LONG-TERM CARE

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file long-term Care

Mr. Chairman and Members of the Committee:

Thank you for inviting me to appear before you today to talk about long-term care. From the outset of the health care reform debate, the President and the First Lady have made long-term care an essential component of their commitment to comprehensive health care. The inclusion of long-term care in the Health Security Act is concrete recognition that the long-term care needs of people with chronic illness and disability...a ventilator dependent child, a young man born with mental retardation, an elderly person with Alzheimer's disease, the survivor of an automobile accident...are as important for this nation to address as the health needs arising from acute illness or injury.

The constituency for long-term care reform is a significant one. It includes many of our Nation's senior citizens, for older people have the highest probability of becoming disabled toward the end of life. It includes 14 million family members and friends of older persons who experience care-giving responsibilities first hand as they respond to the long-term care needs and problems of their loved ones. It includes 10 million people of all ages who as a result of a disability require at least some help from others to carry out routine activities of daily life. Finally, it should include all of us... for any one

of us on any particular day or any of our children could become disabled as a result of accident or chronic illness.
In short, for the elderly, for younger individuals with disabilities, their families and other people who care for them - for each and every one of us - long-term care reform is not expendable. It is a vital piece in solving the health care puzzle. Without basic ongoing supports to live in the community, a person with a severe disability might never get as far as exercising his or her right to universal health care coverage.

THE LONG-TERM CARE PROBLEM

Today I will tell you about the growing long-term care problem, explain our belief that health care reform is not complete without a long-term care component, and tell you about our proposed plan for tackling long-term care reform.

What would you do if you or a member of your family were suddenly not able to take care of themselves...to feed themselves or prepare meals, bathe, go to the bathroom, dress themselves, get in and out of bed, shop for food, manage their money, take medications...unless someone were there to help them. If you were married to such a person, and if you did not have to hold a paying job, you might be able to manage. But suppose you did have to work, or your parent lived 3,000 miles away or you yourself were disabled or had an illness that prevented you from providing assistance...then what?

You would do what the vast majority of people in this country do now in such a situation--make do the best you can with informal care...purchase extra help to the extent you could afford, or do without. Why? Because if you turned to the obvious places that you would turn to if you experienced an acute health problem -- private health insurance, Medicare, the government...you would find precious little.

Most people are surprised to find that Medicare, which provides substantial coverage for acute health services, offers only limited, post acute support services to help beneficiaries get back on their feet. Similarly, even the best private health insurance policies provide virtually no long-term care. The only government program with significant long-term care benefits--the Medicaid program--requires you to literally become impoverished before qualifying for help.

However, Medicaid funding has been, and continues to be, significantly biased towards institutional care. In 1993, almost 85 percent of Medicaid long-term care expenditures were for institutional care. Further, despite increases in Medicaid home and community care spending, access to Medicaid home care services varies tremendously across States. So even though the overwhelming number of people with long-term care needs prefer services in their own homes and communities, these services are not universally available even to very poor people. In fact, in

some sections of the country, you cannot obtain publicly funded home care no matter how poor or how much in need you are.

Long-term care in America today is, at best, a patchwork of financing and delivery systems, frequently piggybacking on programs that were not designed to deliver chronic care; at worst it is not there at all when people need it.

HEALTH CARE REFORM MUST INCLUDE LONG-TERM CARE

Long-term care is part of the health care continuum. No one questions the right to treatment for an acute health problem -- setting a broken leg, putting a cast on the leg, and following through with the necessary medical care to fix the leg. Yet long-term care is often misperceived as an extra service, almost a luxury.

Long-term care is not coverage for "maids and butlers" and other household staff. On the contrary, long-term assistance for many is the vital link that keeps people living at home. In fact, without long-term support at home, many people turn to higher cost institutional care.

THE ADMINISTRATION'S LONG-TERM CARE PACKAGE

The Health Security Act takes bold strides to weave the threads of patchwork into a comprehensive tapestry that makes sense for people when they face the dilemma of needing long-term care. The

plan respects the dignity of people who need support -- it is not means tested and does not discriminate by age. It honors the choices of individuals and their families. It offers public services and incentives for people who can afford to protect themselves.

Importantly, the plan is prudent. It is carefully targeted at people with the highest level of need, people who are least likely to be able to make do only with family care. We recognize that our available resources will not permit us to do everything. It also directly responds to those who fear new entitlement programs and out of control budgets. The Federal budget is capped and the financial liability of Federal and State government limited. It will bring help and hope to millions of Americans without breaking the bank.

While a significant component of the Long-Term Care proposal is a major new expansion in home and community-based care services, the plan also liberalizes Medicaid nursing home requirements; provides tax credits to help defray the costs of personal assistance services for working people with disabilities; and establishes Federal regulations, consumer education and tax incentives for private long-term care insurance.

MAJOR EXPANSION OF HOME AND COMMUNITY CARE

The new home and community-based services program offers highly individualized services tailored to the unique needs of people with severe disabilities. Eligibility is based on a person's level of functional or cognitive impairment, with no limits by income or age or type of disability. Because people of all ages are equally eligible, this program goes a long way toward eliminating much of the historical intergenerational division of the long-term care pie.

Who will be eligible? The goal was to define -- across disability categories and age lines -- people with the most significant needs. The four mandatory eligibility categories include:

- people who need hands-on or stand-by assistance or cuing or supervision to perform three of five activities of daily living (eating, bathing, dressing, toileting, and transferring);
- people with severe cognitive or mental impairments;
- people with severe mental retardation; or
- children under six who have chronic disabilities and would otherwise require hospitalization or institutionalization -- after age six, children's eligibility is measured using the other three criteria.

Based on these criteria, it is estimated that approximately 3.1 million people will be eligible for this program; 71% or 2.2 million will be over age 65.

FEDERAL STATE PARTNERSHIP

The new long-term care program is a Federal/State partnership. The Federal contribution is generous...28 percentage points higher than current Federal Medicaid match rates, with the upper limit set at 95%. The high match rate is intended to encourage all States to participate. The President wants to create a universally available floor of home and community-based services for all people with significant disabilities no matter where they live.

The new home and community program is a free standing program, separate from Medicaid, so States have flexibility to build on the most creative practices of their communities and design service packages that meet consumers' needs.

BENEFITS AND SERVICES

Each State must guarantee that every person who receives services has been carefully assessed and has an individualized plan of care. In addition, each State must offer personal assistance services, support in daily living activities -- although every participant may not use this particular service. States must

also offer consumers the opportunity to direct their own services if they are able.

In addition, States are required to have something, somewhere in their service menu to address the needs of each category of eligible individuals. Beyond that, States are encouraged to include whatever services can best accomplish this -- case management, homemaker and chore services, home modifications, respite services, assistive technology, adult day services, habilitation, supported employment, home health...whatever people need to lead successful lives at home.

In addition, the program allows States to offer consumers cash or vouchers instead of services, permitting those who want to to take on the responsibility of controlling their own services to do so. In the words of many disability advocates: "we are not cases and we don't want anyone to manage us."

FINANCING AND BUDGET

The legislation establishes a national budget for the new home and community services program. Although there is no individual entitlement to services, the budget was estimated as if there were; it is based on the cost of providing an adequate level of service to the eligible population and then it is capped. It is not funded to replace family caregiving. In fact, it assumes that family caregivers will continue their support. There is also

a sliding fee scale for consumers to pay a portion of the cost of services under this program, ranging from 10% of costs for those at 150% of the poverty level to 25% of costs for those above 250% of poverty.

The funding for this program will be phased-in, incrementally, over seven years, starting in 1996. Over the first five years, the Federal government plans to spend 56 billion new dollars for this program. In addition, during the phase-in, the law permits the Secretary of the Department of Health and Human Services (HHS) to increase these specified amounts if there are reductions in Medicaid home and community care expenditures for persons with severe disability. The exact funding levels are specified in the legislation; the funding for the program is not discretionary, it is an entitlement to States so that consumers (and States) can count on it being there when they need it.

QUALITY

Experts in the quality field have noted that one of the best ways to ensure that services are of high quality is to involve program participants and their families in the quality assurance process. Therefore, the President's plan, in addition to requiring States to develop and obtain Federal approval of a thorough system for assuring the health and safety of consumers, also requires that consumers be involved in every step of the design of the program, its implementation and its evaluation. To ensure consumer input,

States must set up special consumer dominated boards who help design the program and monitor its implementation. The board is also responsible for assessing the consumer-responsiveness of the plan as part of the Federal approval of the State program.

MEDICAID NURSING HOME IMPROVEMENTS

The plan also takes a series of steps to strengthen the resource protections of the Medicaid program for nursing home residents. All States will be required to establish medically needy eligibility criteria -- to take medical expenditures into account in determining financial eligibility for nursing home care. Also, the amount of income that nursing home and other institutionalized residents may keep for their personal needs will be raised from a minimum of $30 to $50 per month, making a real difference in the dignity and quality of life of many residents. Finally, States will be allowed the option of increasing the level of assets that residents may retain from $2,000 up to $12,000.

NEW WORK INCENTIVE TAX CREDIT

Having a severe disability can be very expensive; it can cost so much to buy the personal assistance services, home and vehicle modifications, specialized equipment, and services, that many people with disabilities throw up their hands and ask: "Why work? It costs more to work than to stay home." What a terrible waste; an explicit vision in this plan is to help all members of the

community, including those with disabilities, to bring their talents and skills to the fore, to be productive, contributing members of their communities.

To accomplish this goal, the plan includes a 50% tax credit for persons with disabilities for out of pocket expenditures on personal assistance and related services, up to a maximum of $15,000 per year (or a maximum credit of $7,500).
This tax credit phases out for persons with income between $50,000 to $70,000. People with disabilities welcome this new incentive to work. This provision also works well with the employment provisions of the Americans with Disabilities Act.

IMPROVING LONG-TERM CARE INSURANCE; OFFERING INCENTIVES TO BUY

As we complete the solution to the long-term care puzzle, the final piece is a series of improvements to the quality and reliability of the long-term care insurance market and make it more affordable. Unlike acute health care, private insurance pays very little of the nation's long-term care bill. Many people would be able to protect themselves against catastrophic long-term care costs if affordable and high quality insurance products were available. If an employer-based group market can be created, the number of people who can purchase private insurance to protect themselves will increase even more.

The President's plan takes a variety of steps to improve the quality of insurance and make it more affordable. New Federal regulations will be developed, implemented, and enforced by the States. A new Federal matching grant program will be initiated to help States with enforcement of new standards. Grants will also be made available to States and national organizations to provide education for consumers about their risks of needing long-term care, as well as the pros and cons of various kinds of insurance products.

The new insurance standards will be developed by HHS, in consultation with a long-term care insurance advisory board of national experts, including representatives of the National Association of State Insurance Commissioners. The Federal standards will include: a required nonforfeiture benefit, an offer of inflation protection; limits on pre-existing condition exclusions; notifications of pending lapse and required reinstatement in the event of incapacitation; clear definitions of coverage and eligibility triggers; and rules regarding continuation and conversion of group policies. Federal standards governing the business practices of agents and insurers as well as penalties for noncompliance will also be included.

The plan also includes a set of tax provisions to treat long-term care insurance more like health insurance. Consumers will be allowed to exclude from taxable income the amounts they pay for

services or benefits (including cash payments) received under long-term care policies. The cost of policies may be included as an itemized medical expense deduction. To promote the group market; there are also tax incentives for employers to begin providing long-term care insurance.

PERFORMANCE REVIEW

Finally, the plan also includes a performance review -- an interim and final report card so we can check up on how the new public and private long-term care system is working, and identify areas for improvement. On a related note, there are provisions for a series of demonstrations studying various ways to integrate acute and long-term care.

SUMMARY

In summary, we face a crossroads. Left untouched, the problem of unmet long-term care needs will not go away and will only get worse as the population ages. It's a problem that is unalterably entwined with the problems in our health care delivery and financing systems. We must address it in that context and demonstrate our commitment to all Americans to meet a range of health and related needs.