible as possible, not only to meet different and changing needs of individuals, but also to assure appropriate consumer choice in settings across the continuum of care. Two people with the same level of functional need should receive the same level of assistance but be able to use that assistance differently.

- There needs to be a new publicly financed program that provides a national, uniform system of disability assessment and assistance, which offers both information and assistance in arranging for appropriate services

- There needs to be a critical examination of the development of guidelines for disability and long term care to help ensure integrated coverage for supportive services over the course of one's lifetime.

Private Insurance and Employers

- The acquisition of private insurance, especially at a younger age, for those for whom it is most appropriate must be encouraged and supported through publicly supported tax incentives.

- Insurers have a responsibility to help educate consumers and work with employers, the government, and consumer groups to develop ways to expand the pool of privately insured risks, ensure adequate consumer protections, and to ensure that private resources are used to improve the organization and delivery of long term care.

- Employers have a critical role to play. Employers, working with government, have a responsibility for helping people to better understand the financial consequences of long term care and their options to plan for this risk. Employers are also in a better position than individuals to choose and organize disability and/or long term care insurance options.

- Individuals and their families have a responsibility to plan for the financial consequences of needing long term care. For some people, at various stages of their life, the only effective way to plan for the future will be by working and paying taxes. Others, however, will have the opportunity to build on the protections provided by the social commitment and use tax incentives to purchase private insurance or to finance other options that insure long term care needs.

Medicare

- Medicare needs to be reformed to cover the most appropriate level of support for the health care needs of those with chronic illness and disabling conditions.

- Medicare must also be reformed in ways that ensure more beneficiaries are able to either avoid or delay the onset of chronic and disabling conditions. In addition, Medicare must better define the difference between chronic health care and long term care services so that the health needs of those with chronic conditions are better met.

Medicaid

- Medicaid as a safety net must be available to those who need long term care but have no other source of financial assistance, and it must expand the choices available for long term care.

This approach establishes a national framework to improve the financing, organization, and delivery of long term care. It offers the potential to pool public and private resources towards the development of an efficient and equitable market of long term care providers, and has the potential to help families better organize, coordinate, and integrate needed care with their own efforts.

Call For a National Dialogue

The transition from the current welfare-based system of financing long term care to this new national public/private system will be difficult; it will take time and it will require the skills of our nation's most respected and visible leaders. As Hubert Humphrey said "[t]he moral test of government is how it treats those who are in the dawn of life, the children; those who are in the twilight of life, the elderly; and those who are in the shadows of life, the sick, the needy, and the handicapped." Today, with respect to long term care, we fail that moral test. We fail the test, not out of willful conduct, but rather, as the result of long ago adopted policies and programs that never recognized the nature and cost of long term care.

There are questions on which Citizens For Long Term Care has not yet reached agreement. Answering these questions will require a national dialogue about long term care. Only by engaging the people of this nation will our leaders serve to educate the public and move beyond the concerns of the interest groups represented in this process. Therefore, it is imperative that our nation's leaders, led by the President, undertake a national dialogue with the people to address the size, scope and cost of our commitment to long term care financing. This public dialogue, which must take place as part of our current dialogue on Social Security and Medicare reform is the only way we can educate people about the need and cost of long term care. At stake are the financial security of families and the economic security of the nation.

By developing a national dialogue that recognizes long term care financing reform as an integral part of financial security, we can close the gaping hole in our financial safety net. In doing so, we can develop a financing system that supports an integrated system of care. Such a change would ensure that those not capable of caring for themselves can maintain the highest quality of life, according to their preferences, with the greatest degree of independence, autonomy, participation, personal fulfillment, and dignity.

We have the opportunity to develop a financing system that supports the varying goals of a diverse population with diverse long term care needs. In order to seize this opportunity we must commit ourselves to a national dialogue today, before the demographic tidal wave of aging Baby Boomers overwhelms us.

Thank you, Mr. Chairman, and Members of the Committee, for your commitment to begin this dialogue.