

Health Policy Studies Division  
National Governors' Association  
Center for Best Practices

# Challenges and Opportunities for States in Providing Long-Term Care for the Elderly

Since their initial meeting in 1908 to discuss interstate water problems, the Governors have worked through the National Governors' Association to deal collectively with issues of public policy and governance. The association's ongoing mission is to support the work of the Governors by providing a bipartisan forum to help shape and implement national policy and to solve state problems.

The members of the National Governors' Association (NGA) are the Governors of the fifty states, the territories of American Samoa, Guam, and the Virgin Islands, and the commonwealths of the Northern Mariana Islands and Puerto Rico. The association has a nine-member Executive Committee and three standing committees—on Economic Development and Commerce, Human Resources, and Natural Resources. Through NGA's committees, the Governors examine and develop policy and address key state and national issues. Special task forces often are created to focus gubernatorial attention on federal legislation or on state-level issues.

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The Center for Best Practices is a vehicle for sharing knowledge about innovative state activities, exploring the impact of federal initiatives on state government, and providing technical assistance to states. The center works in a number of policy fields, including agriculture and rural development, economic development, education, energy and environment, health, social services, technology, trade, transportation, and workforce development.

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# Executive Summary

As the elderly population grows, states face an expanding range of long-term care challenges and opportunities. Individuals and families, who already play a significant role in financing and delivering long-term care services, are under pressure to provide more assistance to their aging spouses and parents. There is a growing demand to increase the supply of long-term care providers and to develop new alternatives, services, and settings in long-term care. Moreover, there is an increasing need for government to integrate and streamline fragmented programs to be more client-friendly and cost-effective for government and to assure quality in the delivery of long-term care services.

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While the federal government will play an important role in helping to finance services, states will design the innovative strategies that will address the multiple challenges of providing long-term care services for the elderly. The design of a successful strategy can benefit from the assistance of the Governor's office. State programs that finance, deliver, and regulate long-term elderly care services often are located in three or more agencies, making it difficult to delegate to one department overall responsibility for creating a strategy. Some actions will have to take place in the private sector. Hence, state agencies, consumers, and providers will look to the Governor's office for some guidance on addressing these complex issues.

States will face these five critical challenges in developing a strategy to address the growing long-term care needs of the elderly:

- building on the importance of family and community;
- expanding home- and community-based services;
- streamlining services;
- using public funds in strategic ways; and
- addressing concerns about quality.

## **Building on the Importance of Family and Community**

Long-term care is often informal and nonmedical in nature and is usually provided by family and community volunteers. Yet, time for volunteer work is shrinking because today's families often have two wage earners with long commute times. Encouragement by the state and assistance for individuals and community members providing care are important components in addressing the need for more service delivery.

Individuals can also play a greater role in preparing for their eventual long-term care needs. Many people make financial plans for retirement, but most do not plan ahead for their long-term health care needs. This oversight can severely compromise the financial security of their retirement. Too many individuals continue to rely on Medicaid for long-term care and end up impoverishing themselves to become eligible. Purchasing long-term care insurance is an important option.

Some states are disseminating information about the need to provide caregiving to elderly relatives and friends too, and are considering ways to improve the purchase of long-term care insurance.

## **Expanding Home- and Community-Based Services**

Most people prefer to be close to family and friends in familiar surroundings. Home- and community-based care provides favorable alternatives to nursing homes because people receive services more tailored to their needs. Unfortunately, home- and community-based alternatives are limited. The challenge is to meet the demand without substituting informal care with costly provider-delivered home- and community-based services.

States are responding with new financing plans that encourage home- and community-based long-term care settings. Some states use Medicaid waivers to divert clients from institutional settings; others provide subsidies to low-income individuals. New assessment and case management models are being developed to better facilitate the match between client need and the growing number of optional settings.

## **Streamlining Services**

People seeking long-term care services find the current delivery system bewildering. Fragmentation exists among public-sector financing programs and acute and long-term care delivery systems, which results in administrative inefficiency and reduced program effectiveness. People often can't find the right array of services in a timely manner, which puts

their health in jeopardy. New programs must reduce inefficiency, contain costs, improve health care, and increase consumer satisfaction.

States are using several strategies to address the problem of fragmented services, such as creating interagency committees, consolidating agencies, and delegating administrative functions to local organizations. States also are implementing demonstration programs that integrate the delivery of acute and long-term care services by enrolling eligible Medicaid and Medicare clients in a managed-care setting.

### **Using Public Funds in Strategic Ways**

Absent a significant infusion of funds—whether federal or private-sector—and with a lessening of regulations that determine who can receive which type of service, states must use current programs more strategically. Public financing options beyond Medicaid and Medicare need to be identified and further developed.

States are successfully coordinating and integrating their long-term care plans by supplementing categorical funds with flexible federal and state funds so that the entire array of services are delivered.

### **Addressing Concerns About Quality**

While states need more long-term care services, simply increasing the supply is not sufficient. Consumers demand that services be of high quality and improve patient outcome and satisfaction. This is a significant challenge and states are responding by implementing new inspection mechanisms to ensure that an appropriate level of quality is being delivered. New oversight models are being created that are client-focused and encourage continuous improvement in quality.

This report discusses the many facets of long-term care for the elderly, describes how the pieces are interrelated, and provides examples of state best practices. During the past decade, states invested a significant amount of time in testing new strategies to address these challenges. Collectively, these options will expand the availability of high-quality services while controlling the growth of public programs. To keep current in this dynamic field, the National Governors' Association Center for Best Practices has created a Web page devoted to long-term care issues. Many of the best practices and other types of information mentioned in this report are available at <<http://www.nga.org>>.



# Long-Term Care for the Elderly: A Growing Priority for States

While much is being said about the future consequences of an aging population on society, states are facing significant long-term health care challenges *today*. States have *primary* responsibility for administering programs to assist the elderly and chronically ill and for regulating the providers who deliver the services.<sup>1</sup> States also are major financiers of long-term care. In 1995 elderly beneficiaries represented only 11 percent of all Medicaid recipients, yet they accounted for more than 26 percent of all Medicaid expenditures (three-fourths of which went toward long-term care).

Nonetheless, the nation will devote ever more attention to long-term care issues because of the projected increase in the elderly population. The elderly growth rate is predicted to remain steady until 2010; however, by 2030 one in five Americans will be elderly. More significantly, the oldest population (85 years

and over) is predicted to double between 1990 and 2010, and more than double again by 2040.<sup>2</sup> This population growth is significant because of the increased prevalence of disability in the oldest population.<sup>3</sup> Because Medicaid is a major payer of long-term care services, states will face a much greater financial burden than they do today.

The phrase “long-term care” is broadly defined to include a wide array of services that are both medical (nursing or physician care) and social (respite care or chore services). People with chronic health conditions who cannot be cured by medicine need long-term care. The chronically ill may lack the ability to perform basic life functions or activities expected for their age (e.g., bathing, shopping, cleaning house, dressing, and eating).<sup>4</sup>

Many people have physical and mental disabilities or chronic health conditions that

## What is Long-Term Care?

“Long-term care includes a range of services for people who have functional limitations or chronic health conditions. Their needs include sub-acute, rehabilitative, medical, skilled nursing, and supportive social services. Long-term care services are provided in a variety of settings, including nursing or assisted living facilities, respite care, adult day care, and home- and community-based setting.” (American Health Care Association)

## What Types of Services Make Up the Long-Term Care Continuum?

### Services:

- ◆ Chore services
- ◆ Home visitors communities
- ◆ Senior centers
- ◆ Adult day care
- ◆ Home health care facilities
- ◆ Rehabilitation programs
- ◆ Respite care

### Settings:

- ◆ Retirement housing communities
- ◆ Continuing care retirement/continuing care centers
- ◆ Assisted living centers
- ◆ Nursing facilities/skilled nursing
- ◆ Subacute care
- ◆ Acute care

Source: McKnight's Long-Term Care NEWS

require some type of long-term care. However, this report focuses on long-term care for the elderly (ages 65 and over).

#### Mounting Pressures for Long-Term Care

For several decades, long-term care for the elderly has been a concern for states. States have regulated nursing home providers for some time and have been a major financier of long-term care since Medicaid's inception. Nevertheless, three powerful forces have coalesced to increase the pressure on state policymakers to look at the future of long-term care:

- an increasing need for long-term care services,
- a growing consumer demand for less restrictive settings, and
- a growing shortfall in financing.

#### *Increasing Need for Long-Term Care Services*

The supply of publicly funded long-term care services has never been equal to the demand. Waiting lists for home- and community-based services are common nationwide. With the healthy economy and resultant tight labor market, nursing homes

and home- and community-based providers are having trouble recruiting and retaining qualified staff. Exacerbating these shortfalls is the predicted high growth rate for people age 65 and over.

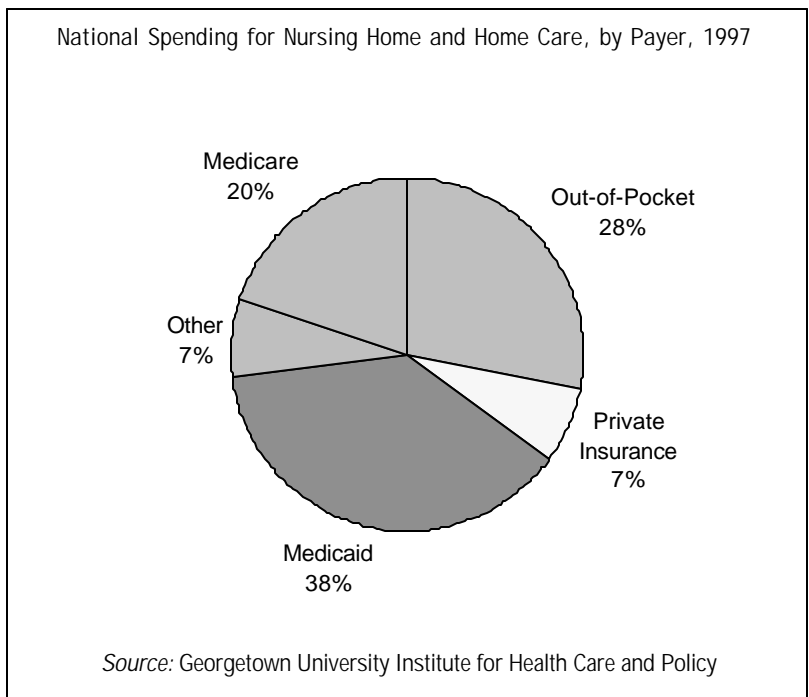
#### *Growing Demand for Less Restrictive Settings*

Nursing homes are still the most widely used setting for long-term care, and a majority of Medicaid funding for elderly long-term care services is for this kind of care. However, seniors prefer services that promote greater independence and self-sufficiency so that they can live in their homes. Even when more intensive care is needed than can be provided at home, other alternatives to nursing homes, such as assisted living environments, are sought. Responding to this preference, the assisted living industry has been growing at a tremendous rate—between 15 percent and 20 percent in the last several years<sup>5</sup>—yet, this is still not sufficient to meet demand.

#### *Growing Shortfall in Financing*

Someone must pay for the increase in long-term care services. Medicare covers only short-term home care services for the elderly in limited situations. The largest payers of

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### Medicare's Limited Coverage of Long-Term Care Services

Medicare coverage for long-term care is limited to home health agency services and short-term, post-hospital, skilled nursing facility care.

#### *Home Health Services:*

- ◆ To qualify for these services, Medicare enrollees must need intermittent or part-time, home-delivered, skilled nursing care or therapy services.
- ◆ Home health aide services to help with personal care and housekeeping may also be provided as long as the beneficiary also requires skilled services.
- ◆ These services are available to all Medicare beneficiaries solely on the basis of medical need (i.e., without a means test).
- ◆ There is no prior hospitalization requirement or limit on the number of visits a person may receive.

#### *Skilled Nursing Facilities:*

- ◆ To qualify for these services, Medicare enrollees must need short-term, skilled nursing home care following a period of hospitalization.
- ◆ Beneficiaries must have had a hospital stay of at least three days in the past thirty-day period.
- ◆ Coverage is limited to 100 days for each spell of illness.

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long-term care are Medicaid and the patients, who pay with their own funds. In comparison, private health insurance coverage, a dominant player in the acute health-care sector, is a relatively small player in financing long-term care.

States are wary of unilaterally expanding Medicaid to address the growing long-term care demand, remembering the devastating effects on their budgets from runaway Medicaid cost increases during the late 1980s and early 1990s. While cost increases have lowered in the past few years the potential for cost increases is still present. The total number of Medicaid recipients increased by 40 percent from 1990 to 1996, and recent studies are indicating that the medical care inflation rate is increasing.<sup>6</sup> Thus, new sources of financing must be developed.

#### Five Critical Challenges for States

During the next few years, many Governors increasingly will hear demands from constituents, advocates, agency officials, and legislators to address the complex financing and

service delivery issues of long-term care.

However, the models for responding to these demands will include multiple state agencies and the actions of the private sector. No single policymaker can unilaterally design and implement an integrated public-private response so consumers, agency officials, legislators, and the private sector will look to Governors' offices for guidance in addressing the long-term care needs of the elderly. Such guidance must consider five critical challenges:

- building on the importance of family and community;
- expanding the supply of home- and community-based services;
- streamlining and integrating services;
- using public funds in strategic ways; and
- addressing concerns about quality.

Fortunately, there are many models that states have developed to address these critical challenges.

# Building on the Importance of Family and Community

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The first critical challenge facing states is to engage the family and community in helping to finance and deliver long-term care. The family has long played a major role in caring for the elderly. In the past, it was often expected that the parents would move in with their children when they were no longer able to financially or physically care for themselves.

Today, the elderly, whose financial circumstances have improved, want to continue to live their lives as independently as possible. They still turn to their family and friends for caregiving assistance, but in their own homes. Since this type of care is informal, nonmedical, and usually provided by family, friends, and volunteers, the public program costs are minimal. The role of family and community in providing informal care will continue to be a critical component of addressing the long-term care needs of the elderly.

While informal caregiving is important, there is another role for the family. As people age, they are at risk for long-term chronic illnesses and the expenses they entail. Unfortunately, few people make the necessary financial provisions. Thus, a second role families can play is to make early plans for financing such care in the event it is needed. Encouraging people to purchase long-term care insurance is the most popular option for creating a new stream of private-sector funds.

## Expanding Informal Caregiving Programs

The nation relies extensively on family, community groups, religious organizations, and other informal caregivers to finance and deliver less intensive, nonmedical long-term care. Approximately one in four Americans provides some kind of care to an older person

with disabilities. Almost 75 percent of the elderly with disabilities receive home care through relatives, friends, and neighbors.<sup>7</sup> Informal caregiving is still the backbone of long-term care.

People delivering informal care are not licensed or certified providers. Their services tend to be social in nature. These may include shopping, light housekeeping, chore services, transportation, and assistance with grooming. These services play a significant role in keeping people happier and healthier longer. This kind of care helps the elderly avoid depression, poor nutrition, or falls, all of which can result in a rapid decline in health and an increased need for more intensive and expensive medical care. A number of state programs, often financed by Medicaid, provide formal caregiving to disabled elderly and reimbursement to family caregivers. However, public assistance in caregiving is limited.<sup>8</sup> Efforts to promote informal, voluntary caregiving by friends, relatives, and others in the community have increased.

Programs that recruit volunteers other than friends and families are especially desirable as family networks become smaller and potential family caregivers are unavailable because of work demands outside the home. Many volunteer programs are developed at the community level. At the national level, the Robert Wood Johnson Foundation created the Interfaith Volunteer Caregivers Program (IVCP) in the 1980s. The program involves churches, synagogues, and other community institutions in working with agency and health care providers to develop programs that recruit, train, and organize volunteer caregivers. There are currently about 1,000

IVCP sites nationwide. IVCP has been so successful that the foundation plans to establish 2,000 additional coalitions nationwide.

#### Promoting the Purchase of Long-Term Care Insurance

It is often assumed that Medicare pays for long-term care, but Medicaid and individuals are responsible for the bulk of long-term care expenses. Because of this misconception and a lack of planning for future long-term care needs, many people end up relying on Medicaid after they exhaust most of their life savings and assets to become eligible for the program. While Medicaid is needed to help meet the long-term care requirements of low-income people, many middle-income individuals can make financial plans for their own long-term care. Planning for long-term care needs allows those with substantial means to avoid impoverishment and, in turn, ease reliance on Medicaid.

By 1997 almost 5 million long-term care insurance policies had been sold in the United States.<sup>9</sup> More than 600,000 policies were purchased in 1996 alone. Long-term care insurance benefits vary widely, but most are similar to the long-term care benefits under the Medicaid program. The largest sellers offer policies that cover nursing homes, home health care, adult day care, respite care, and alternative care services. Other services such as assisted living facilities, homemaker/chore services, and caregiver training are also covered.

Premiums vary widely, depending on the entry age of the policyholder and the benefit package selected.<sup>10</sup> For example, in 1997 the average annual premium for a standard policy with inflation protection ranged from \$247 for a 40-year-old person to \$5,592 for a 79-year-old person.

#### *Individual Insurance*

Almost 80 percent of long-term care policies were sold in the individual market. The policy is purchased directly from the insur-

ance company and not through the place of employment. The individual market has numerous consumer options, but it does have some disadvantages. For example, there are extra administrative costs resulting from marketing, enrollment, and agent commissions.

Another disadvantage results from adverse risk selection. People who purchase long-term care insurance know they are more likely to use the covered services. Therefore, insurers have medical underwriting rules that either screen out those with preexisting conditions or charge higher premiums to ensure future claims are adequately covered. Some individual policies are so expensive that people are discouraged from purchasing them or, because of medical underwriting, the policies are simply unavailable at any price. If long-term care insurance is to become a significant source of financing, another product must be developed to complement individual policies.

#### *Employer-Sponsored Insurance*

A promising strategy for enhancing the purchase of long-term care insurance borrows from the acute care health insurance model: employer-sponsored health insurance for workers. Individual policies are sold in the acute care insurance market, but the dominant form of private health insurance is employer-sponsored group coverage. Offering long-term care insurance to employees reduces the premiums by lowering administrative costs, widens the pool to include lower-risk people, and encourages employees to purchase insurance at a younger age (the average age of a purchaser for group coverage is 47, compared to 67 for purchasers of individual coverage). Employer-sponsored long-term care insurance also can result in a more cost-effective level of benefits because large groups have better leverage with insurers.

Since 1990, a growing number of private-sector employers have offered their employees long-term care benefits. However, less than a third of these employers paid the

entire premium or even part of it.<sup>11</sup> This small contribution by employers is often blamed for the low participation rates of the employees. However, even without an employer subsidy, the lower premium and ease of enrollment provided by group sponsorship presents significant advantages.

Increasingly, public-sector employers are exploring the offering of long-term health care insurance to their employees. The California Public Employee Retirement System (CalPERS) has had considerable success in promoting the purchase of long-term health care insurance by its public employees. More than 110,000 people are enrolled, making the program the most successful self-funded, not-for-profit program in the nation. President Bill Clinton and the U.S. Congress are considering making private long-term care insurance available to federal employees, retirees, and eligible family members at group rates.

#### *Growth Potential for Long-Term Care Insurance*

While buying long-term care insurance is the most promising way to improve long-term

care financing, the insurance has limitations. First, the premiums can be expensive. Despite the recent trend of decreasing premiums, many lower-income individuals still can't afford the insurance, especially those who delay purchasing until they are older and in need of long-term care. Second, many discontinue paying the premiums and the policies do not remain in force.<sup>12</sup> Third, the public is not purchasing the policies in sufficient numbers to make an impact.

State policymakers see a fourth limitation: that increased purchase of long-term care insurance will reduce their current Medicaid expenditures. People with high incomes purchase more private long-term care insurance. This population is less likely to rely on Medicaid for long-term care even without private insurance.<sup>13</sup> Thus, states with the highest levels of purchased long-term care insurance policies have not seen a decrease in Medicaid costs.

Two things must happen before long-term care insurance policies become a significant source in financing. First, a broad-based education campaign is necessary. This would raise awareness about how little Medicare

#### CalPERS Long-Term Care Plans

Under CalPERS, all California public employees, retirees, their spouses, parents, and parents-in-law are eligible for the CalPERS Long-Term Care Program. This includes members of CalPERS, teachers, school employees, University of California and California State University employees, and retirees, county and city employees and retirees, judges, legislators, and all other California public employees and retirees.

- ◆ Three basic plans are offered: comprehensive plan, nursing home/assisted living facility only, and partnership plan. With the partnership plan, policyholders are responsible for initially funding their care and, if there is a subsequent need for Medicaid coverage once the insurance benefits are exhausted, they can become eligible for Medicaid without having to deplete all of their savings and assets.
- ◆ Plans include care advisory services that help in locating appropriate long-term care services and monitor services by various long-term care providers.
- ◆ Plan costs about 30 percent less than comparable commercial plans.

covers and how lack of coverage can threaten retirement plans. The campaign should focus on people in their late 40s and early 50s, when insurance premiums are still affordable. Second, employer-sponsored plans must

grow substantially so that middle-income families are protected. Government-sponsored plans for civil servants may serve as a catalyst for private-sector employers to offer plans to their employees.

#### President Clinton's Long-Term Care Proposal

The Clinton Administration's proposal would make private long-term care insurance available to federal employees, retirees, and eligible family members at negotiated group rates. Coverage would be paid entirely by those who choose it. The cost of administering this benefit is estimated at about \$15 million over five years.

Long-term care coverage would be handled separately from the Federal Employees Health Benefits Program, which covers 8.7 million federal workers, retirees, and members of their families. However, a similar number of persons would be eligible to obtain long-term care coverage through their or their sponsor's federal job, should they choose to do so. The Office of Personnel Management projects that approximately 300,000 people would take advantage of this opportunity to obtain group long-term care coverage.

The initiative has two goals: to educate federal employees and retirees about long-term care options; and to offer high-quality, long-term health care at group rates estimated to be 15 percent to 20 percent below individual policy costs.

People eligible to purchase the insurance would include:

- ◆ federal employees and retirees,
- ◆ spouses of federal employees and retirees,
- ◆ former spouses who are entitled to annuities under a federal retirement system, and
- ◆ parents and parents-in-law of federal employees and retirees.

# Expanding Home- and Community-Based Services

Expanding the supply of home- and community-based care facilities is a critical challenge for states. Consumers prefer long-term care services in home and community settings, yet Medicaid historically has devoted most of its long-term care payments to nursing homes. In 1996 only 20 percent of Medicaid's long-term care expenditures went toward home- and community-based care, while 80 percent went toward nursing home care.

Central to a state's concerns about expanding home and community services is the fear of escalating costs in Medicaid and other long-term care programs. While home- and community-based services cost less than institutional care—on a per-recipient basis—policymakers worry that, unless carefully controlled, total long-term care costs will soar. This cost explosion would result from the pent-up demand for institutional and community-based long-term care. Home services would not substitute for current nursing home care. And, so much informal care is already being provided that there are fears that should reimbursement be made

available, informal caregivers would cease to provide care.

Despite concerns about cost increases, some innovative states expanded the definition of long-term care to include nonmedical services and the delivery of services in new residential settings such as assisted living. **Oregon**, in a substantial fifteen-year effort, has succeeded in expanding their home- and community-based programs while controlling costs.

Expanding the number of services and settings provides the opportunity to better match a client's needs and preferences with service options that allow the client to live in the most independent setting possible. However, with more options available, there is a greater need to develop methods and tools that facilitate linking a client's needs with services. States have developed assessment tools, resource centers, and training for providers to deliver the necessary services. States also are using case managers to coordinate care among different providers.

## Home- and Community-Based Services: Medical and Social

There are many long-term care services that can be provided outside of a nursing home setting. These services can be delivered within a home, day, or health care center, or in a residential setting that is less restrictive than an institution. Home- and community-based services can be medical or social in nature.

- ◆ Medical services include skilled nursing, adult day health care, medical equipment and supplies, therapy services, extended prescription drug benefits, personal emergency response systems, and extended physician services.
- ◆ Social services include home-delivered meals, home and vehicle modifications, homemaker services, transportation, adult day care, caregiver training, respite care, and case management and other similar services, which often include services at alternative care facilities, such as assisted living facilities.

## Current Public-Sector Sources of Home- and Community-Based Services

Medicaid is the primary financer of home- and community-based services. Services include mandatory Medicaid state plan benefits, optional plan benefits, and home- and community-based waivers.<sup>14</sup>

### *Mandatory and Optional Home- and Community-Based Services Under Medicaid*

A mandatory service for all Medicaid recipients is home health care, including nursing services, home health aide services, and medical equipment and supplies for home use. Optional Medicaid services include personal care, rehabilitation, hospice care, physical and occupational therapy, targeted case management, and services for individuals with speech, hearing, and language disorders.

### *Home- and Community-Based Services Under Medicaid Waivers*

Medicaid's home- and community-based services waiver program gives states flexibility in delivering an expanded scope of services. The primary goal of waivers is to keep people in the least restrictive setting for as long as possible.<sup>15</sup> Currently, every state except Arizona has a Medicaid waiver program—many have more than one—that serves the elderly or a combination of the elderly and disabled. Additional services covered under Medicaid waiver programs include long-term nursing care, assisted living, caregiver respite, case management, homemaker services, home health aid services, personal care services, adult day health care, rehabilitation, and respite care. Waivers may cover a variety of other services, such as meal services, home modifications, and adult day care.

The waivers also give states flexibility to target who receives the services and where the services are provided. Medicaid rules require all services be provided statewide, but under a waiver states can target people within specific geographic locations, such as

counties, and services can be restricted to specific populations, such as the frail elderly.

There are some disadvantages with the Medicaid home- and community-based service waivers. First, they are administratively cumbersome. To cover additional populations or services, the usual Medicaid restrictions must be waived, meaning all home- and community-based waivers are subject to Health Care Financing Administration (HCFA) approval. Another disadvantage of the waivers is that they tend to be limited in scope (i.e., serve a relatively small number of people).

### *Supportive Housing Options*

There are older people who can no longer live independently in their own home, yet do not have conditions requiring the medical services delivered in a nursing home. Typically, home- and community-based services are delivered in the patient's home; however, they also can be delivered in alternative settings that are not institutional facilities like nursing homes. Supportive setting options offer moderate assistance in daily living and allow for more independence than a nursing home. Clients can choose from assisted living facilities, congregate housing, and board-and-care homes. Since Medicaid does not pay for the room and board (except in nursing facilities), the majority of alternative housing residents are private paying clients. However, some residents receive services through Medicaid waivers and Social Security income.<sup>16</sup>

**Florida** has been especially aggressive in expanding the supply of supportive housing, creating a supply nearly equivalent to that of nursing home beds in the state.<sup>17</sup> As of June 1999, Florida had licensed approximately 2,200 assisted living facilities.<sup>18</sup> While most assisted living facilities are private pay, the state does offer a subsidy program to assist low-income individuals. An assisted living waiver program helps those eligible to pay for services within the assisted living facilities. The state also developed a specialty license for extended congregate care facilities, which

provides additional nursing services and assistance. Florida also licensed more than 400 adult family care homes that each provide room, board, and personal care to a small number of individuals.

Some states encourage the development of supportive housing by offering incentives to nursing homes to convert wings of the facility to lower levels of care and to developers to build new residences. For example, the **Nebraska** Department of Health and Human Services administers a state grant program called the Health Care Trust Fund Grant that helps nursing homes convert some of their beds into assisted living facilities.\*

#### Identifying Need and Linking to Services: Assessment and Case Management

With the increase in alternative settings for home- and community-based services, there is a concomitant growth in the need for effective assessment and management tools to facilitate the match between a person's needs and available services. States have created individual assistance screening and assessment tools to identify specific consumer needs and case management models to coordinate the services.

Assessment and case management goals determine individual long-term care needs and find an appropriate array of services to satisfy those needs. Assessment evaluates an individual's level of functioning. Activities of daily living (ADLs) and measures of medical, physical, and mental needs are assessed to determine the appropriate services.

Case management, which relies on the assessment to determine service needs and program eligibility, provides the care planning, authorizes the delivery and payment of services, coordinates the care, and monitors and reassesses an individual's care plan. Case management is also used to "fill the gaps." Individuals often have some source of long-term care, such as family caregivers, but still need supplemental services. Since long-term care resources are

limited, efficient assessment and case management help determine which individuals have the greatest need for specific services.

Those who conduct the assessment and provide case management can be government employees or care providers, such as registered nurses. Area agencies on aging, state government district offices, or local social service departments are predominantly used by states.<sup>20</sup> Some states have designated local-level agencies or organizations throughout major areas of the state as single points of entry. The single point-of-entry system allows consumers to receive assessment, case management, information, and referral for long-term care services in one location, reducing fragmentation.

Two states that have been active in using assessment and case management tools are **Florida** and **Indiana**. Florida's Comprehensive Assessment and Review (CARES) for long-term care services program helps guide those eligible for nursing home care away from unnecessary or premature admission to a nursing home and toward a more suitable supportive housing option. In Indiana, assessment and case management are required in conjunction with the provision of any service received through the Indiana Home Services Program (IN-Home). Sixteen area agencies on aging in Indiana serve as points of entry. These agencies have access to all sources that fund Indiana's IN-Home program. Case managers determine eligibility for waiver services, other program services, and nursing facility placement.

Once the assessment process begins, Indiana uses a data tracking system that allows for efficient and coordinated case management. Case management includes locating, managing, coordinating, and monitoring all proposed waiver services, other state plan services, and needed publicly-funded services, regardless of funding source. The system tracks all referrals, applications, care plans, and service authorizations; automates assessments and care plans; and reports case management.

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\*See the Center *Issue Brief*, "Creating Assisted Living Facilities: Expanding Options for Long-Term Care."

## Supportive Housing Alternatives

A number of states have seen tremendous expansion in the development of supportive housing during the past decade. There are a variety of residential options to choose from; each offers a varying degree of assistance. Listed below are a few of the most common housing arrangements and their attributes.

### Assisted Living Facilities

- ◆ These facilities aim to enhance the capabilities of older persons so that they can live as autonomously as possible in a home-like setting.
- ◆ Group or congregate living arrangements provide room and board as well as social and recreational opportunities—residents usually live either in private rooms with baths or small apartments.
- ◆ Assistance is provided to residents who need help with nonmedical aspects of daily activities including around-the-clock assistance.
- ◆ This alternative is typically private pay.

### Congregate Housing

- ◆ Residents live relatively independently.
- ◆ Facilities typically consist of residential buildings with separate apartments and some common services.
- ◆ Services include moderate support such as meals, housekeeping, and transportation, but not protective oversight and around-the-clock assistance.
- ◆ This alternative is typically private pay.

### Board-and-Care Homes (also called residential care homes or personal care homes)

- ◆ Residents live in a home-like setting.
- ◆ Rooms are often provided on a semi-private basis and there are shared common areas.
- ◆ Services include meals, personal care, protective oversight, and some assistance with other activities of daily living.
- ◆ About one-half of these homes are publicly supported.

### Continuing Care Retirement Communities

- ◆ Facilities usually offer a variety of independent living options for residents coupled with full medical and nursing services.
- ◆ A variety of residential units are offered, depending on services needed.
- ◆ Typical services and amenities include nursing services, meals, transportation, housekeeping, emergency help, personal care, and recreational activities.
- ◆ This alternative is expensive and private pay.

## Scales Used to Assess an Individual's Level of Functioning

### Activities of Daily Living (ADLs)

- ◆ Usually include bathing, dressing, eating, getting in and out of bed or chairs, and using the toilet.
- ◆ Sometimes include getting around inside the house, walking, or continence.

### Instrumental Activities of Daily Living (IADLs)

- ◆ Usually include several or all of the following: meal preparation, shopping, using the telephone, managing money, managing medications, light and heavy housework, inside mobility, and distance travel.

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*Source:* Harriet Komisar, *People with Long-Term Care Needs* (Georgetown University Institute for Health Care Research and Policy).

# Streamlining Services

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A third critical challenge for states is to make fragmented programs and service providers in the long-term and acute care system more accessible and integrated. The responsibility for administering and financing state and federal long-term care programs is often dispersed among several state agencies (e.g., social services, public health, Medicaid, aging, and insurance) and often involves local agencies. Each program operates under its own rules. This lack of cohesion causes higher administrative costs and consumer difficulties with locating the appropriate services.

Fragmentation also is evident in the delivery and funding of acute and long-term care services. This results in seniors having difficulties receiving the necessary continuum of care as they move from primary care to specialty care for acute episodes to management of chronic conditions.<sup>21</sup> For the elderly eligible for both Medicare and Medicaid, services often must be accessed from multiple systems with different rules, locations, and case managers.

Strategies to alleviate this fragmentation include coordinating programs through interagency committees, consolidating agencies into smaller numbers of agencies, or delegating responsibility for coordination to regional or local agencies.<sup>22</sup> Another option is integrating acute and long-term care services under managed care to better coordinate services. This is particularly useful for dual-eligible beneficiaries, such as low-income elderly who receive an array of acute and long-term care services from Medicare and Medicaid.

## Coordinating and Integrating State Long-Term Care Programs

Long-term care for the elderly is so broad and complex that consolidation of the numerous programs into a single umbrella agency can be difficult to accomplish and manage. Yet some states administer virtually all long-term care programs under one agency. **New Jersey** created the department of health and senior services in 1996. New Jersey's Executive Reorganization Act provided for the transfer, consolidation, and reorganization of all senior services (except for Medicaid and insurance) within the department of health and for the department's redesignation as the department of health and senior services.

Four departments of the executive branch that administered health and well-being programs for New Jersey's elderly were transferred to the new agency, which consolidated 20 state and federal programs. Programs under the divisions of consumer support, long-term care systems development and quality, and senior affairs are now administered under the department of health and senior services. With this department in place, New Jersey plans to expand service options, improve service delivery, provide policy priority to seniors, and efficiently implement a coherent public policy for the elderly.

Another model used by some states is to coordinate long-term care programs within a health and human services umbrella agency. Typically, a committee in the primary agency sets broad policy for all long-term care programs.<sup>23</sup> **Wisconsin** is an example of this model. The department of health and family

services houses both the division of health care financing, which is responsible for Medicaid, and the division of supportive living, which is responsible for the bureau of aging and long-term care. Though it does not use the single-agency approach, Wisconsin's commitment to interagency coordination has been recognized for its efforts to develop comprehensive long-term care community services.<sup>24</sup>

Wisconsin plans to further coordinate long-term care programs through the creation of a proposed Family Care program. This program will allow the department of health and family services to share authority and responsibility with consumers and local organizations that will primarily manage services and funding. The Family Care program will integrate long-term care services at the county level at local aging and disability resource centers. The department of health and family services will contract directly with county and tribal governments or, in areas where neither government applies nor meets eligibility standards, private nonprofit organizations.

The proposed Family Care program will go beyond integrating services and funding streams under one agency: the program also pools and manages public funding sources to create one flexible benefit with one set of eligibility criteria to provide an individualized service plan.<sup>25</sup> Resource centers will not only determine functional eligibility and cost-sharing levels for potential family care enrollees, but also will provide information for elderly people, their families, the general public, and for a variety of referral sources, such as physicians and hospitals. These centers will have prevention and early intervention programs to help people avoid or delay severe disabilities.

#### Integrating Acute and Long-Term Care Under Managed Care

Historically, long-term care financing and delivery systems have been separate from the acute medical care system, such as physician-

led primary care and hospital care. Thus, rarely does a single provider have primary responsibility for an individual's care as the patient moves among the physician's office, hospital, home health, assisted living facility, and nursing home. The patient is at risk of suboptimal care, which may lead to a decline in health status resulting in being placed in an institutional setting such as a nursing home or hospital.

A number of states have developed programs that integrate acute and long-term care services and financing sources for persons eligible for both Medicaid and Medicare. This dual-eligible population is targeted because they tend to use more health care resources. The separation of financing sources between the two programs also can adversely affect care and increase costs.<sup>26</sup> Under the integrated delivery model, recipients enroll in some form of managed care.

The **Texas** STAR+PLUS program is a Medicaid-mandatory integrated care model for elderly and disabled persons who qualify for Social Security cash benefits (i.e., Medicare) and Medicaid or those who are eligible for Medicaid because they need care at the nursing facility level. Individuals covered only by Medicaid must enroll in a STAR+PLUS health maintenance organization (HMO) to receive both acute and long-term care services.

The STAR+PLUS program requires the dual-eligible recipient to enroll in one of the program's HMOs to obtain long-term care services covered by Medicaid. The dual-eligible recipient is free to obtain acute care services from providers of Medicare benefits through traditional fee-for-service or through an HMO offering a Medicare risk product. As an incentive, dual-eligible recipients can receive unlimited prescriptions through the state's vendor drug program if they also enroll in the Medicare risk product offered by the STAR+PLUS HMO responsible for their Medicaid long-term care services.

Medicaid prescriptions for adults are typically limited to three per month.

**Arizona** integrates Medicaid's acute and long-term care services, but does not explicitly include Medicare. The Arizona long-term care system (ALTCS) is a mandatory Medicaid managed care program targeted to those who qualify for long-term care services.<sup>27</sup> The program integrates Medicaid acute and long-term care services. However, a degree of integration with Medicare also is achieved as most beneficiaries receive their care from Medicaid contractors. Beneficiaries are persuaded to remain in the network for all services because Arizona's Medicaid waiver allows the state to deny Medicare cost shar-

ing to providers who are not part of the ALTCS network.<sup>28</sup>

While promising, these acute and long-term care integration models face two obstacles in their implementation. First, with so much turmoil in the competitive market, it may be difficult to convince managed care plans to enter the long-term care market where they have little experience. Second, the federal government has been reluctant to allow states to integrate Medicaid and Medicare funds for dual-eligibles (HCFA argues the Medicare freedom-of-choice provision prohibits them from mandating enrollment into managed care even for those receiving Medicaid assistance).

# Using Public Funds in Strategic Ways

A fourth critical challenge is in making more effective use of existing monies. Absent a significant infusion of federal funds and a loosening of spending restrictions, states are thinking creatively about how to use current programs more strategically. States are improving the financing of long-term care beyond the Medicaid program by using two public financing models. The first approach combines new private financing with public money to pay for long-term care insurance policies. In the second model, states supplement Medicaid funds with other public-sector programs serving the elderly.

## The Public-Private Partnership Program

The previously described models of individual and group long-term care insurance were financed entirely by private-sector monies, usually individuals, but sometimes employers, too. Another model encourages the purchase of long-term care insurance by combining an individual's resources with a public program. The public-private partnership (used in **California, Connecticut, Indiana, and New York**) combines private insurance benefits with the public Medicaid program. Connecticut became the first state to implement this model in 1992. Its partnership for long-term care program targets potential Medicaid eligibles by providing an alternative to exhausting their savings and assets to qualify for Medicaid.

With a partnership policy, policyholders must initially fund their care by paying premiums for their private insurance policy. The private insurance company then reimburses providers for the care. If more coverage is needed after the insurance benefits are ex-

hausted, policyholders can become eligible under Medicaid without facing the standard "spend-down" rules. Under Connecticut's partnership program, an individual can protect one dollar in assets for every dollar paid out in benefits on their private policy and still be eligible for Medicaid. By avoiding the spend-down requirement and protecting assets, a person can pass on assets to their children.

Although partnership programs had limited success initially, the number of partnership policies purchased during the past few years has increased. While there is still room for growth, the programs are significantly impacting the quality of coverage purchased and the size of the long-term care insurance market.

However, a significant obstacle has limited the spread of partnership programs to other states. The Omnibus Budget Reconciliation Act (OBRA) of 1993 placed restrictions on other states wishing to develop partnership policies. Although OBRA allows for states to implement partnership programs, it requires them to recover assets protected through the partnership once a Medicaid client dies (the four current partnership states are exempt from the OBRA recovery provisions). A repeal or modification of the OBRA partnership restrictions could lead to these programs' expansion because a number of states have legislation enabling implementation of a partnership program.

## Taking Advantage of Flexible Federal Funding

While Medicaid is the dominant public-sector program serving the long-term care

needs of the elderly poor, states can tap other programs to finance these long-term care services. One is the Older Americans Act, which finances a variety of services for the elderly. States use these funds to provide supportive services and senior centers, in-home services, and nutrition services. These funds can be used to assist state units on aging and area agencies on aging to foster the development of community-based systems of service for the elderly. Federal dollars also fund disease prevention programs and health promotion services at a variety of sites. The Older Americans Act also funds long-term care ombudsman services and programs to prevent elderly abuse and neglect. In fiscal 1997, approximately \$800 million was appropriated for these programs.

The other major federal program is the Social Services Block Grant (SSBG), which provides funds for a variety of long-term care services, including community-based services such as homemaker services, assessment and case management, transportation, and nutritional assistance. While these funds do not have to be used solely for low-income or elderly populations, most are directed toward these individuals. In the 2000 federal budget, \$1.75 billion was appropriated for SSBG, a \$750 million reduction from the 1997 budget.<sup>29</sup>

### Supplemental State Funds

Some states have been highly successful in integrating federal, state, and local financing sources in conjunction with Medicaid.

**Indiana's** IN-Home Services Program has enjoyed great success in bringing together a host of funding streams to provide comprehensive home- and community-based care. The program combines funding from four home- and community-based Medicaid waivers, Title III of the Older Americans Act, SSBG, U.S. Department of Agriculture (which provides funding for meals), the Older Hoosier Account, local funds (which come from sources such as program income and fundraising by the sixteen area agencies on aging), and the CHOICE program.

Under the IN-Home Services Program, Indiana has created a state-only funding pool that serves as the program of last resort. The CHOICE program finances those services that the elderly are ineligible to receive under any of the IN-Home Service Programs. CHOICE services are available to Indiana residents who are elderly and/or disabled and found to be at risk of institutionalization. While eligibility is not related to income level, those who are financially able must contribute to the cost of the services provided to them by the program.

# Addressing Concerns About Quality

The fifth critical challenge is to create multiple long-term care systems that are cost effective and protect the consumer. Just as in the acute care side of medical care, where purchasers and consumers are demanding high-quality services from physicians, hospitals, and managed care plans, similar demands are being made on long-term care providers.

As the primary regulators of long-term care providers, states ensure quality oversight through a number of mechanisms. These include licensing requirements for care providers, scheduled and unannounced inspections of homes and sites where care is delivered, investigation of public complaints, and mandatory reporting of abuse or neglect to the state. Some states promote quality-of-life measures and safety by involving clients in assessing quality. Client satisfaction surveys and toll-free numbers are two other approaches. Case management, greater client choice, and the delivery and coordination of appropriate services are also being used to measure quality.

## Quality Assurance in Institutional Care

Consumer protection concerns have been raised at the national level<sup>30</sup> and many states have developed effective enforcement actions. **Washington** has had great success in regulating nursing homes, adult family homes, and boarding homes. Inspections are performed annually or with greater frequency for homes that do not comply or are reported to have problems. Self-reports conducted by the homes also are required. Licensors and surveyors make unannounced visits, which can last for two to three days. All

investigators must have nursing or master's degrees and be trained. Caregivers must also receive training.

To empower clients, Washington has developed a toll-free number that nursing home residents can call to complain or report problems. All homes must post a sign about residential care abuse and neglect, along with this phone number. This telephone hotline also can be used for public complaints. Each complaint is investigated. Lastly, quality in residential care settings is improved through ongoing case management that provides choice and safety in care.

**California** is considering a gubernatorial proposal to create a cash award of \$50,000 to exemplary nursing homes. Part of the initiative is the addition of 100 inspectors that will increase the number of nursing home inspections. Another 50 positions are to be added to guarantee a 48-hour response time to nonemergency complaints regarding patient care.<sup>31</sup>

## Quality Assurance in Home- and Community-Based Care

Unlike nursing homes, whose standards are more uniform because the services are provided in a single setting and the clients often have similar medical needs, home- and community-based care is more varied and complex. States monitor quality and safety in home- and community-based care through case management, on-site visits, monitoring, and reviews of service provision, costs, and compliance with the care plan by registered nurses and agency staff. Client satisfaction surveys, client/family forums, and client

reporting are a few techniques used to assess quality in waiver services.<sup>32</sup>

**Washington** has had success in assuring quality in home- and community-based care by focusing on case management, nurse expertise, consultation, and client assessment monitoring. Case managers are required—following an initial visit and assessment of a client’s needs—to visit at least yearly if the client is residing in their own home or more often if the client’s needs change during the 12-month period. If the client is residing in a residential setting, such as an adult family home, assisted living facility, or an adult residential care setting, case managers must visit at least two times annually, or more often as needs change.

Washington’s case managers can decide which clients require more, less, or no moni-

toring by registered nurses. Until recently, each community-based care client was seen an average of once a year. This didn’t include clients with no long-term care needs that required monitoring by a registered nurse. This new manager role now allows nurses to use their skills for clients with the greatest needs.

Consistent with a client-oriented approach, Washington developed a fund that allows its field offices to contract with and pay for consultation services for specific clients.

Washington also provides client assessment monitoring. Each of the state’s six regions has comprehensive plans to assure quality: a full-time quality coordinator, a random reliability review, and scheduled local training to dovetail with statewide training.

# Building a State Strategy

The program and policy terrain of long-term care for the elderly is vast and complicated. It is financed by three major sources: states, federal government, and families. None of these sources can unilaterally increase spending to meet the rising demand for services. Many state, federal, local, and private-sector programs are largely uncoordinated. Yet, no single entity can unilaterally affect program integration. Moreover, nonprofit and for-profit providers need to change their array of services and settings to be more aligned with consumer preferences. That will continue to be a slow process. Each of these challenges brings different stakeholders with differing interests and needs.

It will take time to affect change and to create a strategy that includes all stakeholders. A first step is to develop a process that brings these diverse interests together. A recent example is **Michigan**. In September 1999, the Michigan long-term care workgroup, consisting of state legislators and executive branch officials, submitted a preliminary report to the public for consideration. The report included recommendations to reinforce personal responsibility, assist people with living independently, coordinate care, integrate agency programs, develop demonstrations that meld acute and long-term care providers, and improve the quality of long-term care services.<sup>33</sup>

These efforts will become more common as states take the lead in addressing long-term care challenges. Like Michigan other states will look to one particular state for guidance and inspiration: **Oregon**.

## The Oregon Experience

Oregon's long-term care system serves as a model for many states because of its success in containing costs while serving more people. In the late 1970s, Oregon adopted explicit policies and principles that have guided other reforms of the state's long-term care system:

- facilitate aging in place;
- respect client autonomy;
- use resources appropriately;
- embrace consultative problemsolving techniques; and
- demedicalize long-term care.

Before adopting statewide reforms, Oregon performed several studies and local pilot projects to develop a more cost-effective, coordinated delivery system. In 1980 the state created a unified plan for the delivery of long-term care services. The state also conducted a planned demonstration—using a Medicaid waiver—that expanded home- and community-based services in lieu of inappropriate nursing home use.<sup>34</sup>

In 1981, with the passage of state senate bill 955, Oregon reorganized the agencies that administered long-term care services for the elderly. The senior and disabled services division of the department of human resources now oversees all programs financed with federal and state dollars, including SSBG, Medicaid, Older Americans Act, and Oregon Project Independence. Oregon Project Independence is a state-funded program that provides case management for individuals who need home services but are not Medicaid eligible. Area agencies on

aging also took on the primary responsibility for administering long-term care service delivery at the local level. In 1989 the senior services division became the senior and disabled services division, becoming responsible for serving the disabled and for determining eligibility for food stamps and medical and cash assistance for seniors and disabled people.<sup>35</sup>

By consolidating programs, Oregon developed a wide range of home- and community-based services, as well as provided alternate living arrangements to supplement nursing home services. More people are taking advantage of the alternative services that Oregon offers because the state uses the same eligibility criteria for nursing homes as home- and community-based care. Only 27 percent of Medicaid beneficiaries were projected to receive services from nursing facilities in 1999 as opposed to 60 percent in 1985. Similarly, more than 38 percent of beneficiaries will receive care in the home and more than 20 percent in assisted living facilities.<sup>36</sup>

Nursing homes are assuming a different role because of a shift in caregiving environments. Oregon residents no longer use nursing homes as a residence, but rather as a setting for rehabilitation and end-of-life care. Savings realized because of this shift are innovatively reinvested into home- and community-based care, which is embraced by the private sector. However, these changes have not been without controversy. The nursing home industry is concerned about a possible insufficient supply for those who would best be served in nursing homes.

#### Policy Considerations for States

Like Oregon, other states can benefit from creating a vision that clearly states policy goals in assisting the elderly with access to appropriate services and that provides a clear message to each player about their role. States can consider the inclusion of several elements in this vision.

First, states can encourage the private sector to understand its role in addressing the problems. The private sector—individuals, families, communities, and employers—has a key role in financing and delivering long-term care. Families and communities provide extensive amounts of informal long-term care. States can highlight the importance of family and community and then can work with them to create networks to match people with caregivers.

For financing, people can make plans for some type of financial assurances to cover their future long-term care needs. This could include long-term care insurance, personal savings, or some other kind of financial instrument. Employers can play a critical role in sponsoring long-term care insurance. A comprehensive education campaign that discusses the importance of preparing for the future—including the benefits of insurance, Medicare's limited role in long-term care, and the potential for depletion of assets because of not planning ahead—will be important for success. Although such a message needs to be made at the federal level too, state policymakers should not wait.

Second, states can provide incentives for finding alternatives to typical long-term care services. When carefully planned and implemented, home- and community-based services can save states money and benefit consumers who want to remain in their homes for as long as possible. While Medicaid can serve as a public-sector catalyst to expand home- and community-based services, private-sector involvement—new provider systems and new private pay consumers—is necessary.

Third, states can streamline and integrate services so they are client-friendly. Fragmentation exists among programs within the acute and long-term care systems. This causes administrative inefficiency and ineffectiveness, which lead to difficulties in providing the right array of services in a timely manner. New information technology should help

improve coordination and integration, contain costs, and increase consumer satisfaction.

Fourth, states can identify and develop public financing options beyond Medicaid and Medicare. It is unlikely that major new federal financing or greater flexibility in existing federal funds is on the horizon. In the short term, however, states can use public funds more strategically by taking advantage of a variety of federal programs and local funds created to serve the elderly's needs. States can make a wider array of services available, integrating and supplementing the categorical federal/state programs with state revenues.

Finally, states can take the lead in assuring the public that long-term care services—whether

they be institutional or home- and community-based care—are of high quality. States must involve providers and clients to determine what models will best ensure the greatest degree of quality in their long-term care systems.

The long-term care issue will continue to grow inexorably. Citizens, particularly baby-boomers, are becoming increasingly aware of the needs of the elderly and of the challenges that lie ahead. There is no easy solution and no entity can unilaterally assume sole responsibility for solving the problem. However, it is certain that states will continue to be at the forefront in developing innovative models that help address some of the pressing long-term care needs of the elderly.



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