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LONG-TERM SERVICES AND SUPPORTS

INTRODUCTION

America faces a major challenge in health care and long-term services and supports (LTSS) as the US population ages and people live longer lives. The country lacks a comprehensive LTSS system that serves the needs of millions of older people and people with disabilities. Instead LTSS today are largely uncoordinated, fragmented and costly and paid for by consumers and their families and, in limited circumstances, with public dollars. Millions of vulnerable Americans are denied access to LTSS because they cannot pay for them; do not qualify for public funding; cannot find or are unaware of the types of services and supports they need and can afford; or because the LTSS do not exist in their community. Recently, because of low wages and inadequate benefits, understaffing, lack of respect or appreciation, lack of advancement opportunities, inadequate training, changes in the economy, state funding crises, and other factors, it has become increasingly difficult to recruit and retain sufficient staff members to provide nursing home, supportive housing or home-care services. Thus, direct service workers may carry workloads well beyond the safe limits recommended in professional standards.

For many Americans advancing age means the increasing likelihood of chronic illness and disability. Millions of younger adults and children also need LTSS, including younger people with disabilities, people with chronic illnesses, and people with cognitive and other mental impairments. If a broad functional definition of “disability” is used, an estimated 11.5 million individuals of all ages have disabilities severe enough to require LTSS (Figure 7-1).

\[\text{Figure 7-1} \]

**People with Disabilities Who Need Long-Term Services and Supports,* 1997**

<table>
<thead>
<tr>
<th>Age</th>
<th>People (millions)</th>
</tr>
</thead>
<tbody>
<tr>
<td>&lt;15</td>
<td>0.2</td>
</tr>
<tr>
<td>15–64</td>
<td>4.5</td>
</tr>
<tr>
<td>&gt;65</td>
<td>5.3</td>
</tr>
</tbody>
</table>

*Assistance with one or more activities of daily living or instrumental activities of daily living.
Prepared by AARP Public Policy Institute.
The population age 85 and older is expected to increase from 4.2 million in 1999 to 8.5 million in 2030 and is projected to reach 18 million in 2050 (Figure 7-2). Even with potential breakthroughs in health research and efforts to reduce or delay chronic illnesses and disabilities, the number of people needing long-term services and supports is expected to rise dramatically over the next three decades (for a discussion of efforts to promote health and prevent chronic illness and disability, see Chapter 6, Health Care: Protecting and Improving Public Health and Access to Care—Protecting and Promoting the Public’s Health).

What are long-term services and supports? LTSS encompass a broad range of services and supports needed by people of all ages with physical or mental impairments who have lost or never acquired the ability to function independently. LTSS include assistance with performing self-care activities and household tasks, habilitation and rehabilitation, adult day services, case management, social services, assistive technology, home modification, and some medical care. They are provided in a variety of settings, including at home, in assisted-living and other supportive housing settings, and in nursing homes. Many people with disabilities prefer the term “long-term services and supports,” rather than “long-term care,” because the term “care” may imply dependence and seem paternalistic. In this book the term “long-term care” is used only when referring to specific programs or products that use that term.

Surveys indicate that most people who need LTSS strongly prefer to remain in their homes, receiving assistance from family or friends, especially if less than 24-hour help is needed. According to a 2002 AARP study, when people age 50 and older with disabilities were asked their first choice for receiving help with everyday activities, 61 percent of respondents preferred help from
family or friends, 26 percent viewed agency-provided home-care services as their first choice, 8 percent preferred care in an assisted-living or other residential setting, and only 1 percent preferred care in a nursing home. When asked about their preference for 24-hour help, 43 percent preferred that family and friends provide all the assistance at home, 30 percent said care provided at home by an agency was their first choice, 17 percent preferred care in an assisted-living or other residential setting, and only 6 percent preferred care in a nursing home. Many individuals prefer to receive home-care services from individual providers rather than agencies.

As demand for LTSS grows, the marketplace for them is undergoing a major transformation. New forms of supportive housing, such as assisted living and adult foster care, have emerged as alternatives to nursing homes. The use of home-care services, adult day services, and respite services for family caregivers has surged dramatically. (Throughout this chapter, “family caregivers” refers to people who provide long-term services and supports to family members, relatives, friends and neighbors. Some family caregivers are unpaid; some are paid to provide care through government programs, private funds or long-term care insurance policies. The term “unpaid caregivers” is used when referring to family caregivers who are not paid for providing care.)

Despite these changes, millions of people still equate long-term services and supports only with nursing home care and are unaware of publicly and privately funded home- and community-based services, as well as opportunities people now have to manage their own services and supports. Moreover, access to LTSS in any setting is severely restricted for millions of Americans because of high costs coupled with limited public funding.

LTSS financing—The US does not have a comprehensive system to finance long-term services and supports. Medicare provides only modest funding for LTSS through limited coverage of short stays for rehabilitative care in nursing homes and some home health care services. The major public financing for LTSS comes through the federally and state-funded Medicaid program. Medicaid has stringent financial eligibility criteria, however, and requires people to exhaust most of their assets and income to qualify for coverage.

Rising expenditures make Medicaid a frequent target for both state and federal budget-cutters. Private long-term care insurance is too costly for many older Americans and may be unavailable to some individuals because of medical underwriting. The fact that people are living longer and with more chronic or disabling conditions will likely increase the public pressure to address the LTSS needs of our population.
AARP PRINCIPLES

The following principles for long-term services and supports (LTSS) are designed to guide the association’s efforts to bring about comprehensive reform that includes a public LTSS program and a system of quality assurance and improvement in every setting in which LTSS are delivered. These principles do not address every issue relating to LTSS, but they do provide criteria for evaluating and comparing reform proposals. They also serve to guide the association in its participation in the public debate about LTSS reform at both the federal and state level.

Long-term services and supports programs should receive adequate public financing through a social insurance program. Under social insurance programs (e.g., Social Security or Medicare), individuals pay into the system and then are entitled to benefits when they are needed. If the cost is spread across the entire population, universal protection can be achieved in an affordable, equitable manner. The US should use its resources to finance an LTSS program through taxes earmarked to a trust fund. Revenue sources could include payroll or other taxes, modest premiums or other cost-sharing mechanisms.

Implementation of a comprehensive public long-term services and supports system should be phased in. Implementation of any comprehensive public program must be phased in to ensure orderly development of the new system. Expansion of services should be accompanied by development of an LTSS infrastructure, including health care and direct services workers, social workers, case managers, and other needed personnel, that will permit the delivery of a comprehensive range of home, community and institutional services.

A comprehensive range of long-term services and supports should be guaranteed to all who need them, regardless of age or income. Long-term services and supports programs should base eligibility on a person’s physical and cognitive or other mental functioning, including limitations on activities of daily living (e.g., eating, bathing and dressing) and on the types of assistance (e.g., hands-on care, supervision, and assistive devices) a person needs. Uniform assessments should determine whether a person meets the eligibility criteria for the program and what type and level of services a person requires. To ensure that people have service options, these assessments should be completed in a timely manner. Services should include in-home assistance, community services, a full range of supportive housing options, institutional care, rehabilitative services, and other enabling services, as well as assistive devices and home modifications.
Services should be provided in the least restrictive setting appropriate to the individual’s assessed needs and wishes. Services and supports should enhance the ability of people of all ages and incomes to participate as fully as possible in all aspects of community living. Wherever possible, consumers should have the opportunity to direct their own services, if that is their preference.

**Public long-term services and supports programs should give meaningful support to families and friends who provide LTSS.** Any new national program should support, not necessarily replace, current caregiving by families and friends. Families and friends need access to assistance so that they are not unreasonably burdened and can continue to provide care. This assistance should include respite care, adult day services, programs that help individuals pay relatives and friends who provide care, and other types of assistance financed through such means as tax incentives.

**Private-sector insurance should supplement public long-term services and supports financing.** The new public program must provide a solid foundation for protection on which the private sector can build. The private sector could supplement the public program with insurance products similar to Medigap policies that would cover the program’s copayments and deductibles, as well as services that the public program does not provide. Any private-sector approach (e.g., long-term care insurance) should be subject to strong standards to protect consumers from inadequate products and deceptive marketing practices. In addition, consumers should be protected from discrimination that favors individuals with insurance or private funds in admission to nursing homes and supportive housing.

**Provider payments should be adequate.** Payment to LTSS providers must be reasonable and offer appropriate incentives to deliver quality services and supports, including incentives to attract and retain qualified staff. Reimbursement systems for home, community and institutional services must respond to clients’ needs, promote delivery of quality care, and recognize the outcomes of services provided to clients.

**Cost-containment mechanisms should be built into public long-term services and supports programs.** Appropriate cost-containment mechanisms could include those that combat fraud, waste and abuse; promote efficiency in service delivery; tie the amount of benefits to disability levels; and phase in the scope of the public benefit over time. Cost-containment should not reduce access to adequate and affordable services and supports.

**It is the responsibility of federal and state governments to ensure delivery of quality long-term services and supports.** To protect the health and safety of consumers, federal and state governments should swiftly and vigorously apply sanctions when needed to enforce laws and regulations for nursing homes and home- and community-based
services. Governments should explore additional methods of protecting people from abuse and ensuring the quality of LTSS, such as incentives to encourage providers to seek continual service improvements.

**Long-term services and supports should promote consumer independence, dignity, autonomy and privacy.** To the extent they are capable, consumers should make their own decisions about and direct the long-term services and supports they receive. The design and delivery of all services should promote independence, dignity, autonomy and privacy.

**The federal government and the states should recognize and support consumer choices to the maximum extent possible.**

**The rights of consumers receiving long-term services and supports should be protected.** Consumers’ rights include the right to timely information concerning their care, including access to their medical records; the right to meet with advocates and express grievances without fear of reprisal; and the right to keep personal possessions. Consumers receiving services from any provider should have a private right of action in court to ensure their rights. Residents should be protected from undue hardship when they are transferred in the event of a facility closing or other circumstance.

**Consumers of long-term services and supports have a right to privacy.** Consumers, regardless of their source of payment, should not have to share rooms or bathrooms unless they choose to do so. When consumers share rooms, providers must work to protect privacy with visual and auditory barriers. Consumers in all LTSS settings should have private areas for visitation, security protections for personal property, and access to private telephones.
ACHIEVING COMPREHENSIVE REFORM

Background

While the population in need of long-term services and supports (LTSS) is increasing, relatively few people need them at any one time. Because it is difficult to predict who will need assistance, LTSS lend themselves to insurance protection, which is based on the principle of shared risk. Since everyone is at some risk of needing LTSS, everyone should contribute to the cost of providing them. Such a social insurance program can provide coverage for a comprehensive range of LTSS in home, community and institutional settings, protecting all participants from potentially devastating financial costs. Because many people share the risk, each person’s payments are small. A means-tested program like Medicaid, which takes a different approach, bases eligibility on categories (e.g., pregnant women, children, and people who are “aged, blind or disabled”) and medical and financial criteria.

AARP seeks, in the long run, the introduction, passage and enactment of both health care and LTSS legislation that integrates the features outlined below. The association’s short-term goal is to enact policy that moves the nation toward a comprehensive LTSS system that provides coordinated, integrated, affordable and high-quality services and supports.

FEDERAL & STATE POLICY

ACHIEVING COMPREHENSIVE REFORM

AARP is committed to achieving reform in comprehensive long-term services and supports (LTSS) as a top priority.

Consistent with AARP’s long-term services and supports principles, the federal government should finance LTSS through a universal, comprehensive, publicly administered program such as Medicare or a similar social insurance program of shared risk. Such a program should be part of a comprehensive system that provides universal access to a range of health care services and LTSS. The program should emphasize the independence, dignity and autonomy of individual consumers so they can maximize their physical and psychosocial potential. To the extent that they are capable, consumers should have the option of making their own decisions about the LTSS they receive. Services from all providers should be designed and delivered in a way that promotes independence. The system’s key activities and components should address the following areas:

Quality and consumer participation

- Federal and state oversight—The federal government and the states should conduct regular, thorough and consistent oversight to ensure
consumers’ quality of care and quality of life and protect consumers’ rights in all LTSS settings.

- **Federal oversight**—Strong federal oversight is needed to ensure the equitable treatment of all people eligible to receive services.

- **Consumer participation**—The consumer should be the focus of all LTSS programs and services. Consumers using LTSS should participate in all aspects of program development, implementation and oversight. Consumers (or their caregivers) should have the option to manage their own services and supports.

**Improved coordination and administration**

- **Improved coordination with health programs**—Medicare coverage of health services for those with chronic illness and disabling conditions should be improved (see Chapter 6, Health Care for policy on Medicare and chronic care).

- **Coordination of federally and state-funded LTSS programs**—Care management should be used to coordinate health care and LTSS for people who need both types of services. Covered services should be fully portable so people can receive services in a wide range of settings.

- **Flexible, innovative and efficient administration**—The system must have an administrative structure capable of meeting the needs of beneficiaries. The system should build on states’ experiences or require state and local agencies to have a major role in running any new program.

- **Integration with existing long-term services and supports programs**—The effects of integrating other public LTSS programs, such as state and Department of Veterans Affairs programs, into a new system should be carefully considered. Whether integrated or not these existing programs should receive adequate federal funding to ensure veterans’ access to LTSS.

- **Single point of entry**—States should be required to implement a single point of entry for LTSS that can determine financial and programmatic eligibility and authorize services.

**Expanded access to home- and community-based services**

- **Appropriate and fair eligibility criteria**—Eligibility for services should be based on how LTSS relates to an individual’s functional needs, chronic illness and medical condition. Assessments should measure needs for assistance due to impairments in activity of daily living (ADL), for supervision due to cognitive and other types of mental impairment and behavioral problems, and for long-term nursing services and medical management.
- **Access to Medicare-funded services**—Medicare’s role in potentially meeting beneficiaries’ LTSS and medical needs should be reexamined. Medicare should be expanded to assist people who depend on family caregivers by including improved home health care and skilled-nursing facility benefits, personal care designed to help people with ADL, and adult day care and other services such as respite care.

**Reforms in financing**

- **A new publicly financed social insurance program**—This program would form the base of LTSS financing. Individuals would pay into the program and be entitled to benefits, including cash payments, when they meet the program’s eligibility criteria.

- **Neutral financial incentives**—The program should not provide financial incentives to use one type of care rather than another. No one service in the array of long-term services and supports is more important than another; the most important service is the one the consumer wants and needs. Benefits must be designed to enable beneficiaries to choose services they deem most appropriate for their needs.

- **A strong Medicaid program**—Improved benefits should serve as a LTSS safety net for vulnerable populations with low incomes and few assets and for those who become impoverished because of medical or LTSS needs.

- **Tax measures**—These should help individuals and their families finance LTSS costs and should include tax credits for caregivers.

- **Improved long-term care (LTC) insurance**—LTC insurance should be subject to stronger consumer protections and greater standardization so that consumers can make informed comparisons among policies.

- **Progressive financing and low-income protections**—Older Americans and working people should be required to pay a portion of LTSS program costs. Both taxes and premiums might be used. A contribution equal to the full actuarial cost of the LTSS benefit is simply too expensive for many Americans, so the financing provisions must protect people with low incomes. However, people must have equal access to services regardless of the source of payment.

- **Cost-sharing**—Cost-sharing should be addressed through the program’s financing (i.e., taxes and premiums). Beneficiary cost-sharing for either community or institutional services should be modest. To protect people with low incomes, public funds should support individuals who cannot afford to contribute to cost-sharing.

- **Adequate financing and reserves**—Some tax revenues for a new LTSS program should be earmarked to an LTSS trust fund to build adequate
reserves to cover later generations. To help defray the federal government’s costs, the new LTSS program should require some maintenance of states’ current spending on long-term services and supports.

- **Phased-in coverage**—A comprehensive public program can be introduced gradually. The program should cover people who currently need services and build an adequate program for future generations through a range of financing resources. A financing package should consider the fact that many people with disabilities would be eligible for benefits before a large reserve fund could be built up.

Reforms must move toward—and not diminish—future opportunities to achieve the goal of a comprehensive LTSS program. All intermediate reforms must advance the goal—and be building blocks—of a comprehensive LTSS program. Intermediate steps should include the following:

- improvements in coordination among LTSS programs and between the health and LTSS systems for people who need services from both;
- the expansion of services in consumer-preferred settings—primarily in the home and community—to improve access to services, particularly those that will enable family caregivers to continue providing care;
- the option of a cash payment or service benefit based on level of disability;
- the strengthening of consumer protection mechanisms; and
- until a national, comprehensive LTSS program is available, state implementation of comprehensive LTSS programs that are affordable for those who do not meet Medicaid’s eligibility requirements.

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**ACCESS TO LONG-TERM SERVICES AND SUPPORTS**

**Introduction**

People who need long-term services and supports (LTSS) want to remain in control of their lives as much as possible and remain close to family and friends. They want to avoid impoverishing themselves and their families. Most of all they want to retain independence, dignity and autonomy. Access to affordable, high-quality LTSS can be very difficult, however, under the country’s multiple, fragmented and poorly financed LTSS systems.

Neither the federal government nor most states offer individuals and their families the comprehensive support that allows beneficiaries to direct their own care or that helps families and friends bear the financial and emotional burdens of caregiving. Some states provide people with opportunities to
manage their own LTSS. Federal or state programs to assist caregivers are limited even though unpaid family and friends provide the bulk of LTSS in the US. Between 1987 and 1997 the proportion of US households involved in unpaid caregiving activities for a person over the age of 50 jumped from approximately 8 percent (7 million households) to more than 22 percent (more than 21 million households). Through Medicaid and state-funded home- and community-based services programs, some states provide limited respite care for caregivers, while others allow payments to relatives and friends who care for people with LTSS needs. Still, services for caregivers are insufficient.

The ability to pay also affects access to long-term services and supports. Many people are unable to pay out-of-pocket for services, which can be costly, especially if the services are needed for months or even years. Yet these individuals may be unable to meet stringent federal and state income and asset requirements to qualify for publicly funded benefits.

States also may make access to LTSS more difficult through restrictive medical and functional eligibility criteria that many people with LTSS needs may not be able to meet. People with serious mental illness face special problems due to regulations that restrict their access to nursing homes but do not guarantee alternative services in home- and community-based settings.

Most people prefer to receive LTSS in their homes or at least in a home-like setting, such as residential housing or an assisted-living residence. But public funding (e.g., Medicaid) is largely available only for institutional care. In recent years states have been increasing Medicaid and state spending on home- and community-based services, but these programs still serve only a fraction of the people who want to avoid institutionalization.

In June 1999 the US Supreme Court ruled that the Americans with Disabilities Act requires states to provide care for people with disabilities in community settings when appropriate (Olmstead v L.C. and E.W.). This ruling is another step toward reducing unnecessary institutionalization of people with disabilities, including nursing home residents, who could with assistance remain in the community. However, the decision leaves many questions unanswered, because it allows states some flexibility in making placement decisions as long as they have an equitable plan to provide care in less restrictive settings (see also this chapter’s section Access to Long-Term Services and Supports—Expanding Home- and Community-Based Services).
ACCESS TO LONG-TERM SERVICES AND SUPPORTS

Background

**Chronic Illness and Long-Term Services and Supports**

It is increasingly common as one grows older to have a chronic condition with accompanying disability or limitation in daily functioning. For 47 percent of chronically ill people ages 50 to 64 their illness has no impact on their ability to function. However by age 85 most people have some functional limitation due to a chronic illness. Only 17 percent of people age 85 and over have no functional limitation when they have a chronic condition. Such data highlight the overlap between chronic disease and the need for long-term services and supports (LTSS). They also illustrate why frail older people need not only primary and acute medical care but also a range of services and supports that insurers typically do not define as medically necessary. Such services include personal care, adult day care, homemaker services, transportation and supportive housing.

Some state programs for people dually eligible for Medicare and Medicaid have recognized the range of services needed. For example, there have now been more than two decades of experience with programs, such as the Program of All-Inclusive Care for the Elderly (PACE) and social health maintenance organizations (SHMOs), that combine Medicare and Medicaid funding for health care and LTSS into a single, capitated payment. While these and other integrated care models have pioneered promising approaches, they are still not widespread, reaching relatively few frail older people (for policy on PACE and SHMOs, see Chapter 6, Health Care: Health Care Coverage—Publicly Administered Health Insurance—When Medicare and Medicaid Meet—Federal-State Flexibility).

Specific policies that address the needs of chronically ill people who need long-term services and supports may be found throughout this chapter. Some of the sections that include such policies are:

- Creating a Consumer-Directed Long-Term Services and Supports System,
- Support for Family Caregivers,
- Expanding Home- and Community-Based Services,
- Appropriate Health and Functional Criteria,
- Access and Quality Issues for People with Cognitive and Mental Disorders, and
- Coordination and Integration of Long-Term Services and Supports.
Chronic Illness and Long-Term Services and Supports

AARP supports developing comprehensive, coordinated approaches to financing and delivering care to chronically ill people. Such coordination should involve physical and mental health care and long-term services and supports (LTSS). An example is joining Medicare and Medicaid funds through a waiver authority to test integration of health care and LTSS (see this chapter’s section Coordination and Integration of Long-Term Services and Supports—Integrating Health Care and Long-Term Services and Supports—Federal & State Policy).

AARP believes there should be new initiatives to identify specific financing mechanisms and delivery systems to serve subgroups of chronically ill individuals who need both ongoing medical care and LTSS, e.g., people with physical versus mental disabilities and those eligible for Medicare or Medicaid (for Medicare policy, see Chapter 6, Health Care: Health Care Coverage—Publicly Administered Health Insurance—Improving Care for Beneficiaries with Chronic Conditions and Preventive Health Care).

AARP supports increased emphasis on preventing disabilities and functional limitations among those with chronic illnesses and on minimizing disability or functional loss if it occurs.

ACCESS TO LONG-TERM SERVICES AND SUPPORTS

Background

Creating a Consumer-Directed Long-Term Services and Supports System

Most consumers, regardless of their age or disability, want control in managing their long-term services and supports (LTSS). To the extent they are capable, consumers want the opportunity to make their own decisions about the LTSS they receive so they can maintain their dignity and maximize their independence and autonomy.

A consumer-directed approach to services assumes that consumers can assess most of their own needs, determine who will best meet them, and monitor the quality of services received. Consumer direction ranges from the consumer making all decisions to an advocate or surrogate managing services for the consumer. But the underlying philosophy presumes that consumers are the experts on their own service needs and that meaningful choice can be introduced into all service environments.
Publicly funded LTSS programs have provided opportunities for consumer direction in this and other countries for decades. There are a variety of programs that cover a wide range of age groups and specific conditions, with programs in almost every state. Some of these programs have been studied using methodologies ranging from small pilot projects to large beneficiary surveys. One consistent finding is that the majority of people with disabilities who participate in consumer-directed programs believe that the programs provide them with independence and control over their lives, improved quality of care, and the ability to buy more services than they could under traditional LTSS programs.

For example, a 2000 study of California’s In-Home and Supportive Services program found that people who directed their own services were more satisfied with their choice and control over services and with the technical quality of their care—and reported higher levels of well-being—than did beneficiaries who relied on agencies to manage their services. California’s program is the largest in the nation, serving more than 250,000 low-income people of all ages with disabilities.

In addition, the Robert Wood Johnson Foundation, in partnership with the US Department of Health and Human Services, funded cash-and-counseling demonstration programs in three states (Arkansas, Florida and New Jersey). Cash-and-counseling programs are just one type of consumer-directed LTSS program. The demonstration programs provide Medicaid beneficiaries who are eligible for personal care services with monthly payments to choose, purchase and manage their own care or to pay a care manager. The programs also offer counseling to assist consumers who want help managing their services.

A 2003 Mathematica study of the cash-and-counseling demonstration programs found that they successfully served people of all ages with various impairments. With help from representatives, counselors and fiscal agents, nearly all consumers who were interested in receiving the cash allowance and were able to hire workers learned to manage their own supportive services. Abuse of the cash allowance was almost nonexistent. In Arkansas (the only state for which complete data were available on consumer satisfaction), more than three-quarters of those who received the allowance said it had improved the quality of their lives. The percentage was roughly the same or higher for early participants in Florida and New Jersey. Moreover, in Arkansas, cash-and-counseling participants had health outcomes as good as or better than members of a nonparticipant control group, and participants were less likely to report unmet needs and were more satisfied with their services.

A separate 2003 study of the Arkansas program found that it cost no more than Medicaid coverage of traditional agency care. Although program participants had higher Medicaid personal care expenditures, by the second year after enrollment these were offset by lower spending for nursing homes and other Medicaid services. Future research will complete similar analyses.
for Florida and New Jersey and examine the experiences of paid workers and unpaid caregivers. These three states have already decided to make the program permanently available to all eligible Medicaid beneficiaries. In October 2004, 11 new states were granted funding of $250,000 each to replicate and expand the cash-and-counseling programs. The 11 states are Alabama, Iowa, Kentucky, Michigan, Minnesota, New Mexico, Pennsylvania, Rhode Island, Vermont, Washington and West Virginia.

The potential benefits of consumer direction include the following:

- Consumers would have maximum choice and control over their LTSS.
- If consumers purchase services themselves, they could avoid the more costly charges of home-care agencies.
- The program would allow development of a flexible service package that could be tailored to meet the unique needs and preferences of consumers.
- The program could increase the pool of available providers by allowing payments to family caregivers.
- Consumers who self-direct their care can help states identify problems and gaps in the current array of services and recommend ways to improve them.

The potential problems associated with cash-and-counseling programs include the following:

- Some consumers may enter the program and find that they have misjudged their ability or desire to perform some or all of the tasks involved in managing their own care.
- Negative outcomes are possible if consumers are unable to find reliable caregivers and backup caregivers when their primary caregivers are unavailable.
- As with all new programs, many issues need to be considered as proposals are developed. These issues include appropriate financing mechanisms and provisions to prevent adverse selection, fraud and abuse. Another issue involves the need for emergency procedures that would allow people who have chosen consumer-directed services to return to traditional agency-based home-care services if they find they cannot manage their own care or are unable to find a care provider.

Another program that promotes consumer direction is the Independence Plus demonstration program. Created by the federal government in 2002, Independence Plus helps states apply and receive approval for family- or individual-directed services to promote self-direction, control and choice.
States with Independence Plus programs include California, Florida, Louisiana, New Hampshire, North Carolina and South Carolina.

FEDERAL & STATE POLICY

ACCESS TO LONG-TERM SERVICES AND SUPPORTS

Creating a Consumer-Directed Long-Term Services and Supports System

Consumers or their caregivers should be screened to determine whether they are able to direct a plan of service. If they are, they should have the option of purchasing their own long-term services and supports (LTSS) using the public funds for which they are eligible. These consumers must be afforded all the same protections in terms of quality of care and access to appeal procedures as currently exist for consumers of Medicaid-funded LTSS.

Efforts to establish or offer consumer-directed services and supports should include:

■ guidelines and standards for care;

■ consumer education, including safety and employment information, and information about accessing available LTSS resources and referral services;

■ counseling, as requested, to assist people in arranging for services and maintaining financial records—Inability to manage financial aspects of consumer-directed care should not prevent participation in the program;

■ semiannual reviews of quality of care and the maintenance of each consumer’s health and functional status;

■ timely grievance and appeal procedures for consumers dissatisfied with or turned down for services;

■ flexibility to allow consumers to perform certain care-management tasks themselves and to receive assistance with other tasks; and

■ emergency procedures and funds to allow people to return to traditional agency-directed home- and community-based services, funded by Medicaid or other sources, if they find they cannot manage their own care.

Federal and state oversight should ensure the safety of participants in consumer-directed services and supports programs. Special attention should be paid to determining whether very vulnerable groups are appropriate candidates for this program.
States should not require home health care consumers, even if they are able to do so, to purchase and manage their own services and supports.

ACCESS TO LONG-TERM SERVICES AND SUPPORTS

Background

Support for Family Caregivers

Throughout this chapter, “family caregivers” refers to people who provide long-term services and supports to family members, relatives, friends and neighbors. Some family caregivers are unpaid; others are paid to provide care through government programs, private funds or long-term care insurance policies. The term “unpaid caregivers” is used when referring to people who provide care without pay. Based on a 2004 national survey, the typical caregiver is a 46-year-old woman who has at least some college experience and provides more than 20 hours of care each week. Many caregivers, especially adult daughters, balance multiple demands, providing care both to parents and to children under age 18.

But caregivers are a diverse group, with varying characteristics and needs. These differing factors include the ages of the caregiver and care recipient, the nature of the caregiving situation, cultural influences, and income.

According to the US Census, in 2000 roughly 6 percent of children under age 18, or 4.5 million individuals, lived in grandparent-headed households. About one-third of these children had no parent present in the household (see Chapter 5, Low-Income Assistance for a discussion of grandparents raising grandchildren).

Existing federal and state programs offer only limited assistance to unpaid caregivers, typically in the form of tax credits and deductions. Federal law allows a caregiver, under specific circumstances, to classify an older person receiving care as a dependent and claim a personal exemption. To qualify, the caregiver and recipient must live in the same home, the caregiver must provide at least 50 percent of the older person’s support for the year, and the older person’s income must not exceed the personal exemption amount—about $3,100 in 2004. Because many older people receive a Social Security benefit or pension income that exceeds that amount, relatively few caregivers can claim their older relative as a dependent. The federal dependent-care tax credit can be used only by employed caregivers who pay a third party for the care of a dependent person.

Another possible source of assistance is the Health Insurance Portability and Accountability Act, which allows taxpayers who itemize their tax deductions to deduct qualified long-term services and supports (LTSS) expenses.
(including for a dependent) if combined medical and LTSS expenses exceed 7.5 percent of the taxpayer’s adjusted gross income.

Some employers provide flexible spending accounts for dependent care as a benefit for employees who are caring for a dependent child under 13 years old or a dependent over 13 who is incapable of caring for himself or herself. These accounts allow employees to reduce their taxable salary by the amount of money they elect to contribute, to a maximum of $5,000 per year ($2,500 per year if they are married and file a separate tax return). Contributions may be used to pay for services that allow the employee to work outside the home, such as sitters, day care centers and housekeeping, if part of the service is for the dependent’s care.

The Older Americans Act Amendments of 2000 established a new source of assistance, the National Family Caregiver Support Program. The program calls on all states to provide five basic services for family caregivers:

- information about available services;
- assistance in gaining access to supportive services;
- individual counseling, support groups and caregiver training;
- respite care, which allows caregivers temporary relief from their responsibilities; and
- supplemental services, on a limited basis, to complement the services that caregivers provide.

Other forms of assistance for family caregivers include the following:

- The Family and Medical Leave Act allows workers in companies with 50 or more employees to take up to 12 weeks of leave to care for an ill parent. Employers are not required to provide paid leave (see Chapter 4, Employment: Economic Security for Workers—Family and Medical Leave).

- Some states give families who care for older relatives limited support through either Medicaid- or state-funded home-care programs or tax policies. These programs include respite care, cash allowances, tax incentives, family leave policies, workers’ compensation and health care benefits.

While the above policies provide incentives for family caregiving, the Supplemental Security Income program reduces benefits for beneficiaries who live with their families, creating a disincentive for family caregiving (see Chapter 5, Low-Income Assistance: Low-Income Assistance Programs—Supplemental Security Income; for more information on support for family caregivers, see Chapter 8, Social Services and Education).
FEDERAL & STATE POLICY

ACCESS TO LONG-TERM SERVICES AND SUPPORTS

Support for Family Caregivers

Federal and state governments should:

■ ensure that long-term services and supports (LTSS) programs cover services, such as respite care and adult day services, that supplement caregiving by family, friends, relatives and neighbors;

■ offer additional services geared to the special needs of caregivers, such as caregiver training programs, support groups and mental health counseling; home-modification programs; hospice and respite care; and income support and transportation—Supplemental programs and support services should reflect the concerns and needs of diverse populations of caregivers;

■ establish and coordinate information and referral systems to let caregivers know about the full range of available LTSS, including caregiver support services; and

■ provide an LTSS tax credit for individuals who need these services, or for their caregivers, in order to give some measure of relief from the high costs of LTSS.

FEDERAL POLICY

ACCESS TO LONG-TERM SERVICES AND SUPPORTS

Support for Family Caregivers

The federal government should:

■ amend the Supplemental Security Income rules so they do not reduce benefits for people living with family members;

■ extend the Family and Medical Leave Act to provide paid leave and cover more workers for longer periods (see Chapter 4, Employment: Economic Security for Workers—Family and Medical Leave);

■ encourage employers to take advantage of existing tax incentives, such as flexible spending accounts for dependent care, to provide dependent or family care benefits; and

■ study the cost-effectiveness of paying spouses for providing LTSS.
Support for Family Caregivers

States should establish and coordinate policies to pay relatives and friends who care for people with long-term services and supports needs as part of a plan of services and supports. States should also explore expanding such policies to allow payments to spouses. Programs and policies should be designed to protect consumers, guard against fraud and abuse, train family members and friends, and provide sufficient oversight to ensure high-quality services.

Background

Strengthening Financial Protections for Medicaid Beneficiaries and Their Families

Medicaid coverage for long-term services and supports (LTSS) provides a safety net for vulnerable older people who have low incomes and few assets or who become impoverished because of medical and LTSS needs. However, federal and state eligibility criteria can seriously hamper access to Medicaid coverage and threaten the protections for beneficiaries and their families.

To be eligible for Medicaid, an applicant must meet strict income and asset rules, which vary widely from state to state, within broad federal standards. In most states older people who are eligible for cash assistance under the Supplemental Security Income (SSI) program are considered categorically needy and hence eligible for Medicaid. In 2004 the federal SSI limits for individuals were $564 in countable monthly income and $2,000 in liquid assets. However, 11 states, known as 209(b) states, impose even more restrictive Medicaid eligibility rules (for a further discussion of SSI, see Chapter 5, Low-Income Assistance).

Spend-down programs—As of 2000, 29 states and the District of Columbia had “medically needy” programs that allow people over age 65, and younger people with disabilities and large medical expenses, to spend down to meet their state’s income eligibility test for Medicaid coverage of long-term services and supports in a nursing home. Nine of these states applied spend-down rules to nursing home services but not for waiver programs covering LTSS at home or in the community. In medically needy programs, medical and LTSS expenses are subtracted from a person’s total adjusted income to determine whether the remaining income meets the state’s eligibility standard. The income eligibility standard must be no less
than 100 percent of the federal SSI standard, but states have the discretion to raise it to 300 percent of SSI.

In states without medically needy programs, nursing home applicants whose total incomes are greater than the eligibility standard cannot get Medicaid nursing home coverage—even if their nursing home expenses exceed their income—unless they have a Miller Trust. A Miller Trust allows individuals to create a trust made up only of the individual’s income on the condition that when the individual dies, the state receives any amount remaining in the trust up to the amount Medicaid paid for the individual. Medicaid-eligible nursing home residents are permitted to keep a personal needs allowance of approximately $30 per month to cover basic expenses such as personal hygiene supplies and phone calls.

**Financial protections for spouses**—Medicaid’s income and asset allowances are indexed to keep pace with inflation. States can provide higher allowances if they choose, up to $2,267 per month in income and $90,660 in assets. States also can offer the same protection to the spouses of Medicaid recipients who receive home- and community-based services under a waiver program. These spousal protections do not affect the eligibility standards for Medicaid recipients other than to ensure that spouses do not become impoverished. Medicaid requires states to protect the income and assets of the spouses of nursing home residents. For 2003 the amount an institutionalized spouse could have deducted from his or her monthly income for the benefit of a spouse in the community was $1,515 (in 48 states). That same year the community spouse could keep at least $18,132 in assets, excluding the couple’s home, car and other personal goods. As of 1998, 19 states had failed to offer the spouses of waiver recipients (so-called because states must obtain waivers to offer services outside of nursing homes) the full level of income and/or asset protection afforded the spouses of nursing home residents.

**Estate recovery**—Medicaid beneficiaries also may be subject to estate recovery by the state. Under the Omnibus Budget Reconciliation Act of 1993 (OBRA 1993), all states must recover Medicaid costs for care in a nursing home from the estates of people who received benefits at age 55 and above. States may, at their option, also recover Medicaid costs for providing home- and community-based waiver services from the estates of recipients. Recoveries can be made only if there is no surviving spouse or dependent child. A number of states recover expenditures by filing liens on the homes of Medicaid recipients. State recovery from these liens cannot be made until the recipient and spouse die, the house is sold, and any surviving children reach the age of 21.

OBRA 1993 defines “estate” to include the assets that are part of the probate estate under state law. States have the option to include other property in which the individual has any legal interest at the time of death, including property passing by joint tenancy or living trust.
Transfers of assets—In determining Medicaid eligibility, states must “look back” three years to determine if an applicant for benefits transferred assets for less than fair-market value. If assets are sheltered in a trust, the look-back period is five years. If assets were transferred for less than fair-market value during the look-back period, a penalty period is imposed, during which the applicant would be ineligible for benefits. Some states have begun to seek waivers that would allow them to look back beyond three years and assume that any undocumented transfers were made to improperly qualify for Medicaid. AARP has strongly opposed these waiver proposals in letters to states and the federal government, arguing that they might deny care to low- and moderate-income people who never made transfers for the purpose of qualifying for Medicaid.

Section 217 of the Health Insurance Portability and Accountability Act imposed criminal penalties on certain transfers of assets when such transfers affect eligibility for Medicaid benefits. Changes in the law and recent court decisions have removed all criminal penalties.

FEDERAL & STATE POLICY

ACCESS TO LONG-TERM SERVICES AND SUPPORTS

Strengthening Financial Protections for Medicaid Beneficiaries and Their Families

The federal government and states should not use more restrictive financial criteria for determining the Medicaid eligibility of the aged, blind and disabled than the criteria used in the Supplemental Security Income program. (This recommendation applies only to the 11 “209(b)” states with more restrictive eligibility rules.)

States should not seek, nor be granted, waivers allowing them to look back beyond three years at asset transfers when determining Medicaid eligibility.

FEDERAL POLICY

ACCESS TO LONG-TERM SERVICES AND SUPPORTS

Strengthening Financial Protections for Medicaid Beneficiaries and Their Families

The federal government should:

- reduce the wide variability in income and asset limits for Medicaid program eligibility and for eligibility under medically needy and categorically needy programs—At a minimum, all individuals with incomes at or below 100 percent of the poverty line ($9,310 per year for an individual in 2004)—should be considered categorically eligible;
- require states to implement medically needy programs for all people regardless of setting;

- increase (according to the Consumer Price Index) the minimum personal needs allowance for Medicaid beneficiaries in nursing homes and supportive housing and adjust it annually to account for changes in the cost of personal needs;

- retain current financial protections for spouses, caregivers and dependent children and continue prohibiting the federal government and states from requiring that the children or grandchildren of Medicaid beneficiaries receiving long-term services and supports assume financial responsibility for their parents’ or grandparents’ care;

- provide the spouses of people receiving Medicaid home- and community-based services with the same financial protections afforded community spouses of nursing home residents;

- define the word “estate” under the estate recovery program no more broadly than the term is defined under state probate law—Heirs should have an extended period of time to reimburse the state so they are not forced to sell the deceased person’s home and should be protected from coercive tactics designed to force repayment of Medicaid expenditures. States should use all money recovered from the estates of Medicaid recipients to improve the program;

- establish procedures for waiving estate recovery and the transfer-of-assets penalty when undue hardship would result; and

- exempt Medicaid recipients who receive home- and community-based waiver services from estate recovery programs—States should not place liens on the property of Medicaid recipients who receive long-term services and supports in the home and community.

**STATE POLICY**

**ACCESS TO LONG-TERM SERVICES AND SUPPORTS**

**Strengthening Financial Protections for Medicaid Beneficiaries and Their Families**

States should:

- maintain the medically needy programs for nursing home residents and keep the income test at 300 percent of the Supplemental Security Income program’s benefit level,

- enact a medically needy program if they do not have one,
- apply medically needy programs to both institutional and home- and community-based long-term services and supports, and
- set the highest “community spouse resource allowance” and “spousal maintenance needs allowance” possible under federal law to provide community spouses with the greatest financial protection.

ACCESS TO LONG-TERM SERVICES AND SUPPORTS

Background

Expanding Home- and Community-Based Services

People of all ages prefer to receive long-term services and supports (LTSS) in their own home whenever possible or in home-like environments such as supportive housing. In a group residential setting, this kind of housing provides nonmedical care and assistance with activities of daily living. Supportive housing makes it possible for people who do not require the level of care provided by nursing homes to obtain services and remain independent in a home-like setting rather than move to an institution (see Chapter 9, Housing: Supportive Housing for descriptions of supportive housing options, including assisted-living residences, congregate care facilities, continuing care retirement communities, board and care homes, and adult foster care homes).

More than three-quarters (78 percent) of older Americans in need of long-term services and supports live in private homes or apartments in the community. Most do not receive paid services; unpaid family members and friends provide the majority of long-term care. However, these caregivers often need to supplement the care they provide with paid home- and community-based services (HCBS). Moreover, as levels of disability increase, the need for paid long-term services and supports becomes greater.

Medicaid coverage of HCBS—The LTSS portion of the Medicaid program has a bias toward nursing home care, which is a mandatory benefit, although spending on HCBS has been increasing (Figure 7-3). Total Medicaid expenditures for long-term services reached $83.8 billion in 2003. Sixty-seven percent of these funds paid for nursing home care and intermediate care facilities for people with mental retardation, while just 33 percent paid for HCBS. States have several options for providing long-term HCBS under Medicaid. All states must provide medically related home health care to people who meet the eligibility criteria for nursing home care. The Medicaid state plan also may provide HCBS through optional benefits for case management or personal care services. To receive services under the personal care option, beneficiaries must meet the standard financial criteria for Medicaid, which generally require that a recipient’s income be at or below
the Supplemental Security Income level, which is lower than the poverty guideline.

States also may provide HCBS to some categories of people through waiver programs, so called because states must obtain waivers from certain federal Medicaid requirements (e.g., the requirement that services be available to people in all parts of the state) in order to offer these programs. States have more flexibility to determine financial eligibility in waiver programs than they do in the regular Medicaid program. For example, they can use the higher income levels allowable for applicants for Medicaid nursing home coverage. Since 1998, however, 13 states have had more restrictive income eligibility criteria for waiver participants than for nursing home participants. In two states, the amount of income a person can have and still receive Medicaid nursing home benefits is triple that for receiving HCBS through Medicaid. In 11 states, applicants with incomes over the allowed amount can spend down their assets and become eligible for nursing home care but not for waiver services. Participants must spend the excess income (income over the allowed amount) on long-term services and supports or medical services. States may allow beneficiaries to have somewhat higher levels of income, but these participants must spend some of the excess income to help pay for services received.
A major barrier to expanding Medicaid’s HCBS waiver programs is the eligibility requirement that people be at risk of institutionalization. States determine this risk by requiring waiver applicants to meet the same health and functional eligibility criteria required for nursing facility admission. Because of concerns about nursing facility costs, several states have very stringent criteria. Yet since the states use the same criteria for home- and community-based waiver services, more stringent criteria result in fewer people being eligible for both nursing facility care and waiver services. In addition, people who are eligible may be too ill or impaired to be cared for safely and cost effectively in HCBS settings.

Every state provides HCBS through waiver programs. (Arizona is the only state with a special statewide Medicaid Section 1115 waiver to provide a continuum of LTSS on a prepaid capitated basis to elderly people, people under age 65 with physical disabilities, and people with mental retardation or developmental disabilities. See Chapter 6, Health Care: Health Care Coverage—Publicly Administered Health Insurance—When Medicare and Medicaid Meet.) In addition, from 1998 to 1999, 26 states used the personal care option to provide at least one form of HCBS to adults. An additional five states used the personal care option to provide HCBS to children only.

In fiscal year 2003 Medicaid paid $6.3 billion for personal care services, $18.6 billion for waiver services, and $2.9 billion for home health care. Expenditures for long-term HCBS have been growing more rapidly under Medicaid than have expenditures for institutional care, primarily because states are trying to serve more people in less costly HCBS settings, which is where most consumers want to be served. Despite the cost increases HCBS accounted for just 33 percent of total Medicaid LTSS spending in 2003; institutional care—including nursing homes and intermediate care facilities for people with mental retardation—accounted for 67 percent.

The US Supreme Court’s 1999 decision in *Olmstead v L.C. and E.W.* held that the Americans with Disabilities Act prohibits states from unnecessarily institutionalizing people with disabilities and from failing to serve them in the most integrated setting appropriate to their needs, if the provision of community services represents a reasonable accommodation. The *Olmstead* decision has direct implications for state Medicaid programs and states’ ability to serve people with disabilities in home- and community-based settings. Currently, most states are engaged in planning processes designed to identify the barriers to serving people with disabilities in home and community settings and to develop strategies for expanding HCBS.

**Presumptive and expedited eligibility**—Federal rules require that determinations of financial eligibility for Medicaid be made within 45 days from the date of application, or within 90 days when a disability determination must be made. Delays in determining Medicaid eligibility can be a barrier to accessing services in the home or community. Nursing homes
are generally more willing to admit individuals while their Medicaid application is pending; community service providers are less likely.

A presumptive eligibility option can ensure that delays in the Medicaid eligibility process do not result in unnecessary nursing home placements. Presumptive eligibility allows eligibility workers or case managers, nurses or social workers to decide whether the individual is likely to be eligible and to initiate services before the official determination has been made by eligibility staff. Currently, the federal government reimburses for erroneous decisions for only three categories of Medicaid beneficiaries: pregnant women, children under the age of 19, and patients with breast or cervical cancer. Several states use presumptive eligibility for HCBS, despite the lack of federal reimbursement for erroneous decisions.

In addition to presumptive eligibility, some states use a variety of other strategies to address the barrier to community services caused by delays in the Medicaid eligibility process. One strategy is to expedite (but not presume) the Medicaid eligibility process for HCBS waiver applicants. Another strategy is to provide interim services to HCBS waiver applicants through a state-funded HCBS program.

**Other state approaches to expanding access to HCBS**—States have a strong interest in reducing institutional LTSS and shifting resources to home- and community-based services because of consumer preference and potential cost savings. Many states view HCBS as cost-effective alternatives to nursing home care because services typically cost less per person.

States are improving access to affordable LTSS outside the Medicaid program in a number of ways, for example, by targeting individuals with serious mental illness for state-funded services. In some states these programs provide important LTSS to people who do not meet Medicaid’s financial or health and functional eligibility criteria. In other states these programs offer services to Medicaid beneficiaries that are not available through the Medicaid program. States also administer federal block grants, many of which can be used to fund LTSS, and can establish programs such as volunteer credit banks, which enable volunteers to earn LTSS credits by providing services and supports and to redeem credits when they require services.

Some states have certificate-of-need programs to limit the supply of nursing home beds in the state. However these programs in and of themselves will not expand HCBS unless states initiate nursing home diversion programs, create alternatives to institutional care, and increase funding for these alternatives. Nursing home diversion programs can help people who need LTSS stay in their homes or other community settings.

In an attempt to meet consumer demand for self-directed, more accessible and affordable home and community services, some states have allowed
registered nurses to delegate some nursing tasks to unlicensed direct-care staff in home-care settings. To ensure nurse participation, this approach requires liability protection for nurses and high-quality training and supervision of unlicensed direct-care staff.

FEDERAL & STATE POLICY

ACCESS TO LONG-TERM SERVICES AND SUPPORTS

Expanding Home- and Community-Based Services

Congress and the states should expand funding for a wide range of home- and community-based services through Medicaid, the Older Americans Act, the Social Services Block Grant program, and other programs that offer long-term services and supports. Expanded funding should include provisions for tracking fraud and abuse (see Chapter 8, Social Services and Education for additional discussion and policies related to these programs).

The federal government should vigorously enforce the Americans with Disabilities Act (ADA) and help states to expeditiously develop and implement state plans to deinstitutionalize nursing home residents and expand services to people with disabilities in community settings. This applies only when the residents can be adequately cared for in the community and do not oppose moving to the community, as required by the ADA and the US Supreme Court’s Olmstead decision.

FEDERAL POLICY

ACCESS TO LONG-TERM SERVICES AND SUPPORTS

Expanding Home- and Community-Based Services

The federal government should:

- eliminate Medicaid’s bias favoring nursing homes in the funding of long-term services and supports by mandating the provision of home- and community-based services (HCBS) for all people who meet Medicaid eligibility criteria and choose to receive services in home- and community-based settings;

- ensure that HCBS are adequately monitored to prevent fraud and abuse;

- amend the Supplemental Security Income program’s regulations that reduce benefits for beneficiaries who live with family members, creating a disincentive to family caregiving; and

- permit states to implement nursing facility and waiver eligibility criteria that recognize the need for a comprehensive array of long-term services
and supports. States should have more flexibility to set separate eligibility criteria for nursing facility care and waiver services. Only people who cannot be safely, adequately, appropriately and cost-effectively served in the community should be admitted to nursing facilities, unless they choose to receive services in a nursing facility.

STATE POLICY

ACCESS TO LONG-TERM SERVICES AND SUPPORTS

Expanding Home- and Community-Based Services

States should carefully evaluate the need for all of the different kinds of long-term services and supports (LTSS) and should design their budgets and policies to eliminate institutional bias, expand access to home- and community-based services (HCBS), and allow consumers to choose the setting in which they receive services. States also should:

■ expand HCBS through waiver and optional personal care programs—Particularly important are programs that provide LTSS for low-income residents of assisted-living or board and care homes who are at risk of entering a nursing home. However, individuals who currently receive Medicaid services should not be forced to move or have benefits reduced by the implementation of a waiver or other program;

■ allow presumptive eligibility and establish other processes to reduce delays in Medicaid eligibility determinations, help avoid unnecessary nursing home admissions, and increase access to services in the home and community;

■ develop and implement plans that address the Supreme Court’s *Olmstead* decision—These plans should include specific action steps, timelines and strategies for securing the necessary funding for HCBS;

■ ensure that consumers fully participate in designing, implementing and monitoring state *Olmstead* plans and waivers at the state and local levels—Such participation would include serving on advisory committees and governing boards;

■ offer Medicaid optional services, including care management, personal care and adult day services;

■ establish policies to pay relatives and friends who care for people with LTSS needs as part of a plan of care, and design programs and policies to protect consumers and avoid the erosion of family care networks—Programs and policies should protect consumers, guard against fraud and abuse, and avoid disincentives for unpaid caregiving;
identify barriers that unintentionally curtail consumers’ ability to self-direct their care or to arrange to have limited nursing tasks provided by unlicensed direct-care staff who are authorized and trained to do so by a registered nurse—States must ensure that registered nurses are protected from liability if they have followed prescribed protocols for the delegation, training and supervision as outlined in the states’ nurse practice acts;

initiate nursing home diversion programs and expand the availability of home- and community-based services through LTSS programs funded by state general revenues—These programs should offer a comprehensive range of services to meet beneficiaries’ health and functional needs. At a minimum services should include home care, care management, personal care and respite care. Eligibility for these home- and community-based services must be determined quickly, so that consumers have viable options other than a nursing home. Services should be offered in a range of settings, including supportive housing and adult day centers. In initiating such programs, states must ensure that they do not further limit the access of people with chronic conditions and low incomes to nursing facilities or lead to an increase in the cost of health care or LTSS; and

support innovative programs such as volunteer service credit banks for expanding access to LTSS—These banks should be carefully regulated to protect clients and volunteers and should not be used as alternatives to public LTSS. Regulations should address liability issues and the need to ensure an adequate supply of volunteers.

States with a formal process for allocating the number of nursing home beds should base decisions on the number of people who need a specific level of care and on data projecting the need for LTSS in different areas of the state.

**ACCESS TO LONG-TERM SERVICES AND SUPPORTS**

**Background**

**Appropriate Health and Functional Criteria**

Determining the number and characteristics of people who will receive services is a major policy issue in every long-term services and supports (LTSS) program. People of all ages may need LTSS because of functional impairments of different kinds. They may be limited in their ability, or completely unable, to perform a variety of physical activities, including walking, lifting and reaching.

One component of the functional definition of disability—the ability to perform self-care—is typically measured using the activity of daily living (ADL) scale, which includes eating, transferring (e.g., from bed to chair),
toileting, dressing, bathing and continence. The instrumental activity of daily living (IADL) scale is another measure used to determine people’s ability to care for themselves. IADL includes a person’s ability to manage medications and personal finances, do housework and laundry, shop, and use a telephone and public transportation. As the older population increases, so too will the number of people who need assistance with ADL and IADL.

Potential beneficiaries of publicly funded services must be categorically and financially eligible and must meet health and functional criteria. Then they are assessed for the type and amount of services they need.

In the Medicaid program most states refer to health and functional criteria as “level of care” criteria, because individuals must need a specific level of nursing home care to receive services. People who apply for home- and community-based services through a program (in which a state obtains a waiver from certain federal restrictions) must meet the same eligibility criteria as those who apply for nursing home care. The Medicaid criteria vary among states and among LTSS programs within a state. People who would be eligible for services in one program may not be eligible for another program within the state nor for that same program in another state.

Researchers, policymakers and advocates suggest that eligibility for LTSS be based solely on health and functional criteria and not on financial measures. Once eligible for the program, a person would receive a comprehensive assessment to determine the type and amount of services needed. Because people requiring long-term services and supports are of all ages, with a variety of physical conditions and chronic illnesses, determining eligibility for a program or for specific services can be complex. Eligibility criteria must be appropriate for all these populations and permit the exercise of professional judgment, so exceptions may be made when indicated.

In many states the criteria for determining eligibility for nursing home care or waiver services have a medical bias. More weight is given to medical and nursing needs than to functional impairments, particularly those caused by mental conditions. But existing measures of cognitive and other mental impairments are limited in their ability to indicate whether a person can function independently and to identify those individuals who need services. The need for supervision is a critical factor in determining the presence of cognitive impairment and is an important eligibility criterion. However, adequate measures to evaluate the need for supervision do not currently exist.
FEDERAL & STATE POLICY

ACCESS TO LONG-TERM SERVICES AND SUPPORTS

Appropriate Health and Functional Criteria

Federal and state long-term services and supports (LTSS) programs should have eligibility criteria that appropriately measure the need for LTSS. These measures must accurately assess people with physical impairments, mental impairments and chronic illnesses. People should be eligible for LTSS on the basis of functional needs.

Programs also should include appropriate functional criteria, such as measures of cognitive and other mental impairments, as well as physical impairments. People with physical impairments should become eligible for LTSS benefits if they have difficulty performing two of the five basic activities of daily living.

STATE POLICY

ACCESS TO LONG-TERM SERVICES AND SUPPORTS

Appropriate Health and Functional Criteria

In the absence of federal policy, state governments should develop uniform assessment instruments for use in all state long-term services and supports programs, including Medicaid.

ACCESS TO LONG-TERM SERVICES AND SUPPORTS

Background

Access and Quality Issues for People with Cognitive and Mental Disorders

Older adults with mental disorders include people whose conditions develop in old age and those whose disorders begin earlier and continue as chronic or recurrent illnesses. Mental disorders among older adults encompass a range of serious conditions such as clinical depression, bipolar mood disorders, schizophrenia, Alzheimer’s disease, vascular dementia and delirium. They also include depression, anxiety, and conditions that are the secondary consequences of physical ailments or medical interventions. (A recent National Institutes of Health consensus panel on depression in late life noted that depression in the aging and the aged is a major public health problem.) Alcoholism and other substance abuse disorders also are found among older adults.
The occurrence of some forms of cognitive disorders—Alzheimer’s disease and other kinds of dementia—increases with age. One in ten people over 65, and nearly half of those over 85, have Alzheimer’s disease. A 2000 study found that 27 percent of people in assisted-living facilities had moderate or severe cognitive impairment. (The study included residences that had 11 or more beds, primarily served older people, and provided high levels of service, privacy or both.) By comparison, 60 percent to 70 percent of nursing home residents have moderate to severe cognitive impairment, and 20 percent experience depression.

Too often, mental disorders such as depression go undiagnosed or are misdiagnosed. Moreover, treatment for mental disorders among older people is generally provided by primary care physicians or physicians who lack training in psychiatric care. This problem is exacerbated by the shortage of mental health professionals trained in geriatrics and by the scarcity of nursing facility staff with education and training in the care of people with mental disorders. For example, it is estimated that there will be approximately 2,640 geriatric psychiatrists by the year 2030 (or one per 5,682 older adults with a psychiatric disorder). However, 4,000 to 5,000 geriatric psychiatrists who provide patient care are estimated to be needed to meet demand in the near future, as well as an additional 2,100 physician and nonphysician faculty members to provide training in geriatric psychiatry.

Other professionals who can provide mental health services to older people, including gerontological social workers and geriatric nurse practitioners, are also in short supply. For example, less than 3 percent of graduate students pursuing social work degrees (about 1,000 students) select an aging concentration, although it was projected over a decade ago that 60,000 or more gerontological social workers would be needed by 2020. Other barriers to mental health services are inadequate Medicare and Medicaid reimbursement and a lack of coordination among personnel in long-term services and supports settings.

Nursing homes—Despite the high prevalence of cognitive and mental disorders among nursing home residents, few have access to mental health professionals. In addition, research has shown frequent, inappropriate administration of psychotropic medications to nursing home residents. Also, facilities with fewer than 120 beds are not required to employ a full-time clinical social worker.

The 1987 Nursing Home Reform Act, part of the Omnibus Budget Reconciliation Act of 1987 (OBRA 1987), required nursing homes to develop and administer a resident assessment and care planning instrument to be used upon admission of a resident and every year thereafter. The instrument assesses care needs related to cognitive impairment and behavioral problems, among other issues. The Nursing Home Reform Act also mandated the Preadmission Screening and Annual Resident Review (PASARR) program for states participating in the Medicaid program.
PASARR aims to prevent the inappropriate placement of people with serious mental illness (SMI), mental retardation/developmental disabilities (MR/DD), and related disorders in nursing homes and to ensure that people with such conditions receive necessary treatment and services in the most appropriate care setting.

Federal law requires that people who are eligible for Medicaid and have SMI, MR/DD or related conditions be admitted to nursing facilities only if they meet the minimum standards for admission and their treatment needs do not exceed the level of services that can be delivered in a nursing home setting, either by the nursing home alone or through supplemental services provided or arranged for by the state. Confusion over the PASARR requirements made nursing homes reluctant to admit people with a psychiatric diagnosis or history of depression or who use psychotropic drugs, particularly if they are Medicaid recipients.

In October 1996 Congress repealed the requirement for an automatic annual review of people identified through the PASARR screen. Now, nursing homes must conduct subsequent reviews only in response to a “significant change in the physical or mental condition of mentally ill or mentally retarded nursing facility residents.” However, allowing nursing facilities the discretion to determine when a reassessment is needed (as opposed to having a mandatory annual evaluation) allows them the chance to circumvent the main objective of the program: ensuring that residents with mental illness and mental retardation receive the services they need (see Chapter 6, Health Care for additional information and policies on mental health).

**Supportive housing**—Requirements for assisted-living residences and board and care homes serving residents with cognitive impairments vary greatly from state to state. As of 2002, 36 states reported that they have specific requirements for assisted-living residences or board and care homes serving people with Alzheimer’s disease or other dementia.

**Special care environments**—Special care environments (SCEs) provide specialized care either in terms of tailored services or programs, a discrete unit, or a discrete facility. Because there is no consistent definition or set of standards, there is much variation in the type of services provided in SCEs. A National Institute on Aging study found that SCEs, on average, had better trained staff, programming and facilities than did non-SCEs. Many nursing facilities, supportive housing residences, continuing care retirement communities, and home-care service providers (e.g., home health agencies, respite services and hospice care providers) have developed SCEs or services to meet the needs of residents with dementia. As of 2000, 28 states have enacted specific requirements for SCEs in one or more of these settings.
FEDERAL POLICY

ACCESS TO LONG-TERM SERVICES AND SUPPORTS

Access and Quality Issues for People with Cognitive and Mental Disorders

The federal government should:

■ ensure that people with mental disorders receive necessary treatment and long-term services and supports (LTSS) in the most appropriate and least restrictive setting;

■ develop regulations defining the “significant change” in a person’s physical or mental condition that triggers reassessment under the Preadmission Screening and Annual Resident Review (PASARR)—The rules must recognize that people with serious mental illness may not show significant change but still may have mental health needs;

■ ensure that residents of nursing homes and supportive housing have access to the full range of mental health services provided by qualified mental health professionals with training and experience in treating mental health problems specific to this population;

■ require the Centers for Medicare and Medicaid Services to evaluate why PASARR appears to have been effective in meeting its objectives only in some states;

■ require that staff in special care units who care for residents with cognitive and mental disorders receive supervision from a licensed health care professional with gerontological training or experience and participate in annual continuing education relevant to the condition; and

■ increase funding for research into the prevention and treatment of mental disorders affecting older people, particularly Alzheimer’s disease and other forms of dementia.

STATE POLICY

ACCESS TO LONG-TERM SERVICES AND SUPPORTS

Access and Quality Issues for People with Cognitive and Mental Disorders

States should:

■ ensure that all long-term services and supports (LTSS) training programs, particularly training programs for certified nursing assistants and other
direct care workers, address the care of people with acquired brain injuries or mental disorders such as serious mental illness, mental retardation and developmental disabilities, and Alzheimer’s disease and other dementias;

■ require facilities without a social worker or registered nurse (RN) on staff to contract for social work, RN and other psychiatric and psychological services as needed to ensure that residents with mental disorders and psychosocial problems receive professional help and that physical illness and disorders are not adding to cognitive and mental symptoms;

■ ensure coordination of mental health services with all appropriate health, LTSS and aging network services—At the local level, area agencies on aging should have cooperative working agreements with community mental health centers to meet the mental health needs of older people in the community;

■ establish mechanisms to ensure that LTSS agencies and mental health authorities address the mental health needs of older people who require long-term services and supports and the LTSS needs of people with mental illness; and

■ ensure that people with mental illness or retardation who are not admitted to a nursing home as the result of a Preadmission Screening and Annual Resident Review have home- and community-based services and receive appropriate treatment in the most appropriate setting.

COORDINATION AND INTEGRATION OF LONG-TERM SERVICES AND SUPPORTS

Background

Steps to Improve Coordination

People needing long-term services and supports (LTSS) often require a mix of services to promote their independence, depending on their condition and the amount of assistance they receive from family and friends. They may need limited or 24-hour nursing, assistance with meals, tube feeding, therapy or a range of social services, such as help paying bills or transportation to adult day services.

**Single entry points**—Arranging appropriate services for people with disabilities so they can remain in their community is often daunting. People who may be eligible for public funding face LTSS programs that are fragmented and difficult to access in many states. Services and funding are often divided among different state agencies. To make it easier for consumers to access services, some states use a “single entry point,” in which
a single agency or organization serves as the entry point to all long-term services and supports. In some states, single entry points are actually multiple sites that are coordinated and standardized so that there is no wrong door for individuals seeking services. Such systems aid consumers by offering a local or regional access point where they can receive information and assistance, including needs assessment, care planning and, in some systems, service authorization. Single entry points vary from state to state in the populations they serve and the services they provide. They are most frequently state agency field offices, followed by community-based nonprofits and area agencies on aging.

Single entry points that determine both financial and functional eligibility or coordinate the process can expedite access to home- and community-based services. Yet most single entry points do not determine both financial and functional eligibility.

Care managers—One mechanism for ensuring that LTSS clients receive the most appropriate mix of services is care management—called case management in the Medicaid program and sometimes referred to as service coordination. Care management emphasizes individual choice and control and helps people find and coordinate community LTSS. Many publicly funded state programs use care managers to assess a person’s need for LTSS and organize the delivery of services.

People whose incomes are too high for publicly funded services may hire private geriatric care managers (GCMs) to assess needs, arrange services and monitor care. A well-trained GCM can determine an individual’s needs and then coordinate assistance from paid service providers and unpaid help from family and friends to enable people with disabilities to live as independently as possible. However, consumers need a professional who is trained to assess medical and functional impairment and can advise them on appropriate services and providers. Many GCMs are licensed nurses or social workers, but these licenses do not necessarily guarantee an ability to address a client’s financial or legal questions or knowledge of all service options. In addition, many GCMs are not members of any licensed profession. In most states, any person can call himself or herself a geriatric care manager and offer services to the public. There is little information on whether there is fraud and abuse in this unregulated field and whether clients are getting informed advice.

**FEDERAL & STATE POLICY**

**COORDINATION AND INTEGRATION OF LONG-TERM SERVICES AND SUPPORTS**

**Steps to Improve Coordination**

All federal and state agencies with a key role in financing or delivering long-term services and supports (LTSS) should coordinate their efforts and, when appropriate and feasible, help coordinate activities among LTSS agencies and
agencies serving people who use LTSS (e.g., agencies dealing with income support and housing). For example, the federal government and the states should ensure that LTSS agencies and mental health authorities address the mental health needs of older people in need of long-term services and supports and the LTSS needs of people with mental illness. At the local level, area agencies on aging should have cooperative working agreements with community mental health centers to meet older people’s mental health needs.

Care management should be an essential part of any LTSS system because it can address the fragmentation of present delivery systems and help ensure that clients’ needs are met cost effectively.

**STATE POLICY**

**COORDINATION AND INTEGRATION OF LONG-TERM SERVICES AND SUPPORTS**

**Steps to Improve Coordination**

States should:

- establish a single entry point for people seeking publicly or privately funded long-term services and supports (LTSS)—The entry point should determine functional and financial eligibility for services in a timely manner;

- use a comprehensive assessment to determine beneficiaries’ LTSS needs—States should have uniform assessment instruments to reduce paperwork for people covered by more than one program. Assessments should take into account the different needs of people with different conditions and should focus on both the person’s current level of care needs and his or her potential ability to live in the community with appropriate LTSS; and

- ensure that services to address a person’s health and LTSS needs are appropriately and cost effectively coordinated.

In overseeing care management systems, states should:

- ensure that care management is available through a community organization (such as an area agency on aging) that does not directly provide LTSS—This would not apply to people in managed care programs;

- require training, annual continuing education, and supervision for care managers—States should require care managers to practice according to professional standards and norms, which include attention to recommended safe caseload limits;
- require training for care managers so they can develop high-quality service plans that meet client needs and program cost constraints;

- require care managers to use a client-centered approach that emphasizes the autonomy of the individual, incorporates the client’s goals in the development of the LTSS plan, and develops the service plan in partnership with the client and relevant family members—Care managers should inform consumers about the costs of service options;

- require care management agencies to have strong consumer representation on their boards, particularly consumers who use LTSS;

- require that geriatric care managers, public or private, are registered nurses or clinical social workers with documented geriatric training; and

- ensure that individual care plans are based on clients’ LTSS needs.

**COORDINATION AND INTEGRATION OF LONG-TERM SERVICES AND SUPPORTS**

**Background**

**Integrating Health Care and Long-Term Services and Supports**

In the 1980s Congress authorized two demonstration projects to examine the financing and coordination of health care and long-term services and supports (LTSS) systems. The first project, On Lok Senior Health Services, is a nonprofit community-based organization providing a full range of coordinated health care, LTSS and social services to frail elderly residents of San Francisco. On Lok combines funds from many sources, including Medicare and Medicaid, to provide these services for a capitated payment. The On Lok model was expanded and tested as the Program of All-Inclusive Care for the Elderly (PACE) at sites around the country. The Balanced Budget Act of 1997 changed PACE from a demonstration project to a permanent component of the Medicaid and Medicare programs.

Social health maintenance organizations (SHMOs) represent another type of organized delivery system that integrates acute care and some long-term services and supports—primarily community-based and in-home services—for Medicare beneficiaries who are enrolled in a Medicare+Choice plan (see Chapter 6, Health Care: Health Care Coverage—Publicly Administered Health Insurance—The Medicare Program—Private Health Plans in the Medicare Program—Medicare+Choice/Medicare Advantage). However, the SHMO plans are paid 5.3 percent more than the Medicare+Choice county rates to cover the expanded benefits not provided by Medicare. Congress authorized the first demonstration of SHMOs in 1984 and has since
extended it six times. A revised model, identified as “second generation,” was authorized in 1990 (and begun in 1996) and designed to reflect greater emphasis on geriatric care and more comprehensive case management than the first plans. Three SHMO I plans (in Brooklyn, NY; Long Beach, CA; and Portland, OR) and one SHMO II plan (in Las Vegas, NV) are currently operating. They have a combined enrollment of 115,000 individuals. The SHMO program evaluations showed mixed results. In general, there was no conclusive evidence of positive effects on beneficiaries’ health or functioning. According to the Centers for Medicare and Medicaid Services’ evaluation, any favorable effects were attributable to the characteristics of tightly organized managed care rather than the features of the demonstration. The Medicare Payment Advisory Commission (MedPAC) has recommended that the demonstration be terminated and that the remaining SHMOs be incorporated into the Medicare+Choice program.

**Dual eligibility**—Almost all Medicaid beneficiaries over age 65, and 25 percent of disabled Medicaid beneficiaries under age 65, are also eligible for Medicare. This population, known as dually eligible beneficiaries, makes up less than a quarter of Medicaid beneficiaries but accounts for more than half of program spending. States believe that integrating the financing of Medicare and Medicaid would help control the growth in spending for dually eligible people by improving the coordination of service delivery. Some policymakers believe that the savings achieved in the acute care system could be used to finance additional long-term services and supports. However, the idea needs more research to determine if such savings are realistic.

To implement integrated programs states must apply for waivers from the federal government to provide Medicare and Medicaid services in a manner different from that currently permitted by federal law. To date, Florida, Minnesota and Texas are the only states that have received such waivers, although six New England states, along with Colorado, New York and Wisconsin, are working toward integrated programs.

Changes in service delivery systems that facilitate the integration of health care and LTSS through better coordination of services and other management approaches have the potential to improve care. Such coordination is particularly important for individuals with chronic disabling illnesses. However, to meet the needs of people with disabilities, integrated delivery systems must include the full range of services—preventive, primary, acute, rehabilitative and long-term services and supports.

Integrating Medicare and Medicaid financing could have several negative effects. For example, integrated programs might use a strictly medical model of LTSS to determine eligibility for services, and quality measures give greater weight to medical outcomes than to functional outcomes. Although medical and nursing needs are important factors to consider, functional impairments are critical in determining LTSS needs. Subcontracting long-term services and supports to managed care plans also could disrupt current
provider-beneficiary relationships. Managed care networks might not be able to serve vulnerable populations adequately. In most states these networks are not fully developed and have had little experience providing services to people with physical and mental disabilities and complex health conditions. Finally, there are concerns about turning federal money over to the states and using Medicare trust funds to subsidize Medicaid (see Chapter 6, Health Care for a further discussion of managed care).

**FEDERAL & STATE POLICY**

**COORDINATION AND INTEGRATION OF LONG-TERM SERVICES AND SUPPORTS**

**Integrating Health Care and Long-Term Services and Supports**

Policymakers should use existing Medicare and Medicaid waiver authority to test the integration of health care and long-term services and supports (LTSS), with the following provisions:

- Beneficiaries must retain their rights to full Medicare and Medicaid benefits.
- Enrollment and disenrollment must be voluntary.
- Cost-sharing should be permitted only if it is not a barrier to receipt of services.
- Cost-sharing and other participation requirements must not result in coercive inducements to enroll.
- Strong consumer protections, including an independent ombudsman program and external grievance procedure, must be in place.
- The state and the federal Centers for Medicare and Medicaid Services must provide strong and timely oversight.
- Consumers must participate in the development, implementation and oversight of the waiver program.
- Eligibility criteria for LTSS should consider and appropriately measure the need for these services and supports among people with physical and/or mental impairments and chronic illnesses. Individuals should not have to meet medical criteria to be eligible for LTSS.
- Quality assurance standards, including measures of functional and medical outcomes, must be strong.
Federal and state governments should:

- rigorously evaluate waiver programs to address concerns about quality of care, choice of providers and plans, access to services, grievance and appeals procedures, and financial solvency;

- require hospitals to have discharge-planning programs that help patients obtain the array of equipment and services to meet their home-care needs following hospital discharge—Discharge planners should inform patients of the costs of equipment and services before they are incurred. To effect a smooth transition for the patient, the hospital discharge planner should be required to coordinate planning with the patient’s care manager if the patient has one in the community;

- ensure that Medicaid beneficiaries in capitated plans do not lose their guarantee of LTSS and have timely access to such services;

- prohibit waiver programs from conditioning the receipt of LTSS on enrollment in a managed care plan;

- ensure the participation of beneficiaries and their families and caregivers in developing LTSS plans; and

- ensure appropriate coordination of the full range of health care and LTSS.

LONG-TERM SERVICES AND SUPPORTS: QUALITY AND CONSUMERS’ RIGHTS

Background

The changing long-term services and supports industry—The long-term services and supports (LTSS) industry is undergoing a major transformation. The number of people in nursing homes decreased from 1.8 million in 1990 to 1.48 million in 2000, while the number of people receiving care in other settings, such as assisted-living residences and adult foster care homes and at home, has increased. Some providers now offer varying levels of services, from supportive housing arrangements to skilled-nursing care, all at one location.

A positive aspect of these developments is that older consumers who need services and supports have more choices than in the past. Since most people prefer to receive services outside institutional settings for as long as possible, the growth of noninstitutional alternatives and their often lower costs is a welcome change for both consumers and government funders. However, the growing array of LTSS has surpassed the capacity of many state governments to monitor quality and enforce minimum standards.
Mechanisms for quality improvement and protecting residents’ rights—States monitor quality and protect residents’ rights through licensing requirements that address a wide range of topics related to quality, such as staffing, periodic inspections (called surveys) of providers, and responsiveness to complaints. However, many state regulatory and quality improvement systems are underfunded and poorly staffed, and enforcement mechanisms vary depending on the LTSS setting and the state (see this chapter’s sections on Nursing Homes, Supportive Housing and Home Care for additional information on enforcement in each setting). A range of sanctions may be used, such as levying fines, banning new admissions, requiring a plan of correction, and revoking the facility’s license. Additional quality improvement strategies to supplement state monitoring and enforcement systems include reviewing and revising quality standards and disclosing information on quality to consumers. Federal and state governments have been slow to recognize the need for more comprehensive approaches to quality monitoring and improvement that recognize the diversity of LTSS and promote pro-consumer innovations while sufficiently protecting vulnerable LTSS recipients.

Some policy analysts have suggested that LTSS provider payment policies might be revised to give providers financial incentives to reduce noncompliance and improve quality. Such “pay-for-performance” approaches are gradually being tested and introduced with hospitals and other providers in the Medicare and private health care systems. However, little research has been done to determine effective measures of outcomes in LTSS settings or the most promising ways to risk-adjust those outcomes when reimbursing services in the LTSS system. If state Medicaid reimbursements to LTSS providers are less than the costs of providing quality care, then pay-for-performance programs are unlikely to improve quality.

The Long-Term Care Ombudsman Program, authorized by the Older Americans Act, provides an additional mechanism for ensuring quality and protecting residents’ rights. The program provides ombudsmen for residents of nursing homes and supportive housing in every state. The ombudsmen advocate for residents and investigate and respond to complaints. However, ombudsmen sometimes lack the staff and resources necessary to ensure that complaints are resolved and violations of state standards are corrected. Ombudsmen also do not have the power to enforce laws and regulations.

In 1995 the Institute of Medicine (IOM) published the first and only national evaluation of the ombudsman program. The institute recommended a staffing ratio of one full-time equivalent paid ombudsman per 2,000 long-term care beds. To ensure adequate management of volunteers, the IOM suggested a minimum standard of one paid full-time equivalent ombudsman for every 40 volunteers, while strongly encouraging the programs to maintain paid-staff-to-volunteer ratios at the level of one to 20.
Providers and consumers also have a role in quality improvement. Providers can improve quality through voluntary private accreditation and internal quality improvement programs, in addition to adhering to minimum standards established by the federal government and the states. Mechanisms for consumers to improve quality include resident and family councils and laws allowing for a private right of action, which authorizes individuals aggrieved under the law to bring suit. As of 2000, 21 states had enacted a private right of action for nursing home residents. Sixteen states and the District of Columbia had enacted a private right of action for assisted-living residents.

**Deeming**—Voluntary accreditation has the potential to enhance provider quality and public confidence. Voluntary accrediting organizations also could help develop standards for service delivery. Efforts have been made to “deem” nursing homes, home-care agencies and assisted-living residences that meet private accreditation standards as meeting federal or state licensing requirements. However, this may create conflicts of interest and lack of public accountability, inhibit redress of consumer grievances and enforcement of standards, compromise full public disclosure of documented problems, and fail to provide sufficient consumer/beneficiary representation. A 1998 Centers for Medicare and Medicaid Services study compared the processes and products of accrediting organizations with the current nursing home survey and certification systems and concluded that “the potential cost savings of deeming would not appear to justify the risk to the health and safety of the vulnerable nursing home population.” These findings might also be applied to the deeming of home health agencies and assisted living residences.

**FEDERAL & STATE POLICY**

**LONG-TERM SERVICES AND SUPPORTS: QUALITY AND CONSUMERS’ RIGHTS**

The federal government and the states should:

- require that all settings providing long-term services and supports (LTSS) have staff training sufficient to ensure quality outcomes;

- require that all LTSS settings monitor staff levels to ensure that residents’ needs are being met and make needed adjustments in staffing levels;

- increase support for training programs for surveyors and funds for survey activities—Surveyors should receive thorough and ongoing training about all aspects of nursing facility, supportive housing and home care and the unique needs of older people;

- hire sufficient surveyors to inspect all facilities annually, to conduct follow-up inspections as needed to ensure that quality problems are corrected, and to respond promptly to complaints;
- in conjunction with a strong enforcement system (which includes sanctions for substandard care), encourage providers to establish ongoing quality improvement programs—Such programs should objectively and systematically monitor and evaluate the quality and appropriateness of care, determine ways to improve care, resolve identified problems, and base staffing on residents’ and clients’ care needs. Consumer advocates and consumers should be able to participate fully in quality improvement activities; and

- protect consumers’ access to the judicial system—Legislatures should not limit the amount of punitive damages or joint and several liability, or unreasonably limit damage awards for pain and suffering (see Chapter 13, Personal and Legal Rights: Individual Enforcement of Legal Rights for additional policy on access to the judicial system).

AARP supports voluntary accreditation. However, AARP opposes allowing nursing homes, home health agencies or supportive housing residences to be considered or “deemed” in compliance with federal or state requirements for certification or state licensing requirements simply because they meet the accreditation standards of a private accreditation organization. The federal government and the states should not accept accreditation by private bodies in lieu of federal or state licensing, certification or enforcement of standards. States that permit such practices must monitor closely the performance of these accreditation agencies and their ability to apply federal quality standards appropriately in their accreditation process.

Minimum standards for confidentiality of medical and LTSS records would best be established through a single federal law applicable to the entire health and LTSS system (see Chapter 6, Health Care: Protecting and Improving Health and Access to Care—Health Information, Privacy and Confidentiality).

Further research and demonstration programs are needed to assess the effects of pay-for-performance programs on residents in LTSS settings. States considering basing payments to LTSS providers on improved quality outcomes should first conduct pilot projects developed with strong consumer participation. Such pilot projects should include comprehensive evaluation components to determine the validity and reliability of the measurement instruments used and the pilots’ effectiveness in promoting quality for consumers.

Pilot projects should consider among other factors the audited real cost of providing services and the impact of frozen or declining state budgets. The first element of any pay-for-performance program should be basic reimbursement levels adequate to pay for quality care.
FEDERAL POLICY

LONG-TERM SERVICES AND SUPPORTS: QUALITY AND CONSUMERS' RIGHTS

The federal government should:

■ provide additional resources for monitoring state activity on the quality of long-term services and supports;

■ strengthen requirements for the states to implement long-term care ombudsman programs;

■ establish minimum staffing ratios for state ombudsman programs, equivalent to the Institute of Medicine’s recommended ratios of one paid full-time equivalent ombudsman for every 2,000 licensed long-term care beds within the state and one full-time equivalent paid ombudsman for every 40 volunteers—States should be encouraged to exceed the minimum ratio and maintain a minimum of one paid equivalent full-time ombudsman for every 20 volunteers; and

■ enforce the federal requirement that the ombudsman program be independent of the state regulatory agency.

STATE POLICY

LONG-TERM SERVICES AND SUPPORTS: QUALITY AND CONSUMERS' RIGHTS

States should:

■ protect against abuse and neglect—States should enact laws making institutions liable for criminal and civil penalties for abuse and neglect of those in their care (see Chapter 13, Personal and Legal Rights: Elder Abuse and Protective Services for additional policy on elder abuse and neglect);

■ enact licensing requirements for all long-term services and supports (LTSS) providers, including assisted-living residences, board and care homes, adult foster homes, continuing care retirement communities, hospitals, adult day services, and any agency providing home health or personal care services;

■ set licensing standards to screen out providers whose past performance or current inability to provide services makes them a poor risk for providing high-quality services;

■ bar the following people from owning, obtaining a license for, or receiving construction approvals for nursing homes, supportive housing or home-care agencies: people with criminal records; people with a bad credit history; and providers whose facilities or service agencies have
been cited repeatedly for deficiencies in major quality-of-care requirements, consistently providing poor-quality care, or routinely discriminating against Medicaid recipients;

- set licensing standards that address quality-of-care issues, including requirements for an adequate number of well-trained staff and a range of services to meet consumers’ needs, safety and sanitation and that protect applicants from discrimination;

- monitor quality through performance-based outcome measures, including client satisfaction measures—States should use a common set of assessment and outcome measures to assess performance quality among all types of providers. Monitoring efforts should intensify as problems are detected in quality outcomes and as the complexity and intensity of services increase. States should focus monitoring efforts on improving resident outcomes, with attention to clinical, functional and quality-of-life outcomes;

- ensure that survey results and other information regarding quality, including comparisons with other national standards when possible, are made available to the public in an easily comprehensible format and electronically, if feasible—This information should be updated at least annually and the availability of this information should be publicized;

- collect and make public information about nursing homes, supportive housing, and home-care agencies regarding quality, including staffing levels in nursing homes and supportive housing;

- require providers to have internal quality improvement mechanisms;

- enact, and enforce with all available sanctions, laws requiring mandatory reporting of suspected abuse to appropriate authorities;

- provide whistleblower protections for staff and others who report fraud and poor-quality care to the appropriate authorities; and

- require the establishment of internal appeals mechanisms in long-term services and supports programs for consumers dissatisfied with the delivery, quality or scope of services and set up external appeals mechanisms through a neutral third party—Appeals mechanisms must ensure that consumers receive an immediate decision of their appeal or as rapid a decision as the consumer’s condition requires.

In setting up and administering long-term care (LTC) ombudsman programs, states should:

- collect data for evaluating the effectiveness of the ombudsman program and make information about the program available to the public;
■ implement and fund strong LTC ombudsman programs that go beyond federal requirements and include an adequate number of ombudsmen;

■ require ongoing in-service training and supervision for ombudsmen;

■ extend the purview of the ombudsman program to include noninstitutional care;

■ allow ombudsmen, residents and families and/or their representatives to participate actively in state-initiated enforcement actions by giving testimony or making arguments for or against a proposed action;

■ require that all suspected cases of resident abuse or neglect be reported to the official state ombudsman or the appropriate state agency—Such information should be used in the state survey and certification process;

■ authorize the state LTC ombudsman to sue to redress violations of federal and state law that deal with residents’ rights and quality of care; and

■ coordinate all LTC ombudsman activities and ensure that ombudsmen have adequate funding, including enough funding to monitor home- and community-based services.

LONG-TERM SERVICES AND SUPPORTS: QUALITY AND CONSUMERS’ RIGHTS

Background

Nursing Homes and Supportive Housing

Options for long-term services and supports (LTSS) outside the home include nursing homes and supportive housing settings, such as assisted-living residences, board and care homes, and adult foster care.

Ensuring quality can be difficult, because states often have inadequate numbers of trained and experienced surveyors to monitor all facilities and ensure that problems are detected and corrected. Problems related to staffing—insufficient numbers of staff to meet residents’ needs, inadequate staff training, and problems with recruitment and retention—are among the most common problems affecting quality.

Private right of action—A private right of action exists when a statute authorizes individuals aggrieved under the law to bring suit. With a private right of action, LTSS consumers can sue a provider or the government for breach of statutory or regulatory rights, duties or responsibilities. The primary purposes of the private right of action are to obtain compensation for injuries and ensure performance of duties. A secondary purpose is to
supplement traditional government regulatory enforcement with private oversight and enforcement. Some state legislatures have established a private right of action for both nursing home and assisted-living residents.

Alternative dispute resolution—Residents in nursing homes and assisted-living residences often do not have the resources needed to sue a facility, because of cognitive impairments or limited finances. Mediation and other alternative forms of nonbinding resolution may help with some kinds of disputes, such as when a resident has problems with a roommate. However, alternative dispute resolution is inappropriate for some issues, including disputes about the life, health or safety of a resident (see Chapter 13, Personal and Legal Rights: Alternative Dispute Resolution).

Video technology—Video technology can facilitate frequent visits and communication between nursing home or supportive housing residents and their loved ones. Such virtual visitations can also help family members monitor and document a resident’s care. In 2001 Texas passed a law that protects the right of nursing home residents to request electronic monitoring devices. The state added assisted-living residences to the electronic monitoring statute in 2003. The law requires nursing homes and assisted-living residences to provide reasonable accommodations for electronic monitoring and prohibits them from refusing to admit or release an individual because he or she requests monitoring. The resident must have the mental capacity to make such a request and must place a conspicuous notice on his or her door to alert others to the monitoring. To protect the privacy of roommates, the law requires that residents who wish to use video technology obtain consent of any other residents living in the same room. Other residents living in the same room may condition consent on the camera being pointed away from them or limiting or prohibiting use of an audio monitoring device. Electronic monitoring must stop when a new resident moves into a room until he or she consents to the monitoring.

Unit hold—Residents who are temporarily absent from their nursing home or supportive housing may want to return to their own rooms in the facility following their absence. Federal law requires that when nursing home residents are temporarily absent from the facility, they must be allowed to return to the next available bed in the facility. Medicaid coverage during a temporary absence varies from state to state. Some states provide no Medicaid coverage during temporary absences. In these states, if the residents are unable to pay privately, they may not be able to return to their room or even to the same facility. Laws regarding unit holds in supportive housing residences vary from state to state.

Admitting mixed populations—Recently, concerns have been raised about people with a record of violent crimes, including sexual assault, being admitted to nursing homes and assisted-living residences. For example, incidents of sex offenders living in nursing homes have been reported in many states. Although these offenders may be disabled, they can still put
vulnerable residents at risk. Virtually no facilities have the staffing levels, training and security needed to care for these residents and ensure the safety of other residents. In addition, as states enact mandatory sentencing laws, the possibility increases for potentially violent, elderly offenders being paroled with LTSS needs.

**FEDERAL & STATE POLICY**

**LONG-TERM SERVICES AND SUPPORTS: QUALITY AND CONSUMERS’ RIGHTS**

**Nursing Homes and Supportive Housing**

The federal government and the states should require providers to hold residents’ units for them during temporary absences as long as the fees continue to be paid. Government reimbursement programs should provide funding to hold a unit or bed for eligible individuals during temporary absences of reasonable duration.

The federal government and the states should enact laws that clearly establish the right of nursing home and supportive housing residents—or in the case of residents unable to provide consent, their legally recognized decisionmakers—to use video technology for the purpose of surveillance, documentation of care and virtual visitation. Video technology should be allowed only when protections are in place to ensure that it does not infringe on roommates’ right to privacy. In the case of residents who are unable to provide consent, care must be taken to balance the benefits of video technology with the need to protect the resident’s right to privacy. Such laws should prohibit nursing facilities and supportive housing residences from removing or refusing to admit a resident who chooses to use such video technology.

Nursing homes and supportive housing facilities must ensure the safety of residents. For this reason, agencies that refer individuals to nursing homes or supportive housing should be required to inform the facility when an applicant poses a potential threat to the safety of other residents. Pre-admission screenings should include questions to identify individuals who present a risk of violent behavior. When facilities deny access to an individual who is otherwise eligible for publicly funded services on the basis of a criminal history (i.e., when a judicial sentence has been completed), the federal government and the states must provide for alternative access to needed services. This should include access to services in the home and community, specialized facilities for those who present a risk of violence and need facility-based care, and enhanced family caregiver supports.

The federal government and the states should not parole or pre-release violent offenders to facilities that serve the general population. Individuals subject to the jurisdiction of federal or state correctional agencies who need long-term services and supports (LTSS) should be served by the correctional
agencies in units that meet appropriate staffing and training requirements for their proper care. LTSS agencies and state corrections agencies should begin to plan for release of elderly offenders.

FEDERAL POLICY

LONG-TERM SERVICES AND SUPPORTS: QUALITY AND CONSUMERS’ RIGHTS

Nursing Homes and Supportive Housing

The federal government should:

- conduct research to develop measures of clinical, functional and quality-of-life outcomes and to explore innovative approaches to achieving quality outcomes in both existing and new facilities; and

- couple new standards with financial assistance to states, through Medicaid and other sources, to improve resident services, increase monitoring and enforcement efforts, train operators and staff, and help owners retrofit homes when necessary and feasible.

STATE POLICY

LONG-TERM SERVICES AND SUPPORTS: QUALITY AND CONSUMERS’ RIGHTS

Nursing Homes and Supportive Housing

States should:

- ensure that licensing laws specify the conditions of care for each type of facility, including all subacute and long-term services and supports beds in hospitals and special care units for residents with dementia;

- require all nursing homes and supportive housing residences to create a board or an advisory body to review operations—The board should include at least two independent consumer representatives;

- enforce the family and resident rights of the 1987 Nursing Home Reform Act and require nursing facilities, assisted-living residences and board and care homes to facilitate the formation of community, resident and family councils—Such facilitation includes permitting the posting of notices of meetings, permitting mailings to prospective members, providing a meeting room within the facility, and providing a contact person to respond to the council’s concerns. Facilities should arrange for staff to attend the council meeting and should allow the presence of outside representatives, only upon the council’s request;
■ provide adequate funding to permit state long-term care ombudsmen to visit all facilities;

■ have a full range of sanctions available, including but not limited to, civil money penalties, a ban on all new admissions, monitoring of directed plans of correction, denial of Medicaid payment for new admissions, and appointment of temporary managers and receivers—Remedies should be swiftly imposed, with harsher sanctions for recurring, serious or widespread deficiencies;

■ ensure policies and procedures are in place to safely move residents from unsafe facilities or facilities that can no longer provide care;

■ streamline the administrative and judicial appeals process to minimize a facility’s ability to avoid or delay penalties;

■ encourage facilities to involve family members and the local community in facility activities and help residents develop and maintain relationships in the broader community;

■ guarantee and protect the rights of residents, including the right to pursue a private right of action in court when facilities violate state laws and regulations or the government fails to enforce them;

■ establish a resident’s right to alternative forms of dispute resolution, such as mediation, provided they do not inhibit or discourage residents or their families from resolving disputes through other means, including the federal and state enforcement system, the ombudsman program, and the courts;

■ prohibit facilities’ use of binding arbitration and dispute resolution agreements as a condition of admission or continued stay;

■ ensure a fair and timely hearing process for residents who wish to challenge proposed transfers or discharge decisions—The process should include the same due process protections that apply to Medicaid fair hearings;

■ enact and strictly enforce antidiscrimination and civil rights laws to protect the fundamental right of all nursing home and supportive housing applicants and residents to be free from discrimination (see Chapter 13, Personal and Legal Rights for additional policy on antidiscrimination laws); and

■ ensure confidentiality of resident information.
Nursing Homes

The likelihood of living in a nursing home increases dramatically with age. In 1999 people over age 85 made up 35.8 percent of the total nursing facility population. Compared with supportive housing residents and people receiving home care, nursing home residents, on average, need help with more activities of daily living and are more likely to have cognitive impairment. Thus, nursing homes provide long-term services and supports (LTSS) to the most vulnerable people with disabilities who need protection from poor-quality care, discrimination and rights violations. In addition to providing LTSS, skilled-nursing facilities also provide short-term rehabilitation and postacute care to patients following in-patient hospitalizations. (For additional policy on the care of these patients, see Chapter 6, Health Care: Health Care Coverage—Publicly Administered Health Insurance—The Medicare Program—Original Medicare—Access Issues—Postacute and Subacute Care.)

The 1987 Nursing Home Reform Act—In 1987 Congress responded to widespread concern about poor nursing home quality by enacting the Nursing Home Reform Act, part of the Omnibus Budget Reconciliation Act of 1987. The Nursing Home Reform Act established state requirements for certifying nursing facilities that participate in the Medicare and Medicaid programs. The act established quality standards for nursing homes nationwide, established resident rights, and defined the state survey and certification process needed to enforce the standards.

The 1987 Nursing Home Reform Act includes significant provisions on the rights of nursing facility residents and the rights and responsibilities of ombudsmen. The act’s Residents’ Bill of Rights includes the right to self-determination, personal and privacy rights, transfer and discharge rights, protections of personal funds and against Medicaid discrimination, and the right to be free of physical and chemical restraints. The law also establishes a resident’s right to unrestricted access to visitors who are family members and the right to access to other visitors subject only to reasonable restrictions by the facility. The law also requires each nursing facility to “care for its residents in such a manner and in such an environment as will promote maintenance or enhancement of the quality of life of each resident.”

Under the act, states must implement and enforce a number of provisions on the rights and responsibilities of nursing home ombudsmen. Ombudsman programs and councils advocate for residents of nursing homes and board and care homes.
The law also mandates comprehensive assessments and includes provisions to prevent nursing homes from inappropriately admitting and keeping people with mental disabilities unless they can provide or arrange for appropriate care. Taken together these provisions constituted a major step toward improving the quality of care provided in nursing facilities.

However, the act does not address a number of consumer protection issues, including discrimination against Medicaid recipients in admissions and the financial screening of applicants. Although nursing homes may not require applicants to provide oral or written assurance that they are not eligible for or will not apply for Medicaid benefits, they may ask applicants how they will pay for their care. Some facilities use this information to exclude applicants who do not have the resources to pay privately for a certain period.

Also, the act’s quality standards and protections do not apply to private-pay residents in nursing home beds not certified for Medicare and Medicaid reimbursement. In addition, because some nursing facilities certify only a limited number of beds for Medicaid, private-pay residents who exhaust their savings and become eligible for Medicaid could be discharged if no certified bed is available. The lack of certified beds also makes it more difficult for Medicaid-eligible people to be admitted to nursing facilities.

Enforcement of the 1987 Nursing Home Reform Act—In 1998 the federal government announced the Nursing Home Initiative, a series of steps to improve enforcement of nursing home quality standards. Actions included making inspections less predictable, inspecting more frequently those nursing homes that are repeat offenders with serious violations, and ensuring that state survey agencies enforce sanctions against nursing homes with serious violations.

Although the prevalence of reported serious problems in nursing homes declined following the initiative, the incidence of such problems remains “unacceptably high,” according to a 2003 study conducted by the US Government Accountability Office (GAO). Key findings include:

- Between July 2000 and January 2002, 20 percent of the nation’s nursing homes were cited for an abuse violation that caused actual harm to residents or immediate jeopardy (i.e., placed residents at risk of or actually caused death or serious injury), compared with 29 percent for the prior 18-month period.

- Although state surveyors had improved their detection of serious care problems, such as pressure sores, malnutrition and dehydration, their underreporting of quality-related problems remained a cause for concern. On surveys completed from June 2000 through February 2002, federal surveyors found actual harm or immediate jeopardy in 22 percent of homes where state surveyors had found no such deficiencies, compared with 34 percent for surveys completed from June 2000 through February
2002. This problem reflected weaknesses in state survey methods, a large number of inexperienced surveyors, and the predictable timing of the surveys.

- Policies and procedures for investigating complaints were inadequate in many states. Most state agencies did not investigate serious complaints made by residents, family members or nursing home staff within ten days, as required by law. Fifteen states did not provide toll-free hotlines to facilitate the filing of complaints. Other problems included inadequate systems for managing complaints and failure to prioritize complaints correctly.

- When nursing homes had a pattern of harming residents, states frequently failed to refer a substantial number of such homes to the Centers for Medicare and Medicaid Services (CMS) for immediate sanction, as required.

- Although the CMS had increased its oversight of state survey activities by initiating annual performance reviews, the agency had significantly delayed implementation of three key initiatives—strengthening the survey methodology, improving surveyor guidance for determining the scope and severity of deficiencies, and producing greater standardization in state complaint processes.

In some states there have been attempts to change the enforcement system, for example by establishing an alternative informal hearing process for providers who wish to dispute survey findings and requiring states to pay for the hearing when they lose. Such changes could make surveyors less likely to cite deficiencies and impose penalties.

**Swing beds**—Hospital swing beds that can be converted temporarily from acute care to chronic care use can improve access to services by residents of rural areas with severe shortages of nursing home beds. Swing beds are most appropriate for delivering short-term skilled care. Patients who require skilled nursing or rehabilitative services at a level of care between hospital and nursing home care can receive care in “subacute” or “transitional” care facilities. These facilities may be freestanding or part of a hospital or nursing home.

**Staffing levels**—The Nursing Home Reform Act requires that nursing homes provide, at a minimum, eight hours of registered nurse (RN) and 24 hours of licensed practical nurse (LPN) coverage per day. In addition, the law requires nursing homes to provide the scope of care and services (including sufficient qualified staff) to ensure that each resident can attain or maintain his or her “highest practicable physical, mental and psychosocial well-being.”

A 2002 CMS study titled Appropriateness of Minimum Nurse Staffing Ratios in Nursing Homes evaluated the relationship between staff levels and quality
of care in nursing homes. Based on a representative sample of more than 5,000 nursing homes in ten states, the study identified minimum staffing thresholds below which residents were at significantly greater risk of harm. These thresholds were 2.8 hours per resident per day for nurse aides, 1.5 hours for RN and LPN combined staff time, and .75 hours for RNs. Residents in facilities that fell below the minimum staffing thresholds were at significantly greater risk of the following: hospitalization for potentially avoidable causes, lack of functional improvement, incidence of pressure sores and skin trauma, lack of improvement in resisting assistance from staff (a sign of problems in the relationship between residents and staff), and weight loss.

In addition, more than 91 percent of nursing homes had less than the minimum amount of nurse-aide time per resident necessary to provide five basic care tasks on a timely basis. The tasks are:

- consistently changing wet linens for incontinent residents who could not successfully toilet if given assistance,
- providing timely toileting assistance for incontinent residents who could successfully toilet,
- providing feeding assistance to either physically dependent residents or those with low food intake,
- providing exercise to all residents, and
- providing assistance that enhances the ability of residents to dress and groom independently.

According to the report, these staffing thresholds fall short of the 1987 Nursing Home Reform Act requirement that facilities ensure that each resident attain or maintain his or her “highest practicable physical, mental and psychosocial well-being,” for several reasons:

- The analysis of time needed to perform the five basic care tasks included several unrealistic assumptions, such as very few unscheduled care demands; a convenient facility layout; very high staff motivation, knowledge and productivity; and “unrealistically efficient” deployment of staff.
- The five tasks do not cover all the services that residents might need.
- Even higher levels of staffing would be needed to take into account quality-of-life aspects, such as developing relationships between staff and residents and adjusting to residents’ preferred schedules.

While the absolute minimum staffing thresholds are far lower than levels needed to provide high-quality care, they are higher than the status quo in
most facilities. The study provides evidence that 97 percent of nursing homes had staffing levels that fell below the thresholds the CMS identified as minimally necessary to provide needed care and avoid serious quality problems (see also this chapter’s section Long-Term Services and Supports: Quality and Consumers’ Rights—Qualified Long-Term Services and Supports Personnel).

**Staff training**—The Nursing Home Reform Act requires nursing aides who work in nursing homes to complete a 75-hour certified nursing assistant (CNA) training course and pass a competency test. Many states require more than 75 hours of training, believing that the federal standard is inadequate to protect the welfare of residents and the safety of workers. In the 2002 CMS report on nursing home staffing, a project consultant recommended requiring more than 75 hours of CNA training and adding training in such areas as communication, problem solving and cultural sensitivity to the curriculum requirements.

In 2001 the CMS issued administrative guidance to the states, eliminating CNA training requirements and criminal background checks for workers hired for the sole purpose of transporting residents, e.g., driving a van or pushing a wheelchair. In 2003 the CMS issued new regulations that gave states the option of exempting from the training requirements staff hired to feed and hydrate residents who are unable to eat or drink independently. Such staff would have to receive a minimum of 8 hours of training. Proposals at the federal level and in many states would exempt workers designated to perform various other single tasks for residents (sometimes referred to as single-task workers) from CNA training requirements. Such policies could put residents at risk: Staff might be unable to respond to emergencies and could lack a rudimentary understanding of some of residents’ common conditions, including osteoporosis, incontinence and dementia (see also this chapter’s section Long-Term Services and Supports: Quality and Consumers’ Rights—Qualified Long-Term Services and Supports Personnel).

**Paperwork**—In November 2002 a Department of Health and Human Services advisory panel issued a final report on regulatory reform, which included several recommendations for reducing the time doctors and nurses are required to spend on paperwork. Some of the recommendations have already been implemented. Nursing homes can now use a shorter assessment form for residents covered by Medicare.

**Quality indicators**—The CMS launched the National Nursing Home Quality Initiative in 2002. It promised consumers new information about the quality of care provided in individual nursing homes. It reports ten quality measures on key quality factors, such as pain management, preventable bedsores and use of restraints. The measures fall into two categories: seven for chronic care (long-stay) residents and three for postacute care (short-term) residents.
The ratings are risk-adjusted, so nursing homes that take care of sicker residents do not receive unfairly low scores and the ratings can be compared across all types of nursing homes. A poor score is reason for greater scrutiny of the care provided by a particular nursing home.

The quality measures are still being refined. This is one factor that prompted a recent GAO report to conclude that while quality measures have merit, their use nationally was premature. The GAO expressed concern about the potential for public confusion, as well as doubts about the accuracy of the underlying data.

FEDERAL & STATE POLICY

LONG-TERM SERVICES AND SUPPORTS: QUALITY AND CONSUMERS’ RIGHTS • Nursing Homes and Supportive Housing

Nursing Homes

Quality measures are not a substitute for strong enforcement of quality standards. AARP supports strong federal nursing home quality standards and opposes efforts to deregulate the nursing home industry or change the survey system in ways that could hamper a state’s ability to enforce standards and impose sanctions against poor quality providers. To ensure quality and protect residents’ rights in nursing homes, federal and state governments should:

■ provide effective oversight of nursing homes and create strong sanctions for violations of health and safety standards and residents’ rights;

■ monitor and enforce regulations as mandated by the nursing home quality reform provisions of the 1987 Nursing Home Reform Act and other laws and regulations affecting nursing homes—For example, the resident has the right to immediate and unrestricted access to family members and others with whom they have established relationships (subject to reasonable and nondiscriminatory restrictions the facility may adopt for resident health and safety and facility security). Federal and state governments should provide necessary funding to carry out the provisions of the Nursing Home Reform Act;

■ hire sufficient surveyors to inspect all nursing homes in the time frame required by the Nursing Home Reform Act—AARP opposes proposals to lengthen the period between nursing home inspections;

■ in order to prevent harm to residents, vigorously enforce the Nursing Home Reform Act requirement that facilities ensure that each resident attain or maintain his or her “highest practicable physical, mental and psychosocial well-being”—As a minimum step federal and state governments should establish specific minimum staffing levels not less
than the minimum thresholds identified by the Centers for Medicare and Medicaid Services (CMS): 2.8 hours for nurse’s aides, 1.3 hours for registered nurses (RNs) and licensed practical nurses combined, and .75 hours for RNs per resident per day. The goal should be to increase the thresholds to at least the levels determined necessary to ensure adequate care;

■ enact regulations beyond the Nursing Home Reform Act’s standard of eight hours of RN time per nursing home per day and require nursing homes to have at least one RN or geriatric nurse practitioner with clinical responsibilities on duty 24 hours a day, seven days a week—Waivers should be granted only for professional staff and only if efforts to recruit such staff at adequate pay levels have failed. However, even under a waiver the quality of care and safety of residents must be assured 24 hours a day, seven days a week by providing sufficient professional staff to meet these goals. Ombudsmen should be notified when waivers are requested or granted;

■ encourage additional research that will advance understanding of the relationship between staffing levels and quality of care—CMS should complete, in a timely manner, research to determine staffing levels needed to ensure adequate care and to develop methods to adjust staffing levels based on case mix and the needs of residents;

■ require all unlicensed individuals responsible for resident care, including single-task workers, to complete certified nursing assistant (CNA) training, pass a CNA competency test, undergo a period of probationary supervision, and fulfill annual continuing education requirements;

■ require that nursing home staff are trained and demonstrate needed skills before implementing any new technology or equipment for residents;

■ provide Medicare and Medicaid beneficiaries with a private right of action to sue nursing homes for violating federal laws and regulations or to sue the government for failing to enforce federal laws and regulations pertaining to care and services—Federal and state law should require providers to reimburse the legal costs of beneficiaries or their representatives if the court finds in the beneficiaries’ favor;

■ enforce quality standards similar to those for freestanding nursing homes to protect against improper use of hospital swing beds;

■ closely monitor facilities that are reducing beds, merging or closing—or that have filed for bankruptcy or have other financial difficulties—to ensure that these events do not adversely affect resident care;

■ define uniform service and quality standards for subacute care providers; and
look for additional ways to reduce paperwork in nursing homes without adversely affecting resident care or interfering with federal quality initiatives—Consumers should have input regarding changes made to paperwork requirements.

FEDERAL POLICY

LONG-TERM SERVICES AND SUPPORTS: QUALITY AND CONSUMERS’ RIGHTS • Nursing Homes and Supportive Housing

Nursing Homes

The federal government should ban discrimination in admission practices against Medicaid beneficiaries, particularly through the financial screening of applicants. The secretary of Health and Human Services should ensure vigorous enforcement of such protections.

STATE POLICY

LONG-TERM SERVICES AND SUPPORTS: QUALITY AND CONSUMERS’ RIGHTS • Nursing Homes and Supportive Housing

Nursing Homes

States should:

■ require that all beds in a nursing facility be Medicaid- and Medicare-certified as a condition for the facility’s participating in the Medicaid program;

■ require surveyors to interview residents in private when inspecting facilities and conduct private interviews with family members and independent family councils who request an interview;

■ require facilities to post the Residents’ Bill of Rights in prominent places accessible to residents and families—States should require that facilities give the bill of rights to prospective residents, their families and/or their representatives and provide a translation to non-English-speaking people;

■ require facilities to establish ethics committees to help staff, residents and families deal with end-of-life treatment decisions, such as refusal of nutrition and hydration and do-not-resuscitate orders;

■ enforce standards to eliminate the unnecessary use of physical and chemical restraints—Providers should not use restraints except in an emergency and under a physician’s order; the physician’s order should not last more than 12 hours. “Emergency” should be defined as an unanticipated and rarely occurring situation that poses an immediate and serious danger to the resident or other individuals in the facility. States should ensure that physicians, nursing home staff and families are
educated about the negative effects of restraints and about alternatives to their use;

- require that when restraints are applied, residents are checked on a schedule that is at least as strict as the Centers for Medicare and Medicaid Services (CMS) requirements under the 1987 Nursing Home Reform Act;

- ensure that providers do not transfer residents to facilities that are far from family or friends unless it is a resident’s wish or is unavoidable;

- enact laws against discrimination in admissions based on source of payment, ability to pay or socioeconomic status—States should strictly enforce these laws and monitor facilities to ensure compliance;

- provide access to a separate visiting room for people in semiprivate rooms;

- encourage the development of nursing facility designs that provide privacy and security (e.g., single rooms and private baths), protect residents’ personal belongings from theft, and are responsive to residents’ preferences; and

- require facilities to provide residents or their representatives with a monthly itemized statement of charges.

States should address nursing home staffing issues by:

- requiring that facilities exceed the absolute minimum number of staff, as determined by CMS, to ensure that each resident can attain or maintain his or her “highest practicable physical, mental and psychosocial well-being” as required by the Nursing Home Reform Act;

- creating incentives that encourage providers to hire as many permanent workers as possible—Extensive use of temporary workers is a disincentive to staff recruitment and retention and can lead to poor-quality care because such workers are unfamiliar with residents’ needs and may be inexperienced, and because the high cost of training new staff may divert funds from providing quality care;

- establishing continuing education requirements for registered nurses, licensed practical nurses and nurse aides; requiring employer-provided paid leave for this purpose; and encouraging employers to pay tuition and fees for continuing education; and

- ensuring that social workers and other mental health professionals who work in nursing homes or under contract to nursing homes have training in the special needs of older people and people with all types of physical and mental disabilities.
LONG-TERM SERVICES AND SUPPORTS: QUALITY AND CONSUMERS’ RIGHTS • Nursing Homes and Supportive Housing

Background

Supportive Housing

Supportive housing includes board and care homes, assisted-living residences and group homes that provide or arrange for services and supports, including help with activities of daily living, in a residential setting. In addition, residents themselves can arrange for medical and nursing services if they need them.

Different types of supportive housing provide different levels of service. Board and care homes, for example, provide protective oversight on a 24-hour basis. Assisted-living residences provide similar oversight, minimize the need for residents to relocate as they require greater care, and emphasize a philosophy of individual autonomy, privacy and dignity. They also may offer a higher level of services than board and care homes do. Assisted-living residences usually cost more than many board and care homes, and residents usually pay privately, rather than with public funds (see Chapter 9, Housing for more information on the housing aspects of supportive housing). The availability of supportive housing is growing as increasing numbers of older people need assistance that is less intensive than nursing home care. Critical to the industry’s success will be its ability to innovate and respond to consumer needs and preferences.

Ensuring quality in supportive housing is complicated by several factors. “Assisted living” has no federal definition. Regulation occurs only at the state level, and states use varying definitions. As of 2002, 32 states and the District of Columbia used the term “assisted living” in a licensing statute or regulation. The remaining states used a wide range of different terms to refer to these settings. In these states, consumers may be unsure what to expect in residences that are advertised as assisted-living facilities. In 2002, 28 states reported that their regulations include a statement supporting the philosophy of assisted living. However, some states still regulate assisted-living residences under their board and care regulations, which is usually not appropriate given the philosophy of assisted living.

Homes also vary widely in quality, with the most glaring deficiencies existing in some board and care homes serving mainly Supplemental Security Income (SSI) recipients. Board and care and assisted-living licensing standards and enforcement efforts vary widely. Efforts to identify unlicensed board and
care homes are uniformly weak—and few states require even licensed homes to encourage resident autonomy or privacy. Inadequate regulation and funding have contributed to chronic problems of poor care, financial exploitation and abuse and neglect. The level of reimbursement available through SSI, even with state supplementation, is frequently inadequate to meet minimum food, shelter and service requirements of board and care residents. Potential federal resources for improving the affordability of care include Medicaid community care funds and waivers, low-income housing tax credits, federal SSI supplements, and food stamps.

Although SSI is the major funding source for board and care, the federal government has not played an active role in either guiding the development of board and care or helping states develop effective regulatory systems. The only available federal sanction to enforce standards is to deny benefits to SSI recipients. A federal study indicated that in states with more extensive regulation of board and care homes, residents enjoyed a somewhat higher quality of care and life, as well as more safety features, than did residents in states with weaker regulatory involvement.

**FEDERAL POLICY**

**LONG-TERM SERVICES AND SUPPORTS: QUALITY AND CONSUMERS’ RIGHTS • Nursing Homes and Supportive Housing**

**Supportive Housing**

The federal government should assume a much stronger role in improving the quality of care in board and care homes and ensuring quality in assisted-living residences and other types of supportive housing. Specifically, the federal government should:

- develop common definitions and minimum national standards on services and facilities for board and care homes, assisted-living residences, and other types of supportive housing;

- develop a common base of data on assessment and outcomes;

- conduct surveys of assisted-living, board and care, and other supportive housing residences to ensure that standards are adequately met—The surveys should include information on resident satisfaction, involvement in care plans and outcomes;

- provide increased funding and authority for long-term care ombudsmen to intervene on behalf of supportive housing residents—Residents and ombudsmen should have a private right of action to sue operators that are abusive or fail to maintain state or federally established quality standards; and
require the Social Security Administration to share Supplemental Security Income information with states, while protecting beneficiaries’ privacy rights, to help identify unlicensed board and care homes.

STATE POLICY

LONG-TERM SERVICES AND SUPPORTS: QUALITY AND CONSUMERS’ RIGHTS • Nursing Homes and Supportive Housing

Supportive Housing

States should:

- require all supportive housing residences to maximize each resident’s dignity, independence, autonomy and privacy—All new or retrofitted residences should provide private living quarters, except when residents request to share rooms or apartments;

- require resident assessments and the development and regular updating of individual care plans—Residents, their family members and/or their representatives (as appropriate) should be fully involved in developing care plans;

- require adequate numbers of appropriately trained staff to ensure a high quality of care—Required staff training should include behavioral management; recognition and handling of dementia; handling of medications; cultural sensitivity; and promotion of residents’ independence, dignity and autonomy;

- ensure adequate training and careful supervision in statutes allowing registered nurses to delegate certain nursing tasks to workers in supportive housing—The statutes must provide adequate consumer protections and appropriate liability protections for nurses;

- designate a lead agency to coordinate policy, including licensing, monitoring, improvement and enforcement efforts—Licensing standards and monitoring should reflect residents’ level of disability and the provider’s performance history;

- require public agencies to ensure that the same social and medical services available to people residing in the community are also available to residents of supportive housing;

- ensure that residents and/or their agents have the right to autonomy and privacy and to keep personal possessions, manage personal funds, inspect records of any personal funds the facility manages for them, and meet with advocates and community organizations; and
LONG-TERM SERVICES AND SUPPORTS: QUALITY AND CONSUMERS’ RIGHTS

Background

Home Care

Ensuring the delivery of quality services in home care can be difficult. The quality of home care is monitored primarily by regulation of home-care agencies through a combination of state licensure, Medicare certification, and accreditation by private nongovernmental organizations. Yet these licensing measures are more oriented toward evaluating the quality of medical services than of personal assistance services. As the use of home- and community-based services (HCBS) grows, it is imperative that states develop adequate methods for assuring quality, with appropriate federal oversight for federally funded services.

No quality measures can assess the delivery of services provided daily in hundreds of thousands of private homes across America. Moreover, as people with disabilities take a more active role in the care they receive, the entire paradigm of what constitutes quality is being reevaluated. Many people with disabilities believe that the individual receiving services should be the one to determine this. A worker may be technically proficient at performing personal assistance tasks, but if the services are not delivered in a respectful and caring manner, they fail to enhance the recipient’s quality of life. A great proportion of home-care services are highly personal in nature—bathing, dressing, toileting and grooming. People who require these types of services want to retain their dignity and be treated with respect. New models of quality measurement are beginning to consider not just the quality of service delivery but also the consumers’ quality of life.

In part, concerns like these have fueled the movement to promote consumer-directed services. Many individuals believe that they are more likely to be satisfied with the quality of the care they receive if they are able to hire their own workers, rather than using workers provided through an agency. That way, they are more likely to be able to schedule tasks at the times they most prefer, rather than at the agency’s convenience. Consumers of home-care services also prefer to have the continuity of a single-service provider who can become familiar with their needs and preferences, rather than having to retrain a possibly changing array of workers sent by an agency.

Still, it is critical that states implement the federal requirements of the Omnibus Budget Reconciliation Act of 1987 (OBRA 1987), which upgraded
home health care quality standards and increased accountability for federally reimbursed services.

In addition, current oversight of quality assurance in Medicaid HCBS waiver programs is inadequate. According to the Government Accountability Office, there are no specific federal requirements on how states will ensure quality in service delivery, nor is there specific guidance as to what components make up an adequate quality assurance system. In addition, although the ten Centers for Medicare and Medicaid Services (CMS) regional offices are responsible for ongoing monitoring of HCBS waivers, CMS does not hold these offices accountable for completing periodic waiver reviews. This weak federal oversight results in widespread problems in provision of necessary services, adequacy of care plans, and case managers’ oversight of quality.

FEDERAL & STATE POLICY
LONG-TERM SERVICES AND SUPPORTS: QUALITY AND CONSUMERS’ RIGHTS

Home Care

AARP supports the requirements of the Omnibus Budget Reconciliation Act of 1987, which include beneficiary rights, standards for employee competence, and federal sanctions for failure to enforce standards. The federal government should:

■ require states to conduct annual unannounced in-home surveys that assess client satisfaction, involvement in care plans and outcomes;

■ require states to make complete public disclosure of all survey findings, while safeguarding the privacy of consumers;

■ provide resources so state agencies that staff home health hotlines can train workers to collect, maintain and update information useful to consumers in choosing a home health agency; to receive and investigate complaints about services; and to answer general questions;

■ require states to submit detailed information on their quality assurance approaches when applying for a Medicaid home- and community-based services (HCBS) waiver, including data on the program’s design, methods for discovering quality problems, and methods of remediation and improvement; and

■ hold the Centers for Medicare and Medicaid Services regional offices and states accountable for oversight of the quality of services provided under Medicaid HCBS waiver programs.
FEDERAL POLICY

LONG-TERM SERVICES AND SUPPORTS: QUALITY AND CONSUMERS’ RIGHTS

Home Care

The federal government should:

- develop a range of enforcement options;
- ensure readily available grievance mechanisms;
- develop external review mechanisms to monitor care management and services;
- provide a role and adequate funding for ombudsmen in monitoring the quality of home care;
- gather data and conduct research on standards for quality care, particularly in the area of unskilled care—Special attention must be paid to the development of outcome measures to assess quality of care;
- promote home-care quality assurance standards that are guided by flexible consumer-oriented principles—The principles must provide beneficiaries with access to a broad range of services and providers, safety and freedom from exploitation, the right to participate in care decisions, and maximum self-sufficiency and independence;
- create a national home health aide registry that documents training, lists references, and includes findings of abuse or neglect—Providers would have to clear home health aides through the registry before hiring them; and
- stipulate the necessary components of a quality assurance program for home- and community-based services, including participant access; participant-centered service planning and delivery; provider capacity and capabilities; participant safeguards, rights, responsibilities, outcomes and satisfaction; system performance; and privacy concerns.

STATE POLICY

LONG-TERM SERVICES AND SUPPORTS: QUALITY AND CONSUMERS’ RIGHTS

Home Care

States should:

- require agencies to establish grievance and appeals procedures and
provide clients with copies of notices outlining their right to voice grievances;

■ go beyond requirements of the Omnibus Budget Reconciliation Act of 1987 for home health hotlines and ensure that all clients know, through their patient bill of rights, about the hotline before they come under an agency’s care;

■ ensure that the hotline is adequately staffed during normal working hours and accessible 24 hours a day through voice messaging or other means;

■ require that home-care providers adequately train family caregivers in the use of technology, such as home dialysis and continuous intravenous infusion, and that agencies provide family caregivers 24-hour emergency assistance by telephone;

■ create a unit to coordinate and investigate complaints about each state agency’s response to findings of deficiencies and their disposition, including sanctions imposed—This unit should send a report to the complainant that specifies the corrective action taken;

■ require that clients of all home-care agencies be protected by a standardized bill of rights—Agencies should be required to provide clients and/or their representatives with a copy of the bill of rights and ensure that they understand it;

■ extend the purview of the ombudsman program to include home- and community-based services (HCBS) and ensure that ombudsmen have adequate funding to monitor such services;

■ gather data and conduct research needed for planning and monitoring the cost and quality of HCBS and on ensuring quality services and client autonomy; and

■ prohibit care managers and care management agencies from providing other home-care services, except in areas where the number of providers is inadequate.

LONG-TERM SERVICES AND SUPPORTS: QUALITY AND CONSUMERS’ RIGHTS

Background

Qualified Long-Term Services and Supports Personnel

Personnel problems—from shortages of specific types of personnel to inadequate training or lack of staffing—affect the quality of long-term services and supports (LTSS) provided in nursing homes and in home- and
community-based settings. An insufficient number of bilingual staff or staff who are aware of and sensitive to different cultures is another serious problem.

Staff who have committed abuse or who have criminal backgrounds are a further problem. All states are required to have registries with information on nurse aides who are eligible to work in nursing homes, including their certification information and any proven records of abuse. Some states have expanded their registries to include a variety of other direct service workers, including medication aides, home health aides and developmental disability aides. Increasing numbers of states are requiring criminal background checks of LTSS workers. As of 2003, 40 states required that criminal background checks be performed for certified nursing assistants. The same number of states required statewide criminal background checks of assisted-living staff; 25 of these states barred employment if certain offenses were found. Eight of these states required national background checks of assisted-living staff, and another seven required a national check under specific circumstances, such as when an applicant has recently moved to the state.

Because no national registry of abusive workers exists, people who have a record of abuse or serious crimes in one state can simply travel to another state to find work. Workers with a criminal background or history of abuse can also move from working in nursing homes to home health agencies or supportive housing without ever undergoing a criminal background check.

Of major concern is the lack of registered nurses (RNs), licensed practical nurses (LPNs) and direct services staff, such as home health aides, personal care attendants and certified nursing assistants (CNAs) (see this chapter's section Long-Term Services and Supports: Quality and Consumers’ Rights—Nursing Homes and Supportive Housing—Nursing Homes). People who can afford home-care services often have difficulty locating competent, trained personnel. Most paid LTSS services are provided by direct services staff. Providers are experiencing staffing shortages, especially among direct services staff. Annual turnover rates in nursing homes, supportive housing residences, and home-care agencies are high, in some cases exceeding 100 percent for direct services staff.

Nursing homes, supportive housing residences and home-care agencies have trouble recruiting and retaining direct services staff in part because of low wages and inadequate benefits. Other key factors affecting retention of direct services staff include understaffing, lack of respect or appreciation, lack of opportunity for meaningful input about care and organization of work, inadequate education and training, inadequate supplies and equipment, lack of advancement opportunities, and the physically and emotionally demanding nature of the work. Other factors include a good economy that offers better job alternatives, expanded career opportunities for women, and demographic changes.
The 2002 Centers for Medicare and Medicaid Services (CMS) report on nursing home staffing found that facilities with high staff turnover were significantly more likely to have quality-of-care problems. CMS identified five management practices associated with improved staff retention. They were:

- offering recognition, feedback and the opportunity to see one’s work as valued;
- establishing an organizational culture of valuing and respecting the nursing caregivers and residents;
- offering “high performance” human resources policies in such areas as wages and benefits, training and career ladders, and scheduling;
- establishing “thoughtful and effective motivational work organization and care practices”; and
- maintaining adequate staffing ratios and support for providing high-quality care.

Initiatives to recruit and retain more direct-care workers are now occurring within both government and the LTSS industry. State government actions include:

- wage and benefit “pass-through” legislation, which increases provider reimbursement earmarked for wages and benefits;
- health insurance programs for home-care workers;
- minimum staffing regulations; and
- job training and welfare resources.

Industry practices include job redesign programs and new recruitment, training and career pathways consortia among regional employers.

In addition, many assisted-living residences are developing models of care that maximize personnel resources while promoting client autonomy. For example, some residences encourage training the client in self-help activities. They also cross-train personnel to perform a variety of housekeeping and personal assistance tasks, both to provide more flexible assistance to residents and to give personnel more responsibility for residents’ overall care needs.

Oregon and Kansas allow nurses in assisted-living residences to provide carefully prescribed training for staff in selected skilled-nursing procedures.

Some evidence suggests that the use of geriatric nurse practitioners (GNPs) may improve quality of care for older people and give nurses stronger
economic and professional incentives to enter the LTSS field. Nursing homes seem to be particularly appropriate sites for the specialized care that GNP\s provide, particularly because nursing homes often have trouble recruiting physicians.

Home health aides provide the majority of direct home- and community-based services. The appropriate training and supervision of workers is an essential part of ensuring quality care and should be subject to state approval. The Omnibus Budget Reconciliation Act of 1987 requires states to establish a competency evaluation program for home health aides who provide federally reimbursed services.

FEDERAL & STATE POLICY
LONG-TERM SERVICES AND SUPPORTS: QUALITY AND CONSUMERS' RIGHTS

Qualified Long-Term Services and Supports Personnel

To increase the availability of qualified long-term services and supports (LTSS) personnel, the federal and state governments should:

■ ensure that Medicaid and other public reimbursement for provider labor costs is sufficient to pay wages and offer benefits that will attract and retain LTSS workers—Wages and salaries should be commensurate with the region of service and with the time, skill and effort required to render high-quality services and supports;

■ require pass-throughs or other mechanisms to increase compensation for direct-care workers—These mechanisms should include adequate accountability procedures, such as audits, to ensure that reimbursement increases designated for staffing costs are actually used for that purpose;

■ support payment reform and the provision of adequate health benefits, educational opportunities and career ladders to encourage recruitment and retention of LTSS workers;

■ document the shortage of personnel and their training needs—The federal government should offer matching funds or incentives and technical expertise to help states collect data and assess yearly the adequacy of the supply and competency of LTSS workers;

■ support research to identify effective ways of addressing LTSS staffing shortages;

■ fund education and training for LTSS workers, especially those in short supply, such as certified nursing assistants;
support programs to increase the supply of health care personnel with geriatric training (see Chapter 6, Health Care: Protecting and Improving Health and Access to Care—Availability and Training of Health Care Personnel and Geriatric Specialists);

remove barriers to the effective use of geriatric nurse practitioners (GNPs) and other “physician extenders,” where appropriate, in all LTSS settings—States should permit GNPs, working in collaboration with a physician, to perform home visits, and GNPs should be reimbursed directly by Medicare or Medicaid for their services;

encourage education and training programs for all appropriate health professions to require gerontology courses and practical experience in nursing homes and home- and community-based settings;

encourage schools to include LTSS-related specializations—such as home health, supportive housing and nursing home care—in the curricula for nurses and physicians; and

require national criminal background checks prior to employment on all staff who provide LTSS and prohibit employment of individuals who have been convicted of violent crimes or crimes involving abuse or neglect of vulnerable individuals.

STATE POLICY

LONG-TERM SERVICES AND SUPPORTS: QUALITY AND CONSUMERS’ RIGHTS

Qualified Long-Term Services and Supports Personnel

States should establish training requirements for all individuals who provide personal care in home and community settings and are paid through public funds. These training requirements are in addition to voluntary training programs for unpaid family caregivers (see this chapter’s section Access to Long-Term Services and Supports—Support for Family Caregivers—Federal & State Policy).

The programs should include:

- a requirement that providers notify appropriate state licensing or registration boards of all employees convicted of a felony, resident abuse, or having knowledge of but failing to report abuse—After due process the state board should consider suspending or revoking the employee’s license, registration or certification;

- state-approved training, including a core curriculum covering the needs of people who require long-term services and supports and, in particular, the needs of older clients—Such training should include both classroom
instruction and practical experience. Special emphasis should be placed on training programs for family members of special populations (e.g., children) and strengthening training in mental health, services for people with disabilities, health promotion and disease prevention;

- requirements that all workers who provide care in home and community settings pass a competency test, undergo a period of probationary supervision, and fulfill annual continuing education requirements (exemptions should be made for family members who provide care);

- regular training, supervision and documented performance evaluations by home-care agencies and community care providers of their aides and other workers;

- incentives for providers to hire bilingual staff when appropriate and train all staff to be sensitive to clients’ different cultural backgrounds—States also should establish incentives for providers to ensure that workers not proficient in English get training in English as a second language;

- integrated training and competency evaluation programs for home health and nursing home aides;

- training about dementia and in personal assistance for all assisted-living residence staff who have direct contact with residents—The training would result in more flexible assistance to residents, give personnel more responsibility for residents’ overall care needs, and reduce staff frustration and stress. Training and continuing education also should focus on how to maximize quality of care while supporting residents’ autonomy, dignity and privacy; and

- efforts to promote changes in the work environment that encourage staff recruitment and retention—These could include requiring adequate staffing; providing adequate salaries and health benefits; dedicating staff to specific units; encouraging workers’ participation in decisions on resident care; offering training in accordance with government standards; ensuring appropriate supervision and in-service training; providing programs, career ladders and educational incentives to facilitate advancement, and providing day care for children of staff.

States should establish a registry of aides who have completed a training course and passed a competency test. The registry should include documented findings of client abuse or neglect, misappropriation of individual property, and other criminal conduct. States should ensure that ombudsmen have access to the registry. States should also develop a national clearinghouse for sharing information among themselves.
LONG-TERM SERVICES AND SUPPORTS: QUALITY AND CONSUMERS’ RIGHTS

Background

Adequate Funding and Reimbursement Policies

As part of the Balanced Budget Act of 1997 (BBA), Congress repealed the Boren Amendment, which had required states to pay “reasonable and adequate” reimbursement to “efficiently and economically operated” facilities including nursing homes, hospitals, and intermediate care facilities for the mentally retarded. This standard has been replaced by a requirement that states ensure that their rate-setting process is clearly defined and that they provide an opportunity for public comment on the process.

The BBA also enacted a Medicare prospective payment system (PPS) for services provided in a skilled-nursing facility (SNF). Previously, Medicare payments for SNF services were paid on the basis of cost. Under the new system the prospective payments are intended to cover the routine, ancillary and capital costs incurred in treating an SNF patient. The BBA also established an interim payment system intended to control the growth in home health care spending until the Medicare PPS for home health services is in place. Before the BBA, home health agencies were paid by Medicare on the basis of cost, subject to limits based on cost per visit.

In response to the perception that BBA payment reductions to SNFs and home health agencies were too deep, the Balanced Budget Refinement Act of 1999 increased Medicare payments to SNFs and home health agencies. Additional reimbursements were required by the Budget Improvement and Protection Act of 2000. However, the debate among providers, consumers and policymakers concerning adequate reimbursement continues.

Nursing facilities and other long-term services and supports (LTSS) providers cannot ensure high-quality services without adequate funding. In some states, Medicaid’s low nursing home reimbursement rates may adversely affect quality of care and reduce access by causing facilities to leave the Medicaid program. Furthermore, Medicare’s change from a cost-based to a prospective payment system alters the financial incentives for LTSS providers. As a result, Medicare beneficiaries may experience difficulty in obtaining needed care, as providers respond to new incentives.

Many LTSS payment systems use a process called case-mix adjustment to link payment levels to the beneficiary’s need. Case-mix adjustment offers providers an incentive to accept residents who have heavy care needs and give them appropriate services.
Adequate Funding and Reimbursement Policies

In implementing payment changes resulting from the Balanced Budget Act of 1997, federal and state governments should ensure that funding is adequate to safeguard access to high-quality long-term services and supports, without regard to the intensity or duration of care required. To foster efficient delivery of quality care, the federal and state governments should ensure that:

- payments for home and institutional services are adjusted for the resources required to provide appropriate services to people with varying levels of disability;
- reimbursement methods include incentives for rehabilitating and restoring residents to the highest possible level of functioning;
- reimbursement systems require frequent assessment of beneficiary needs;
- residents actually receive the services for which the system pays;
- reimbursement systems are structured to recognize the link between financing and quality and provide incentives to deliver high-quality care;
- reimbursement systems not using case-mix adjustment have other mechanisms to encourage providers to accept residents who have heavy care needs;
- contracts for nursing facility admission define Medicaid-covered services so that facilities deliver appropriate services and do not overcharge residents by billing their personal funds for items or services covered under Medicaid—Regulatory agencies should retain copies of facilities’ contract forms, which should be available to the public; and
- public payments are adequate—Financial incentives (e.g., the use of prospective case-mix reimbursement systems to link payment to the intensity of services provided) should encourage providers to care for all clients, particularly those with heavy care needs. Cases with extraordinary costs outside the normal range require additional rate-setting measures.
The Need for Long-Term Services and Supports

Financing Reform

Although the majority of long-term services and supports (LTSS) are provided by unpaid family members and friends, LTSS can be costly for people who do not have family caregivers available or who need more care than family caregivers can provide. The average annual cost of a private-pay nursing home stay in an urban area is $70,080 for a private room and $61,685 for a shared room, according to a 2004 MetLife study. The total cost of just three home-care visits per week can reach about $13,000 a year. For people with severe impairments and no family support, the cost of home care can be much higher. Costs for other community-based services, such as adult day services and services in assisted-living residences, vary with the services provided. Many people cannot afford to pay for LTSS. Public funding for LTSS is limited, and few LTSS consumers have private insurance that pays for these programs.

The major source of public LTSS funding is the joint federal and state Medicaid program, which pays for nursing home care and a limited amount of home- and community-based services (Figure 7-4). However, Medicaid has stringent financial eligibility criteria. Individuals do not qualify financially for Medicaid unless they have extremely low assets and income, or until they have spent almost all of their assets and income to pay for their health care and LTSS. Medicare, which pays for about 12 percent of LTSS expenditures, funds medically necessary home health care, but beneficiaries must be homebound and need skilled health care in order to receive the benefit. Medicare also helps pay for a limited amount of skilled rehabilitative nursing home care for beneficiaries with skilled care needs who have had a prior hospital stay of at least three days (for policy on these Medicare benefits, see Postacute and Subacute Care in Chapter 6, Health Care: Health Care Coverage—Publicly Administered Health Insurance—The Medicare Program—Original Medicare—Access Issues).
The smaller public programs that provide LTSS include the US Department of Veterans Affairs, the Social Services Block Grant program, and Title III of the Older Americans Act. Each program has its own eligibility criteria and covers only a limited amount of LTSS (see Chapter 8, Social Services and Education for a description of these programs). Most states also have their own LTSS programs paid for out of general revenues, but these programs are limited in the number of people they can serve.

Private sources of LTSS financing include out-of-pocket payments by individuals, donated services provided by unpaid family and friends, and private long-term care (LTC) insurance. Out-of-pocket payments by individuals account for about 27 percent of total LTSS expenditures, a higher share than for health care expenditures (about 20 percent for Medicare beneficiaries). The Department of Health and Human Services estimates that the value of donated long-term services ranges from $45 billion to $94 billion per year.

Many people cannot afford private LTC insurance, which accounts for 8 percent of LTSS expenditures. Such insurance is medically underwritten, i.e., insurance companies charge higher premiums, or deny coverage to, people who have preexisting health conditions that may increase their chances of needing services. This medical underwriting puts LTC insurance out of reach of millions of people who currently need or may later need services. It also may lack important consumer protections and may not cover the LTSS a person needs (see this chapter’s section Financing Long-Term Services and Supports—Private-Sector Approaches—Private Long-Term Care Insurance).
Because of the high cost of LTSS and limited third-party coverage, many older people fear impoverishing themselves and becoming a burden to their families. Clearly, millions of Americans of all ages need LTSS, and the number will increase dramatically in the coming decades. Despite these pressures the US does not have a comprehensive system to finance LTSS. New sources of both public and private financing are critically important. A mix of financing sources (including social insurance, private insurance, individual contributions and tax incentives), accompanied by adequate protections for low-income people, could make it possible to finance LTSS comprehensively and adequately.

**FEDERAL POLICY**

**FINANCING LONG-TERM SERVICES AND SUPPORTS**

### The Need for Long-Term Services and Supports Financing Reform

The criteria for evaluating financing sources for long-term services and supports (LTSS) reform should include the extent to which such sources are progressive, broadly based, stable, and capable of growing with enrollment.

Consistent with AARP’s principles on LTSS, government and individuals should share the responsibility of any additional financing required to implement LTSS reforms. The revenue sources for incremental or comprehensive reform should adhere to the AARP taxation principles (see Chapter 2, Taxation).

**FINANCING LONG-TERM SERVICES AND SUPPORTS • The Role of Public Programs**

**Background**

**Social Insurance**

For the past 60 years, Americans have relied on a combination of social insurance and private insurance to pool risk and offer financial security. The most important goal of social insurance is to provide universal coverage and access; the best examples of social insurance are Old Age, Survivors and Disability Insurance and Part A of Medicare. Medicare provides nearly universal health care coverage for people 65 and older but pays for only limited amounts of skilled care in nursing homes and some home health care. There is currently no social insurance program for long-term services and supports.
FEDERAL & STATE POLICY
FINANCING LONG-TERM SERVICES AND SUPPORTS • The Role of Public Programs

Social Insurance

AARP supports the development of a publicly financed social insurance program that would form the basis of long-term services and supports financing. Individuals would pay into the program and be entitled to benefits defined in law, including a cash payment option, when they need services. Eligibility for this entitlement should be based on functional criteria and social needs that take into account cognitive, physical and social limitations and the need for support, supervision or training.

FINANCING LONG-TERM SERVICES AND SUPPORTS • The Role of Public Programs

Background

Medicaid

Medicaid is the nation’s long-term services and supports (LTSS) safety net. In fiscal year 2003 Medicaid paid $83.8 billion for LTSS, or 32 percent of our nation’s total LTSS expenditures. Institutional care still accounts for the great majority (67 percent) of Medicaid LTSS spending, while spending for community-based services (personal care, home- and community-based care waivers, and home health services) makes up 33 percent. The Medicaid share of total spending for nursing home care has fluctuated between 45 percent and 51 percent since the mid-1970s.

Medicaid plays a central role in providing LTSS to people of all ages with various physical and mental disabilities and is essential to protecting the most vulnerable.

FEDERAL & STATE POLICY
FINANCING LONG-TERM SERVICES AND SUPPORTS • The Role of Public Programs

Medicaid

AARP supports:

- maintaining the federal and state guarantee to long-term services and supports (LTSS) through Medicaid;
- ensuring that people who qualify for Medicaid have a choice between home- and community-based care or nursing home care;
- ensuring adequate federal and state Medicaid funding, and
- expanding the Medicaid program to improve access to LTSS.

FINANCING LONG-TERM SERVICES AND SUPPORTS

Introduction

Private-Sector Approaches

Strategies for financing long-term services and supports (LTSS) also must consider private-sector options, which include private insurance, reverse mortgages, and “living benefits,” which certain life insurance policies offer. Instead of paying the beneficiary at the policyholder’s death, living benefits allow policyholders to receive a portion of their life insurance benefits (see this chapter’s section Financing Long-Term Services and Supports—Private-Sector Approaches—Living Benefits). These financing mechanisms can help some older people meet part of their LTSS costs. However, none of these approaches can pay for all or even most of the nation’s LTSS expenses, because the private sector cannot offer universal coverage or full insurance protection. The primary answer to the LTSS financing dilemma still lies with the public sector.

FINANCING LONG-TERM SERVICES AND SUPPORTS • Private-Sector Approaches

Background

Private Long-Term Care Insurance

Individuals can purchase coverage for nursing home, assisted-living and home-care services through a private long-term care (LTC) insurance policy. In recent years these policies have become more comprehensive; most insurers now cover home health care, respite care, adult day services, assisted living, personal care and hospice care. Some companies offer policy innovations that include reimbursement of family caregivers, payments for caregiver training, and the option to receive a cash benefit that consumers can use for any purpose.

Despite such improvements, these products have limited potential reach. LTC insurance, especially the more comprehensive policies that provide meaningful coverage and appropriate consumer protections, is relatively expensive and unaffordable for many people. For example, in 2002 a typical base policy (i.e., one without inflation protection or nonforfeiture benefits) that paid $150 per day for four years of nursing home, assisted-living and home-care benefits cost from $564 per year for a 50-year-old purchaser to
$5,330 per year for a 79-year-old purchaser. The same policy with 5 percent compound inflation protection cost an average of $1,134 for a 50-year-old purchaser and $7,572 for a 79-year-old purchaser. Most Americans cannot afford these premium costs. In addition, insurers medically underwrite these policies and generally exclude individuals with health problems and those beyond a certain age.

**Policy limits and protections**—Many LTC insurance policies have serious limitations. For example, because LTC insurance is a relatively new product, insurers have limited experience pricing premiums. In the past, to increase market share, some companies underpriced their products and increased premiums later. This practice caused some older people with fixed or declining incomes to drop their policies. Thus, state regulators need to oversee carefully the initial rates and rate increases on LTC policies. The National Association of Insurance Commissioners (NAIC), an organization of insurance regulators from the 50 states, the District of Columbia and the four US territories, develops model regulations that establish high consumer protection standards. States, however, are not obligated to adopt the NAIC standards. In 2000 the NAIC adopted amendments to its LTC model regulation to stabilize premiums and ensure that consumers are aware of the potential for future rate increases when they purchase the policies. As of 2002, 13 states had adopted these recommendations.

When policyholders drop their coverage because it is no longer affordable, they can lose their entire premium investment; insurers are not required to return any portion of it (no matter how large) in cash or benefits if the policy lapses. Policies that require some return of the value of premiums invested have a “nonforfeiture” benefit. Nonforfeiture provides a reduced level of benefits after an insurance policy lapses or has been canceled. However, because it provides only limited benefits—often no more than three months of nursing home care—nonforfeiture is a last resort for consumers who no longer can afford their premiums because of rate increases or life changes. One consumer protection alternative is to give policyholders a contractual right to reduce the amount or duration of benefits, in any combination.

**Consumer information needs**—Because of the high cost and complexity of LTC insurance, prospective purchasers need objective information to help them determine whether to buy private LTC insurance based on their financial circumstances, age, living situation and health status. Such information also would help ensure that consumers purchase appropriate coverage. For example, many people do not buy inflation protection because they are unaware that the value of their daily insurance benefit will erode as the cost of long-term care increases over time. Given the fact that most consumers will have an LTC policy for 20 years or more before they use it, a policy without inflation protection will provide less and less protection each year. It is also important to standardize policy definitions and describe benefit triggers in a clear, uniform format to help consumers compare policies, benefits and costs.
Federal and state efforts to encourage the purchase of LTC insurance—A number of federal and state efforts encourage the purchase of LTC insurance. One approach is the provision of tax incentives. In 1996 Congress enacted the Health Insurance Portability and Accountability Act (HIPAA), which amended the Internal Revenue Code to clarify the tax treatment of LTC insurance, out-of-pocket expenditures for LTC services, and “living benefits.” Some of the major provisions are:

- Taxpayers who itemize deductions can deduct qualified LTC expenses (including qualified LTC insurance premiums), in addition to other medical expenses, as long as their combined medical expenses and outlays for long-term services and supports exceed 7.5 percent of adjusted gross income.

- Employers can offer LTC insurance as a tax-free employee benefit.

- Qualified living benefits are no longer taxable.

Almost half of older people would not benefit from the federal tax deductibility provision, however, because they have insufficient incomes to owe taxes. Many others may not have sufficient deductions to justify itemizing.

While universal coverage is the most effective solution, tax incentives can provide an incremental step toward expanding coverage in the short term.

HIPAA also established consumer protections that LTC policies must provide in order to receive preferential tax treatment (i.e., to be a “qualified” policy). For example, the law established more uniform standards for qualified policies, such as a provision requiring third-party notice if a policy lapses. HIPAA requires that qualified policies be governed by state consumer protection standards similar to the 1993 NAIC model. However, the NAIC has updated its standards almost every year since 1993. Therefore, states retain the authority for ensuring the strength of their consumer protection standards.

As of 2002 federal employees, retirees and their families have access to group LTC insurance coverage, for which they pay the full premium. This new program could serve as a model for private employees nationwide.

In addition, at least 19 states have laws making private long-term care insurance benefits an option for state employees and retirees. Although many states are in the beginning stages of offering private long-term care insurance, as of 2001 five states (California, Colorado, Connecticut, Washington and Wisconsin) had about two years of experience in offering private LTC insurance to their public employees. None of these states helps pay the premiums for policies. Rather, they use their purchasing power to negotiate good-quality products and somewhat better prices than are available to
individuals. Despite efforts by states to increase public investment in private LTC insurance, only a small percentage of state employees and retirees (less than 7 percent) have purchased policies.

As of 2002, 24 states provided either a tax credit or a tax deduction more generous than that allowed at the federal level to purchasers of private LTC insurance.

**Additional concerns**—The enactment of federal tax incentives in isolation from broader reforms raises several other issues. First, the legislation has nearly eliminated the market for nonqualified policies (those that may not receive preferential tax treatment). Currently, only about 10 percent of new policies sold have benefit triggers less restrictive than those allowed under the new law. (Benefit triggers are used to define when a policyholder is considered chronically ill.) Eventually, insurers may stop selling these policies because purchasers will be ineligible for preferential tax treatment.

Moreover, it is unclear whether the Internal Revenue Service (IRS) will tax the insurance payments of policyholders whose levels of disability do not meet the definition of chronically ill under the new tax law. Chronically ill individuals are people who are unable to perform at least two activities of daily living for at least 90 days, who require substantial supervision because of severe cognitive impairment, or who have a comparable level of disability as defined in federal regulations. This definition could be a problem for people with nonqualified policies, who may be eligible to receive home-care benefits at a lesser level of disability than allowed under the new tax law. Unless a beneficiary is severely impaired, the IRS may consider these insurance payments as taxable income.

The IRS also might tax the insurance payments of all nonqualified policies. Under HIPAA, benefits paid by qualified policies will not be taxed, but the law is silent on the taxation of benefits paid under nonqualified policies. The act has unintentionally increased the ambiguity regarding the tax treatment of LTC insurance policies.

**FEDERAL & STATE POLICY**

**FINANCING LONG-TERM SERVICES AND SUPPORTS**

- Private-Sector Approaches

**Private Long-Term Care Insurance**

Private-sector approaches should be considered as partial solutions to the problem of financing long-term services and supports (LTSS).

The public and private sectors should educate consumers about private long-term care (LTC) insurance and other private financing methods to avoid the potential risk of purchasing products that are of questionable value or poorly regulated.
Strong consumer protection standards and regulatory oversight should protect purchasers of LTC insurance from inadequate policies, overly restrictive benefit triggers and abusive sales practices.

In evaluating proposed government incentives to encourage the purchase of private LTC insurance, policymakers should consider both the impact on tax revenues and who will likely benefit from the incentives. Tax incentives should be provided only in conjunction with strong consumer protection standards.

Under a public social insurance system, private insurance could be considered as a supplement to the public system, for example by covering extra services.

LTC insurance should not be funded through pension funds, because many pension plan funds are already inadequate to provide economic security in retirement.

Purchasers of LTC insurance should be advised of the difference between the payment rates their policy covers (e.g., $150 per day, $200 per day) and the actual daily rates for nursing home and home- and community-based care in their area.

Federal and state governments should:

■ improve the quality of LTC insurance by enacting the strongest possible consumer protection standards;

■ implement new insurer reporting requirements so that consumers have access to information in a standardized format that enables them to make comparisons about insurance companies, policies and benefits;

■ monitor the marketplace, ensure adherence to regulatory standards by insurers and agents, and vigorously enforce these standards, including through monetary penalties should infractions or abuses occur;

■ provide incentives for private employers to offer LTC insurance coverage to their employees and encourage employers to pay a part of the insurance premium;

■ ensure that policyholders receive a nonforfeiture benefit if their policy’s premium increases beyond a certain level;

■ provide incentives for insurers to set initial premiums appropriately and limit the number and magnitude of premium increases;

■ ensure that insurers and agents educate prospective purchasers about the importance of inflation protection;
require that all insurance purchasers have the opportunity to select inflation protection when they purchase the policy and periodically thereafter;

require insurers to offer policyholders the opportunity to upgrade their policies in a fair and timely manner;

require that insurers permit reductions in the amount, type and duration of benefits for a reduced premium to people who can no longer afford the full premium—Consumers should receive notice of such clauses when they receive a policy and with each rate increase;

require that insurers offer a full range of LTSS options, including personal care or homemaker services that are portable across all LTSS settings, including assisted living;

encourage the portability of LTC insurance across all geographic areas;

monitor the marketing practices of LTC insurance policies to ensure that such products are not sold to individuals who cannot afford the premiums and to prohibit fraudulent or misrepresentative advertising;

collect adequate data on all aspects of the sale, use and cost of LTC insurance as well as insurers’ marketing practices—These data should include uniform information about denied claims, lapse rates and premium increases. Such data should be insurer- and state-specific and available to consumers; and

encourage LTC insurance companies to provide coverage for both nursing facility care and home- and community-based care services, so that people can receive care in the most appropriate, least restrictive setting and can maximize the LTC insurance benefit.

FEDERAL POLICY

FINANCING LONG-TERM SERVICES AND SUPPORTS

• Private-Sector Approaches

Private Long-Term Care Insurance

Congress should enact minimum national consumer standards for long-term care insurance polices stronger than the standards enacted by the 1996 Health Insurance Portability and Accountability Act. The federal government should ensure that consumers have access to the information needed to compare long-term care insurance policies.
Private Long-Term Care Insurance

States should:

- adopt a rate-stability standard that provides incentives for insurers to set initial rates at actuarially correct levels and minimizes the probability of insurer requests to increase premiums in the future;

- implement consumer protection standards that are at least equivalent to the most current version of the Long-Term Model Act and Regulation adopted by the National Association of Insurance Commissioners;

- require state insurance departments to approve all federally qualified long-term care (LTC) insurance policies sold in the state to ensure that they meet the consumer protection requirements of the Health Insurance Portability and Accountability Act;

- ensure solvency of insurance companies that offer LTC policies by establishing appropriate reserve requirements and monitoring companies’ financial performance;

- provide consumers with a range of comparative information about insurers and their policies, including historical information about premium increases—States should make this information available to consumers in marketing materials and through the state regulator’s website;

- expand the availability of affordable LTC insurance products to private- and public-sector employees, retirees and their families; and

- adopt adequate procedures to review requests for rate increases.

Background

Public-Private Partnerships

Public-private partnerships also can encourage the purchase of long-term care (LTC) insurance. Under this approach Medicaid modifies its asset test for people who buy insurance covering a specified amount of long-term services and supports (LTSS), such as two years of nursing facility coverage.
People still in need of services and supports after they have used all their insurance benefits would be eligible for Medicaid without having to spend down a comparable amount of their assets. Some programs waive the asset requirement entirely for people who privately insure their care in a nursing home for a specified period.

Currently, these partnerships are limited to four states (California, Connecticut, Indiana and New York). At the end of 2003 there were 54,632 active partnership policies in California, 26,938 in Connecticut, 25,103 in Indiana, and 42,881 in New York (New York data are for 2002). These states are not required to seek recovery from the individual’s estate for LTC expenses paid by Medicaid. Other states, which are not exempt from this requirement of the Omnibus Budget Reconciliation Act of 1993, are reluctant to participate in partnership programs.

Careful analysis of such programs is needed to determine their cost to taxpayers and the outcomes for both participants and nonparticipants. For example, no data show that partnerships would reduce Medicaid expenditures. In fact, this approach may increase public expenditures for LTSS if people with significant assets are able to access Medicaid services more easily. Unless states are willing to spend more on Medicaid, additional beneficiaries could reduce the resources available to truly impoverished people who need care.

In addition, many people may mistakenly believe that they will benefit from a partnership policy. For example, people may assume that they would be eligible for Medicaid after their LTC insurance runs out only to find that they do not meet the program’s income test. The Medicaid program also may change over time and varies by state. Because most current partnership policyholders will not need LTSS for many years, they have no assurance that the services covered by Medicaid today will be covered in the future. To date, fewer than 1,500 individuals have received benefits from these programs in the four states combined. There may be other new and innovative approaches that use public and private resources to make LTC insurance or LTSS more accessible.

**FEDERAL & STATE POLICY**

**FINANCING LONG-TERM SERVICES AND SUPPORTS**

- Private-Sector Approaches

**Public-Private Partnerships**

AARP opposes programs that link Medicaid eligibility to the purchase of private long-term care insurance unless these programs:

- do not endanger the Medicaid safety net for low-income people who need long-term services and supports;
have strong consumer protections, particularly regarding nonforfeiture and inflation protection, premium stability, and clear disclosure of current income requirements for Medicaid benefits and the state’s right to change those requirements;

ensure that partnership policyholders are permitted to spend down to meet Medicaid’s income eligibility requirements (this would require that all states have medically needy programs);

guarantee the types of services (particularly home- and community-based services) that the state would provide to eligible partnership policyholders under Medicaid; and

require that states monitor admissions to nursing homes to ensure that equal access is available to everyone on the waiting list regardless of source of payment (see this chapter’s section Long-Term Services and Supports: Quality and Consumers’ Rights—Nursing Homes and Supportive Housing—Nursing Homes—Federal Policy).

FINANCING LONG-TERM SERVICES AND SUPPORTS • Private-Sector Approaches

Background

Living Benefits

Accelerated death benefits and viatical agreements are often called living benefits, and they can aid some people by providing additional sources of funding for long-term services and supports. Consumers can purchase long-term care (LTC) benefits as part of an individual life insurance policy. Under accelerated death benefit riders, the insurer pays a portion of the life insurance benefit to the policyholder instead of paying the beneficiary at the policyholder’s death. Currently, three types of conditions trigger acceleration: terminal illness resulting in life expectancy of less than 12 months; catastrophic (or dread) disease, such as stroke; or permanent confinement to a health facility, such as a nursing home. Payouts are typically limited to 25 percent to 50 percent of the policy’s face value. Accelerated benefits have limitations. Unless the policy includes an LTC rider at the time of original purchase, preexisting conditions may hinder purchase at a later date.

Individuals who are likely to die within six months can sell their life insurance policy to a viatical settlement company for an immediate payout. Viatical settlement companies typically purchase a life insurance policy for 50 percent to 80 percent of the death benefit. Recently the market for viatical settlements has expanded to include terminally ill people with longer life expectancies and even healthy seniors. People with longer life expectancies receive a smaller percentage of the face value of the policy.
FEDERAL POLICY

FINANCING LONG-TERM SERVICES AND SUPPORTS
- Private-Sector Approaches

Living Benefits

Federal and state governments should regulate accelerated death and viatical benefits to ensure full disclosure of information to consumers on the effect of accelerating benefits and should ensure that consumers receive fair actuarial compensation for the value of their life insurance (see Chapter 12, Financial Services and Consumer Products: Financial Services—Investment Issues for more general policy on investments).

FINANCING LONG-TERM SERVICES AND SUPPORTS • Private-Sector Approaches

Background

Reverse Mortgages

Reverse mortgages can allow older people who own their own home—77 percent of older households—to convert their home equity into cash. However, only a few plans allow people to tap their equity to pay for long-term services and supports, and the amount of equity available, particularly to low-income owners, may be limited. Moreover, many older people may be apprehensive about depleting their equity because their home represents their financial security (see Chapter 9, Housing for additional information on reverse mortgages).

Problems also arise when an individual who has a reverse mortgage applies for means-tested public benefits and does not meet the income or asset tests. If the eligibility test excludes the home’s value, theoretically it should also exclude the income and assets a person gains through a reverse mortgage. At the same time, public benefit programs should help those most in need. Policymakers must strike a balance between these two concerns to ensure that people with modest incomes can integrate public and private funding options.

FEDERAL POLICY

FINANCING LONG-TERM SERVICES AND SUPPORTS
- Private-Sector Approaches

Reverse Mortgages

The federal government must require strong consumer protections for reverse mortgage plans. These protections must include assurances that owners can remain in their home for as long as they wish. The federal
government must not further restrict access to public benefits for people who derive income and assets from reverse mortgages.

FINANCING LONG-TERM SERVICES AND SUPPORTS

Background

Managing Long-Term Services and Supports Costs

The public and private cost for long-term services and supports (LTSS) was about $132 billion in 2001, or roughly 9 percent of total US health care spending for that year. While expenditures for nursing home and home care have experienced considerable growth in the last decade, this pattern of growth changed little in 1999 (-0.6 percent) and 2000 (3 percent) compared with previous years. Yet annual growth for all national health expenditures was 5.7 percent in the period from 1994 to 2000, when prescription drug spending accelerated by 13.1 percent.

Projections of LTSS costs and utilization are sensitive to a host of assumptions, including whether longer life will mean more years of good health or more years of chronic physical or mental illness. Other factors include changes in technology, lifestyle, the way services are delivered, the supply of services, and the mix of payment sources. Because of the relatively low birth rates in the US between 1929 and 1945, the increase in individuals age 75 and older during the next two decades will be relatively modest. In addition, medical improvements and the favorable demographic and socioeconomic characteristics of the cohorts entering late life should moderate demand for LTSS. This suggests that demand for LTSS, especially in nursing homes, will grow very slightly, if at all. Demographic and socioeconomic trends are likely to create a more consumer-driven market that will demand higher quality services and a higher quality of life. The relatively manageable increase in demand for services during the next two to three decades presents an opportunity to make consumer friendly changes in the system of public financing for LTSS—before the baby boomers reach late old age.

FEDERAL & STATE POLICY

Managing Long-Term Services and Supports Costs

Avoiding unnecessary institutionalization by providing home- and community-based services—such as home care, care management, personal care, respite care, adult day services and supportive housing—is one of the most important ways to control the costs associated with long-term services and supports (LTSS) (see this chapter’s section Access to Long-Term
Services and Supports—Expanding Home- and Community-Based Services). In addition, beneficiaries of publicly financed LTSS should receive a standardized assessment of their needs to determine the appropriate type and intensity of services.

Other possible approaches to achieving cost savings should include consideration of the following:

- **Global budgeting**—Global budgeting allocates a set level of funds within which providers must operate (whether applied at the federal, state or institutional level). However, global budgets must be based on the projected needs of the population and the anticipated changes in LTSS delivery, and be adjusted for expected inflation.

- **Capitation**—Capitated systems require strong consumer protection standards and accurate inflation and trending factors. Capitated rates also must reflect the needs of the served populations and be sufficient to meet those needs.

- **Improved data collection**—Accurate and timely LTSS data are central to evaluating services and client outcomes and to making sound policy decisions regarding the cost-effective allocation of financial resources. Federal and state governments should ensure that standardized systems collect data on service use, costs and quality, particularly for the Medicaid program.

- **Administrative simplification**—Elimination of unnecessary paperwork and inefficiencies through administrative and systems reform would help contain costs. For example, providers could use standard, simple terms and billing forms, including electronic billing. Current data on nursing home charges and on all other LTSS providers should be available to the public.

- **Curbing fraud and abuse**—States should adequately fund Medicaid fraud and abuse units and investigate and prosecute providers who defraud Medicaid or abuse beneficiaries in all services and supports settings.

- **Care management**—Care management should ensure efficient coordination of client services.

- **Cash options**—Consumers who receive cash payments and manage their own services and supports may do so more economically than they would under an agency-administered model (see this chapter’s section Access to Long-Term Services and Supports—Creating a Consumer-Directed Long-Term Services and Supports System).

- **Risk-sharing**—Organizations and governmental agencies that provide any care management, including health maintenance organizations and
social health maintenance organizations, should share the financial risk of cost overruns and the financial rewards of effective cost containment. Governmental oversight (e.g., periodic audits and look-back surveys) should help prevent conflicts of interest within the care management system.

- **Phased-in coverage**—The benefits under a comprehensive public program can be phased in gradually.

- **Private payments**—A social insurance program should be supplemented by private payments. Protections for people with low incomes must be ensured.