Chapter 8

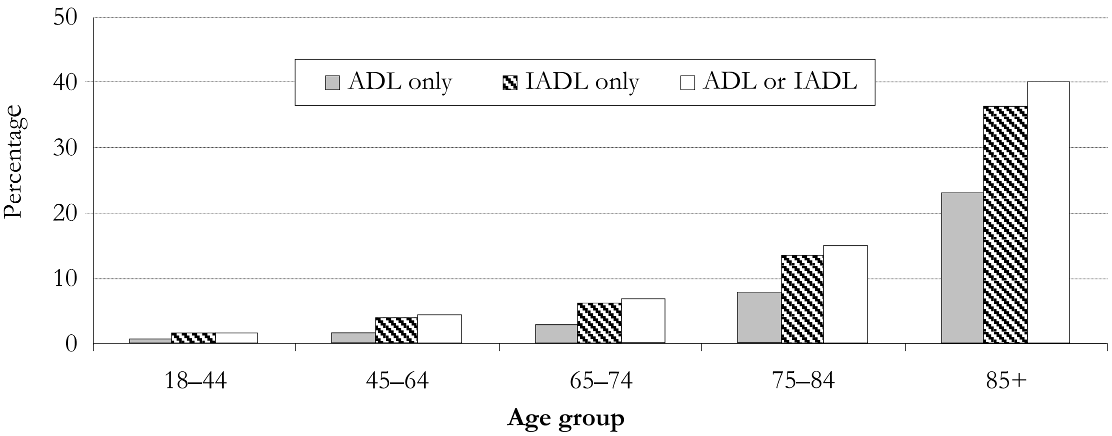
Long-Term Services and Supports

INTRODUCTION

An estimated 5.2 million individuals 18 and older require help with activities of daily living, and 9.8 million require help with instrumental activities of daily living (Figure 8-1). Long-term services and supports (LTSS) generally provide ongoing help with these activities.

Figure 8-1

US Adults with Limitations in ADLs* and IADLs, by Age Group, 2011**



*ADLs are activities of daily living, such as eating, dressing, and bathing and getting around inside the home.
**IADLs are instrumental activities of daily living, such as household chores and paying bills.
Source: NHIS, *National Health Interview Survey, Public Use Data Release,* 2011.
Prepared by AARP Public Policy Institute.

LTSS encompass a broad range of assistance needed by people of all ages who have physical, cognitive, or mental impairments and have lost or never acquired the ability to function independently. LTSS include help with performing self-care activities and household tasks, habilitation and rehabilitation, adult day services, care management, social services, assistive technology, home modification, some medical care, and services to help people with disabilities maintain employment. They are provided in the home, in assisted living and other supportive housing settings, in nursing facilities, and elsewhere. LTSS include supports provided by family members, friends, and unpaid caregivers. It also includes supports provided to family members, friends, and other unpaid caregivers, such as care consultation, education and training, counseling, support groups, and respite care. 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.

The current system for providing and funding LTSS is largely uncoordinated, fragmented, and costly. The majority of services are provided by unpaid family caregivers. Surveys indicate that most people who need LTSS strongly prefer to remain in their homes, especially if less than 24-hour help is needed. When they need or want to move to receive services, people strongly prefer to live in an assisted living residence or other residential setting, rather than a nursing facility. In fact demand for institutional services is predicted to grow very slowly. Despite large increases in the older population, the number of people in nursing facilities declined slightly from 1.5 million to 1.4 million from 2003 to 2008. Further declines are likely in the near future as the result of increased service options available to older people with disabilities, the growth of home care and assisted living, increased use of technology, and increased public funding for home- and community-based services.

However, because of the high cost of services; lack of private, affordable financing options; and limited public funding, people often do not have access to the service options they prefer. Others cannot find the services they need and prefer or are unaware of what is available.

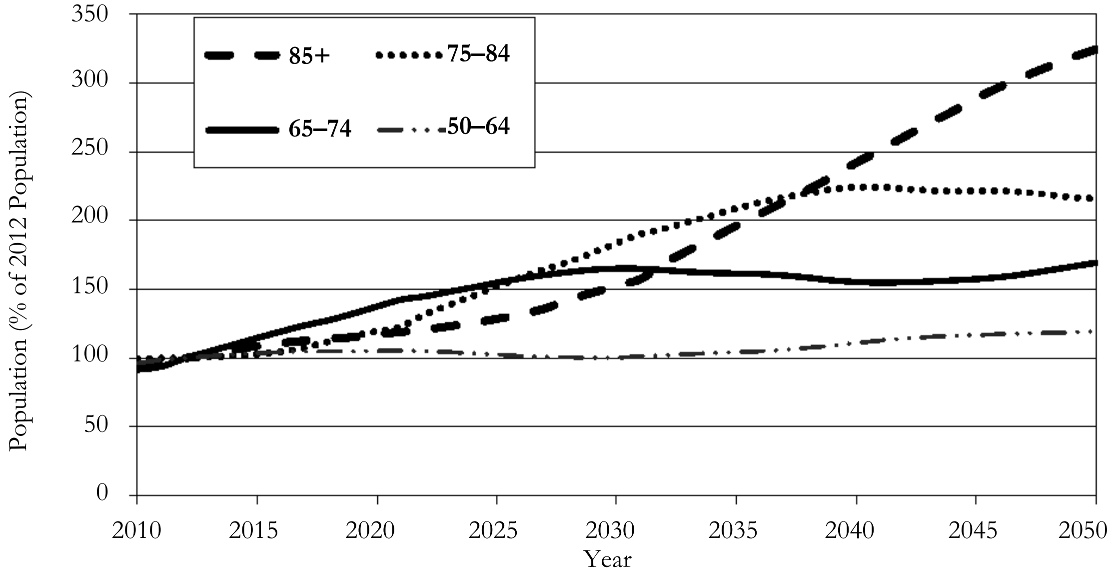
Medicare provides only modest funding through limited coverage of short stays for rehabilitative care in nursing facilities and some home health care services. And so, the major public financing for LTSS comes through the federally and state-funded Medicaid program. But Medicaid's stringent financial eligibility criteria require people to exhaust most of their assets and income to qualify for coverage. Programs to assist unpaid family caregivers are limited, even though they provide the lion's share of LTSS.

Moreover, rising expenditures make Medicaid a frequent target for both state and federal budget cuts. Private long-term care (LTC) insurance is too costly for many older Americans. Insurance companies can also increase premiums for entire classes of individuals (e.g., all policyholders age 75 or older) based on their experience in paying benefits. Raising premiums on older Americans can price existing policyholders out of the market. Private LTC insurance may also be unavailable to some individuals because of medical underwriting; people with preexisting health conditions, for example, may not qualify for coverage. Consumers who purchase private insurance cannot always predict their future needs accurately. As a result, their policy may not provide or pay for the services they need or want at the time they attempt to use benefits.

Yet the number of people needing LTSS is expected to rise after 2021, when the oldest baby boomers begin to turn 75. A better barometer for the potential demand for LTSS is the growth in the population age 85 and older, which is expected to increase 224 percent between 2012 and 2050. People age 85 or older not only have much higher rates of disability, but they are also much more likely to be widowed and without someone to provide assistance with daily activities (Figure 8-2).

Figure 8-2

Projected Growth in the Older Population in the United States as a Percentage of 2012 Population, by Age Group

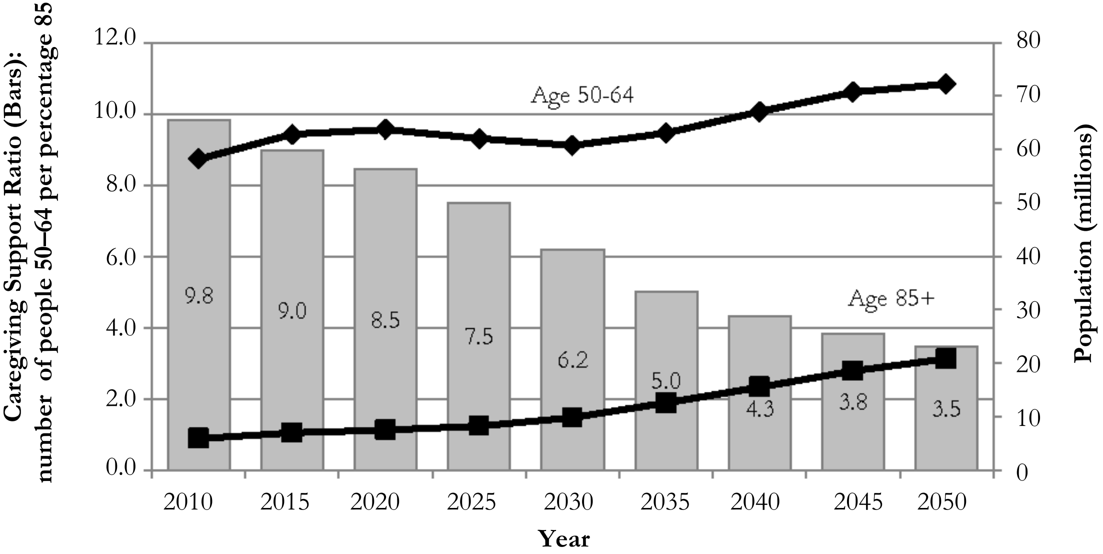


Source: REMI (Regional Economic Models Inc.) 2012 baseline demographic projections.
Prepared by AARP Public Policy Institute

Given that most people with LTSS needs receive services from family caregivers, it is important to look at changing demographics. As the population most likely to need services (i.e., people age 85 and older) increases, the number of adult children in the primary caregiving years (ages 50 to 64) is declining, due in part to smaller family size. In 2010 there were approximately 10 individuals age 50 to 64 for every one individual age 85 and older, a 10 to 1 ratio. In 2030 the ratio drops to 6 to 1, and in 2050, it falls to 3.5 to 1. As a result the availability of potential family caregivers (mostly adult children) will decline over time (Figure 8-3).

Figure 8-3

Projected Population Age 85+ and Age 50-64, and Caregiving Support Ratio, 2010-2050



Source: AARP Public Policy Institute calculations from REMI (Regional Economic Models, Inc.), 2012 baseline demographic projections.

To address this rising demand, the country needs a comprehensive national LTSS policy. Without it, programs operate individually and fail to achieve the best outcomes for people with health care and LTSS needs. For too long, LTSS have lacked a holistic focus—one that helps individuals overcome the full range of obstacles to living in the least restrictive setting possible and maximizes their potential for self-determination. A comprehensive, person- and family-centered LTSS policy would both serve the needs of individuals, provide support to family and friends to continue in their caregiving role, and allow efficiencies in public spending. A system that starts with the needs of the individual would address personal care, nutrition, housing (including home modification), mobility, and medical needs, which could help prevent unnecessary use of institutions and keep people in their homes and communities.

For LTSS system to be effective, people must be able to access easily an array of affordable choices of services in a variety of settings. This array of services should be high quality and maximize consumers' ability to maintain control over what services they receive and who provides them. Critical to this is the development of state systems that allow people to access a robust range of information and assistance in understanding what services are available and how they might pay for them. Most states are developing Aging and Disability Resource Centers (ADRCs) to be a single source of information and assistance about the full range of services available to people with disabilities, regardless of income or type of disability. A critical function of ADRCs is conflict-free care management services. Care managers who are well-versed in all area services should be available to potential beneficiaries and their families. In order to be "conflict-free," care managers must act without self-interest or financial reward with regard to the services they recommend. Care management and ADRC single points of entry systems are necessary external components to support family caregivers.

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 as it participates in the public debate about LTSS reform at the federal and state levels.

The design and delivery of all LTSS should promote consumer independence, choice, dignity, autonomy, and privacy.

The federal, state, and local governments should recognize and support consumer choices to the maximum extent possible. Consumers have the right to decide on and direct the LTSS they receive. In the event they are unable to do so, they should be entitled to appoint a representative on their behalf.

Public LTSS should give meaningful support to families and friends who provide them. Both existing LTSS programs and any new national program should support—not necessarily replace—the care that families and friends currently give. In a person- and family-centered approach, the needs and situation of family caregivers are assessed and addressed. Families and friends need access to assistance so they are not unreasonably burdened and can continue to provide care. Caregiver assistance should include education and training, counseling, legal consultations, respite care, adult day services, programs that help individuals pay relatives and friends who provide care, and other types of help. In a person- and family-centered approach, family caregivers are also viewed by health and LTSS professionals as part of the care team.

Access to a comprehensive array of LTSS should be guaranteed to all who need them, regardless of age or income. LTSS programs should base eligibility on a person's physical and cognitive or other mental functioning and on the types of assistance a person needs. Uniform assessments should determine whether a person meets the eligibility criteria for a program and what type and level of services a person requires. Furthermore financial and functional eligibility should be determined in a timely manner.

LTSS programs should be easy to access and affordable. Consumers and their families should have access to information about the full range of LTSS programs and services that are available to meet their needs. Conflict-free counseling and information should be available to assist families and individuals in choosing the LTSS that align with their preferences. Single points of entry in each state should facilitate system navigation. Services should be affordable for people with moderate and higher incomes and a safety net should be available for those who cannot afford services.

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 responsive to the needs of the individual and be provided in the least restrictive setting appropriate and 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.

The federal and state governments must ensure the delivery of high-quality LTSS. Quality of life is as important as quality of care. The maintenance of quality of life is a critical component of LTSS quality and should include measures of consumer experience. Federal and state governments should protect consumers' health and safety by swiftly and vigorously applying sanctions to enforce laws and regulations against nursing facilities and providers of home- and community-based care. 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.

Services should be organized to promote effective transitions between levels and types of care. LTSS should be effectively coordinated or integrated with social supports and health-related services.

Provider payments should be adequate. Payment to LTSS providers must be reasonable and offer appropriate incentives to deliver high-quality services and supports, including incentives to attract and retain qualified workers and pay them a fair wage and benefits. Reimbursement systems for home, community, and institutional services must respond to clients' needs, promote delivery of quality care, and recognize service outcomes.

The rights of LTSS consumers should be protected. Consumers should have the right to timely information concerning care, including access to their medical records; to meet with advocates; and to express grievances without fear of reprisal. Anyone receiving services from any provider should have a private right of action in court to pursue grievances. Residents of nursing facilities, assisted living facilities, or other residential alternatives, should be protected from undue hardship when they are transferred in the event of a facility closing or other circumstance. In addition, the rights of vulnerable persons who need assistance in times of disaster to remain free from harm should be safeguarded.

LTSS consumers 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 take steps 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.

LTSS programs should receive adequate public financing through a social insurance program. Under social insurance programs like Social Security and Medicare, individuals pay into the system and are then entitled to benefits when they need them. If the cost is spread across the entire population, universal protection can be affordable and equitable. The US should use its resources to finance a LTSS program through taxes, which would go into a trust fund. Revenue sources could include payroll or other taxes, modest premiums, or other cost-sharing mechanisms.

Implementation of any comprehensive public program must ensure orderly development of the new system. Development of an LTSS infrastructure that will permit the delivery of a comprehensive range of home, community, and institutional services should accompany expanded services. Social workers and direct-services workers, care managers, health care, and other needed personnel should be included.

Private-sector insurance should supplement public LTSS financing. A new public program must provide a solid foundation for consumer protection on which the private sector can build. The private sector could supplement the public program with insurance products, which—much like Medigap policies—would cover copayments, deductibles, and services the public program does not provide. Any private-sector approach (e.g., long-term care insurance) should be subject to strong standards that protect consumers from inadequate products and deceptive marketing practices. In addition, individuals with insurance or private funds should not receive preferential treatment in being admitted to nursing facilities and supportive housing.

Public LTSS programs should include cost-containment mechanisms. Cost containment could focus on measures to 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.

REFORMING LONG-TERM SERVICES AND SUPPORTS TO CREATE AN ADEQUATELY FINANCED, COMPREHENSIVE, AND INTEGRATED SYSTEM INCLUDING CONSUMER CHOICE AND SUPPORT FOR FAMILY CAREGIVERS

Achieving Comprehensive Reform

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 at some time in their life, everyone should contribute to the cost of providing them. A social insurance program could cover 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 would be small. A means-tested program like Medicaid, takes a different approach, and 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, and includes consumer choice and support for family caregivers.

LTSS funding and financing—The majority of LTSS are provided by unpaid family members and friends. These services have an estimated economic value of $450 billion for people of all ages, which exceed the value of all paid LTSS services. In addition, many individuals pay out-of-pocket for some or all services. Out-of-pocket payments by individuals account for about 17 percent of total LTSS expenditures.

LTSS can be expensive. The average annual cost of a private-pay nursing facility stay was $87,769 for a private room and $80,975 for a shared room, according to a 2012 Genworth study. The average hourly rate charged by agencies for non-Medicare certified home health aide services was $20, and $19 for licensed homemaker services. The average annual cost for a private one-bedroom unit in assisted living was $41,238, while the cost of adult day services averaged $66 per day. For people with severe impairments and no family support, the cost of home care can be much higher.

While some people pay for LTSS in part through long-term care (LTC) insurance, which accounts for less than 12 percent of LTSS expenditures, many others cannot afford the coverage. 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. LTC insurance 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).

The major source of public LTSS funding is the joint federal and state Medicaid program, which pays for nursing facility care and a limited amount of home- and community-based services. However, Medicaid has stringent financial eligibility criteria. Individuals do not qualify financially for Medicaid unless they have extremely low assets and income or have spent almost all of their assets and income to pay for their health care and LTSS. Medicare, which paid for about 24 percent of LTSS expenditures in 2009, 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 facility 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 Chapter 7, Health: Health Care Coverage—Medicare).

The smaller public programs that provide LTSS include the US Department of Veterans Affairs program, 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 this chapter's section The Older Americans Act and Chapter 6, Low-Income Assistance, for a description of these programs). Most states also have their own LTSS programs paid for out of general revenue, but these programs are limited in the number of people they can serve.

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 may increase in the coming decades. Despite these pressures, the US does not have a comprehensive system to finance LTSS.

Since the establishment of the Social Security program, 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 facilities and some home health care.

The public and private cost for LTSS was about $262 billion in 2009, or roughly 10 percent of total US health care spending for that year. From 2004 to 2009 expenditures for nursing facility and home health care rose 25 percent and 69 percent respectively. Spending on Medicaid home- and community-based services for older people and adults with physical disabilities increased 70 percent. During this same period, spending for all national health expenditures grew by 33 percent and prescription drug spending increased by 30 percent.

Projections of LTSS costs and utilization depend on a host of assumptions, including whether longer life will mean more years of good health or more years of disability. Other factors include changes in technology, lifestyle, the way services are delivered, the supply of services, family supports, and the mix of payment sources.

Although short of a comprehensive social insurance approach to LTSS, in 2010, Congress enacted a new national, voluntary LTSS insurance program as part of health care reform. Called the Community Living Assistance Services and Supports, or CLASS program, most working individuals age 18 and older would have the opportunity to contribute premiums to the program and, after paying for at least 5 years, would be able to receive a cash benefit should they meet the program's eligibility criteria. In October 2011, however, the Department of Health and Human Services decided, primarily because of solvency issues, not to move forward with CLASS. As part of the American Taxpayer Relief Act of 2012, Congress repealed CLASS and created a new LTC commission to study and make recommendations for establishing a comprehensive, coordinated and high quality LTSS system.

ACHIEVING COMPREHENSIVE REFORM: Policy		
Creating a comprehensive long-term services and supports (LTSS) program	FEDERAL STATE	A top priority for AARP is achieving comprehensive LTSS reform. There needs to be a serious national conversation about how to expand options for Americans to plan for and obtain the services and supports they need in the most appropriate setting, followed by federal and state legislative action. An LTSS program should be part of a comprehensive system that provides universal access to a range of LTSS and health care services.
New funding sources including a new publicly financed social insurance program	FEDERAL STATE	New sources of both public and private financing are critically important to providing access to LTSS. A mix of financing sources (including social insurance, private insurance, individual contributions, and tax incentives), accompanied by adequate protections for low-income people, are necessary to finance LTSS comprehensively and adequately. Consistent with AARP's LTSS principles, 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 3, Taxation: Principles). The criteria for evaluating efforts to reform LTSS financing should include the extent to which such sources are progressive, broad based, stable, and capable of growing with enrollment.

New funding sources including a new publicly financed social insurance program (cont'd.)	FEDERAL STATE	Consistent with AARP's LTSS 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. This program would form the base of LTSS financing. Individuals would pay into the program and be entitled to benefits defined in law, including a cash payment option, when they need services and meet the program's eligibility criteria. 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, and training. 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, autonomy, and privacy of individual consumers so they can maximize their physical and psychosocial potential. Services from all providers should be designed and delivered in a way that promotes independence. Consumer-directed LTSS should always be available, promoted, and supported regardless of payer or provider.
Oversight	FEDERAL STATE	The federal and state government should conduct regular, thorough, and consistent oversight to ensure consumers' quality of care and quality of life and protect their rights in all LTSS settings. Strong federal and state oversight is also needed to ensure the equitable treatment of all people eligible to receive services.
Consumer focus	FEDERAL STATE	The consumer should be the focus of all LTSS programs and services. LTSS consumers, including those from diverse communities, should participate in all aspects of program development, implementation, and oversight. Consumers, to the extent they are capable, or their caregivers or legal representatives, should have the option to make decisions about the LTSS they receive and manage their own services and supports. Benefits should be designed to enable consumers to choose services they deem most appropriate for their needs.
Improved coordination with other health programs	FEDERAL STATE	Medicare coverage of health services for those with chronic illness and disabling conditions should be improved (see Chapter 7, Health, for policy on Medicare and chronic care). Care management should be used to coordinate health care and LTSS for people who need both types of services. Care management should be conflict-free, multidisciplinary, and available to all, regardless of payer. Covered services should be fully portable so people can receive them in a wide range of settings. The effects of integrating other public LTSS programs, such as state-funded and Department of Veterans Affairs programs, into a new system should be carefully considered to ensure that program changes enhance participant access. Existing programs should receive adequate federal funding to ensure veterans' access to LTSS.

Flexible, innovative, and efficient administration	Federal State	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. States should be required to implement a single point of entry for LTSS that can determine financial and program eligibility and authorize services in a prompt and timely fashion.
Expanded access to home- and community-based services	Federal State	Eligibility for services should be based on how LTSS relate to an individual's functional needs, chronic illness, and medical condition. Assessments of eligibility for services should measure needs for assistance due to impairments in activities of daily living (ADLs), for supervision due to cognitive and other types of mental impairment and behavioral problems, and for long-term nursing services and medical management. Medicare's potential role in meeting beneficiaries' LTSS and medical needs should be reexamined and 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 ADLs, and adult day care and other services such as respite care. Improved Medicaid benefits should serve as an LTSS safety net for vulnerable populations with low incomes and few assets and for those who become impoverished because of medical or LTSS needs. Services provided through the Older Americans Act and Social Services Block Grant should receive adequate funding because they are important to the home- and community-based LTSS system. Conflict-free care management should be available through public agencies to help individuals and their families access the full range of LTSS.
Neutral financial incentives	Federal State	A comprehensive social insurance program should not provide financial incentives to use one type of care over another. No one service in the array of LTSS is more important than another; the most important service is the one the consumer wants and needs.
Improved long-term care (LTC) insurance	Federal State	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	Federal State	Cost-sharing in a new publicly financed social insurance program should be addressed through the program's financing (i.e., taxes and premiums paid by older Americans and working people). 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 based on ability to pay. People must have equal access to services regardless of payer. Beneficiary cost-sharing for either community or institutional services should be modest and not favor one type of service over another. To protect people with low incomes, public funds should support individuals who cannot afford to contribute to cost-sharing.
Adequate financing and reserves	Federal State	Some tax revenues for a new LTSS program should be earmarked to an LTSS trust fund to build adequate reserves to cover later

Adequate financing and reserves(cont'd.)	Federal State	generations. To help defray the federal government's costs, the new LTSS program should require some maintenance of states' current spending on LTSS. A financing package should consider the fact that, even if the program were phased in, many people with disabilities would be eligible for benefits before a large reserve fund could be built up.
Phased-in coverage	Federal State	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.
Intermediate steps for achieving comprehensive reform	Federal State	Reforms must advance and build toward the goal of a comprehensive LTSS program. Coordination should be improved among LTSS programs and between the health and LTSS systems for people who need services from both. Services in consumer-preferred settings—primarily in the home and community—should be expanded to improve access to services. Services that support family caregivers' ability to continue providing care should be included. In evaluating all the options available to people who need LTSS, federal and state governments could develop a cash payment or service benefit based on level of disability, which could be part of existing programs or could supplement services. Consumer protection mechanisms need to be strong in any LTSS system. Until a national, comprehensive LTSS program is available, states should implement comprehensive LTSS programs that are affordable for those who do not meet Medicaid's eligibility requirements but who still cannot afford LTSS.
Appropriate services	Federal State	Avoiding unnecessary institutionalization by providing home- and community-based services—such as home care, conflict-free care management, personal care, respite care, adult day services, and supportive housing—is one of the most important and effective ways to control the costs associated with LTSS (see this chapter's section Expanding Home- and Community-Based Services). In order to help control LTSS costs, federal and state governments should use a standardized assessment of beneficiaries' needs to determine the appropriate type and intensity of services in a consistent manner.
Capitation	Federal State	If federal and state governments use capitated payment systems, they should require strong consumer protection standards and accurate inflation and trending factors. Capitated rates must also reflect the needs of the served populations and be sufficient to meet those needs.
Improved data collection	Federal State	Federal and state governments should ensure that standardized systems collect data on service use, costs, and quality, particularly for the Medicaid and Medicare programs. 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.

Curbing fraud and abuse	FEDERAL STATE	Federal and state governments 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.
Conflict-free care management	FEDERAL STATE	Conflict-free care management should ensure effective and efficient coordination of high-quality client services.
Cash options	FEDERAL STATE	Federal and state agencies should offer consumers the option of cash payments to manage their LTSS. There is evidence that many consumers who receive a cash benefit manage their LTSS more economically than those who receive benefits under an agency-administered model (see this chapter's section Creating a Participant-Directed Long-Term Services and Supports System).
Risk-sharing	FEDERAL STATE	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. Effective governmental oversight (e.g., periodic audits and look-back surveys) must be in place to help prevent conflicts of interest within the care management system.
Private payments	FEDERAL STATE	A social insurance program should be supplemented by private payments and ensure protections for people with low incomes.

Supporting Family Caregivers

Federal or state programs to assist caregivers are limited, even though unpaid family and friends provide the bulk of long-term services and supports (LTSS) in the US. In 2009, an estimated 42 million caregivers age 18 and older were providing unpaid care to an adult family member or friend at any given time. The number of adults providing care at some point during the year is significantly higher, estimated at 62 million in 2009. The total economic value of caregivers' contributions is estimated at $450 billion, more than the total amount spent on formal LTSS.

Caregivers vary by age, care recipient, cultural influences and income. They also vary by the kind of care they provide. Not only do family caregivers provide help with activities of daily living (such as bathing and dressing) or instrumental activities of daily living (such as shopping and transportation), but they also perform medical and nursing tasks for care recipients with multiple chronic conditions (such as managing multiple medications and providing wound care). Based on the Caregiving in the US 2009 national survey, two-thirds (65 percent) of family caregivers are women. The average age of caregivers is 49 and they provide, on average, nearly 20 hours of care each week. More than eight in ten caregivers provide care to a relative or friend age 50 or older.

More supports are needed to meet the mental and physical health needs of caregivers of older adults. These caregivers face issues similar to the older person for whom they are providing care. Caregivers age 65 and older are the most likely to have the highest burden of care, according to the Caregiving in the US 2009 national survey. These caregivers are the frontline support for millions of Americans with chronic care needs, including mental health. Thus, it is imperative that providers who see older patients observe the informal caregiver's physical and mental health status, too.

Existing federal and state programs offer only limited assistance to unpaid caregivers, typically in the form of tax credits and deductions. Under specific circumstances, a caregiver can classify an older person receiving care as a dependent and claim a personal federal tax exemption. But because many older people receive Social Security benefits or pension income, relatively few can meet the income requirements to qualify as a dependent. Only employed caregivers who pay a third party for the care of a dependent person can claim the federal dependent-care tax credit.

Another possible source of assistance is the Health Insurance Portability and Accountability Act, which allows taxpayers who itemize their income tax deductions to deduct qualified LTSS expenses (including for a dependent) if combined medical and LTSS expenses exceed 7.5 percent of the taxpayer's adjusted gross income (AGI). Starting in 2013, this threshold will increase to 10 percent of AGI for taxpayers under age 65. In 2017 the provision will go into effect for those over age 65.

Some employers also provide flexible spending accounts for employees to set aside up to $5,000 in pretax dollars to care for a dependent child under age 13 or a dependent over 13 who is incapable of caring for himself or herself. Contributions may be used 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.

In 2000 the Older Americans Act established the National Family Caregiver Support Program, which funds 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.

(For more information, see this chapter's section The Older Americans Act.)

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. (For background and policies on family medical leave, see Chapter 5, Employment: Time Off from Work. For background and policies on family caregiver discrimination, see Chapter 5, Emerging Discriminatory Practices and Preserving and Strengthening Statutory Protections.)

While these 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 6, Low-Income Assistance Programs: Supplemental Security Income, and this chapter's section Expanding Home- and Community-Based Services, for additional background and policy information on benefits for beneficiaries who live with their families.)

SUPPORTING FAMILY CAREGIVERS: Policy		
Necessary programs and services to assist caregivers	FEDERAL STATE	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. Federal and state governments should offer additional services geared to the special needs of caregivers, such as caregiver assessments to help improve targeting of supportive services, caregiver training programs, support groups, and mental health counseling; home-modification programs; hospice and respite care; and income support and transportation. Education and training programs should ensure that family caregivers are well trained and prepared to perform not only difficult LTSS tasks such as bathing, but also how to handle medical and nursing tasks such as medication management and wound care. Supplemental programs and support services should reflect the concerns and needs of diverse populations of caregivers. Federal and state governments should establish and coordinate information and referral systems to let caregivers know about the full range of available LTSS, including caregiver support services.
Supplemental Security Income	FEDERAL	Supplemental Security Income rules should be amended so they do not reduce benefits for people living with family members.
Tax incentives	FEDERAL STATE	Tax credits or other financial assistance aimed at easing the cost of LTSS should be available for caregivers. Employers should be encouraged to take advantage of existing tax incentives, such as flexible spending accounts for dependent care, to provide dependent- or family-care benefits.

Paying relatives for LTSS	FEDERAL STATE	Policymakers should promote the expansion of consumer-directed models in publicly funded home- and community-based services (HCBS) programs that permit payment for family caregivers. Such models would allow consumers and their families to choose and direct the types of services and supports that best meet their needs. States should establish and coordinate within the LTSS delivery system policies to pay relatives and friends who care for people with LTSS needs.
Person- and family-centered care plan	FEDERAL STATE	Federal and state governments should recognize and assess family caregivers' own needs as part of a person- and family-centered care plan, such as through publicly funded HCBS programs, hospital discharge planning, chronic care coordination and care transition programs, and other models of care under the Affordable Care Act. States should provide or refer caregivers to supportive services. Service providers should be trained to recognize mental health and substance abuse disorders in family and other caregivers and should be required to refer them for services when needed.
Fraud protection	STATE	Programs and policies should be designed to protect consumers, guard against fraud and abuse, offer training to family members and friends, and provide sufficient oversight to ensure high-quality services.

Expanding Home- and Community- Based Services

Congress and the states should expand funding for a wide range of home- and community-based services (HCBS) through Medicaid, the Older Americans Act, the Social Services Block Grant program, and other programs that offer long-term services and supports (LTSS). (See this chapter's section The Older Americans Act, and Chapter 6, Low-Income Assistance, for additional discussion and policies related to these programs.)

AARP supports initiatives to balance LTSS systems, so consumers and their families have viable options in the type of services they want and need. "Balancing" or "rebalancing" means ensuring that people with LTSS needs have viable access to a variety of services to meet their needs and their preferences for assistance. This will require that states plan, develop, and fund an array of LTSS. Because most individuals prefer to receive services and supports in their homes and home-like settings, it also will require states to allocate a greater share of resources toward HCBS to "balance" Medicaid LTSS spending between nursing facilities and HCBS. A balanced LTSS system has proven a more cost-effective and efficient use of scarce resources while meeting the needs and preferences of individuals who want to remain in their homes and communities.

As part of the 2010 health care reform law, Congress established two new financial initiatives to facilitate states' expansion of their HCBS programs, improved existing HCBS options, provided additional funding for several existing programs, and made other improvements.

One of the new initiatives is the State Balancing Incentive Payments Program, a four-year program providing grants to qualifying states that commit to making structural changes in their Medicaid program to improve the balance of spending between HCBS and institutional services. The grant will increase a state's Federal Medical Assistance Percentage (FMAP) by either 2 or 5 percentage points, depending on the state's current allocation of Medicaid spending for HCBS. Another initiative is the Community First Choice option. This increases a state's FMAP by 6 percentage points if the state—without enrollment restrictions—offers statewide home- and community-based attendant services and supports to certain Medicaid-eligible individuals with disabilities.

The law also strengthens the Money Follows the Person (MFP) Rebalancing Demonstration program, which encourages states to identify individuals in institutions who want to return to the community. When states transition such individuals, they receive an enhanced FMAP for the Medicaid-funded HCBS they provide to those individuals for the first year of their relocation, enabling these individuals to live in the most appropriate and preferred setting. The ACA extends the MFP program through September 30, 2016 and appropriates an additional $450 million for each of the five years (FY 2012–2016). Any unused grant funds as of 2016 can be used until 2020.

Aging and Disability Resource Centers (ADRCs), which are one-stop, single-entry access points to LTSS administered by state offices on aging, also are extended for an additional 5 years, receiving $10 million in each of those years. The ADRC program provides states with an opportunity to effectively integrate the full range of LTSS into a single, coordinated system.

In addition, the new law modifies the existing 1915(i) Medicaid state plan amendment option for HCBS to help make it easier for states to use this authority to expand HCBS. It also requires all states for five years starting January 1, 2014, to apply spousal impoverishment protection rules to HCBS, as they already are required to do for the spouses of Medicaid beneficiaries who reside in nursing facilities.

To further balance LTSS-related spending, the federal government should vigorously enforce the Americans with Disabilities Act (ADA) and help states to develop and implement expeditiously plans to deinstitutionalize nursing facility 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 1999 *Olmstead v. L.C.* decision.

States, with federal funding and support, should also establish nursing facility transition programs. These programs would provide independent transition specialists to visit nursing facilities to help residents learn about other types of LTSS and gain access to them.

States that have achieved greater success in transforming their LTSS systems to give people choice and reduce their reliance on nursing facilities share certain characteristics. They include:

- **Philosophy**—The state's intention to deliver services to people with disabilities in the most independent living situation and to expand cost-effective HCBS options guides all other decisions. How a state views quality of life for older adults and people with disabilities, and the importance of participants having a choice in how their services are provided, may be the most important factor in having a balanced LTSS system.
- **Array of services**—States that provide a comprehensive array of services designed to meet the particular needs of each individual and address the needs of people of all income levels are less likely to channel people into institutions than states providing few options.
- **Organization of responsibilities**—Assigning responsibility for overseeing the state's LTSS system to a single administrator is a key decision in some of the most successful states.
- **Coordinated funding sources**—Coordination of multiple funding sources can maximize a state's ability to meet the needs of people with disabilities.
- **Single appropriation**—This concept, sometimes called "global budgeting," allows states to transfer funds among programs and, therefore, make more timely decisions to facilitate serving people in their preferred setting.
- **Timely eligibility**—Hospitals account for nearly half of all nursing facility admissions. When decisions must be made quickly at a time of crisis, state Medicaid programs must be able to arrange for HCBS in a timely manner. Failure to determine timely eligibility for Medicaid HCBS often results in unnecessary nursing facility placement. Successful states have implemented procedures that either presume financial eligibility for Medicaid HCBS or fast-track the eligibility determination process.
- **Standardized assessment tool**—Some states use a single tool to assess functional eligibility and service needs, and then develop a person- and family-centered plan of services and supports. This standardized tool helps to minimize differences among care managers and prevent unnecessary institutionalization and can be used to collect consistent data, leading to better system management.
- **Single entry point**—A considerable body of literature demonstrates the need for a single access point making a comprehensive array of LTSS available to people of all ages with disabilities. Effective systems that determine eligibility, coordinate services, and monitor quality can support people who have their own resources to pay for services, as well as those who qualify for public programs. A robust system of information and assistance is critical, as most people with disabilities and their families have a difficult time negotiating a complex system. One model is the ADRCs, which most states are in various stages of implementing.
- **Participant direction**—The growing movement to allow individuals a greater role in determining who will provide them with services, as well as

when and how they are delivered, responds to the desire of people with disabilities to maximize their choices and control over their lives.

- **Nursing facility relocation**—Some states have made systematic efforts to regularly assess the possibility of transitioning people out of nursing facilities and into their own homes or more home-like community alternatives. Medicaid payment for transition services is critical to the success of these efforts. Some states assign staff to visit nursing facilities regularly to identify, assess, and help people relocate from the nursing facility to the community.
- **Quality improvement**—States are beginning to incorporate participant-defined measures of success in their quality improvement plans.
- **Integrating health services and LTSS**—A few states have developed methods for ensuring that the array of health services and LTSS provided to people with disabilities are coordinated and delivered in a cost-effective manner. The ability of states to do this is complicated by differences in how Medicare and Medicaid programs are administered. Yet among people age 65 and older, the great majority of those receiving Medicaid are eligible for Medicare as well.

EXPANDING HOME- AND COMMUNITY-BASED SERVICES: Policy

Medicaid	FEDERAL	The federal government should eliminate Medicaid's bias favoring nursing facilities in the funding of long-term services and supports (LTSS) 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 HCBS settings. The federal government should provide federal matching funds to reimburse states for erroneous presumptive eligibility determinations regarding beneficiaries who receive Medicaid HCBS and nursing facility services. The federal government should give states 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, based on uniform and independent assessments, should be admitted to nursing facilities, unless they choose to receive services in a nursing facility.
Supplemental Security Income (SSI)	FEDERAL	The federal government should amend SSI regulations that reduce benefits for people 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 LTSS (see Chapter 6, Low-Income Assistance: Supplemental Security Income, for additional policy on SSI to support informal caregiving arrangements).
Expanding home- and community-based services (HCBS)	FEDERAL STATE	Federal and state governments should carefully assess the impact of any proposed budget cuts on their efforts to balance their LTSS systems and their ability to serve people in the most integrated setting the individual chooses. Federal and state governments also should: • develop a philosophy that consumer choice and quality of life should drive the LTSS system; • allocate a greater proportion of Medicaid funding for HCBS instead of nursing facility care; • develop a single point of entry to provide consumers with unbiased information about their range of options (allowing potential consumers to access services other than nursing facilities) and to determine financial and functional eligibility in a timely fashion;

Expanding home- and community-based services (HCBS) (cont'd.)	Federal State	• provide potential consumers with viable options for HCBS that will help divert people from nursing facility care either before admission or shortly thereafter; • initiate and implement additional nursing facility diversion programs and expand the availability of HCBS through LTSS programs funded by state general revenue—These programs should offer a comprehensive range of services to meet beneficiaries' health and functional needs. At a minimum services should include home care, conflict-free care management, personal care, and respite care. Eligibility for these HCBS must be determined quickly, so that consumers have viable options other than a nursing facility. 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 inappropriately limit the access of people with chronic conditions and low incomes to nursing facilities or increase the cost of health care or LTSS; • create or expand nursing facility transition programs, such as the Money Follows the Person Rebalancing Demonstration program, to move people to more home-like settings if they want to receive care in such settings; • restructure their nursing facility Medicaid reimbursement system to ensure that it does not sustain excess capacity—States should pursue appropriate efforts to address excess capacity by increasing imputed occupancy rates and considering incentives for taking excess capacity off-line; • eliminate HCBS waiting lists—People in need of LTSS cannot wait for services and may end up in nursing facilities; • create or enhance the existing system for quality oversight and enforcement of quality of care standards in all settings; • offer Medicaid optional services, including conflict-free care management, personal care, and adult day services; • expand HCBS through waivers and other processes such as state plan amendments, Administration for Community Living programs, or state-only funding sources—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 facility. However, current Medicaid beneficiaries should not be forced to move or have benefits reduced by the implementation of a waiver or other program; • expand HCBS options to include a range of residential choices as well as home modifications and assistive technologies; • support family caregiver services such as education and training, counseling, legal consultations, and respite care, which can delay or decrease the likelihood of needing to enter a nursing facility; • create the capacity for prompt financial and functional Medicaid eligibility determinations for applicants who need and want HCBS and for using presumptive eligibility for people seeking them; • consolidate LTSS programs, policies, and budgets within one state agency to promote efficiency, true single points of entry for LTSS, and data collection necessary to strategically manage LTSS;

Expanding home- and community-based services (HCBS) (cont'd.)	FEDERAL STATE	- move to a unified global budget for publicly funded LTSS so states can manage expenditures and use the money saved through reduced nursing facility use for HCBS; - develop and implement plans that address the Supreme Court's *Olmstead* decision—These plans should include specific action steps, timelines, and strategies for securing necessary HCBS funding; - 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; - 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 certain nursing tasks provided by unlicensed direct-care staff authorized and trained to do so by a registered nurse—States must ensure that registered nurses are protected from liability if they have followed the prescribed protocols for delegation, training, and supervision outlined in the states' nurse practice acts; and - ensure that states with a formal process for allocating the number of nursing facility beds, such as a certificate of need, base decisions on the number of people who require a specific level of care and on data projecting the need for LTSS in different areas of the state.

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

Most consumers, regardless of age or disability, want to direct how they receive long-term services and supports (LTSS) in order to maintain their dignity and maximize their independence.

A self-directed approach to services assumes that consumers can assess most of their own needs, determine how best to meet them, and monitor the quality of services received. Participant direction ranges from a consumer making all decisions to an advocate or surrogate managing the services. 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.

For decades publicly funded LTSS programs have given consumers the opportunity for self-direction in this and other countries. Programs exist in almost every state, take many forms, and cover a wide range of age groups and specific conditions. Participant-directed programs often expand the available workforce, as many programs allow individuals to pay friends, neighbors, and family members. These programs can also broaden service delivery in rural areas and other communities that are underserved by traditional home-care agencies. However, because many caregivers in such programs would not otherwise be working in the LTSS field, responsibility for ensuring that these independent providers are qualified and competent should be shared among the participant, the state agency, and the family. Requirements should be balanced to ensure appropriate safeguards for the consumer, protect public funds, and avoid measures that are intrusive or diminish individual choice and control.

Cash-and-counseling programs are a type of participant-directed LTSS delivery that provides Medicaid beneficiaries eligible for personal care services with monthly payments to choose, purchase, and manage their own care or to pay a care manager. They also offer counseling to help consumers manage their services. Studies of cash-and-counseling programs have documented the following outcomes:

- Cash-and-counseling significantly reduced unmet needs for personal-assistance services.

- Participants experienced positive health outcomes and improved quality of life.
- There was no misuse of Medicaid funds or abuse of consumers.
- Cash-and-counseling need not cost more than traditional programs if states carefully design and monitor their programs.
- Workers hired directly were twice as likely as home-care agency workers to report satisfaction with their compensation.

Current Medicaid law provides states with extensive options for funding participant-directed services (see this chapter's section Expanding Home- and Community-Based Services).

CREATING A PARTICIPANT-DIRECTED LONG-TERM SERVICES AND SUPPORTS SYSTEM: Policy		
Consumer rights	FEDERAL STATE	Consumers should have the right to direct their own care unless, through a conflict-free assessment process, it is determined that they are unable to do so. In the event they are unable to direct their care, they should be entitled to appoint a representative to do so. Consumers should have the option of purchasing or directing their own long-term services and supports (LTSS) using the public funds for which they are eligible. Participant-directed programs should be flexible enough to allow consumers to perform certain care-management tasks themselves and to receive assistance with other tasks. Emergency procedures and funds should be established 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. States should not require home-care consumers, even if they are able to do so, to contract and pay directly for and manage their own services and supports.
Grievances	FEDERAL STATE	Participant-directed services and supports should include timely grievance and appeal procedures for consumers dissatisfied with or denied services.
Consumer protection	FEDERAL STATE	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. Policymakers should ensure the safety of participants in participant-directed services and supports programs through strong federal and state oversight. Procedures should be in place to ensure adequate backup workers in the event that a home-care worker does not show up.
Standards of care	FEDERAL STATE	Participant-directed services and supports should include guidelines and standards for care. There should be semiannual reviews of quality of care and maintenance of each consumer's health and functional status.
Education and counseling	FEDERAL STATE	Participant-directed programs should include: • consumer education that targets diverse communities and provides information on safety and employment and on accessing available LTSS resources and referral services; • counseling as requested, to help people arrange for services and maintain financial records—Inability to manage financial aspects of participant-directed care should not prevent program participation; and • education for service providers to help them transition to new models of care.

Improving Access, Coordination and Integration of Long-Term Services and Supports

Steps to Improve Long-Term Services and Supports Coordination

The delivery and financing of long-term services and supports (LTSS) differs considerably from state to state. Although Medicaid is the single largest public funding source for LTSS, it does not require a uniform national delivery system. In many states home- and community-based services (HCBS) and supports have evolved as add-ons overseen by different agencies, and LTSS functions and operations are dispersed throughout state government agencies and departments. The result is often confusion for consumers and providers. Many policymakers and state officials believe that strategies to improve coordination should begin with consolidation of LTSS programs, policies, and budgets within one state agency.

Such single entry points make it easier for consumers to access LTSS. Some states' single entry points are actually multiple sites that are coordinated and standardized. These 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 differ from state to state in the populations they serve and the services they provide.

In 2003, the Centers for Medicare & Medicaid Services partnered with the Administration on Aging (reorganized in 2012 and now operating under the Administration for Community Living umbrella) to fund Aging and Disability Resource Centers (ADRCs), which offer one-stop, single-entry access to LTSS. ADRC staff provide information on available public and private services, assistance with obtaining services, needs assessment, conflict-free care management services, and determination of eligibility for public programs. As of 2012, 445 ADRCs operated in 54 states and territories. The new health law provides $10 million for new and expanded ADRCs for each of five additional years (to 2014).

Single entry points that determine both financial and functional eligibility or coordinate that process can expedite HCBS access. Yet most single entry points do not determine both areas of eligibility.

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. Conflict-free 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 service delivery. Evidence shows that people with multiple chronic conditions and those who have both LTSS and acute-care needs benefit by having care managers coordinate and integrate their care across settings and across providers.

People whose incomes are too high for publicly funded services may hire private geriatric care managers (GCMs) to assess their 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 family and friends to enable the client to live as independently as possible. Many GCMs are not members of any licensed profession, however. In most states any person can call himself or herself a GCM and offer services to the public. More research is needed about this unregulated field and how to ensure that clients consistently receive informed advice.

STEPS TO IMPROVE LONG-TERM SERVICES AND SUPPORTS COORDINATION: Policy		
Coordination among long-term services and supports (LTSS) providers	FEDERAL STATE	All federal and state agencies with a key role in financing or delivering 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). Conflict-free 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.

Characteristics of consolidated LTSS agencies	STATE	States should consolidate LTSS agencies. The model structure includes the state agency on aging with its Older Americans Act (OAA) programs. A centralized state LTSS organization should integrate programs supported by OAA funds. The consolidated agency should have responsibility for LTSS administration, policy, and funding. This includes Medicaid-funded institutional care and community-based programs such as personal care, home- and community-based services (HCBS) waiver programs, managed LTSS programs (including Programs for All-Inclusive Care for the Elderly), and state-funded LTSS programs. The consolidated agency also should have responsibility for determining people's financial eligibility for Medicaid and for LTSS quality management. It should cover all populations of people with disabilities: older people, other adults with physical disabilities, and people with developmental disabilities.
Single entry point for LTSS	STATE	A centralized state LTSS administrative body should have a single entry point for people seeking publicly or privately funded LTSS, such as an Aging and Disability Resource Center (ADRC). The entry point should provide comprehensive, conflict-free, consumer-friendly counseling at critical decision points (including at home and within hospitals), conveniently located offices in neutral settings, an 800 number to assist in finding the nearest office, and comprehensive information on care options and funding sources. States should conduct an assessment of and devise care plans based on consumer needs and preferences and promptly determine functional and financial eligibility for all publicly funded services. The assessment of LTSS needs and the delivery of services and support should be conflict-free.
Budget	STATE	A single LTSS agency should have global budgeting, with flexibility and authority to fund an array of LTSS, whether institutional or HCBS. (Global budgeting allocates a set level of funds within which providers must operate, whether the funds are applied at the federal, state, or institutional level). Global budgets must be based on the projected needs of the population and anticipated changes in LTSS delivery and be adjusted for expected inflation.
Streamlined administration	STATE	A centralized state LTSS agency should eliminate unnecessary paperwork and other inefficiencies through administrative and systems reform to help contain costs and streamline the process for people covered by more than one program. Providers should use standard, simple terms and billing forms, including electronic billing. Current data on nursing facility charges and all other LTSS providers should be available to the public.
Setting fees for service providers	STATE	A centralized state LTSS agency should have fair rate-setting and contracting processes for service providers.
Quality control	STATE	A state LTSS agency should have a structure and process for ensuring quality oversight throughout the system.

Uniformity in assessing LTSS needs	FEDERAL STATE	A state LTSS agency should determine beneficiaries' LTSS needs through a comprehensive uniform assessment. The federal government should assist states in developing uniform eligibility criteria, assessment and data collection instruments, and quality control standards and outcome measures. Assessments should take into account the different needs of people with different conditions and should focus on the person's current care needs and potential ability to live in the community with appropriate LTSS. When a care plan includes (or involves) a family caregiver, the family caregiver's own needs and preference should also be assessed and addressed.
Availability of conflict-free care management	STATE	States should ensure that conflict-free care management is available through a community organization (such as an ADRC) that does not directly provide LTSS (this would not apply to people in managed care programs). Conflict-free assessment, counseling, and assistance prior to entering any type of LTSS, shall be afforded to the individual (and family) or at any time regardless of locus or level of care at the request of the individual or family.
Training and professionalism of care managers	STATE	States should require competency-based training, annual continuing education, and supervision for care managers to ensure high-quality service plans that meet client needs and program cost constraints. States should require care managers to practice according to professional standards and norms, which include attention to recommended safe and manageable caseload limits. States should ensure that public and private geriatric care managers can demonstrate competency as required by the state.
Focus on the consumer	STATE	States should require care managers to use a client-centered approach that emphasizes the individual's autonomy, 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 and based on the client's needs and choice of LTSS. Consumers should be guaranteed a choice of care managers and the ability to change care managers. Care managers should inform consumers about the costs of service options, and consumers should sign off on their care plan as equal partners. States should require care management agencies to be conflict-free and have strong consumer representation on their boards, particularly of consumers who use LTSS. States should ensure that individual care plans are based on clients' LTSS needs.

Appropriate Health and Functional Criteria for Access to Long-Term Services and Supports

Determining the number and characteristics of people who will receive long-term services and supports (LTSS) is a major policy issue. People of all ages may need LTSS because they may be limited in their ability, or completely unable, to perform a variety of physical or cognitive activities.

The inability to perform self-care, and thus the need for LTSS, is typically measured using two instruments: the activity of daily living (ADL) scale, which includes eating, transferring (e.g., from bed to chair), toileting, dressing, bathing, and continence, and the instrumental activity of daily living (IADL) scale, which includes a person's ability to manage medications and personal finances, do housework and laundry, shop, and use a telephone and public transportation.

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 care to receive services. People who apply for home- and community-based services through a waiver program must meet the same eligibility criteria as those who apply for nursing facility care. 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 or for that same program in another state (see Chapter 7, Health: Medicaid, for information on eligibility).

In many states, the criteria for determining eligibility for LTSS have a medical bias. In these states medical and nursing needs are given more weight than functional impairments. But existing measures of cognitive and other mental impairments are limited in their effectiveness for determining whether a person can function independently and for identifying individuals who need services. The need for supervision, for example, is critical in determining cognitive impairment and is an important eligibility criterion, and yet adequate measures to evaluate the need for supervision do not exist. This is an area in which further research is needed.

Moreover systems that are overly reliant on a medical orientation to LTSS are more likely to view the needs of the individual from a "safety" perspective in which the goal is to minimize risk and protect the "patient." However, there is a growing preference among people with disabilities to enhance self-empowerment and self-determination, which allows individuals to assume informed risks and make their own decisions about their care. It is important for policymakers to recognize that the majority of services and supports needed by people with disabilities are nonmedical in nature, with medical services needed only intermittently.

APPROPRIATE HEALTH AND FUNCTIONAL CRITERIA FOR ACCESS TO LONG-TERM SERVICES AND SUPPORTS: Policy		
Accuracy of eligibility criteria	FEDERAL STATE	Federal and state long-term services and supports (LTSS) programs should have eligibility criteria that appropriately measure the need for LTSS. Measurements for eligibility criteria must accurately assess people with physical, cognitive, and mental impairments and chronic illnesses. People should be eligible for LTSS on the basis of functional needs. People with physical impairments should become eligible for LTSS benefits if they have difficulty performing at least two of the five basic activities of daily living.
Cognitive, mental and physical impairment	FEDERAL STATE	Programs should include appropriate functional criteria, such as measures of cognitive and other mental impairments, as well as physical impairments.
State assessment tools	FEDERAL STATE LOCAL	In the absence of federal policy, states should develop uniform assessment instruments for use in all state LTSS programs, including Medicaid, and include an assessment of family caregiver needs as appropriate.

Coordination and Integration for Individuals with Chronic Illness

People needing long-term services and supports (LTSS) often require both health-related and personal care services to promote their independence; this varies with their condition and the amount of assistance they receive from family and friends. They may, for example, need limited or 24-hour nursing, assistance with meals, therapy, or a range of social services, such as help paying bills or transportation to adult day services. This is especially the case among people with chronic illnesses.

According to the CDC Chronic Disease Prevention and Health Promotion, *Healthy Aging: At a Glance,* 2011 study, arthritis, hypertension, heart disease, diabetes, and respiratory disorders are some of the leading causes limiting activity among older people. About 80 percent of people age 65 and older have at least one chronic health condition and 50 percent have at least two. Many of these people have conditions that result in functional limitations, requiring some LTSS. While medical insurance will cover services to address acute medical conditions, it does not typically cover personal care, adult day care, homemaker services, transportation, and supportive housing. Thus, many frail older adults lack the services and supports they need to function independently at home.

An increasing number of programs and plans are starting to recognize the benefit of and need to offer a full range of medical and supportive services, as well as a better way to coordinate these services (see the policy discussion on Chronic Care Coordination, Medical Homes and Accountable Care Organizations in Chapter 7, Health, for approaches to improving care for people with multiple chronic illness). With the consent of the individual receiving services, efforts to incorporate family members and caregivers in the coordination and integration of service delivery can improve outcomes. Integrated options for people eligible for both the Medicare and Medicaid programs include the Program of All-Inclusive Care for the Elderly (PACE) and Medicare dual special needs plans, which are Medicare Advantage plans that target people who are dually eligible for the Medicaid and Medicare program (see Chapter 7, Health, for a discussion of dual eligibility). These and other integrated options have pioneered promising approaches but are still relatively new (with the exception of PACE) and reach only a relatively few frail older people.

As part of the 2010 health care reform law, the Center for Medicare and Medicaid Innovation was created to support further efforts to integrate medical and supportive services. The center will test new payment and service delivery models to reduce Medicare and Medicaid expenditures, while preserving or enhancing quality of care. The center is also authorized to test new financing models that enhance care integration, particularly for dual-eligibles. These innovations may address some of the issues typically confronting people who have to receive services through Medicare and Medicaid and navigate two complementary yet separate delivery and financing systems.

COORDINATION AND INTEGRATION FOR INDIVIDUALS WITH CHRONIC ILLNESS: Policy		
Integrating health care and long-term services and supports (LTSS)	FEDERAL STATE	Governments should develop comprehensive, coordinated approaches to financing and delivering care to chronically ill people, including physical and mental health care and LTSS, such as chronic-care self-management. Medicare and Medicaid funds should be joined through a waiver authority to test integration of health care and LTSS.
Financing care for the chronically ill	FEDERAL STATE	New initiatives are needed 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 7, Health). Policymakers should emphasize preventing disabilities and functional limitations among those with a chronic illness and minimizing disability or functional loss if one occurs.

Medicaid Managed Care: Integrating Health Care and Long-Term Services and Supports

Many states are either moving toward or expanding capitated, risk-based managed care for Medicaid enrollees with long-term services and supports (LTSS) needs or enrolling Medicaid beneficiaries in a managed care plan that is expected to coordinate all their care including LTSS if needed. Because these individuals often have one or more chronic conditions, they tend to use more health services than do younger people and people without disabilities. They often depend on nonmedical supports such as personal care to help with activities of daily living. In Medicaid managed LTSS, managed care organizations bear the financial risk by receiving a per-member, per-month rate.

Medicaid managed LTSS provides many opportunities and challenges in care delivery and financing. The opportunities can include having care coordinators and better outcomes of care across multiple settings as well as reducing avoidable hospital admissions, unnecessary use of nursing facility care, and medication mismanagement resulting from multiple parallel systems of care. States can hold managed care organizations accountable for both controlling service use and providing quality care. The fixed payments to managed care organizations make Medicaid costs more predictable for state governments. However, fixed payments may also create incentives for plans to restrict access to services for individuals who have costly health care and LTSS needs. Many plans do not have experience providing LTSS for these high-need, high-cost populations. In light of the vulnerability of this population and in some cases, limited experience among states in administering manage care contracts for older adults and persons with disabilities, the principles and policies guiding the duals demonstrations should also inform the design and implementation of Medicaid managed LTSS (see Managed Care for Dually Eligible Medicaid Beneficiaries in Chapter 7, Health, for related policy).

MEDICAID MANAGED CARE: INTEGRATING HEALTH CARE AND LONG-TERM SERVICES AND SUPPORTS: Policy		
Goals of an integrated system	FEDERAL STATE	All Medicaid managed LTSS plans should offer, promote, and support consumer-directed care. Care coordination should include knowledge of community supports (e.g., housing, transportation, and employment), a reasonable ratio of care coordinators to beneficiaries, standards for frequency of client contact, and specific and adequate reimbursement.
Conditions of enrolling in an integrated system	FEDERAL STATE	Federal and state governments should ensure that Medicaid beneficiaries in capitated plans receive timely access to LTSS. No person should be enrolled in a Medicaid managed LTSS plan without first receiving a conflict-free assessment of their needs and preferences and conflict-free counseling about the range of options applicable to their needs and preferences.
LTSS eligibility criteria	FEDERAL STATE	Individuals should not have to meet medical criteria to be eligible for LTSS. Federal and state governments should prohibit waiver programs from making enrollment in a managed care plan a condition for receiving LTSS.
Role of hospital discharge-planning departments	FEDERAL STATE	Hospital discharge-planning departments should be required to help consumers obtain the array of equipment and services they need to meet their home-care needs following hospital discharge. Discharge planners should inform consumers in advance of the costs of equipment and services and available payment sources, including Medicare and Medicaid. To effect a smooth transition for the consumer, the hospital discharge planner should be required to coordinate planning with the local Aging and Disability Resource Center or other single entry point system; consumer's family caregiver, if appropriate; and care manager, if the consumer is already enrolled in a Medicaid managed LTSS plan and has one in the community.

QUALITY AND CONSUMERS' RIGHTS ACROSS SETTINGS

A number of approaches have been adopted to promote service quality and protect the rights of consumers receiving long-term services and supports (LTSS), including licensure and enforcement, pay-for-performance reimbursement, ombudsman oversight, accreditation, and protection of consumers' right to bring legal action (for discussion on managed care organizations see Chapter 7, Health).

Licensure and enforcement—States monitor service quality and protect residents' rights through licensing requirements that address such topics as staffing, periodic inspections (or "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 Nursing Facilities, Supportive Housing, and Home Care, for additional information on monitoring and 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 a facility's license. Additional quality improvement strategies to supplement state monitoring and enforcement systems include disclosing survey results and other information on quality to consumers, and surveying consumers on their satisfaction with service delivery. 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, promote pro-consumer innovations, and sufficiently protect vulnerable LTSS recipients.

Oversight measures also must ensure that direct-service workers are appropriately screened for criminal backgrounds, including through a national fingerprint check and review of federal and state protective service and abuse registries. However, more research is needed on which crimes should disqualify an individual for working in LTSS settings (see this chapter's section Creating an Adequate Well-Trained Long-Term Services and Supports Workforce).

Reimbursement approaches to promote quality—Several states have experimented with giving nursing facility providers financial incentives to reduce noncompliance and improve quality. Such "pay-for-performance" or "value-based purchasing" approaches have been introduced in hospitals and for other providers in the Medicare and private health care systems. However, little research has been done to determine the effectiveness of these programs in LTSS settings or the most promising ways to risk-adjust those outcomes when reimbursing services in the LTSS system. To address these issues, the Centers for Medicare & Medicaid Services (CMS) launched a three-year Nursing Home Value-Based Purchasing demonstration program in July 2009. The demonstration includes 41 nursing facilities in Arizona, 79 in New York, and 62 in Wisconsin which concluded in December 2012. Results of the demonstration program are expected to provide information on the impact of performance-based incentives on the quality of care.

Ombudsman oversight—The Long-Term Care Ombudsman Program, authorized by the Older Americans Act, provides an additional mechanism for monitoring quality and protecting residents' rights. The program provides ombudsmen for residents of nursing facilities 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 addressed. Ombudsmen also do not have the authority to enforce laws and regulations.

Accreditation—Voluntary accrediting organizations can help to develop standards for service delivery. However, efforts have been made to allow nursing facilities, home health agencies, and 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. These efforts 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 or beneficiary representation. A 1998 CMS study concluded that "the potential cost savings of deeming would not appear to justify the risk to the health and safety of the vulnerable nursing facility population." These findings might also be applied to the deeming of home health agencies and assisted living residences.

Protection of consumers' right to bring legal action—Sometimes the only way to protect consumers is through legal action. In some states consumers can pursue a private right of action to enforce quality regulations and receive redress for harms caused by a provider's noncompliance with such regulations. However, some admissions contracts require that residents and their families submit to binding arbitration for disputes with their service provider and forgo the use of the courts. This requirement may cover a wide range of future disputes, including injuries that may occur due to negligence or abuse. Admission contracts are often presented on a "take it or leave it" basis with no room for the resident to negotiate terms. Residents sometimes are not even aware that a binding arbitration requirement is buried in the fine print of their multipage document. And residents who are aware of the arbitration clause often do not understand its technical language and significant implications for their rights to pursue legal remedies. Some states prohibit mandatory arbitration clauses in nursing facility admission agreements.

QUALITY AND CONSUMERS' RIGHTS ACROSS SETTINGS: Policy		
Quality improvement programs	FEDERAL STATE	In conjunction with a strong enforcement system (which includes swift and meaningful penalties for substandard care), federal and state governments should encourage long-term services and supports (LTSS) providers to establish ongoing quality improvement programs. Quality improvement 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. Consumers and their advocates should be able to participate fully in quality improvement activities. Additional resources should be provided for monitoring state activity on the quality of LTSS. States should require providers to have internal quality improvement mechanisms.
Monitoring LTSS	FEDERAL STATE	Sufficient quality monitors should be hired to inspect all providers at least annually, conduct follow-up inspections as needed to ensure that quality problems are corrected, and respond promptly to complaints. Support for training programs for monitors and funds for monitoring activities should be increased. Quality monitors should receive thorough and ongoing training about the unique needs of older people and all aspects of nursing facility, supportive housing, and home care. Federal and state regulations should require that all LTSS providers monitor staff levels to ensure that individuals' needs are being met and should adjust staffing levels to maintain this standard. States should: • provide ongoing monitoring and independent evaluation of state Medicaid LTSS systems with meaningful consumer input; • focus monitoring efforts on improving outcomes, with attention to clinical, functional, and quality-of-life outcomes; • monitor quality through performance-based outcome measures, including client satisfaction measures—Monitoring efforts should intensify as problems are detected in quality outcomes and as the complexity and intensity of services increase; • provide sufficient oversight infrastructure, resources, expertise, and commitment; and • use a common set of assessment and outcome measures to assess performance quality among all types of providers and encourage provider commitment to quality.
Legal protections	FEDERAL STATE	Consumers' access to the judicial system should be protected, including a private right of action to enforce quality standards. Legislatures should not limit the amount of punitive damages or joint and several liability, or unreasonably limit damage awards for pain and suffering in tort actions involving LTSS providers (see Chapter 12, Personal and Legal Rights: Individual Enforcement of Legal Rights, for additional policy on access to the judicial system). Congress should make pre-dispute mandatory arbitration provisions in LTSS admissions contracts unenforceable(see Chapter 12,

Legal protections (cont'd.)	FEDERAL STATE	Personal and Legal Rights: Individual Enforcement of Legal Rights, for additional policy on mandatory arbitration.) Federal and state governments should protect LTSS applicants and consumers from discrimination.
Licensing	STATE	States should enact licensing requirements for all 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. Licensing requirements should vary depending on the level of care and the services provided. State licensing standards should screen out providers whose past performance or current inability to provide services makes them a poor risk for providing high-quality services. States should bar the following people from owning, obtaining a license for, or receiving construction approvals for nursing facilities, supportive housing or home-care agencies: people with a relevant criminal record or relevant poor credit history and providers whose facilities or service agencies have been cited repeatedly for deficiencies in major quality-of-care requirements, for consistently providing poor-quality care, or for routinely discriminating against Medicaid recipients. States should set licensing standards that address quality-of-care issues, including requirements for an adequate number of well-trained workers and a range of services to meet consumers' needs and safety. Consumer complaints and ombudsman reports should be taken into account during licensing inspections and licensing renewal.
Accreditation	FEDERAL STATE	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.
Confidentiality of medical and LTSS records	FEDERAL	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 7, Health: Quality and Safety—Privacy and Confidentiality of Health Information).
Pay-for-performance programs	FEDERAL STATE	The first element of any pay-for-performance program should be basic reimbursement levels adequate to pay for quality care. Residents' reports of their experiences with care and evaluations by family members and visitors should be included in pay-for-performance programs and used in conjunction with other data on quality outcomes. States considering basing payments to LTSS providers on improved quality outcomes should rely on data from pilot projects developed with strong consumer participation. Pilot projects should consider, among other factors, the audited real cost of providing services and the impact of frozen or declining state budgets, and should include comprehensive evaluation components to determine the validity and reliability of the measurement instruments used and the programs' effectiveness in promoting quality for consumers.

Keeping the public informed	FEDERAL STATE LOCAL	States should 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, including electronically. This information should be updated at least annually, and the availability of this information should be publicized. Information should be collected and made public about the quality of nursing facilities, supportive housing, and home-care agencies, including staffing levels in nursing facilities and supportive housing. States should collect data for evaluating the effectiveness of the ombudsman program and make information about the program available to the public.
Consumer complaints	FEDERAL STATE	States should provide effective complaint systems with prompt resolution. States should require the establishment of internal appeals mechanisms in LTSS programs for consumers dissatisfied with the delivery, quality, or scope of services and should set up external appeals mechanisms through a neutral third party. Appeals mechanisms must ensure that consumers receive an immediate decision on their appeal or as rapid a decision as the consumer's condition requires.
State ombudsmen	STATE	States should implement and fund strong and independent LTSS ombudsman programs that go beyond federal requirements and include an adequate number of ombudsmen. A state LTSS ombudsman should have the authority to sue to redress violations of federal and state laws on residents' rights and quality of care. States should coordinate all LTSS ombudsman activities and ensure that ombudsmen have adequate funding, including enough funding to monitor home- and community-based services. States should extend the purview of the ombudsman program to include noninstitutional care. Ombudsmen, residents, and families and/or their representatives should be allowed to participate actively in state-initiated enforcement actions by giving testimony or arguing for or against a proposed action. States should require ongoing in-service training and supervision for ombudsmen.
Federal role in ombudsman programs	FEDERAL	The federal government should enhance funding and strengthen requirements for states to implement LTSS ombudsman programs. Minimum staffing ratios should be established for state ombudsman programs, equivalent to the Institute of Medicine's recommended ratios of one full-time-equivalent paid ombudsman for every 2,000 licensed LTSS beds within the state and one full-time-equivalent paid ombudsman for every 40 volunteers. States should be encouraged to exceed the minimum staffing ratio for their ombudsman programs and maintain a minimum of one full-time-equivalent paid ombudsman for every 20 volunteers. The federal requirement that the ombudsman program be independent of the state regulatory agency should be enforced.

Abuse and neglect	STATE	State governments should fully fund the agencies responsible for investigating abuse and neglect and ensure that they have the capacity to respond appropriately and follow-up (see Chapter 12, Personal and Legal Rights, for additional policy on elder abuse and neglect). State regulations should require that all suspected cases of resident abuse or neglect be reported to the official state ombudsman and the appropriate state agency. States should enact laws making institutions liable for criminal and civil penalties for abuse and neglect of those in their care. Information from suspected cases of abuse or neglect of nursing facility residents should be used in the state survey and certification process; information from suspected cases of abuse or neglect of people receiving home- or community-based care should be reported to the appropriate state agency.
Whistleblower protection	STATE	States should provide whistleblower protections for staff and others who report fraud and poor-quality care to the appropriate authorities.
Special needs care	STATE	States should provide adequate capacity and infrastructure for necessary care, including dementia and other specialty care, for all eligible individuals in reasonable and appropriate care settings.

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 personal assistance services. There are however many paid individual workers who are not monitored by Medicare or state licensing agencies. As the use of home- and community-based services (HCBS) grows, states must develop adequate methods for ensuring quality, with appropriate federal oversight for federally funded services, including adequate training and wages for direct-care workers (for discussion on managed care organizations, see Chapter 7, Health).

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 what counts as high-quality care. 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 these issues.

In part, concerns like these have fueled the movement to promote participant-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 use an agency's workers, and can therefore schedule tasks at the times they most prefer, rather than at the agency's convenience. Home-care consumers 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.

People with disabilities face an additional risk when authorized personal care services are not delivered. Yet most states have failed to implement comprehensive approaches to ensuring backup services in their Medicaid programs.

Emergency preparedness plans—About 13 million people age 50 or older say they will need help evacuating their homes in a natural disaster; about half will require help from someone outside their household. Older people, who face special health and other risks, will likely be more vulnerable during disasters than the general adult population. Recent disasters have highlighted how devastating to older adults such events are. Physical capacity and resiliency place frail older adults at special risk. For example, during Hurricane Katrina, many older adults lost their lives when they were abandoned in their nursing facilities. When Super Storm Sandy struck the Northeast in 2012, older adults in a nursing facility in New York City were left without food, water, lights, heat, and the ability to communicate with the outside world. Older adults also may lack the ability to get to emergency food and water distribution centers, and they rely disproportionately on informal networks for support. When disaster strikes, these networks may be destroyed, leaving older adults at high risk. Yet government emergency planning documents and processes at any level—federal, state or local—rarely mention the needs of vulnerable older people.

HOME CARE: Policy		
Federal quality assurance standards	FEDERAL	Federal regulations should promote home-care quality assurance standards that are guided by flexible consumer-oriented principles offering beneficiaries 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. Federal regulations must stipulate the necessary components of a quality assurance program for home- and community-based services (HCBS), 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. The federal government should 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.
State quality assurance efforts	STATE	States should be required to submit detailed information on their quality assurance approaches when applying for a Medicaid HCBS waiver, including data on the program's design, methods for discovering quality problems, and methods of remediation and improvement. States should be required to report to the Centers for Medicare & Medicaid Services (CMS) the quality assurance measures used in all Medicaid-funded HCBS, whether through the personal care services option, HCBS waivers, or other mechanisms. States should allocate sufficient funding to collect the data needed to plan and monitor the cost and quality of HCBS and ensure quality services and client autonomy. Funding to monitor quality and take quick action to remediate identified problems is critical. States should adopt a standardized bill of rights for home-care agency clients. 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.
Consumer experience surveys	STATE	States should be required to conduct annual scheduled in-home surveys that assess clients' experience and involvement in care plans and outcomes, and should require that surveyors interview consumers separately from their care providers. States should publicly and timely disclose all survey findings, while safeguarding the privacy of consumers.

Ombudsman program	FEDERAL STATE	Federal and state governments should provide a role and adequate funding for ombudsmen in monitoring the quality of home care. States should extend the purview of the ombudsman program to include HCBS and ensure that ombudsmen have adequate funding to monitor such services.
Emergency management planning	FEDERAL STATE LOCAL	More federal funding should be provided to the Administration for Community Living to develop and implement its emergency management responsibilities on behalf of older people. The Federal Emergency Management Agency (FEMA) should have specific and detailed protocols that address the needs of older adults and vulnerable populations in disasters. FEMA should study the breakdowns in assistance that occurred in previous disasters and use these lessons to guide the development of new emergency response protocols. States should make identifying, registering, and tracking older people who cannot evacuate on their own a high priority in local communities. States should train emergency management personnel in the needs of older people and train aging network personnel in emergency management procedures. Older people and people with disabilities should be included in emergency drills and training exercises. States should include protections for vulnerable older people in state and local emergency preparedness activities, such as planning, communications, evacuations, transportation, and housing.
Grievances and appeals	FEDERAL STATE	The federal government should ensure that grievance mechanisms are readily available and develop a range of enforcement options and an external review mechanism to monitor care management and services. States should require agencies to establish grievance and appeals procedures and provide clients with written notice of their right to voice grievances. States should coordinate and investigate complaints about their response to findings of deficiencies and their disposition, including sanctions imposed, and the responsible agency should send a report to the complainant that specifies the corrective action taken.
Medical training for family caregivers	STATE	States should require that home-care providers adequately train family caregivers who use technology, such as home dialysis and continuous intravenous infusion, and that agencies provide family caregivers 24-hour emergency assistance by telephone.
Backup personnel	FEDERAL STATE	States should be required to demonstrate to CMS the effectiveness of methods they use to ensure that backup workers are available to all individuals who receive Medicaid-funded HCBS. States should specify uniform standards for backup workers who provide personal care services, including required response coverage times and the availability of backup services 24 hours a day, seven days a week. States should monitor the delivery of authorized services in real time and maintain specialized backup agencies and pools of backup workers to fill in on short notice.

Service limits	STATE	Care managers and care management agencies should be conflict-free and thus prohibited from providing other home-care services, except in areas where the number of providers is inadequate to ensure delivery of services to eligible consumers.

Supportive Housing

Supportive housing includes board and care homes, assisted living residences, adult foster care homes, and subsidized housing projects that provide or arrange for services and supports, including help with activities of daily living, in a residential setting (see Chapter 9, Livable Communities, for more information on the housing aspects of supportive housing). In addition, residents 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 room and board and limited supportive services and protective oversight. Assisted living residences generally provide a higher level of services and emphasize a philosophy of individual autonomy, choice, privacy, and dignity. Assisted living residences usually cost more than board and care homes, and residents usually pay privately, rather than with public funds. The availability of supportive housing is growing in response to consumer demand and increased public funding for services in such settings. 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. For example, "assisted living" has no federal definition. Regulation occurs only at the state level, and states use varying definitions. As of 2010, 35 states used "assisted living" in a licensing statute or regulation, but facilities vary widely even in those states with respect to the services they offer. Given the enormous variability, consumers may be unsure what to expect in residences advertised as assisted living facilities.

Facilities also vary widely in quality, with the most glaring deficiencies existing in some board and care homes serving mainly Supplemental Security Income (SSI) recipients. 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.

SUPPORTIVE HOUSING: Policy		
Federal oversight and support	FEDERAL	The federal government should assume a much stronger role in ensuring the quality of care in board and care homes, assisted living residences, and other types of supportive housing, regardless of payment source. Federal oversight of Medicaid waivers used for assisted living and other residential care settings should be strengthened. Federal Trade Commission oversight of advertising and contracting, to ensure that sales claims are justified and backed up by contracts, should be enhanced. Federal agencies should develop a common database on assessment and outcomes across all care settings. The federal government in coordination with states should 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, residents' involvement in care plans, and outcomes. The federal government should provide increased funding and authority for long-term services and supports ombudsmen to intervene on behalf of supportive housing residents.

Federal oversight and support (cont'd.)	FEDERAL	The Social Security Administration should be able to share Supplemental Security Income information with states, while protecting beneficiaries' privacy rights, to help identify unlicensed board and care homes.
Uniform definitions and standards of care	FEDERAL	Federal agencies should monitor the progress of state efforts in developing common definitions of and minimum standards on services and facilities for board and care homes, assisted living residences, and other types of supportive housing. Federal definitions and standards should be considered if states do not develop standards that adequately ensure quality and protect consumer rights.
Private right of action	FEDERAL	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.
State oversight	STATE	States should set and rigorously enforce mandatory minimum standards and make other efforts to promote quality and ensure quality outcomes for supportive housing residents. States should ensure that residents have the right to autonomy and privacy and to keep personal possessions. Residents or their representatives should have the right to manage personal funds, inspect records of any personal funds the facility manages for them, and meet with advocates and community organizations. States should empower ombudsmen to have immediate access to all supportive housing residences, including board and care homes, without advance notice.
Consumer role in developing and assessing care plans	STATE	States should require resident assessments and the development of regularly updated individual care plans. Residents, their family members, and/or their representatives (as appropriate) should be fully involved in developing and updating care plans.
Staff training	STATE	States should 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; promotion of residents' independence, dignity, autonomy, and privacy; and recognition and reporting of abuse and neglect. States should require adequate training and careful supervision in statutes or regulations allowing registered nurses to delegate certain nursing tasks to paid direct-care workers. Allowing nurses to train and delegate certain nursing tasks to direct-care workers can ease the burden on family caregivers. The statutes must follow the Nurse Practice Act guidelines for delegation by registered nurses and provide adequate consumer protections and appropriate liability protections for nurses.
Contracts for supportive housing	STATE	States should require that providers of supportive housing have a contract with each resident and that the contract disclose such information as the services provided and their costs, residents' ability to purchase additional services from outside providers, and the circumstances and conditions that would require the resident to move from the facility.

Coordination of state oversight	State	Each state should designate a lead agency to coordinate policy, including licensing, monitoring, quality improvement, and enforcement efforts. Licensing standards and monitoring should reflect residents' level of disability and the provider's performance history. States should 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.

Nursing Facilities

Nursing facilities provide long-term services and supports (LTSS) to many vulnerable people with disabilities. In addition to providing LTSS, skilled-nursing facilities also provide short-term rehabilitation and post-acute care to patients following in-patient hospitalizations. These nursing facilities should serve as a place of transition between home- and community-based services and acute care services. However, where residents do remain in nursing facilities for more than a short transitional period, nursing facilities should be small home-like settings with an emphasis on resident-centered care and staff empowerment (for additional policy on the care of these patients, see Chapter 7, Health: End-of-Life Care. Also, for discussion on Medicaid Managed LTSS see Chapter 7, Health).

Culture—It has become clear that frail, vulnerable adults fare better (especially in times of disaster) when a personal connection is established between the care provider and the care recipient. When someone truly cares about another person, it is unlikely that they would leave them to fend for themselves when disaster strikes. Further, delivering substandard care is far less likely when a bond between individuals exist. It is vital that the philosophy of practice and the day-to-day milieu of nursing facilities reflect this reality. Nursing facilities should focus on practices that promote relationship building between the care provider and the care recipient and discard practices that inhibit such relationships.

The Nursing Home Reform Act—Congress responded to widespread concern about poor nursing facility quality by passing the Nursing Home Reform Act, part of the Omnibus Budget Reconciliation Act of 1987. The reform act establishes state requirements for certifying nursing facilities that participate in the Medicare and Medicaid programs. It also sets quality standards for nursing facilities nationwide, establishes resident rights, and defines the state survey and certification process needed to enforce the standards.

In addition, the act includes significant provisions on the rights of nursing facility residents and the rights and responsibilities of ombudsmen. Its 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 of 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 facility ombudsmen. Ombudsman programs and councils advocate for residents of nursing facilities and board and care homes.

The law also mandates comprehensive assessments and includes provisions to prevent nursing facilities 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 facilities 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 facility 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.

Quality indicators—In 2002 the Department of Health and Human Services announced the Nursing Home Quality Initiative, which emphasizes consumer information and the use of consultants to help nursing facilities improve care. A centerpiece of the program gave consumers new information about the quality of care provided in individual nursing facilities on the Nursing Home Compare website. It reports 18 measures on key quality factors, such as pain management, preventable bedsores, and use of restraints. The measures fall into two categories: 13 for chronic care (long-term) residents and five for post-acute care (short-term) residents. The website also features an overall five-star rating system based on health inspections, staffing, and quality measures. It is one tool that consumers can use, along with other tools such as state nursing facility ratings and visits to nursing facilities, to help themselves and their families make more informed selections of nursing facilities.

The ratings are risk-adjusted, so nursing facilities that take care of sicker residents do not receive unfairly low scores and the ratings can be compared across all types of nursing facilities. A poor score is reason for greater scrutiny of a particular nursing facility's care.

The initiative has had mixed results. Between 2002 and 2004 nursing facilities that volunteered for help from consultants started out worse and improved more than other nursing facilities in terms of the number of residents with untreated pain or in physical restraints. However, the initiative had no significant impact on other quality indicators, such as the proportion of residents with pressure sores or the proportion of residents who were able to walk, feed themselves, or use the bathroom on their own.

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 (states must pay for the hearing if they lose). Such changes could make surveyors less likely to cite deficiencies and impose penalties.

Nursing facility inspections—State governments oversee the licensing of nursing facilities. States have a contract with the Centers for Medicare & Medicaid Services (CMS) to monitor those nursing facilities that want to be eligible to provide care to Medicare and Medicaid beneficiaries. CMS contracts with each state to conduct onsite inspections that determine whether its nursing facilities meet the minimum Medicare and Medicaid quality and performance standards. The state conducts inspections of each nursing facility that participates in Medicare and/or Medicaid. Surveys may occur anywhere from 9 to 15 months from the previous survey, with the statewide average for inspections no greater than 12 months. If the nursing facility is performing poorly, however, the state inspectors may go in more frequently.

Investigation of residents' deaths—No national policy requires the investigation of nursing facility residents' deaths to determine whether abuse or neglect may have played a role. Arkansas, however, has a unique law that requires coroner investigations of all nursing facility residents' deaths. Coroners who find reasonable cause to suspect that the death is due to neglect or other "maltreatment" report their findings to the state survey agency and the state Medicaid Fraud Control Unit. Referrals may also be sent to a local city or county prosecutor. The state survey agency treats the coroner referrals as complaints and investigates them accordingly.

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 facility beds. Swing beds are most appropriate for delivering short-term skilled care. Patients who require skilled nursing or rehabilitative services at a level between hospital and nursing facility care can receive care in "subacute" or "transitional" care facilities. These facilities may be freestanding or part of a hospital or nursing facility.

Staffing levels—The Nursing Home Reform Act requires that nursing facilities provide, at a minimum, eight hours of registered nurse (RN) coverage and 24 hours of licensed practical nurse (LPN) coverage per day. In addition the law requires nursing facilities 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."

Research shows that RN staff hours in particular are correlated with better quality outcomes, including reduced incidence of pressure sores, lower use of physical restraints, and fewer hospital admissions. While LPN and certified nursing assistant (CNA) staffing is essential, it is not a substitute for RN staffing.

Staff training—The Nursing Home Reform Act also requires that nurse aides who work in nursing facilities complete a 75-hour CNA training course and pass a competency test within four months of when they begin working with residents. Although the needs of nursing facility residents have become more complex since 1987, federal standards for CNA training have not changed. This raises concerns that CNAs may be unprepared to provide good-quality care to today's nursing facility residents. In addition inadequate training contributes to staff dissatisfaction and high turnover, which also adversely affect quality of care.

To address these concerns 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. As of 2002, CMS found, 23 states required only the federal minimum of 75 hours of training, 26 states required more than 75 hours, and 13 states required more than 100 hours. Overall the minimum hours required by states ranged from 75 to 175. The report 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 a survey of CNAs, state officials, and CNA trainers in ten states, respondents agreed that 75 hours was insufficient to prepare CNAs to do their jobs. Although some of the interviewees suggested higher thresholds, the majority suggested an increase to between 100 and 120 hours.

In 2001, CMS issued administrative guidance to the states, eliminating CNA training requirements and criminal background checks for workers hired only to transport residents, e.g., drive a van or push a wheelchair. Two years later CMS issued new regulations that gave states the option of exempting from the training requirements staff hired to feed and hydrate residents unable to eat or drink independently. Such staff would have to receive a minimum of eight 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 Creating an Adequate Well-Trained Long-Term Services and Supports Workforce). Effective September 2007, CMS began permitting the use of paid feeding assistants in skilled-nursing facilities. Feeding assistants are required to complete a state-approved training program and must be properly supervised. Skilled-nursing facilities can use paid feeding assistants if allowed under state law.

Paperwork—In 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 facilities can now use a shorter assessment form for residents covered by Medicare.

Nursing facility transparency and improvement—As part of the 2010 Affordable Care Act, Congress established new provisions to help provide consumers with more complete information about nursing facilities. Publicly available data will include nursing facility ownership, nursing facility staffing based on payroll data instead of data self-reported by facilities, complaint processes and complaints, nursing facility inspection reports, and other information to help inform consumers. The law also modifies civil money penalties for nursing facilities and allows penalties to be collected and held in an escrow account, improves notice in the case of facility closure, and improves staff training, among other items.

Disclosure of information regarding nursing facilities' ownership and management—In 2010 the Government Accountability Office (GAO) found that 1,876 nursing facilities were acquired by private investment firms from 1998 through 2008. Ten firms accounted for 89 percent of nursing facilities acquired during this period. According to GAO the CMS system for tracking information about these firms and nursing facility's ownership, the Provider Enrollment Chain and Ownership System (PECOS), provided a confusing picture of the complex ownership structures and affiliations of the nursing facility chains owned by the private equity firms it reviewed. For this reason and others, Congress included enhanced reporting requirements for nursing facilities in the Affordable Care Act (ACA).

The ACA requires a nursing facility to disclose extensive information regarding the people and entities that own, control, or manage the facility. The facility must disclose information regarding "each person or entity who is an officer, director, member, partner, trustee, or managing employee of the facility, including the name, title, and period of service of each such person or entity." The disclosure also must address corporate structures, by including organizational information that describes the legal interrelationships between the entities and people that own or manage the facility. Immediately after the law was passed, nursing facilities were obligated to provide the required information upon request to the Department of Health and Human Services (HHS) secretary and inspector general, the state in which the facility is located, and the relevant ombudsman. In March 2012, HHS published final regulations that include a standardized format for reporting information and procedures used to make the information public. Effective June 2012 facilities began reporting information to HHS, and by March 2013, HHS is to make this information available to the public.

NURSING FACILITIES: Policy		
Service quality	FEDERAL STATE	Nursing facilities should focus on practices that promote relationship building between the care provider and the care recipient and discard practices that inhibit such relationships. Quality measures are not a substitute for strong enforcement. Thus the federal government should enact and maintain strong federal nursing facility quality standards. AARP opposes efforts to deregulate the nursing facility 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 facilities, federal and state governments should provide effective oversight of nursing facilities and create strong sanctions for violations of health and safety standards and residents' rights.
Nursing Home Reform Act	FEDERAL STATE	Federal and state governments should monitor and enforce regulations as mandated by the nursing facility quality reform provisions of the Nursing Home Reform Act and other laws and regulations affecting nursing facilities. Federal and state governments should provide necessary funding to carry out the provisions of the act, giving residents 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). In order to prevent harm to residents, the act's requirement that facilities ensure that each resident attain or maintain his or her "highest practicable physical, mental and psychosocial well-being" should be vigorously enforced.
Protection of residents' rights	FEDERAL STATE	Facilities should be required to post a 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. States should require facilities to: • provide access to a separate visiting room for people in semiprivate rooms, • have features that protect residents' personal belongings from theft and are responsive to residents' preferences, • provide residents or their representatives with a monthly itemized statement of charges, and • not transfer residents to facilities that are far from family or friends unless it is a resident's wish or the facility clearly documents that such a transfer is unavoidable. Facilities that are reducing beds, merging, or closing—or that have filed for bankruptcy or have other financial difficulties—should be closely monitored to protect residents' rights and quality of care.
Nursing facility inspections	FEDERAL STATE	AARP opposes proposals to lengthen the period between nursing facility inspections. Inspections should not be scheduled in advance.

Nursing facility inspections (cont'd.)	FEDERAL STATE	States should require surveyors to interview residents in private when inspecting facilities and conduct private interviews with family members and independent family councils requesting an interview.
Discriminatory admission practices	FEDERAL STATE	Federal and state governments should ban discrimination in admission practices based on source of payment, ability to pay, or socioeconomic status and should strictly enforce these laws and monitor facilities to ensure compliance.
Medicare-Medicaid certification	STATE	States should require that all beds in a nursing facility be Medicaid- and Medicare-certified as a condition for the facility's participation in the Medicaid program.
Nursing facility deaths	FEDERAL STATE	Federal and state regulations should require the reporting by coroners and the investigation of nursing facility residents' deaths that are suspected to have been caused by abuse, neglect, or other maltreatment. When an investigation uncovers prior abuse, neglect, or other noncompliance associated with the resident's death, the nursing facility should be penalized.
Swing beds	FEDERAL STATE	Federal and state governments should enforce quality standards similar to those for freestanding nursing facilities to protect against improper use of hospital swing beds.
Standards for subacute care	FEDERAL STATE	Federal and state governments should define uniform service and quality standards for subacute care providers.
Staffing requirements	FEDERAL STATE	The goal of minimal staffing requirements should be to increase staffing thresholds to at least the levels determined necessary to ensure adequate care. As a minimum step federal and state governments should establish specific minimum staffing levels not lower than the minimum thresholds identified by the Centers for Medicare & Medicaid Services (CMS): • 2.8 hours for nurse's aides per resident per day, • 1.3 hours for registered nurses (RNs) and licensed practical nurses combined per resident per day, and • .75 hours for RNs per resident per day. Federal and state governments should enact regulations beyond the Nursing Home Reform Act's standard of eight hours of RN time per nursing facility per day and recognize that increased RN staffing hours correlate with better quality outcomes. Nursing facilities should be required to have at least one RN or gerontological nurse practitioner with clinical responsibilities on duty 24 hours a day, seven days a week. States should require 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 act. States should create 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 care.

Waivers for staffing requirements	FEDERAL STATE	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 ensured 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.
Staff training	FEDERAL STATE	All unlicensed individuals responsible for resident care, including single-task workers, should be required to complete certified nursing assistant (CNA) training, pass a CNA competency test, undergo a period of probationary supervision, and fulfill annual continuing education requirements. The required minimum CNA training should be increased to at least 100 hours, and staff should be required to complete training before providing care. Training in communication, problem solving, cultural sensitivity, and recognition and reporting of abuse and neglect should be added to CNA curriculum requirements. Federal and state governments should require that nursing facility staff are trained and demonstrate needed skills before implementing new technology or equipment for residents. States should establish continuing education requirements for registered nurses, licensed practical nurses, and nurse aides; require employer-provided paid leave for this purpose; and encourage employers to pay tuition and fees for continuing education. States should ensure that social workers and other mental health professionals who work in nursing facilities or under contract to nursing facilities have training in the special needs of older people and people with all types of physical and mental disabilities. (See also this chapter's section Creating an Adequate Well-Trained Long-Term Services and Supports Workforce.)
Research on staffing requirements	FEDERAL STATE	Additional research that will advance the understanding of the relationship between staffing levels and quality of care should be encouraged. 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 residents' needs.
Private right of action	FEDERAL STATE	Medicare and Medicaid beneficiaries should be provided with a private right of action to sue nursing facilities 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.
Paperwork	FEDERAL STATE	Federal and state regulators should look for additional ways to reduce paperwork in nursing facilities without adversely affecting resident care or interfering with federal quality initiatives. Consumers should have input regarding changes made to paperwork requirements.

End-of-life decisions	STATE	States should 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.
Use of physical or chemical restraints	STATE	States should 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 facility staff, and families are educated about the negative effects of restraints and about alternatives to their use. States should require that when restraints are applied, residents are checked on a schedule at least as strict as CMS requirements under the Nursing Home Reform Act.
Disclosure of ownership	FEDERAL STATE	Federal and state governments should work closely with consumer groups to develop and implement a standardized format in which nursing facilities will disclose the names of all parties with ownership control or lease, financial, or operational interest in the facility to federal and state governments, the state long-term care ombudsman, and the public. Federal and state governments should notify the public of the availability of this information and make this information readily accessible to the public. Nursing facilities should be required to notify prospective and current residents and their families, and resident councils of the availability of ownership information and provide them with this information upon request.

Quality Improvements in Nursing Facilities and Supportive Housing

Options for long-term services and supports (LTSS) outside the home include nursing facilities and supportive housing settings, such as assisted living residences, board and care homes, and adult foster care (see this chapter's sections Supportive Housing and Nursing Facilities for discussions of these options). While many of these settings offer important benefits to people in need of LTSS, regulators should address several issues that can affect the quality of care in LTSS settings.

Private rooms—Studies consistently show that consumers strongly prefer private rooms and private bathrooms, which they see as essential to dignity and any meaningful protection of privacy. In addition to their importance for resident quality of life, private rooms and bathrooms are also important to protect the security of residents' personal belongings and for infection control. Evidence also indicates less resident conflict and less staff time in resolving conflicts when residents have private rooms.

Culture change—A growing number of facilities are embracing culture-change efforts to become more life enhancing places in which to work and live. Culture change can have many meanings, but it usually includes three major elements:

- changes in the physical characteristics of care facilities to make them more residential in scale and provide more private spaces for residents;
- changes in the staffing model that give more training, autonomy, and career advancement opportunities to direct-care staff; and
- changes in the service delivery model to give care recipients, whenever possible, and their families/caregivers more control over the types and timing of the services they receive.

For example, the Green House Project and similar efforts transform nursing facilities from institutions into small, home-like settings with private rooms and bathrooms and an emphasis on resident-centered care and staff empowerment. Other efforts include moving toward household-living models, resident-directed care practices, and improved workplace cultures within existing facilities. Among assisted living facilities, some settings are using an intergenerational community model, in which residents share a building or campus with staff and their families or with college students. Regardless of the approach, the outcome of culture change should be that the individual's humanity is embraced and interpersonal relationships are formed between care providers and care recipients.

Bed holds—Federal law requires that nursing facility residents who are temporarily absent from the facility be allowed to return to the next available bed in that facility. Medicaid coverage during a temporary absence varies from state to state, with some states providing no coverage. In those 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 such "bed holds" in supportive housing vary from state to state.

Video technology—Video technology can facilitate frequent visits and communication between residents in nursing facilities or supportive housing and their loved ones. Virtual visits can also help family members monitor and document a resident's care. In 2001, Texas passed a law that protects the right of nursing facility residents to request electronic monitoring devices. The state added assisted living residences to the statute in 2003. The law requires nursing facilities and assisted living residences to provide reasonable accommodations for electronic monitoring and prohibits facilities from refusing to admit or release residents because they request monitoring. A 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 the consent of any other residents living in the same room. Those residents may condition their consent on the camera being pointed away from them or on 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.

Admitting mixed populations—Some concerns have been raised about people with a record of violent crimes, including sexual assault, being admitted to nursing facilities and assisted living residences. For example a report by the Government Accountability Office (GAO) identified about 700 registered sex offenders living in LTSS facilities in 2005. Although these offenders may be disabled, they can still put vulnerable residents at risk. Almost no facilities have the staffing levels, training, and security needed to care for these residents and ensure the safety of other residents. In addition, federal and state sentencing policies will place increased pressure on corrections agencies to house and care for large numbers of elderly inmates in the future, with limited experience in doing so. Some advocates have called for consideration of early-release approaches for elderly nonviolent offenders.

Emergency preparedness plans—Federal law requires nursing facilities that participate in the Medicare or Medicaid programs to have detailed written plans and procedures to meet all potential emergencies and disasters, such as fire, severe weather, and missing residents. In addition, the facility must train all employees in emergency procedures when they begin to work at the facility, periodically review the procedures with existing staff, and carry out unannounced drills using those procedures. Requirements for emergency preparedness plans in supportive housing vary from state to state.

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 facility and assisted living residents.

Alternative dispute resolution—Residents in nursing facilities and assisted living facilities 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 other issues, including disputes about the life, health, or resident safety (see Chapter 12, Personal and Legal Rights: Alternative Dispute Resolution).

QUALITY IMPROVEMENT IN NURSING FACILITIES AND SUPPORTIVE HOUSING: Policy		
Promotion of privacy and home-like environments	FEDERAL STATE	The federal government and the states should encourage and provide incentives including, but not limited to, grants and loans for new, affordable models of long-term services and supports (LTSS) that emphasize resident-centered care, a home-like environment, a

Promotion of privacy and home-like environments (cont'd.)	FEDERAL STATE	positive workplace culture, and opportunities for resident involvement in the community. In states where a certificate of need process exists, that process should be employed to promote the development of home-like, consumer-centric supportive housing residences and nursing facilities. The federal government and the states should support the exploration of changes in staffing models to give more person- and family-centered training, autonomy, and career advancement opportunities to direct-care (frontline) staff. Providers with existing facilities that need renovations to create private baths, kitchenettes, and other improvements should have incentives for making such changes. States should require all supportive housing residences and nursing facilities to maximize each resident's dignity, independence, autonomy, and privacy. All new or retrofitted supportive housing residences and nursing facilities should provide private living quarters, except when residents request to share rooms or apartments. States should ensure that any new facilities that are developed meet consumers' needs and preferences. 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.
Funding	FEDERAL	The federal government should couple new quality-related 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.
Bed holds	FEDERAL STATE	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 an eligible individual during a temporary absence of reasonable duration.
Video technology	FEDERAL STATE	The federal government and the states should enact laws that clearly establish the right of nursing facility and supportive housing residents—or 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. For 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. Nursing facilities and supportive housing residences should be prohibited from removing or refusing to admit a resident who chooses to use such technology.

Preadmission screening	FEDERAL STATE	Because nursing facilities and supportive housing facilities must ensure the safety of residents, agencies that refer individuals to nursing facilities or supportive housing should be required to inform the facility when an applicant poses a potential threat to the safety of other residents. Preadmission 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 alternative access to needed services. This should include access to services in the home or community, specialized facilities for those who present a risk of violence and need facility-based care, and enhanced family caregiver support.
Admitting parolees or violent offenders to long-term services and supports facilities	FEDERAL STATE	The federal government and the states should not parole or prerelease violent offenders to LTSS facilities that serve the general population. Violent offenders subject to the jurisdiction of federal or state correctional agencies who need LTSS should be served by correctional agencies in units that meet appropriate staffing and training requirements for proper care. LTSS agencies and state corrections agencies should begin to plan for the release of nonviolent elderly offenders through early-release and other programs.
Emergency preparedness plans	FEDERAL STATE	Federal and state licensing standards should require that nursing facilities and supportive housing residences have well-developed, feasible, and practiced emergency plans for residents, as well as adequate numbers of well-trained staff to carry out such plans. These plans should be prepared and reviewed annually by the local emergency management agency as well as the state regulatory agency. Plans must include procedures for safely evacuating residents; transporting medical records, emergency medicines, and other supplies; and continuing needed care. The standards should require that emergency plans be on file with the state. Emergency plans should be given to family members when a client is admitted to the facility as well as annually following state approval. Facility administrators should be criminally liable for not properly following these plans and any emergency orders issued by federal, state or local authorities. State governments are responsible for ensuring that systems are in place to protect all nursing facility and supportive housing residents in the event of emergencies. These systems should ensure clear communication and points of contact in state and federal government and in LTSS facilities before, during, and after a disaster. States should put policies and procedures in place to safely move residents from unsafe facilities or facilities that can no longer provide care.

Consumer participation in LTSS facilities' operation	STATE	All nursing facilities and supportive housing residences should be required to create a board or an advisory body to review operations. Advisory boards should include at least two independent consumer representatives. States should enforce the family and resident rights outlined in 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. States should require nursing facilities and other supportive housing to allow notices of council meetings to be posted, permit mailings to prospective members, provide a meeting room within the facility, and provide a contact person to respond to the council's concerns. Facilities should arrange for staff to attend council meetings and should allow the presence of outside representatives only upon the council's request.
Ombudsman programs	STATE	States should provide adequate funding to permit state LTSS ombudsmen to visit all facilities.
Regulatory enforcement	STATE	States should 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. States should ensure that licensing laws specify the conditions of care for each type of facility, including all subacute and LTSS beds in hospitals and special care units for residents with dementia.
Community involvement	STATE	States should encourage facilities to involve family members and the local community in facility activities and to help residents develop and maintain relationships in the broader community.
Private right of action	FEDERAL STATE	States should guarantee and protect the rights of residents, including their right to pursue a private right of action in court when facilities violate state laws and regulations or when the government fails to enforce them.
Dispute resolution	FEDERAL STATE	States should 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. States should 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. The administrative and judicial appeals process should be streamlined to minimize a facility's ability to avoid or delay penalties. A facility's use of binding arbitration and dispute resolution agreements as a condition of admission or continued stay should be prohibited.
Antidiscrimination laws	FEDERAL STATE LOCAL	States should enact and strictly enforce antidiscrimination and civil rights laws to protect the fundamental right of all nursing facility and

Antidiscrimination laws (cont'd.)	FEDERAL STATE LOCAL	supportive housing applicants and residents to be free from discrimination. Antidiscrimination laws should be amended to include sexual orientation and ensure the right of same-sex couples to be housed together in assisted living facilities, nursing facilities, and other LTSS settings (see Chapter 12, Personal and Legal Rights: Civil Rights, for additional policy on antidiscrimination laws).
Information confidentiality	STATE	States should ensure confidentiality of resident information.

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 (AD), vascular dementia, and delirium. They also include depression, anxiety, and conditions that are the secondary consequences of physical ailments or medical interventions. A National Institutes of Health panel has noted that depression in the aging and aged is a major public health problem. Alcoholism and other substance abuse disorders also are found among older adults.

The occurrence of cognitive disorders—AD and other kinds of dementia—increases with age. One in eight people over 65 have AD or other dementia. Dementia is even more prevalent in adults age 85 and older. A 2010 study found that 42 percent of people in assisted living facilities had a diagnosis of AD or other form of dementia. By comparison, nearly 60 percent of nursing facility residents have AD or other form of dementia, as many as 75 percent have some form of 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. In 2010 there were 1,382 geriatric psychiatrists in the US. It is estimated that there will be approximately 2,640 geriatric psychiatrists by 2030 (or one per 5,682 older adults with a psychiatric disorder). However, an estimated 4,000 to 5,000 clinical geriatric psychiatrists will 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. There is a strong need to recruit more trained mental health providers of varying backgrounds to work with older people. Overcoming existing silos between mental health and aging services providers is critical and may be addressed by developing partnerships between agencies on aging and community mental health centers.

Other professionals who can provide older people with mental health services include gerontological social workers and gerontological nurse practitioners. Yet both are also in short supply. 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 facilities—Despite the high prevalence of cognitive and mental disorders among nursing facility residents, few have access to mental health professionals. In addition, research has shown frequent, inappropriate administration of psychotropic medications to nursing facility residents. Also facilities with fewer than 120 beds are not required to employ a full-time clinical social worker. The Nursing Home Reform Act, part of the Omnibus Budget Reconciliation Act of 1987, required nursing facilities to develop and administer a resident assessment-and-care-planning instrument to be used upon a resident's admission and every year thereafter. The instrument assesses care needs related to cognitive impairment and behavioral problems, among other issues.

The 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), intellectual disabilities/developmental disabilities (ID/DD), and related disorders in nursing facilities 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, ID/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 facility setting, either by the nursing facility alone or through supplemental services provided or arranged for by the state. Confusion over the PASARR requirements made nursing facilities 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 facilities must conduct subsequent reviews only in response to a "significant change in the physical or mental condition of mentally ill or intellectually disabled 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 program's main objective: ensuring that residents with mental illness and developmental disabilities receive the services they need in the most appropriate care setting (see Chapter 7, Health: Health Care Coverage—Medicare—Mental Health, 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 2011, 46 states had specific requirements for assisted living residences or other residential care settings serving people with AD or other dementia.

Special care environments—Special care environments (SCEs) provide specialized care either through tailored services or programs or in a discrete unit or facility. Because there is no consistent definition or set of standards for SCEs, there is much variation in the type of services they provide. 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.

ACCESS AND QUALITY ISSUES FOR PEOPLE WITH COGNITIVE AND MENTAL DISORDERS: Policy		
Availability of treatment	FEDERAL STATE	The federal and state governments should ensure that people with cognitive and mental disorders, including Alzheimer's disease (AD) and other forms of dementia, receive necessary treatment and long-term services and supports (LTSS) in the most appropriate and integrated setting of their choice. The federal government and states should support efforts to reduce and prevent the inappropriate use of antipsychotic drugs as a means of chemical restraint among residents of nursing facilities and other settings through steps such as: • passage and enforcement of informed consent laws; • prescriber education programs; • provision of information to current and potential nursing facility residents, their families, the public and others regarding the misuse of antipsychotic drugs in nursing facilities; • expanded reporting requirements and data collection efforts in order to monitor the inappropriate use of antipsychotic drugs in nursing facilities; • consideration and enforcement of penalties for inappropriate use of such drugs; and • research on the use of antipsychotic drugs across settings. States should ensure that people with mental illness or intellectual disabilities who are not admitted to a nursing facility as the result of a Preadmission Screening and Annual Resident Review (PASARR) are provided with appropriate treatment in the most appropriate setting. States should establish mechanisms to ensure that LTSS agencies and mental health authorities address the mental health needs of people who may need or require LTSS.

PASARR screening	FEDERAL	Regulations should be developed defining the “significant change” in a person’s physical or mental condition that triggers reassessment under the PASARR. The rules must recognize that people with serious mental illness may not show significant change but still may have mental health needs. The Centers for Medicare & Medicaid Services should evaluate why the PASARR appears to have been effective in meeting its objectives in only some states.
Nursing facility care	FEDERAL STATE	Residents of nursing facilities and supportive housing should be ensured access to a 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. Federal regulations should require that staff in special care units 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 such care. States should 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 exacerbating cognitive and mental symptoms.
Research	FEDERAL	Federal funding for research into the prevention, care, and treatment of cognitive and mental disorders affecting older people and their family caregivers, particularly AD and other forms of dementia, should increase.
Training of mental health workers	STATE	States should ensure that all LTSS training programs for direct-care workers address the care of people with acquired brain injuries or mental disorders, such as serious mental illness, intellectual disabilities/developmental disabilities, AD, and other types of dementia.
Coordination of mental health services	STATE LOCAL	States should coordinate mental health services among 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.

Creating an Adequate, Well-Trained Long-Term Services and Supports Workforce

The care provided in long-term services and supports (LTSS) settings is only as good as the personnel who provide it. Yet workforce challenges, including how to best ensure the skills needed to provide high-quality care, abound in the LTSS industry and need to be addressed swiftly if the nation hopes to respond to the growing need for high-quality care. Lack of staff, inadequate training, and an insufficient number of bilingual workers and workers aware of and sensitive to different cultures are serious problems, as are workers who have committed abuse or have criminal backgrounds.

Registries—All states are required to have registries with information on nurse aides eligible to work in nursing facilities. The data include aides’ certification information and any substantiated findings of abuse, neglect, or misappropriation of property made by the state survey agency. 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. A 2005 study by the Department of Health and Human Services Office of Inspector General found a number of problems with state registries. Twenty-four of the 38 states included in the study did not meet the federal requirement for updating registry records of nurse aides with substantiated findings of abuse, neglect, or misappropriation of property within ten working days.

More than half the states (28) did not remove records of inactive nurse aides from their registries as required. More than 1,500 nurse aides with substantiated findings had certifications in at least one other state and therefore were potentially employable in that state.

Criminal background checks—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 facilities to home health agencies or supportive housing without ever undergoing a criminal background check.

Although the federal government does not require criminal background checks of LTSS workers, increasing numbers of states are doing so. Certain states require statewide or national criminal background checks be performed for certified nursing assistants (CNAs) and assisted living staff. In addition, states that require statewide criminal background checks may also mandate a national background check under certain circumstances, such as when applicants have recently relocated from other states. Some states have barred employment if certain offenses were found. In 2009, 46 states and the District of Columbia had laws mandating pre-employment criminal background checks for defined categories of in-home LTSS workers. According to research by the National Conference of State Legislatures commissioned for a 2009 AARP report, only six states exempt family members or other relatives from criminal background screening. State laws vary considerably in terms of who is screened and exempted, what convictions preclude employment and for how long, use of provisional employment while checks are conducted, and who pays for screening. Some state laws have an exemption clause for workers hired under self-direction. However, in 2009, at least four states required criminal background checks on workers hired under self-directed service programs without exceptions for family or friends of self-directed program participants.

Worker retention and vacancies—LTSS workforce shortages have led to concerns about the lack of registered nurses (RNs), licensed practical nurses (LPNs), and direct-service workers, such as home health aides, personal care attendants, and CNAs (see this chapter's section Quality and Consumers' Rights Across Settings—Nursing Facilities and Supportive Housing).

Direct-service workers provide most paid LTSS, yet people who can afford home-care services often have difficulty locating competent, trained workers. In 2010 the median hourly wage for home health aides was $9.88. Low wages contribute to high staff turnover and low-quality care. Providers, too, are experiencing staffing shortages, especially among direct-service workers. Annual turnover rates in nursing facilities, supportive housing residences, and home-care agencies are high, in some cases exceeding 100 percent for direct-service workers. One key reason for the inadequate supply of competent workers and high turnover rates is the low wages paid (and few benefits provided) to direct-care workers, which in turn is partly the result of federal regulations that exclude home-care workers from the minimum wage and overtime protections provided by Fair Labor Standards Act. The US Supreme Court has ruled that home-care workers are not entitled to these wage protections even when they are employed by a third-party agency. The Department of Labor proposed changes to the regulations, federal legislation has been introduced, and some states are considering "domestic workers' bill of rights" legislation to upgrade these jobs.

Efforts to broaden the scope of clinical responsibilities may also play an important part in attracting and retaining direct-care workers. Exploring ways in which all professionals can provide services to the full extent of their current knowledge, training, experience, and skills is essential for two reasons: Significant access-to-care issues exist due to shortages in providers, and the scope of practice of many care workers may need to change in order to improve the quality and efficiency of care delivery (for AARP policy on scope of practice, see Chapter 7, Health.)

Nursing facility, supportive housing, and home-care problems affecting retention 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. Initiatives to recruit and retain more direct-care workers are now being undertaken by the federal government and the states, the LTSS industry, and workers themselves.

Federal efforts include funding demonstration projects to make health insurance coverage available to direct-care workers, funding development of educational materials and training and mentoring programs, creating a pilot "career lattice" apprenticeship program for CNAs, and designing the National Survey of Direct-Care Workers.

State efforts include higher Medicaid reimbursements designated for wages or benefits (wage or benefit pass-throughs), rate enhancements linked to provider performance goals or targets, reform of methods for rebasing and updating reimbursement rates so they are more competitive, enhanced training opportunities, and media campaigns promoting direct-care careers.

Industry practices in nursing facilities include mentoring programs, involvement of staff in decisionmaking, and flexible work schedules. Managers report that these practices have improved staff satisfaction and retention. In home care, employee-owned agencies have improved wages, benefits, training, and level of workplace participation. The unionization of the workforce has begun to have a positive impact on workloads, training, and levels of pay and benefits in some states. Increased collaboration among federal, state, and local stakeholders is critical and should include industry, public, and private contributors.

Training for direct-care workers—Home health aides (HHAs) in Medicare and Medicaid provide personal care and some clinical care under the direction of nurses or other licensed medical staff. Both CNAs, who generally work in long-term care facilities, and home health aides, who are employed by Medicare-certified home health agencies, are required by federal law to have at least 75 hours of training and/or pass a competency exam. At least 16 hours of this training must be "hands-on clinical care" under the supervision of a registered nurse. States are also required to establish a competency evaluation program for home health aides.

Personal care workers, who provide help with activities of daily living and IADLs, by law cannot provide the clinical care that CNAs and HHAs provide. These workers (also called personal assistance workers, home-care aides, and personal care attendants) include people hired through agencies and independent providers, and family members who provide services in participant-directed programs. Unlike agency workers, individual providers in these programs are hired, screened, trained, and supervised by consumers (see this chapter's section, Creating a Participant-Directed Long-Term Services and Supports System, for participant-directed programs).

At the federal level, the CMS National Direct Service Workforce Resource Center is developing a road map of core competencies for the direct-service workforce across populations. Many states require that agency-hired personal care workers have some training, but requirements vary widely by state and by the site in which the care is provided, e.g., assisted living residence versus private home. The 2010 health care law includes a demonstration project that supports states in developing and evaluating a competency-based uniform curriculum to train qualified personal and home-care aides. The law also includes provisions on the direct-care workforce and how to help strengthen it. Some states require training for workers hired in participant-directed programs, and most states offer support to consumers in training and managing their employees. Responsibility for ensuring that independent providers are qualified and competent is shared among the participant, the state agency, and the family. Consumers receiving such services can be isolated and vulnerable, a potential reality also for those receiving agency-provided home services. The goal is to provide effective safeguards without too much intrusion or diminishing individual choice and control.

Gerontological/Geriatric nurse practitioners (GNPs)—Evidence consistently shows that GNPs improve the quality of care for older people across health-care settings. Care provided by advanced practice registered nurses (APRNs), such as GNPs, results in fewer falls, fewer hospital admissions and readmissions, and higher patient, family, and physician satisfaction. GNPs excel in chronic care management and care transitions. GNPs diagnose and treat a wide range of health problems and serve as patient advocates and role models for nursing staff in all LTSS settings and should receive stronger economic and professional incentives to enter the LTSS field.

CREATING AN ADEQUATE, WELL-TRAINED LONG-TERM SERVICES AND SUPPORTS WORKFORCE: Policy

Qualified workers	FEDERAL STATE	Federal and state governments should support programs to increase the supply of health care personnel with geriatric training. States should work with state nursing association and regulatory agencies to allow nurses to delegate and teach certain health-related tasks to direct-care workers and family caregivers. Nurses must ensure that the direct-care worker or family caregiver demonstrates competency to perform the specific task for that consumer. State

Qualified workers (cont'd.)	FEDERAL STATE	nurse practice acts should provide adequate consumer protections including appropriate follow-up and appropriate liability protections for nurses.
Salaries	FEDERAL STATE	Federal and state governments should ensure that Medicaid and other public reimbursements for providers' labor costs are sufficient to pay wages that will attract and retain long-term services and supports (LTSS) workers. Wages and salaries should be commensurate with others in the region and with the time, skill, and effort required to render high-quality services and supports. Medicaid reimbursement rates should be rebased and updated regularly to take into account relevant economic and financial information, including provider costs. Federal and state governments should require pass-throughs or other mechanisms to increase compensation for direct-care workers. There should be adequate accountability procedures, such as audits, to ensure that reimbursement increases designated for staffing costs are actually used for that purpose.
Employee benefits	FEDERAL STATE	Federal and state governments should support payment reform and the provision of adequate health benefits, educational opportunities, and career ladders to encourage recruitment and retention of LTSS workers.
Identifying workforce shortages	FEDERAL STATE	Federal and state governments should document the shortage of workers and their training needs and support research to identify effective ways to address these problems. The federal government should offer matching funds or incentives and technical expertise to help states collect data and assess yearly the supply and competency of LTSS workers.
Education and training	FEDERAL STATE	Funds should be provided for education and training for LTSS workers, especially those in short supply, such as certified nursing assistants. Federal and state governments should encourage education and training programs to require gerontology courses and practical experience for all appropriate health professions. Schools should be encouraged to include LTSS-related specializations in the curricula for nurses and physicians. States should establish competency-based training requirements for personal care workers in home- and community-based settings hired through agencies. However, when requested by the beneficiary, states may allow exceptions for family caregivers and other nonagency providers when hired through self-directed programs as long as competency, established by state standards, is demonstrated. Workers who are paid to provide care in home and community settings should meet state-established competency-based training requirements, be evaluated for competency, undergo a period of probationary supervision, and fulfill annual continuing education requirements.
Training and certification	STATE	The core training competencies needed by personal care workers, both those who are agency-hired and those who are hired by consumers, and how such competency-based training should be provided, must be evaluated in state demonstrations.

Training and certification (cont'd.)	State	State-approved training and certification should be competency-based and include a core curriculum covering the needs of people who require LTSS. Training should include both classroom instruction and practical experience, such as simulations and real-person or clinical training. Training should include the concept of participant-directed care. Training should also convey the interpersonal aspect of culture change, teaching the personal rewards and positive outcomes associated with culture change. States should require home-care agencies and community care providers to be responsible for regular training, supervision, and documented performance evaluations of aides and other workers. Quality assurance measures must include participant preferences and satisfaction as key quality measures and should evaluate whether a participant is receiving all the services in his service plan and whether there are unmet needs.
Goals of state training programs	State	Training should be completed prior to staff's working independently with consumers. Training and continuing education also should focus on maximizing quality of care while supporting the independence, autonomy, dignity, and privacy of consumers. States should provide training in dealing with dementia and in personal assistance for all direct-care workers in nursing facilities and assisted living residences, and staff employed by home-care agencies. In participant-directed programs, states should be required to allow participants to train their workers, and participants should retain the right to hire workers who meet qualifications based on the participants' needs and preferences. Each person's needs are highly individualized and a standardized training curriculum may not address the specific needs of a particular individual. However, states should make available training opportunities for those participants who prefer that their workers receive standardized training.
Criminal background checks	Federal State	Policymakers should require nationwide criminal background checks prior to employment on all workers who provide LTSS or who are employed in LTSS settings. Background checks should not be required for parents, spouses, partners, close relatives, or close friends when hired through self-directed programs. Individuals who have been convicted of violent crimes or crimes involving abuse or neglect of vulnerable individuals should be prohibited from employment in LTSS settings. The national background checks should be affordable and conducted in a timely manner and should include a fingerprint check. States should require 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.
National registry of LTSS workers	Federal State	The federal government should create a national registry of certified nursing assistants and home health aides that documents training, lists references, and includes findings of abuse, neglect, misappropriation of individual property, and other criminal conduct.

National registry of LTSS workers (cont'd.)	FEDERAL STATE	The federal government should consider broadening the registry to include other unlicensed workers who provide LTSS, including staff in assisted living and other supportive housing settings. Providers should be required to clear potential employees through the registry before hiring them. In the absence of a national registry of LTSS workers, states should ensure that ombudsmen have access to the registry and develop a national clearinghouse for sharing information.
Bilingual workers	STATE	State governments should offer incentives for providers to hire bilingual workers when appropriate and train all staff to be culturally competent. States also should establish incentives for providers to ensure that workers not proficient in English get training in English as a second language.
Recruiting and retaining direct-care workers	FEDERAL STATE	Policymakers should improve labor standards for home care and home health aides, including minimum wage and overtime pay protections, meal breaks, sleep time, and time off. So as not to place an undue burden on LTSS consumers and family caregivers, however, these standards must be appropriately tailored to address the realities of LTSS: Services are provided in private homes, services are often arranged by a family caregiver in another home or another city, services are provided under different models, and services are provided to persons with physical, mental, and/or cognitive impairments. The federal government and ~~s~~tates should initiate efforts to promote changes in the work environment that encourage staff recruitment and retention. These could include expanding roles for direct-care workers commensurate with their demonstrated competency to take on additional roles; 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.
Gerontological/ Geriatric nurse practitioners (GNPs)	FEDERAL STATE	Policymakers should remove barriers to the effective use of advanced practice registered nurses (APRNs) such as GNPs in all LTSS settings. APRNs should be permitted to certify patients for home health and hospice services and should be eligible to perform the admission physical for skilled long-term care. Arbitrary restrictions on APRN care, such as not permitting nurse practitioners to serve as medical directors of skilled-nursing facilities, should be removed. Current state nurse practice acts and accompanying rules should be interpreted and/or amended where necessary to allow APRNs to fully and independently practice as defined by their education and certification. APRNs such as GNPs should be reimbursed directly by Medicare or Medicaid for their services in all LTSS settings.

Public-Sector Approaches

Adequate Public-Sector Funding and Payment

Nursing facilities and other providers of long-term services and supports (LTSS) cannot ensure high-quality services without adequate funding. Several studies suggest that higher Medicaid reimbursements are associated with better care for residents.

For example, in 2009, the GAO reported that compared with other nursing facilities, targeted "Special Focus Facility", nursing facilities that had more deficiencies and more serious deficiencies than other nursing facilities were more likely to be for-profit, be affiliated with a chain, and have more beds and residents. A 2007 study in *Health Services Research* showed a small, positive relationship between state Medicaid reimbursement rates for both registered nurse (RN) and total nurse staffing hours per resident day, and is consistent with other studies that have found that higher Medicaid reimbursement rates encourage facilities to provide more nursing care. Recent AARP studies have found a strong correlation between the occurrence of pressure sores and hospitalizations among long-stay nursing facility residents. Further states with more direct-care RN hours per resident day tended to have better nursing facility quality measures, including a lower incidence of pressure sores, lower use of physical restraints, and fewer hospital admissions.

Several other studies, however, suggest that increased reimbursement does not always lead to higher-quality care. Accountability is needed to ensure that reimbursements intended to improve care quality are used for that purpose. For example, a 2008 study in *Medical Care* examined the impact of state Medicaid payment rates on direct-care staffing levels in nursing facilities. The results showed that higher Medicaid reimbursement rates were associated with increases in total staffing levels to meet a higher recommended threshold, but did not translate into improvements in the skill mix of direct-care staff. Gains in overall staffing were accompanied by a reduction in RN staffing and an increase in both licensed practical nurse (LPN) and certified nursing assistant (CNA) staffing levels.

Many LTSS payment systems use a process called case-mix adjustment to link payment levels to beneficiaries' needs. Case-mix adjustment offers providers an incentive to accept residents who have heavy care needs and give them appropriate services. The 2007 study in *Health Services Research* found that the case mix of residents was a positive predictor of RN hours but a negative predictor of total staffing hours. This suggests that nursing facilities take resident case mix into account for RNs but not for total nurse staffing levels, which could result in inadequate total hours for residents with high care needs. The 2008 study in *Medical Care* found that there was a significant downward trend in RN staffing and an upward trend in both LPN and CNA staffing. Adjusting for reimbursement levels and resident acuity, total staffing did not increase after the implementation of case-mix reimbursement (for discussion on reimbursing a managed care organization, see Chapter 7, Health).

ADEQUATE PUBLIC-SECTOR FUNDING AND PAYMENT: Policy		
Funding adequacy	FEDERAL STATE	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. Funding should be sufficient to ensure a viable, reasonable choice of services, settings, and providers, including home- and community based services and a self-directed option with necessary supports. Funding should provide specific and adequate reimbursement for services and care coordination, and contain no caps on reasonable and necessary services or eligibility.
Linking reimbursement to level of disability	FEDERAL STATE	Payments for home and institutional services should be adjusted for the resources required to provide appropriate services to people with varying levels of disability. Financial incentives (e.g., the use of prospective case-mix reimbursement systems that link payment to the intensity of services provided) should be adequate to encourage providers to care for all clients, particularly those with heavy care needs.

Linking reimbursement to level of disability (cont'd.)	FEDERAL STATE	Reimbursement systems not using case-mix adjustment should have other mechanisms to encourage providers to accept residents with heavy care needs. Cases with extraordinary costs outside the normal range require additional rate-setting measures. Reimbursement methods should include incentives for rehabilitating and restoring residents to the highest possible level of functioning.
Linking reimbursement to quality of service	FEDERAL STATE	Reimbursement systems should be structured to recognize the link between financing and quality, and provide incentives to deliver high-quality care.
Consumer protection	FEDERAL STATE	Federal and state governments should ensure that residents actually receive the services for which the system pays. Reimbursement systems should be required to conduct frequent assessments of beneficiary needs. Contracts for nursing facility admission should define Medicaid-covered services so that facilities deliver appropriate services and do not overcharge residents by billing their personal funds for items or services that Medicaid covers. Regulatory agencies should retain copies of facilities' contract forms, which should be available to the public. Funding should be specific and adequate for creating and maintaining an effective state oversight infrastructure.

Medicaid: Strengthening Financial Protections for Beneficiaries and Their Families

Medicaid plays a central role in providing long-term services and supports (LTSS) to people of all ages with various physical and mental disabilities and is essential to protecting the most vulnerable. Medicaid coverage for 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. In fiscal year 2009, Medicaid paid $127 billion for LTSS (including waiver services, home health care, and personal care services), approximately 34 percent of total Medicaid expenditures. Institutional care still accounts for the great majority (65 percent) of Medicaid LTSS spending for older people and adults with disabilities, while spending for community-based services (personal care services and home- and-community-based service, or HCBS, waivers) makes up 36 percent.

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. In most states older people who are eligible for Supplemental Security Income (SSI) are considered eligible for Medicaid. In 2012 the federal SSI eligibility thresholds for individuals were $698 per month in countable monthly income and $2,000 in liquid assets. Yet certain states, known as 209(b) states, may impose even more restrictive eligibility rules (for further discussion of SSI, see Chapter 6, Low-Income Assistance: Low-Income Assistance Programs—Supplemental Security Income).

In April 2011, the House of Representatives passed the House Budget Committee's budget plan. If enacted, the plan would dramatically restructure Medicaid by converting it into a block grant and sharply reducing funding for the program, by 35 percent in 2022 and by 49 percent in 2030. Implementation would adversely affect tens of millions of low-income Medicaid beneficiaries, including LTSS recipients. Capping federal Medicaid funding would also place significant financial pressure on states to scale back eligibility and LTSS coverage. Deep funding cuts would inevitably shift more nursing costs to elderly and disabled beneficiaries and their families, and lower the quality of nursing facility care, as there would be fewer resources to pay for it (for discussion of block grants, see the Medicaid section of Chapter 7, Health).

In determining eligibility for the program, Medicaid considers the home, one car, and a modest amount of personal goods to be exempt assets. However, the Deficit Reduction Act of 2005 (DRA) put a $525,000 limit on the value of home equity, with states having the option to exempt up to $786,000. Medicaid is then entitled to a lien against the home equal to the total amount Medicaid spends on nursing facility care over the lifetime of the homeowner. Medicaid can collect on the lien when the nursing facility resident dies. People whose home equity is above these amounts are, with some exceptions, ineligible for Medicaid LTSS. The Department of Health and Human Services must establish a process under which the home equity limit may be waived. Individuals who are not eligible for a reverse mortgage or a home equity loan could be forced to sell their homes to get the care they need unless they are granted a hardship exemption from the home equity limit (see also this chapter's section Financing Long-Term Services and Supports—Private-Sector Approaches—Reverse Mortgages).

Financial eligibility—Certain states allow people over age 65, and younger people with disabilities and large medical expenses, to spend down their assets in order to meet their state's eligibility test for Medicaid coverage of LTSS in a nursing facility. States also can use a special income rule to qualify individuals for LTSS services. Income may not exceed 300 percent of the federal SSI benefit.

In states that do not offer a "medically needy" program, but allow individuals who need nursing facility care to qualify for LTSS through the special income rule, applicants whose total incomes exceed the eligibility standard cannot get Medicaid nursing facility coverage unless they place their incomes in a Miller Trust. Under this trust, the state receives any amount remaining in the trust when the person dies, up to the amount Medicaid paid for the individual.

Personal needs allowance—Medicaid-eligible nursing facility residents are permitted to keep a personal needs allowance of between $30 and $90 per month (depending on the state) to cover basic expenses such as personal hygiene supplies and phone calls.

Financial protections for spouses—Medicaid requires states to allow the spouses of nursing facility residents to protect income and assets to prevent spousal impoverishment. In 2012 states had to allow a minimum of $1,838 per month in income, with the option of allowing up to $2,739. Any income above that goes toward the cost of the nursing facility recipient's care. States also had to allow spouses to protect between $21,912 and $109,560 in assets. These amounts are automatically updated annually for inflation.

States can offer the same protection to the spouses of Medicaid recipients who receive HCBS under a waiver program. For five years beginning January, 1, 2014, states will be required to extend spousal impoverishment protections for HCBS waiver beneficiaries. Unmarried domestic partners and same-sex spouses are not eligible for these income and asset protections.

The DRA restricts states to a methodology, called the income first rule, for determining the amount of spousal protection. The rule requires that nursing facility residents transfer their incomes to their community spouse before transferring any income-producing assets. Prior to the law, states could allow spouses to protect additional assets if they were used to generate income needed for spousal maintenance.

The income first rule could have dire consequences for spouses with little income of their own, most often wives. Many times, the institutionalized spouse's income stops upon death when much of the couple's other income-producing assets will have already been depleted. Thus, the surviving spouse will potentially face the loss of two sources of income.

Estate recovery—Under the Omnibus Budget Reconciliation Act of 1993 (OBRA 1993), all states must recover Medicaid costs for care in a nursing facility and for HCBS from the estates of people who received benefits at age 55 and older. OBRA 1993 defines "estate" to include the assets that are part of the probate estate under state law. States can 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.

Almost every state and the District of Columbia has an active Medicaid estate recovery program. Recoveries cannot be made while there is a surviving spouse or dependent child, but unmarried domestic partners and same-sex spouses do not have that protection. A number of states recover expenditures by filing liens on the homes of Medicaid recipients, but no recovery can be made until the recipient and spouse die, the house is sold, and any surviving children reach the age of 21.

States may allow liens to be placed prior to an individual's death. Federal law prohibits states from imposing pre-death liens unless the person is in a nursing facility and expected to be permanently institutionalized. Any pre-death lien must be removed if the individual is discharged from the nursing facility and returns to the community.

Transfers of assets—In determining Medicaid eligibility, states must "look back" for a certain time period to determine if an applicant for benefits transferred assets for less than fair-market value. If so, a penalty period is imposed during which the applicant is ineligible for benefits. Applicants have the option of requesting a hardship waiver, and such individuals should receive assistance in developing a care plan and budget for medical and supportive services and necessities for the duration of the penalty period.

The passage of the DRA tightened the asset transfer rules. AARP strongly opposes two of these changes. First, the penalty period now begins on the date of Medicaid eligibility rather than on the date of the asset transfer. As a result, coverage will be denied when people need it and no longer have the resources to pay for it. The DRA also extended the length of the look-back period from three years to five.

MEDICAID: STRENGTHENING FINANCIAL PROTECTIONS FOR BENEFICIARIES AND THEIR FAMILIES: Policy		
Maintaining existing Medicaid services	FEDERAL STATE	AARP supports: • maintaining existing guarantees of long-term services and supports (LTSS) through Medicaid—AARP opposes a congressionally mandated block grant of federal Medicaid spending, which would shift costs and risks to states. Such a shift would severely undercut LTSS and nursing facility quality (see also Chapter 7, Health: Medicaid); • expanding the Medicaid program to improve access to LTSS; and • ensuring adequate federal and state Medicaid funding.
Choice of service	FEDERAL STATE	AARP supports ensuring that people who qualify for Medicaid have a choice between home- and community-based care or nursing facility care and a choice of providers.
Public input	FEDERAL STATE	AARP supports an open contract development, waiver, or state plan amendment process that provides for meaningful public input.
Medicaid eligibility criteria	FEDERAL STATE	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.) 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 ($11,490 per year for an individual in 2013) should be considered categorically eligible for Medicaid. The federal government should stipulate that a state may not deny eligibility under the home equity provision if the individual is not eligible for a reverse mortgage or a home equity loan.
Making beneficiaries aware of right and responsibilities	FEDERAL STATE	Medicaid beneficiaries and applicants should be clearly instructed about their rights and responsibilities, including grievance and appeals processes.
Deficit Reduction Act of 2005 (DRA)	FEDERAL	Congress should repeal the provisions of the DRA that lengthen the look-back period for asset transfers, change the start date of the penalty period, and impose a cap on home equity. Congress should also not modify these provisions in ways that further restrict eligibility for Medicaid-funded LTSS.

Transfer-of-asset penalties	Federal State	Federal and state regulations should establish clear guidelines on what constitutes a hardship for determining transfer-of-asset penalties. Guidelines on transfer-of-asset penalties should address methods for distinguishing deliberately abusive practices from legitimate transfers that occurred in the normal course of life events. The federal government should define the types of transfers that should be presumed to be legitimate and not subject to a penalty—including donations to churches and charities and to family members for medical and educational expenses and a reasonable level of undocumented expenditures—unless the state can demonstrate an intent to improperly qualify for Medicaid. A threshold limit should be established for transfer-of-assets penalties so that those making reasonable levels of transfers for charities, religious donations, or personal gifts or who are unable to provide documentation of all purchases over a five-year period are not penalized. Government attempts to prevent abusive asset transfers for the purpose of qualifying for Medicaid should focus on deliberately fraudulent or abusive activities and loopholes in state laws, not the ordinary actions of typical moderate- and low-income families. Asset transfers outside the individual's control (those made as a result of court order because of fraud or misrepresentation, for example) or before the individual could reasonably be expected to anticipate the need for long-term care within the following five years (e.g., disabling injury, onset of a disabling disease, or diagnosis of a previously undetected medical condition after the transfer date) should be exempt from consideration when implementing the provisions of the DRA.
Hardship waivers for transfer-of-asset penalties	Federal State	Uniform criteria should be established for evaluating whether denial of coverage under stringent DRA provisions causes hardship. Hardship waivers should be granted to individuals who require LTSS but would be denied Medicaid because of prohibited asset transfers. Federal and state regulations should establish hardship waivers of the home equity limit that protect people who have no other way to pay for needed care and ensure that people are not forced to sell their homes to get necessary care. Federal regulations should require that states give all applicants information about the availability of hardship exceptions, ensure presumptive eligibility until a final decision is rendered, and provide a standardized appeals process for people whose exemption requests are denied.
Penalty periods	Federal State	The imposition of a penalty period should be delayed until it is determined that the applicant has the income and resources sufficient to pay for all necessary medical and support care and treatment, food, housing, utilities, and other necessities of life for the duration of the penalty period. Federal and state regulations should require monitoring during the penalty period to ensure that applicants are not deprived of care or necessities. Federal and state regulations should allow for and promptly process hardship-waiver requests and appeals prior to or during the penalty period.

Penalty periods (cont'd.)	Federal State	Prior to the imposition of a penalty, applicants seeking a hardship waiver of a penalty should receive assistance in developing a care plan and budget for medical and supportive services and necessities for the duration of the penalty period. States should provide advance written notice to the applicant that identifies the income and resources available and the projected costs of medical and support care and treatment, food, housing, utilities, and other necessities of life during the penalty period. Applicants should be afforded the opportunity to appeal state determinations of support costs.
Recovery of transferred assets	State	States should not impose blanket requirements that applicants seek the return of all transferred assets and should not mandate civil or criminal legal action. This could be done by establishing a minimum transfer amount for which recovery is required. Frivolous recovery efforts lacking any lawful basis and criminal complaints that would motivate an applicant to file charges of malicious prosecution should be prohibited. States should establish a hardship exception for those unable to make any recovery effort due to disability.
Home equity barriers to coverage	Federal State	Federal and state regulations should establish hardship waivers of the home equity limit that protect people who have no other way to pay for needed care. The federal government should encourage states to provide clear information about other options to individuals who are denied Medicaid eligibility due to home equity under the DRA. States should be required to use a fair process to determine an individual's home equity (a home's current fair-market value for property tax purposes, minus any outstanding debts against the home). States should be allowed to increase the home equity cap up to the maximum allowed by the DRA with minimal administrative burden. Congress should not modify the home equity cap to further restrict eligibility for Medicaid funded LTSS. States should not deny eligibility under the home equity provision if the individual is ineligible for a reverse mortgage or unable to obtain a home equity loan.
Protection for spouses, domestic partners, and children	Federal State	Unmarried domestic partners and spouses in same-sex marriages should be provided all the financial protections given to opposite-sex community spouses. Current financial protections for spouses, caregivers, and dependent children should be retained. Prohibition of federal and state requirements that the children or grandchildren of Medicaid beneficiaries receiving LTSS assume financial responsibility for their parents' or grandparents' care should continue. States should 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.
Estate recovery program	Federal State	The word "estate" under the estate recovery program should be defined no more broadly than it is under state probate law.

Estate recovery program (cont'd.)	FEDERAL STATE	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. Federal regulations should require states to use all money recovered from the estates of Medicaid recipients to improve the program. Procedures for waiving estate recovery when undue hardship would result should be established. Federal regulations should ensure public accountability by requiring estate recovery programs to provide consistent and readily available data on the total costs of the program and the numbers of beneficiaries affected, as well as other essential information, such as the number of exemptions, deferrals, hardship waivers, liens, and contested recoveries. Federal regulations should ensure that consumers are adequately informed about Medicaid estate recovery. Recovery notices should be timely, clear, and easy to read (e.g., published in an adequate type size) and include vital information concerning exemptions, deferrals, hardship waivers, liens, and consumer obligations and rights. Federal regulations prohibiting states from placing liens on the property of Medicaid recipients who receive LTSS in the home and community should remain in force.
Medically needy programs	FEDERAL STATE	The federal government should require states to implement medically needy programs for all people regardless of care setting, including institutional and home- and community-based LTSS. States should maintain the medically needy programs for nursing facility residents and use the special income rule at 300 percent of the Supplemental Security Income benefit level. States should enact a medically needy program if they do not have one.
Personal needs allowance	FEDERAL	The federal government should increase (according to the Consumer Price Index) the minimum personal needs allowance for Medicaid beneficiaries in nursing facilities and supportive housing and adjust it annually to account for changes in the cost of personal needs.

The Older Americans Act

Title III of the Older Americans Act (OAA) provides for social and nutritional services—including transportation, outreach, homemaker services, assistance with chores, telephone reassurance, legal aid, and family caregiver support—to older people. Its primary objectives are to enable people age 60 and older to live independently in their own homes, to remove individual and social barriers to older peoples' economic independence, and to provide an array of services for vulnerable elderly individuals.

In April 2012 the Department of Health and Human Services (HHS) created the Administration for Community Living (ACL) to establish a single HHS organization focused on community living that would enhance and strengthen HHS efforts to support seniors and people with disabilities. The ACL was created by folding the Administration on Aging (AoA), the Office on Disability (OD), and the Administration on Developmental Disabilities (ADD) into a single agency. The reorganization establishes a formal infrastructure to ensure consistency and coordination in community living policy across the federal government. Goals of the change include increased access to community supports for children with developmental disabilities, adults with physical disabilities, and older adults; increased participation in the community by older adults and people with disabilities; and increased resources focused on their needs. The change will maintain the expertise and resources of the existing organizations. Similarly, the day-to-day management of AoA and ADD programs will remain relatively unchanged, with the current program staff retaining their assignments.

The OAA is administered by the AoA but is operated locally. The primary role of state and area agencies on aging (AAAs) is to coordinate service delivery by contracting with local service providers, which are required not only to target services to people with the greatest social or economic need but also to make programs available to all older people in the community. The targeted populations include people with disabilities or low incomes, minority individuals, people with limited English proficiency, rural residents, and others with special needs.

Title III also authorizes services that support family caregivers, including grandparents or older caregivers, as part of the National Family Caregiver Support Program, established in 2000. Continuing support for family caregivers is critical, as the economic value of their contributions was valued at $450 billion per year in 2009. The program gives each state funds to provide services that include information to caregivers about available services, assistance in gaining access to services, caregiver training, respite care, and a limited amount of supplemental services. Overall an estimated 10 million individuals in the US and territories were served under Title III in 2009. Some 1.7 million individuals received congregate meals, and nearly 900,000 received home-delivered meals.

The OAA also funds the long-term care (LTC) ombudsman program. The LTC ombudsman in each state is responsible for identifying, investigating, and resolving complaints made by or on behalf of residents in long-term services and supports facilities. Although funding for this aspect of the OAA has never been adequate, states have historically received an appropriation dedicated to ombudsman spending.

Under the OAA states may solicit voluntary contributions from participants for all services provided under the act. The 2006 OAA reauthorization encourages states to solicit contributions from individuals with incomes at or above 185 percent of poverty. In addition states may now require beneficiaries to pay a cost-sharing fee for the OAA services they receive. Cost-sharing is not permitted for information and assistance, outreach, benefits counseling, case management, ombudsman services, elder abuse prevention, legal assistance and other consumer protection services, congregate and home-delivered meals, and any services delivered through tribal organizations. States may not subject individuals whose incomes are below the federal poverty line to cost-sharing; they may also exclude other low-income individuals from cost-sharing. However, those services and individuals for which or for whom cost-sharing is prohibited may still be subject to requests for voluntary contributions.

The authority to implement cost-sharing represents a significant change in the way OAA services are administered in the states. As such Congress created safeguards to ensure that services continue to be targeted to the most vulnerable populations. These measures ensure the privacy of participants, prohibit states from considering participants’ asset levels, direct states to apply cost-sharing on a sliding scale, and ban states from denying services to individuals who fail to make cost-sharing payments. In addition, AAAs may request a waiver from cost-sharing policies if a significant proportion of beneficiaries are low-income or if the implementation of cost-sharing would impose an unreasonable administrative burden. State agencies and AAAs also are required to conduct public hearings and solicit the views of older individuals before implementing cost-sharing. States must develop plans to ensure that cost-sharing will not decrease the delivery of services to low-income individuals.

A state must have a cost-sharing plan in place that is intended to ensure that participation by low-income individuals would not decrease as a result of such plan. A 2009 survey conducted by the National Association of States United for Aging and Disabilities (formerly the National Association of State Units on Aging) found that a minority of states, less than one quarter, had a cost-sharing plan in place for OAA services, suggesting that cost-sharing is not being widely used.

A February 2011 report by the Department of Health and Human Services (HHS) Office of Inspector General (OIG) cited administrative burdens as a reason why states do not permit cost-sharing or do not use it more extensively. To maximize program resources during a time of increasing demand and fiscal constraints, the OIG recommended that HHS evaluate the burdens associated with implementing cost-sharing for OAA services and identify ways to help interested agencies implement cost-sharing, which could include recommending legislative changes to the restrictions in the OAA, if warranted.

The OIG also found that while the AoA provides uniform procedures for measuring receipt of services, it does not provide standardized definitions or measurement procedures for need and unmet need that all states are required to use. States use a variety of approaches to measure need and unmet need to varying extents, which leaves the AoA unable to assess the full extent of need and unmet need both nationally and by state. The OIG recommended that HHS develop consistent definitions of need and unmet need and to propose interim and long-term uniform data collection procedures for obtaining information on older adults with unmet needs for services provided from sources like Title III.

Amendments to the act in 2006 made several other important changes to the law:

- Service providers and the business community were added to AAA advisory councils (previously all members were either private citizens or from consumer groups). This dilutes the impact of consumers on advisory boards and could significantly expand the group of stakeholders in policy affecting service to local older people.
- The role of state aging networks in delivering home- and community-based LTC services is increased, including through the creation in all states of Aging and Disability Resource Centers (see also this chapter's section Expanding Home- and Community-Based Services).
- States are encouraged to direct home- and community-based services to people at risk of institutionalization, including people ineligible for Medicaid, and to incorporate participant-directed options and promote healthy aging by developing evidence-based disease prevention programs.

THE OLDER AMERICANS ACT: Policy		
Importance of Older Americans Act (OAA) programs	FEDERAL	Federal and state governments should continue to provide public funding for OAA programs and outreach designed to increase participation by diverse communities in low-income benefit programs. Congress should leave intact OAA language that targets the most vulnerable populations, especially low-income and minority seniors. States should enact legislation establishing the state unit on aging (SUA) as an independent entity. SUAs should have the prominence and funding necessary to promote independence in accordance with the objectives and functions stipulated in the OAA.
Role of the Administration on Aging (AoA) and Administration for Community Living (ACL)	FEDERAL STATE	The AoA and ACL should ensure that states adequately deliver services to the most vulnerable populations, especially low-income, rural, and minority individuals. The AoA's authority to approve state plans and intrastate funding formulas should be clearly stated in both law and regulation. The AoA should enforce the OAA provision that prohibits state and area agencies on aging (AAAs) from directly providing supportive, nutrition, and in-home services except when necessary to ensure an adequate supply of services related to the agency's administrative functions or when the services would be more economical.
Integration of services	STATE	Administrative links between Social Services Block Grant state plans and state plans under the OAA should be strengthened through interagency agreements designed to improve service delivery and coordination.
Cost-sharing and voluntary contributions	FEDERAL STATE	States and the AoA should carefully monitor the implementation of cost-sharing and make a publicly available report of the results to ensure the adequacy of services to target populations. Congress should amend the OAA to require that the AoA approve all state cost-sharing plans prior to their implementation. State cost-sharing plans should be approved only if they contain all the elements designed to protect low-income beneficiaries, including sliding-scale fees, payment-accounting policies, and written materials that explain cost-sharing. The AoA should rigorously monitor and evaluate states' implementation of cost-sharing provisions and expanded authority to solicit voluntary contributions. Before expanding the use of voluntary contributions or implementing cost-sharing, states should obtain public input and especially focus on low-income and minority participants.

Cost-sharing and voluntary contributions (cont'd.)	FEDERAL STATE	States should carefully consider the impact of such changes on their ability to deliver services to the most vulnerable populations, including the possible effects of requesting payment for a multiplicity of services. States that enact cost-sharing should exempt individuals with incomes below 185 percent of the federal poverty level.
Consumer participation in advisory bodies	FEDERAL STATE	Ensuring protection of public and consumer interests on AAAs and other advisory bodies under the OAA requires that consumer representation constitute a distinct majority.
Services for rural areas	FEDERAL STATE	The AoA and the entire aging services network should promote the full participation of older people who live in rural areas and those with special needs in all aspects of the OAA. These efforts should encourage public-private partnerships.
Data collection and metrics	FEDERAL STATE	The AoA's data collection efforts should be used to evaluate the effects of provisions regarding service delivery to rural residents, the expansion of voluntary contributions, and the authority to implement cost-sharing. The AoA should monitor and evaluate its data collection effort, particularly as it pertains to the participation of minorities and special-needs populations in OAA programs. Improvements to the data collection system should be made, based on the findings of the Office of Inspector General at the Department of Health and Human Services. Improvements could include the addition of new data, such as the number of people who request and receive each type of OAA service. States should establish statewide clearinghouses to collect and disseminate data on the elderly population, including on age, race, and gender. States also should collect data, document, and report annually the adequacy of services for older people who are poor, members of minority groups, frail, or otherwise vulnerable and use this information to improve service delivery and promote more consumer choice in options and independence in all social services and long-term services and supports irrespective of program or payer source. States should publish yearly expenditure reports containing age-specific and uniform data on program activities and make the findings available to the public. Lawmakers and regulators should use the data in planning for, and filling gaps in, service needs.
Competitive bidding for services	FEDERAL STATE	State and AAA contracts with direct-service providers under the OAA should be opened periodically for competitive bidding or reviewed to ensure quality. Current and prospective service providers should be evaluated on the basis of standardized criteria, including quality and effectiveness of service provision, capacity, and other factors.
Long-range planning	FEDERAL STATE	The AoA and the entire aging network should ensure that all states engage in a comprehensive long-range planning process that spans all relevant state departments, agencies, and entities (health, housing, transportation, aging, etc.) in order to prepare for a rapidly aging and increasingly diverse population.

Funding	FEDERAL STATE	Congress should adjust appropriations for all Title III programs to reflect both growth in the older population and the effects of inflation, earmark funding for the ombudsman program, and significantly increase funding appropriations for the National Family Caregiver Support Program. States should supplement AoA funds to ensure adequate support for their long-term care ombudsman programs.
Support for family caregivers	FEDERAL STATE	The AoA should expand the capacity of the National Family Caregiver Support Program. States and the AoA should strengthen the National Family Caregiver Support Program and perform a family caregiver assessment to determine the needs of the individual family caregiver.
Substance abuse and mental health	STATE	States should expand programs that identify and increase awareness of and providers' sensitivity to depression, suicide risk, and substance abuse among older people. These programs should particularly target health and social service providers.

Private-Sector Approaches

Strategies for financing long-term services and supports (LTSS) 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 and maximize their choices. 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.

Private Long-Term Care Insurance

Individuals can purchase coverage for nursing facility, 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. Some companies also offer combination or hybrid products, such as life insurance and LTC insurance or an annuity and LTC insurance.

Despite the noted improvements in LTC insurance products, they are not an option for everyone. LTC insurance, especially the more comprehensive policies that provide meaningful coverage and appropriate consumer protections, is relatively expensive and unaffordable for many people. In 2010, the average annual premium for an LTC insurance policy for someone between ages 55 and 64 was $2,261. This represents a policy that covers facility services and home care, five years of coverage, a daily benefit of $150, 5 percent automatic compound inflation protection, and a 90-day waiting period. Premiums in LTC insurance policies increase with age; the average premium for an individual between ages 70 and 74, for instance, was $3,421 for a similar policy. In addition to the prohibitive cost of premiums, insurers medically underwrite these policies and generally exclude individuals with health problems and those beyond a certain age.

Those who choose to purchase private LTC insurance tend to have higher incomes and more substantial assets than nonpurchasers. For example in 2010, the typical purchaser was age 59 and had fairly substantial income and assets. Fifty-seven percent of purchasers had annual incomes over $75,000, and 79 percent had more than $100,000 in liquid assets. By comparison, only 44 percent of the general population age 50 and older had liquid assets in excess of $100,000. According to industry claims data reported in the 2011 Sourcebook for Long-Term Care Insurance Information, 73 percent of LTC insurance claims were for paid care at home or in an assisted living facility. The remaining claims were for care in a nursing facility.

However, due to economic conditions and shrinking policyholder lapse rates, some insurance carriers have decided to stop selling private long-term care insurance products or are raising premiums, tightening medical underwriting, and either eliminating or reducing policy discounts. Insurance carrier profitability is being negatively impacted by extremely low interest rates on investments, and policyholders are not dropping coverage as often as the industry predicted. Low investment returns and higher claim payouts are putting pressure on insurance carriers to address profitability considerations by raising rates and reducing policy incentives and product features, which in turn makes LTC insurance less attractive to new purchasers.

Premium rate stability—An important issue for consumers is whether LTC insurance premiums will increase beyond what they can afford. 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 NAIC standards. In 2000 the NAIC adopted amendments to its LTC model regulation to help protect consumers from excessive or unjustifiable premium increases. As of 2012, 41 states have adopted this provision.

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. Some policies provide some return of the value of premiums invested, also known as 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 facility 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 LTC increases over time. Given the fact that most consumers will have their LTC policy for 20 years or more before they use it, a policy without inflation protection will provide less protection each year as the value of the insurance benefits is likely to erode. It is critical that agents who sell LTC insurance are adequately trained to explain how differences in policy characteristics affect future benefits. For example, differences in the type of inflation protection or the waiting period might make one policy appear less expensive without the consumer understanding that his or her future out-of-pocket costs would be considerably higher under the less expensive policy. 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 provide educational resources to help consumers understand their chance of needing LTSS and options for financing services, such as through the purchase of LTC insurance. These include the federal-state Own Your Future Long-Term Care Awareness campaign and resources such as the National Clearinghouse for Long-Term Care Information.

Nearly all LTC policies sold today meet federal standards, specified by the Health Insurance Portability and Accountability Act (HIPAA) of 1996, for favorable tax treatment. Among other areas, the standards cover consumer information (such as third-party notice if a policy lapses) and protection. Individuals with qualified LTC insurance policies, therefore, can deduct their premiums, up to a maximum limit that increases with age. For example, in 2011, someone age 40 or younger can deduct $340, whereas taxpayers ages 70 and older can deduct up to $4,240. However, to be eligible, the tax payer must itemize deductions and have medical costs in excess of 7.5 percent of “adjusted gross income” (10 percent starting in 2013)—a standard that relatively few taxpayers meet. In addition benefits received under an LTC insurance policy are not subject to federal taxes (the exemption also applies to living benefits; see this chapter’s section Living Benefits). Employers may also offer LTC insurance as a tax-free benefit.

A drawback to tax incentives is that they disproportionately benefit people with higher income, since they face a higher tax rate and, thus, benefit more from each dollar spent on LTC insurance. Moreover many individuals have either insufficient incomes to owe taxes or insufficient deductions to meet the medical deduction threshold.

PRIVATE LONG-TERM CARE INSURANCE: Policy		
Role of private-sector long-term care (LTC) insurance	FEDERAL STATE	Private-sector approaches should be considered partial solutions to the problem of financing long-term services and supports (LTSS). Under a public social insurance system, private insurance could supplement the public system by covering extra services.
Tax incentives for LTC insurance	FEDERAL STATE	In evaluating proposed tax incentives to encourage the purchase of private LTC insurance, policymakers should consider both the impact on tax revenues and whom the incentives will likely benefit. Tax incentives should be provided only in conjunction with strong consumer protection standards.
Consumer education	FEDERAL STATE	The public and private sectors should educate consumers about private LTC insurance and other private financing methods so that consumers can understand their options, make informed choices, and avoid the potential risk of purchasing products that are ill-suited to their needs or for which there are limited consumer protections.
Consumer information needs	FEDERAL STATE	Federal and state governments should implement new reporting requirements for LTC insurers so that consumers have access to information in a standardized format that lets them compare insurance companies, policies, and benefits. Purchasers of LTC insurance should be advised of the difference between the payment rates their policy offers (e.g., $150 per day) and the actual daily rates for nursing facility and home- and community-based care in their area. Federal and state regulations should require that agents are adequately trained to explain how differences in policy characteristics affect the future benefit that the purchaser may receive. Federal and state agencies should make available to consumers the information regulators have collected on all aspects of the sale, use, and cost of LTC insurance, as well as on insurers' marketing practices. The data should include uniform information about denied claims, lapse rates, and premium increases and should be insurer- and state-specific. States should provide consumers with a range of comparative information about insurers and their policies, including what LTSS are available in their state and which are covered by each LTC insurance policy in the state, as well as historical information about premium increases. States should make information it collects on LTC insurance available to consumers in marketing materials and through the state regulator's website.
Consumer protection	FEDERAL STATE	Federal and state governments should adopt strong consumer protection standards and regulatory oversight to protect LTC insurance purchasers from inadequate policies, overly restrictive benefit triggers, and abusive sales practices. Federal and state governments should improve the quality of LTC insurance by enacting the strongest possible consumer protection standards. Federal and state governments should 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.

Consumer protection (cont'd.)	FEDERAL STATE	Congress should enact minimum national consumer standards for LTC insurance policies. The standards should be stronger than those required in the 1996 Health Insurance Portability and Accountability Act (HIPAA). State insurance departments should be required to approve all federally qualified LTC insurance policies sold in the state, to ensure that they meet HIPAA's consumer protection requirements. States should 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.
Inflation protection	FEDERAL STATE	Insurers and agents should be required to educate prospective purchasers about the importance of inflation protection. Insurance purchasers should have the opportunity to select inflation protection when they purchase a policy and periodically thereafter.
Coverage of home- and community-based care	FEDERAL STATE	LTC insurance companies should be required to cover both nursing facility care and a wide range of home- and community-based care services, including participant-directed services, so that people can receive care in the most appropriate, least restrictive setting and can maximize the LTC insurance benefit.
Coverage options	FEDERAL STATE	Federal and state governments should establish standardized benefit packages that insurers would be required to offer. Building on the Medigap model, the packages should allow consumers to compare the prices of products with identical provisions while allowing insurers to offer additional products and features. Insurers should be required to offer policyholders the opportunity to upgrade their policies in a fair and timely manner.
Portability	FEDERAL STATE	Insurers should be required to cover a full range of LTSS options, such as personal care or homemaker services that are portable across all LTSS settings, including assisted living. Policymakers should encourage the portability of LTC insurance across all geographic areas.
Sales practices	FEDERAL STATE	Federal and state governments should monitor the marketing of LTC insurance policies to ensure that they are not sold to individuals who cannot afford the premiums and to prohibit false advertising.
Premium rates	FEDERAL STATE	Federal and state governments should 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 reduction clauses when they receive a policy and with each rate increase. 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. States should adopt adequate procedures to review requests for rate increases.
Nonforfeiture benefits	FEDERAL STATE	Policyholders should be ensured a nonforfeiture benefit if their premiums increase beyond a certain level.

Maintaining reserves	STATE	States should ensure the solvency of insurance companies that offer LTC policies by establishing appropriate reserve requirements and monitoring companies' financial performance.
Encouraging the purchase of LTC insurance	FEDERAL STATE	Private employers should receive incentives to offer LTC insurance coverage to employees and pay a part of the premium. States should expand the availability of affordable LTC insurance products to private- and public-sector employees, retirees, and their families.
Pension funds	FEDERAL STATE	LTC insurance should not be paid for through pension funds, because many pension plan funds are already inadequate to provide economic security in retirement.

Public-Private Partnerships

Public-private partnerships also can encourage the purchase of long-term care (LTC) insurance. Under this approach, individuals who buy and use certain LTC policies may protect a portion of their assets and still qualify for Medicaid if they meet all the other Medicaid eligibility requirements.

The Deficit Reduction Act of 2005 (DRA) allowed these partnerships to become available nationwide if states chose to operate them. As of 2012 most states have implemented partnership programs and are offering partnership policies to consumers. States with partnership programs are not required to seek recovery from an individual's estate for resources protected by a partnership policy. With the exception of California and New York, all states with partnership programs have a reciprocity agreement in place, allowing benefits paid and asset protection to be treated the same by all states that participate in the program.

While such programs can be an attractive option for some consumers, careful analysis is needed to determine the programs' impact on Medicaid. Because these programs are still relatively new, few LTC insurance partnership purchasers have used their benefits and there are insufficient data to determine whether these programs will reduce Medicaid expenditures. The Congressional Budget Office estimated that the expansion of these programs would increase Medicaid spending if, as a result of the partnership, people who otherwise would not have chosen to spend down to qualify for Medicaid do so given the partnership program's asset protection. 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 some purchasers of private LTC insurance may mistakenly believe that their policy includes the benefit of a partnership policy, such as eligibility for Medicaid after their LTC insurance benefits run out. Even with a partnership policy, purchasers have no assurance that the Medicaid services they will be eligible for many years in the future will be the same as those now covered by their policy. Public education around this financing option is critical, and there may be other innovative approaches that use public and private resources to make LTC insurance or long-term services and supports more accessible.

PUBLIC-PRIVATE PARTNERSHIPS: Policy		
Impact on Medicaid eligibility	FEDERAL STATE	Programs that link Medicaid eligibility to the purchase of long-term care insurance (LTC) should not endanger the Medicaid safety net for low-income people who need long-term services and supports (LTSS). People who purchase partnership policies should be allowed to access Medicaid while receiving benefits under their policy if benefits are inadequate to cover the cost of needed services and policyholders are otherwise eligible for Medicaid. Partnership policyholders should be permitted to spend down to meet Medicaid's income eligibility criteria (this would require that all states have medically needy programs).

Consumer protections	FEDERAL STATE	Programs that link Medicaid eligibility to the purchase of LTC insurance should contain strong consumer protections, particularly regarding nonforfeiture and inflation protection, premium stability, and clear disclosures of current income requirements for Medicaid benefits and the state's right to change those requirements. Such programs should guarantee the types of services (particularly home- and community-based services) that the state would provide to eligible partnership policyholders under Medicaid. Federal and state agencies should establish clear and simple documentation requirements to ensure purchasers' smooth access to Medicaid. Partnership policies should be clearly described and written in plain language. States should: • set out suitability standards for partnership policies and clearly educate consumers about Medicaid eligibility standards, • establish the specific inflation protection standards that a policy must provide to qualify as a partnership policy in the state, • educate consumers that 5 percent compound inflation protection offers the best assurance of future benefit adequacy, • prohibit "future purchase option" as an inflation protection option for purchasers under age 61, and • educate consumers so they can make informed decisions about whether a partnership policy is right for them and, if so, which policy best meets their needs.
Home equity cap	FEDERAL STATE	Federal and state regulations should exempt purchasers from the home equity cap established in the Deficit Reduction Act of 2005.
State monitoring and reporting requirements	FEDERAL STATE	Federal regulation should require states to report: • policy costs and features, policyholder demographics, and asset protections earned; • the number of individuals who apply for, purchase, or are denied policies; use benefits under their policies; apply for Medicaid; and are denied or granted Medicaid eligibility; • the length of time between policy purchase, use of benefits, Medicaid application, Medicaid eligibility being denied or granted, and lapse rates; • Medicaid expenditures for those who purchase policies and the amount spent on services by the insured while using the policy; and • the number of partnership and nonpartnership policies sold by an insurer in the state and country.
Medicaid savings	STATE	States should analyze the potential Medicaid savings of partnership policies by examining the current LTSS Medicaid population to determine what portion of it would have been able to purchase LTC insurance (based on finances and medical underwriting criteria) in their 50s and 60s.
Reciprocity	STATE	States should allow reciprocity with all other states' partnership programs.

Agent training	State	States should require training of agents authorized to sell partnership policies in the state. Training should be specifically tailored to knowledge of partnership policies and Medicaid eligibility.
Assigning benefits	Federal State	All partnership policies should allow beneficiaries to “assign” their benefits to qualified service providers.

Living Benefits

Accelerated death benefits and viatical agreements are often called living benefits, and they can help some people by providing additional sources of funding for long-term services and supports.

Accelerated death benefits may be part of an existing life insurance policy or sold separately as a rider. They allow policyholders to access accelerated benefits before death in the case of a terminal illness or catastrophic or long-term care need. Payouts are typically for a portion of the policy’s face value, up to 80 percent. But accelerated benefits have limitations. For instance individuals with a preexisting condition may be unable to purchase an accelerated benefits rider after they have purchased a life insurance policy. Also payouts of accelerated benefits will reduce the amount available to beneficiaries when the policyholder dies.

Individuals who no longer wish to keep a life insurance policy that has a cash surrender value or who are terminally ill can sell their policy to a life settlement or viatical settlement company for an immediate payout. Recently the market for such settlements has expanded to include terminally ill people with longer life expectancies and even healthy seniors. People with longer life expectancies typically receive a smaller percentage of the face value of the policy (see Chapter 11, Financial Services and Consumer Products: Financial Services—Investment and Securities Industry, for more general policy on investments or viaticals).

LIVING BENEFITS: Policy		
Understanding the impact of accelerated benefits	State	States should regulate accelerated death, life settlement, and viatical settlement 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.

Reverse Mortgages

Reverse mortgages enable older homeowners—approximately 80 percent of older households—to tap their home equity without having to repay the loan as long as they live in the house. Repayment of the loan is not required until the last borrower dies, sells the home, or moves out permanently. Many older people may be apprehensive about depleting their equity to meet long-term services and supports (LTSS) needs, because their homes represent a major source of their financial security (see Chapter 11, Financial Services and Consumer Products: Financial Services—Reverse Mortgages, for additional information on reverse mortgages). Some reverse mortgage products have discouragingly high upfront costs.

The Federal Deficit Reduction Act of 2005 (DRA) removed the protected status of homes under the Medicaid program. This means that homeowners can be forced to sell their home or take out costly reverse mortgages or other loans to spend down their equity before becoming eligible for Medicaid. States are already required to tap into an individual’s home equity through estate recovery after death, allowing them to recoup Medicaid LTSS costs (see also this chapter’s section Medicaid: Strengthening Financial Protections for Beneficiaries and Their Families).

Other proposals have suggested offering incentives to use reverse mortgages to purchase private long-term care (LTC) insurance. Even with such incentives, the costs associated with using reverse mortgages to purchase insurance are very high and target those who would not be appropriate candidates for private LTC insurance (see also Chapter 11, Financial Services and Consumer Products: Financial Services—Banking and Credit—Home Mortgage Lending).

REVERSE MORTGAGES: Policy		
Consumer protections	FEDERAL	The federal government must require strong consumer protections in the Home Equity Conversion Mortgage reverse mortgage program. These protections must include assurances that borrowers can remain in their homes for as long as they fulfill the requirements of the loan terms: live in the home as a primary residence; pay property taxes, homeowners insurance, and homeowners association dues and assessments; and maintain the home. The status of the home must be protected under Medicaid eligibility rules (see also this chapter's section Medicaid: Strengthening Financial Protections for Beneficiaries and Their Families).
Benefit restrictions	FEDERAL	The federal government must not further restrict access to public benefits for people who receive loan proceeds from reverse mortgages.
Use of federal incentives	FEDERAL	The federal government must not encourage the use of reverse mortgages through incentives that require purchase of private long-term care insurance. Federal government incentives for using reverse mortgages to pay for long-term services and supports must be voluntary and focus on reducing the high costs associated with these loans. Such incentive programs should be tried only on a demonstration basis first because they place at risk older homeowners' primary asset.