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LONG-TERM CARE

Demography, Dollars, and Dissatisfaction Drive Reform

Statement of Jane L. Ross, Associate Director
Income Security Issues
Health, Education, and Human Services Division

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SUMMARY

Demography, dollars, and dissatisfaction provide a compelling rationale for long-term care reform. The system we have today has evolved over time as a patchwork of multiple programs that individuals find difficult to access. Despite billions of dollars in expenditures, the system often fails to meet the diverse needs of disabled individuals, and many believe that access to more appropriate services could be improved even at current funding levels.

Demographic trends make rising demand for long-term care inevitable across all ages, not just for the elderly. Approximately 11 million Americans of all ages are chronically disabled and depend on others for assistance in the basic tasks of daily living. Unprecedented growth in the elderly population is projected for the 21st century, and the population age 85 and over--those most in need of long-term care services--is expected to outpace the rate of growth for all aged. The population of younger disabled persons has been increasing and is expected to grow, although the exact size is difficult to predict.

Spending will escalate steeply whether or not reform occurs. In 1993, long-term care expenditures nationwide were estimated at approximately $108 billion, of which about $70 billion was government spending. Expenditures for long-term care are projected to more than double in the next 25 years. Today family and friends, mostly women, provide the overwhelming majority of care for disabled persons informally on a nonpaid basis. The future demand for paid services may grow at an even faster rate because informal caregiving will be difficult to sustain as more women join the work force and geographic dispersion of families continues.

Despite the expense associated with the long-term care system, considerable dissatisfaction exists, especially among persons needing care. At the core of their frustration lies a belief that services are often difficult to access. Individuals seeking services often have to contend with a fragmented service delivery system that forces them to negotiate for services from a variety of federal and state agencies. Moreover, existing programs tend to deliver "one size fits all" services. The bulk of federal funding--Medicare and Medicaid--pays for services that are often institutional and medical in nature and may not be appropriate for, nor preferred by, many individuals.

Current government spending of about $70 billion is expected to rise, yet the long-term care system is fragmented, does not meet current demand, and is not well matched to the diverse needs of individuals. GAO suggests two principles to consider in long-term care deliberations--greater tailoring of services to the needs of the individual and greater flexibility in funding. Reform initiatives that reflect these principles will bring about program changes that can better serve individuals even at existing funding levels.

Mr. Chairman and Members of the Committee:

I am pleased to be here to discuss problems with current long-term care programs and services and to suggest some principles that might guide reform efforts. As you know, there is a growing sense on many fronts that long-term care needs to be reformed. The long-term care system we have today has evolved over time as a patchwork of multiple programs that individuals find difficult to access. Despite billions of dollars in expenditures, the system often fails to meet the diverse needs of disabled individuals, and many believe that access to more appropriate services could be improved even at current funding levels.

In my remarks, which are based on work we are doing for your Committee, I will discuss the long-term care system as we know it today and focus on three areas that underpin the need for reform. First, demographic trends make rising demand for long-term care inevitable across all ages, not just for the elderly. Second, spending will escalate steeply whether or not reform occurs. Third, despite high costs, disabled persons are increasingly dissatisfied with available services and their ability to access those services.

DEMAND FOR LONG-TERM CARE INCREASING AMONG ALL AGE GROUPS

Today, approximately 11 million Americans of all ages are chronically disabled and depend on others for assistance in the basic tasks of daily living such as eating, bathing, and other activities that most of us take for granted. In this highly diverse population are people with both physical and cognitive disabilities, including the frail elderly, quadriplegics and paraplegics, persons with developmental disabilities, persons with severe mental illness, and children with chronic conditions. Of the 11 million Americans with disabilities, about 3 million are considered to be severely disabled.

The number of elderly and nonelderly persons needing long-term care is expected to increase substantially in the future. Unprecedented growth in the elderly population is projected for the 21st century, and the population age 85 and over--those most in need of long-term care services--is expected to outpace the rate of growth for all aged. Although most elderly persons are healthy, approximately 7.1 million of them need long-term care, and 1.5 million of these elderly, many of them age 85 or over, are currently in nursing homes.

Less is known about the present and future prevalence of disability among persons under age 65. According to the Pepper Commission, the number of nonelderly persons needing long-term care is about 4 million. However, depending on the definition of disability used, others have estimated higher numbers.

Experts believe that the population of younger disabled persons will continue to grow although the exact size is difficult

to predict. Many attribute the growing numbers of younger disabled persons to factors such as longer life spans for persons born with severely disabling genetic conditions and increased survival among groups such as low birth-weight babies and victims of violence and automobile accidents.

HIGH COSTS BURDEN PUBLIC AND PRIVATE PAYERS

Long-term care expenditures nationwide were recently estimated by the Administration to be approximately $108 billion in 1993, about 65 percent paid by federal and state governments and about 35 percent paid out-of-pocket by private individuals. In 1993, total federal and state Medicaid expenditures for long-term care equalled $42 billion--$26.1 billion for nursing homes, $9.2 billion for intermediate care facilities for persons with mental retardation, and $6.7 billion for home care. States are particularly concerned about their rising Medicaid expenditures, largely for nursing homes. About 70 percent of total public and private long-term care dollars are currently spent for institutional care.

All families worry about the catastrophic costs they could face if a family member should need long-term care. Families also worry about the human costs associated with caring for a disabled family member. Today family and friends, mostly women, provide the overwhelming majority of care for disabled persons informally on a nonpaid basis. A very small but growing number purchase long-term care insurance to prevent financial loss.

Assuming the continuation of current spending patterns for nursing home and home health care, expenditures for long-term care are projected to more than double in the next 25 years. The future demand for paid services may grow at an even faster rate because informal caregiving will be difficult to sustain as more women join the work force and geographic dispersion of families continues.

DISSATISFACTION WITH CURRENT SYSTEM, DESIRE FOR MORE OPTIONS

Despite the expense associated with the long-term care system, considerable dissatisfaction exists, especially among persons needing care. At the core of their frustration lies a belief that services are often difficult to access and not matched well with the diverse needs and preferences of disabled individuals.

Disabled Persons Face Maze of Long-Term Care Services

Individuals seeking services often have their difficulties compounded by a fragmented service delivery system that forces them to negotiate for services from a variety of agencies. For example, a person paralyzed in an automobile accident, newly released from the hospital, might need many services, including meals,

transportation, personal assistance, and homemaking. To negotiate services, an individual may need to contend with the myriad of federal and state long-term care programs that provide services, sometimes with different eligibility requirements. In fact, some states use case managers to help individuals find their way through the maze.

The current long-term care system has been patched together from multiple funding streams, both federal and state. Literally dozens of categorical funding streams provide long-term care to specific populations such as chronically ill children, persons with AIDS, persons with developmental disabilities, persons with mental illness, and the frail elderly.[1] At the federal level, Medicaid is the largest program providing support for long-term care services. Other federal programs include Medicare, the Social Services Block Grant, the Older Americans Act, and the Rehabilitation Act. Each federal program has its own unique rules governing eligibility and prescribing specific services under certain conditions. In addition, a number of state and local governments allocate significant funds to long-term care services.

At the state level, there is significant variation in the way these funding streams are managed. Typically, there is no single long-term care system at the state level. Rather, long-term care programs can be found in a variety of configurations. In one state we studied, 10 state and 3 federal agencies were responsible for administering or funding long-term care. State agencies are frequently organized along disability population lines. For example, states may have different departments dealing with the elderly, children and families, those with developmental disabilities, those with mental illness, and others.

Moreover, the long-term care infrastructure is different for elderly and younger age groups. For example, the Older Americans Act put in place a network for the elderly that includes more than 50 state units on aging and over 600 Area Agencies on Aging. This network has been charged with administering certain long-term care programs for persons over age 60. For persons with severe disabilities under age 60, other networks exist, primarily at the state level. The variation in the depth and comprehensiveness of these networks is a subject we are exploring in our current work for this Committee.[2]

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[1]For a list of major federal programs supporting long-term care services for the elderly and disabled, see attachment I.

[2]For more information about our issued reports and current work, see attachment II.

Services Available Often Do Not Match Individual's Needs

Many existing programs tend to deliver "one size fits all" services. The bulk of federal funding--Medicare and Medicaid--pays for services that are often institutional and medical in nature and may not be appropriate for, nor preferred by, many individuals.

Many federal programs were initially designed to meet acute health care, not long-term care, needs. As a result, disabled persons may only be eligible to receive institutional or medical services when other, less intensive and even less expensive nonmedical services may be more appropriate. Because Medicaid benefits for home and community-based services are limited, institutional care may be the only option available for many individuals, including the frail elderly and persons with severe mental retardation. Similarly, when respite care needed for the family of a person with Alzheimer's or a person with traumatic brain injury is not available, the risk of institutionalization for that person is greater. These sorts of adverse outcomes follow from mismatches between needs and programs.

Some states are trying to better match services to needs by focusing more on the individual. The importance of this focus on the individual is underscored by the variation within the diverse groups of disabled persons, as well as the fact that an individual's needs may vary over the course of a lifetime. For example, persons with cognitive disabilities--limits in their ability to reason--differ from those with physical disabilities in the types of supports they need. At the same time, not all persons with the same impairment need the same type and level of assistance. And a single individual, such as a person with AIDS, can have varying care needs over time as he or she experiences different episodes of acute and chronic illness.

Some states have made apparent progress in tailoring services to individual's needs. These states offer considerably more long-term care options, such as personal assistance services, through their Medicaid state plans or through Medicaid waivers, than do others. Such waivers permit states to provide home and community-based services to severely disabled persons who would otherwise have been institutionalized. In addition, several states' home and community-based programs, funded with state dollars, allow them a considerably greater amount of flexibility in whom they serve and what services are provided. Not all states, however, opt to provide home and community-based services through Medicaid waivers or state funds to all groups of the severely disabled.

PRINCIPLES FOR LONG-TERM CARE REFORM: GREATER FOCUS ON THE INDIVIDUAL AND MORE FLEXIBLE FUNDING STREAMS

The Administration has proposed changes to the long-term care system, and other proposals are before you as well. Current government spending of about $70 billion is expected to rise, yet the system is fragmented, does not meet current demand, and is not well matched to the diverse needs of disabled individuals. Based on our work, we would like to suggest two principles to consider in your deliberations--greater tailoring of services to the needs of the individual and greater flexibility in funding. We believe that reform initiatives that reflect these principles will bring about program changes that can better serve individuals even at existing funding levels.

Some states and other countries already have initiatives to provide services better tailored to individual need. These states and other countries are developing new, flexible delivery systems that they believe may be more appropriate for and preferred by disabled persons. For all disabled persons, whether elderly or not, their systems often begin with an assessment of the individual needs of the disabled person rather than pigeonholing disabled persons into existing programs. They then attempt to develop a customized set of services unique to the individual's needs and preferences. Because we have so much to learn about delivering services to the disabled, state and local governments should be encouraged to try new approaches, to evaluate results, and to share their successes.

More flexibility in funding could also help alleviate the tendency to provide medical services when nonmedical services are needed instead. Much of the support persons with severe disabilities need is not complex medical care, but assistance with everyday activities that could be provided in their own homes or communities. To control utilization, however, funding has often been restricted to medical services and institutional care. Many believe that more home and community-based services tailored to individual needs can provide better care even at current funding levels.

The millions of Americans with severe disabilities today comprise a dynamic and diverse group of all ages, with varying care needs and levels of informal assistance and support. The challenge of reform will be to better meet their diverse needs while assuring maximum value for long-term care dollars.

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Mr. Chairman, this concludes my statement. I will be glad to answer any questions you or the Members of the Committee may have.

ATTACHMENT I

MAJOR FEDERAL PROGRAMS SUPPORTING LONG-TERM CARE SERVICES FOR THE ELDERLY AND DISABLED

Program	Objectives	FY 1993 Federal Spending: Total and Long-Term Care Only (millions)[a]	Administration	Long-Term Care Services
Medicare/ Title XVIII of the Social Security Act	To pay for acute medical care for the aged and selected disabled	Total: $138,810 Long-term care: $15,800 (estimated)	Federal: HCFA/HHS[b] State: None	Home health visits, limited skilled nursing facility care
Medicaid/ Title XIX of the Social Security Act	To pay for medical assistance for certain low-income persons	Total: $77,367 Long-term care: $24,700 (estimated)	Federal: HCFA/HHS State: State Medicaid Agency	Nursing home care, home and community-based health and social services, facilities for the mentally retarded, chronic care hospitals
Social Services Block Grant/Title XX of the Social Security Act	To assist families and individuals in maintaining self-sufficiency and independence	Total: $2,805 Long-term care: (not available)	Federal: Office of Human Development Services/HHS State: State Social Services or Human Resources Agency; other state agencies may administer part of Title XX funds for certain groups; for example, State Agency on Aging	Services provided at the states' discretion, may include long-term care
Rehabilitation Act	To promote and support vocational rehabilitation and independent living services for the disabled	Total: $2,186 Long-term care: $54	Federal: Office of Special Education and Rehabilitative Services/ Department of Education State: State Vocational Rehabilitation Agencies	Rehabilitation services, attendant and personal care, centers for independent living
Older Americans Act	Foster the development of a comprehensive and coordinated service system to serve the elderly	Total: $1,377 Long-term care: $765	Federal: Administration on Aging/Office of Human Development/HHS State: State Agency on Aging	Nutrition services, home and community-based social services, protective services, and long-term care ombudsman

[a]Data represent total Fiscal Year 1993 obligations as reported in the Budget of the United States Government, Appendix, Fiscal Year 1995, except for estimates of Medicare and Medicaid long-term care spending. These figures are estimates for 1993 from the Assistant Secretary for Planning and Evaluation, HHS. Under the Medicaid program, states contributed an estimated $19.0 billion in support of long-term care in addition to the federal share of $24.7 billion.

[b]Health Care Financing Administration, Department of Health and Human Services.

ATTACHMENT II

RELATED PRODUCTS

REPORTS ON LONG-TERM CARE

Administration on Aging: Autonomy Has Increased but Harmonization of Mission and Resources Is Still Needed (June 11, 1991, GAO/T-PEMD-92-9).

Administration on Aging: More Federal Action Needed to Promote Service Coordination for the Elderly (Report, GAO/HRD-91-45, April 23, 1991).

Board and Care Homes: Elderly at Risk from Mishandled Medications (Testimony, Feb. 7, 1992, GAO/T-HRD-92-45).

Health Care Reform: Supplemental and Long-Term Care Insurance (Testimony, 11/9/93, GAO/T-HRD-94-58).

Long-Term Care: Private Sector Elder Care Could Yield Multiple Benefits (Report, 1/31/94, GAO/HEHS-94-60).

Long-Term Care: Projected Needs of the Aging Baby Boom Generation (Report, June 14, 1991, GAO/HRD-91-86).

Long-Term Care: Support for Elder Care Could Benefit the Government Workplace and the Elderly (Report, 3/4/94, GAO/HEHS-94-64).

Long-Term Care Case Management: State Experiences and Implications for Federal Policy (Report, 4/6/93, GAO/HRD-93-52).

Long-Term Care Insurance: Actions Needed to Reduce Risks to Consumers (Testimony, 6/23/92, GAO/T-HRD-92-44). Reports on same topic (3/27/92, GAO/HRD-92-66 and 12/26/91, GAO/HRD-92-14). Testimonies on same topic (5/20/92, GAO/T-HRD-92-31 and 4/11/91, GAO/T-HRD-91-14).

Long-Term Care Insurance: Better Controls Needed in Sales to People With Limited Financial Resources (Report, 3/27/92, GAO/HRD-92-66).

Long-Term Care Insurance: High Percentage of Policyholders Drop Policies (Report, 8/25/93, GAO/HRD-93-129).

Long-Term Care Insurance: Tax Preferences Reduce Costs More for Those in Higher Tax Brackets (Report, 6/22/93, GAO/GGD-93-110).

Long-Term Care Insurance Partnerships (Letter, 9/25/92, GAO/HRD-92-44R).

Long-Term Care Reform: Rethinking Service Delivery, Accountability, and Cost Control (Discussion Paper, 7/13-14/93, GAO/HRD-93-1-SP).

Massachusetts Long-Term Care (Letter, 5/17/93, GAO/HRD-93-22R).

Services for the Elderly: Longstanding Transportation Problems Need More Federal Attention (Report, 8/29/91, GAO/HRD-91-117).

VA Health Care: Potential for Offsetting Long-Term Care Costs Through Estate Recovery (Report, 7/27/93, GAO/HRD-93-68).

CURRENT LONG-TERM CARE WORK

Diverse Long-Term Care Populations and Needs: Implications for Reform

Geriatric Assessment

International Long-Term Care Reform

Long-Term Care Programs and Innovations in Services: Implications for Reform

Older Americans Act: Funding Formula Could Better Reflect State Needs

Public and Private Financing for Long-Term Care: Current Responsibilities and Implications for Reform

Service Quality in Home and Community-Based Services

State Medicaid Home and Community-Based Service Programs: Accomplishments and Implications for Reform

State Survey of Home and Community-Based Services' Lessons Learned

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