



# Long-Term Care (LTC): Financing Overview and Issues for Congress

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## Summary

Most long-term care (LTC) received by people with disabilities and/or other limitations in their capacity for self-care due to a physical, cognitive, or mental disability or condition is provided by informal providers—family and friends—who give care without compensation. Formal LTC services in the United States, however, are financed by a wide variety of public and private sources. The largest public payer of LTC in the country is, by far, the Medicaid program, paying for almost half (48.5%) of all formal LTC services. Medicaid is intended to provide a safety net for those who cannot afford to pay for LTC services. Because Medicaid is administered and partially financed by each state, there is wide variation in eligibility and benefits across the nation. Medicare and other federal and state programs finance an additional quarter (24.8%) of formal LTC services. Each program has distinct eligibility criteria and, thus, distinct target populations, and each covers a different set of services. Multiple programs may also serve persons with long-term care needs simultaneously.

Private financing, including out-of-pocket spending, pays for just over a quarter (26.8%) of formal LTC services. Of this, about 7% of LTC services are financed by private LTC insurance (LTCI). These policies are intended to provide financial protection to individuals and families to insure against the potentially high cost of care.

People who do not have access to private LTC insurance and who are not immediately eligible for Medicaid or other public programs must pay for LTC services out-of-pocket, rely on family and friends, or forgo care. The out-of-pocket costs of LTC services can be catastrophic for some individuals and families, often exceeding annual income and, in some cases, personal savings and assets.

Concern about the way LTC is financed and delivered has drawn congressional attention for several decades. Exacerbating this concern is the potential for increased demand on the nation's LTC system as a result of the aging U.S. population. At the same time, disability among the current cohorts of working-age Americans has been increasing over the past few decades. Congress continues to be concerned about the following issues: (1) barriers to public and private coverage; (2) strains on federal and state Medicaid budgets; (3) coordination of care across Medicaid, Medicare, and other public programs, as well as across provider settings; (4) spending on institutional care versus home and community-based services; (5) challenges facing consumers of LTC; (6) the supply and quality of the LTC workforce; (7) access to affordable housing; and (8) the quality of publicly funded LTC services.

This report provides an overview of LTC and an explanation of the nation's complex financing system of public and private payers. It also describes some of the major challenges facing Congress as it contemplates LTC reform and whether and how to include LTC in health reform legislation.

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## Introduction

As older Americans live longer than previous generations, the probability of their becoming disabled and requiring long-term care (LTC) services at some point in their lifetime may increase.<sup>1</sup> At the same time, disability among the current cohorts of working-age Americans, who will soon be the future elderly, has been increasing over the past few decades. Some research has shown that people under 65 are experiencing fewer disability-free years.<sup>2</sup>

Most care received by people with disabilities is delivered by informal providers—family and friends—who give care without compensation. Formal LTC services—those services for which payment is made—in the United States, however, are financed by a wide variety of public and private sources. The largest public payer of LTC in the country is, by far, the Medicaid program. Medicaid is intended to provide a safety net for those who cannot afford to pay for LTC services. Because states are given flexibility in how they administer Medicaid, there is wide variation in eligibility and benefits across the nation. Medicare and other federal and state programs also finance formal LTC services but on a much smaller scale. Each program has distinct eligibility criteria and, thus, target populations, and each covers a different set of services. Multiple programs may also serve persons with long-term care needs simultaneously.

Private LTC insurance also pays for some formal LTC services. LTC insurance policies are intended to provide financial protection to individuals and families to insure against the potentially high cost of care. However, the share of the older population with private LTC insurance policies is relatively small, and most younger persons with disabilities do not hold such policies.

People who do not have access to private LTC insurance and who are not immediately eligible for Medicaid or other public programs must pay for LTC services out-of-pocket, rely on family and friends, or forgo care. The cost of LTC services can be catastrophic for individuals and families, with expenses often exceeding annual income and, in some cases, overall wealth or assets. Such a large personal financial liability can leave individuals with disabilities and their families impoverished.

In the past, Congress has considered a variety of reform options to the nation's LTC financing system. Some of the methods Congress has considered have been to expand access to long-term care services delivered in home and community-based settings; to better coordinate care delivered across long-term care and acute care settings; to minimize existing barriers to public and private coverage of LTC; to help individuals better navigate the array of federal, state, and local public programs; to increase the supply of adequately trained LTC workers; and to better ensure that services delivered are of high quality.

The House and Senate health reform proposals (H.R. 3692 and H.R. 3590, respectively), debated in the first session of the 111<sup>th</sup> Congress, include provisions that would expand access to coverage

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<sup>1</sup> Peter Kemper, Harriet L. Komisar, and Lisa Alexih, *Long-Term Care Over An Uncertain Future: What Can Current Retirees Expect?* *Inquiry* 42:335-350. Winter 2005-2006. <http://www.inquiryjournal.org>

<sup>2</sup> Jay Bhattacharya, Kavita Choudhry, and Darius Lakdawalla. *Chronic Disease and Trends in Severe Disability Among Working-Age Populations*. In *Workshop in Disability in America, A New Look*. Summary and Background Papers. Institute of Medicine. Washington, DC, 2005. Darius Lakdawalla, Dana P. Goldman, Jay Bhattacharya, Michael Hurd, Geoffrey Joyce, and Constantijn Panis, "Forecasting the Nursing Home Population," *Medical Care*, v. 41, no. 1, 2003.

of formal LTC services. Included in both H.R. 3692 and H.R. 3590 are provisions to establish a national voluntary LTC insurance program, referred to as the Community Living Assistance Services and Supports Program (CLASS program). The CLASS program would provide a cash benefit to eligible enrollees (who have paid premiums for at least five years) with LTC needs to purchase community living assistance services and supports, such as home modifications, assistive technology, accessible transportation, and homemaker services, among others. Other provisions in the Senate bill would expand Medicaid's coverage of persons with LTC needs and, among other things, provide new options to states to deliver LTC services to certain persons age 65 and over and persons with disabilities. These proposals continue to be under consideration by both houses of Congress.

## **What Is LTC?**

LTC refers to a broad range of health and social services needed by people with a limited capacity for self-care due to a physical, cognitive, or mental disability or condition that results in functional impairment and dependence on others for an extended period of time. The need for LTC services and supports is generally measured by the presence of functional limitations in the ability to perform basic personal care activities, known as activities of daily living (ADLs), or by the need for supervision or guidance with ADLs. ADLs generally refer to activities such as eating, bathing, using the toilet, dressing, walking across a small room, and transferring (getting in or out of a bed or chair). Instrumental activities of daily living (IADLs) are also used as a measure of a person's need for LTC. These activities are necessary for an individual's ability to live independently in the community and include activities such as preparing meals, managing money, shopping for groceries or personal items, performing housework, using a telephone, doing laundry, getting around outside the home, and taking medications. Some programs that cover LTC services for people with mental retardation or developmental disabilities, such as Medicaid, also define eligibility for certain groups based on a specific diagnosis, sometimes in combination with other factors such as functional limitations.

Formal services to assist people with LTC needs may be provided either in an institutional-based setting, such as a nursing home, or in a community-based setting, such as a private home, group home, or assisted living facility. In addition to room and board, institutional settings provide 24-hour supervision, personal care to assist with ADLs and IADLs, meal deliveries and nutritional counseling, recreational services, access to nursing and physician services, and habilitation,<sup>3</sup> among others. Examples of formal home and community-based services include home health and personal care aide, case management, private-duty nursing, adult day care, respite care, and transportation, among others.

The population with LTC needs is diverse and includes people of all ages—for example, the elderly with chronic conditions or illnesses, such as severe cardiovascular disease or Alzheimer's disease; children born with disabling conditions, such as mental retardation or cerebral palsy; and working-age adults with inherited or acquired disabling conditions, such as mental illness or traumatic brain injuries.

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<sup>3</sup> Habilitation refers to services designed to assist individuals in acquiring, retaining, and improving the self-help, socialization, and adaptive skills necessary to reside successfully in home and community-based settings.

Regardless of age, people receiving LTC assistance are more likely to receive care at home or in other community settings rather than in an institution. Of the 9.4 million adults receiving LTC assistance, more than three-quarters (7.2 million) reside at home or in other community settings. Among those adults receiving LTC assistance and living in the community, just over half are age 65 and older, and the remainder (47%) are between ages 18 to 64. Another 2.2 million reside in institutional-based settings.<sup>4</sup>

## Sources of Financing for LTC

Total U.S. spending on formal LTC is a significant component of all health care spending. Of the \$2.2 trillion spent on personal health care in 2007, as reported by CMS, an estimated \$233.4 billion, or 10.6%, was spent on LTC services.<sup>5</sup> This spending included payment for services in institutional settings—primarily nursing homes and intermediate care facilities for people with mental retardation—home health, and a wide range of home and community-based services, such as home care, personal care, and adult day care.<sup>6</sup>

Formal LTC services in the United States are paid for by a wide variety of public and private sources. Almost three-quarters of LTC spending is paid for by public sources, including Medicaid, Medicare, and other public programs, such as the Department of Veteran Affairs. In 2007, Medicaid paid for nearly half (48.5%) of LTC expenditures.<sup>7</sup> Medicare funded the next largest share of spending, or 22.4% of LTC expenditures in 2007. Other public sources, such as veterans and state-funded programs, paid for 2.4% of the total.<sup>8</sup>

Individuals who do not qualify for public programs or who have not enrolled must pay for LTC directly out-of-pocket or purchase private LTC insurance. In 2007, out-of-pocket spending by individuals and families for nursing home and home health care represented the largest source of private financing, making up almost 18% (\$41.3 billion) of total LTC spending. Private LTC insurance is also available to finance these costs; about 7% (\$15.3 billion) of LTC spending was paid by LTC insurance in 2007. Other private payers, including charitable organizations, paid 2.5% (\$5.7 billion). See **Figure 1** for a summary of spending by payer.

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<sup>4</sup> CRS calculations based on data from the National Long-Term Care Survey (1999), the National Health Interview Survey, Disability Supplement (1994), and Spector and colleagues, *The Characteristics of Long-Term Care Users*, AHRQ Publication No. 00-0049, September 2000. For additional information, see CRS Report RL33919, *Long-Term Care: Consumers, Providers, Payers, and Programs*, by Carol O'Shaughnessy et al.

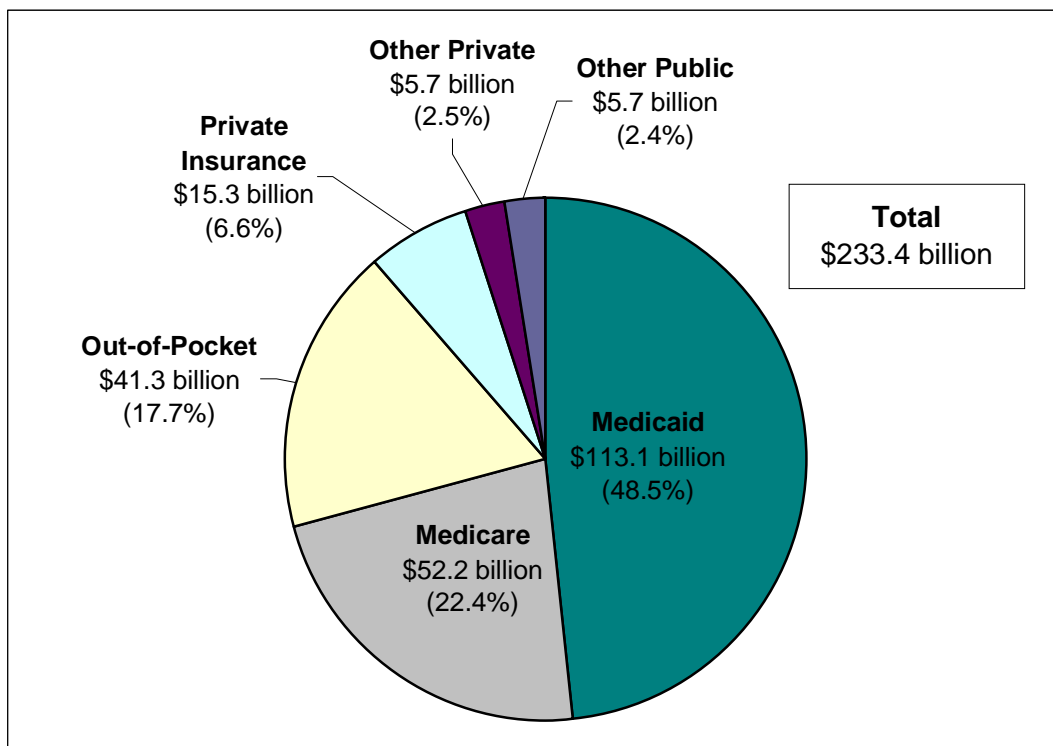
<sup>5</sup> CRS estimates based on National Health Expenditures by Type of Service and Source of Funds: Calendar Years 1960-2007.

<sup>6</sup> *Ibid.*

<sup>7</sup> This amount does not include all of the program's LTC expenditures, such as the state plan personal care services and the section 1915(i) home and community-based state plan option.

<sup>8</sup> This number, however, does not include spending on LTC from all other public sources, as it includes only that spending on nursing facilities and home health agencies. The range of home and community-based services paid for through grant funds, state-only funds, and other public programs is not included.

**Figure I. LTC Spending, by Payer**  
CY 2007



**Source:** CRS estimates based on the calendar year (CY) 2007 National Health Expenditure Data, Centers for Medicare and Medicaid Services (CMS). This analysis includes CY 2007 unpublished data from CMS, National Health Statistics Group on Medicaid and Medicare expenditures for hospital-based nursing home and home health providers, and spending data for the Medicaid section 1915(c) home and community-based waivers. It does not include expenditures for the hospital-based nursing home and home health providers paid for by other sources, and certain expenditures similar in nature to the Medicaid 1915(c) waiver which are paid for by other sources (e.g., home modifications, housekeeping, etc.)

**Notes:** The total percentages do not add to 100 due to rounding.

Despite the large public commitment to financing care, most LTC is provided by informal sources—family and friends—who provide care without compensation. The total value (non-economic as well as economic) of caregiving to older persons with disabilities can be substantial, and estimates of this value vary widely.<sup>9</sup>

## Public Sources of Financing for LTC

A range of public programs cover LTC services for targeted populations across the country. Although Medicaid and Medicare are the largest payers with the widest reach, other public programs, such as the Older Americans Act (OAA), the Social Services Block Grant (SSBG), and the Veterans Health Administration (VHA), also finance services for specific populations. Each program has distinct eligibility criteria and, thus, distinct target populations, and each covers

<sup>9</sup> For information on caregiving, see CRS Report RL34123, *Family Caregiving to the Older Population: Background, Federal Programs, and Issues for Congress*, by Kirsten J. Colello.

distinct services. The eligibility criteria and services offered under Medicare and the Veterans Health Administration are standardized across the country, yet access can differ across geographic areas. Other programs, such as Medicaid, the OAA programs, and SSBG have significantly different eligibility criteria and offer different benefits across states. As a result, some individuals may qualify for services in one state and not in a second state.

The following briefly describes the general rules for coverage and the scope of eligibility for the public payers of LTC. Because state Medicaid programs are the largest public payers of LTC, the bulk of the information below describes these programs.

## **Medicaid**

Medicaid coverage of LTC is intended to serve as a safety net for persons who cannot afford the cost of institutional care or home and community-based services. Medicaid is an entitlement program for many, but not all, categories of eligibles.<sup>10</sup> The term “entitlement” has two meanings in this context. Individuals who meet state eligibility requirements are entitled to enroll in Medicaid. However, once enrolled, individuals are only entitled to those services according to the amount, duration, and scope criteria established by each state and for which they can demonstrate medical necessity (as determined by the state).<sup>11</sup> For the purposes of LTC, medical necessity is often measured by level-of-care criteria, which measures individuals’ limitations in functional and/or cognitive capacity and the need for supervision.

### ***Eligibility***

Two groups of persons are eligible to receive Medicaid LTC services: (1) those who are already enrolled in Medicaid because they meet certain categorical and financial criteria and who demonstrate a medical need for the LTC services offered by the state (which may include, but are not limited to, the need for the level of services offered in an institution, such as a nursing home), and (2) those who qualify for Medicaid because they meet a states’ financial criteria and because they demonstrate the need for the level-of-care that is offered in a nursing home, hospital, or intermediate care facility for the mentally retarded (ICF/MR), as measured by a state-defined assessment.<sup>12</sup>

### **Eligibility Criteria: Group One**

To enroll in Medicaid under the first group, persons must be considered categorically eligible and meet certain financial requirements. Persons who require LTC services generally fall under Medicaid’s categorically eligible categories of the elderly or disabled, as measured by the rules used by the Supplemental Security Income (SSI) program. Members of families with dependent children, and certain other pregnant women and children, may also be categorically eligible. In recent years, states may extend eligibility under Medicaid to additional groups with specific

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<sup>10</sup> Some Medicaid waiver programs allow states to cap enrollment or institute waiting lists. As a result, individuals who meet the state-defined income and asset criteria could enroll and be determined eligible, but because current enrollment exceeds the program cap (as stipulated in the waiver terms and conditions), these individuals would not be permitted to receive services.

<sup>11</sup> 42 CFR 440.230.

<sup>12</sup> Persons must also meet certain citizenship and state residence criteria.



characteristics, including certain women with breast or cervical cancer and uninsured individuals with tuberculosis.

Financial requirements place limits on the amount of income and assets individuals may possess to become eligible for Medicaid (often referred to as standards or thresholds). The specific income and asset thresholds that apply to each eligibility group are set through a combination of federal parameters and state definitions. Consequently, these standards vary considerably among states, and different standards apply to different population groups within a state.

The major income pathways through which the categorically eligible elderly and people with disabilities often qualify include receipt of cash assistance from the SSI program (mandatory for many states, exceptions apply to so called 209(b) states);<sup>13</sup> individuals with income that does not exceed 100% of the federal poverty level; and people with medical expenses that deplete their income to specified levels (i.e., spend-down groups, which are optional for many states and mandatory for some). Note that low-income elderly persons without LTC needs and younger persons with disabilities who do not need LTC services also qualify for Medicaid through some of these pathways.

Financial standards also include asset tests that specify the maximum amount of countable assets a person may have to qualify; assets above these amounts make an individual ineligible for coverage. For the treatment of most types of assets, states generally follow SSI program rules. Under SSI rules, countable assets, such as funds in a savings account, stocks, or other equities, cannot exceed \$2,000 for an individual and \$3,000 for a couple.<sup>14</sup> Special Medicaid rules apply to the treatment of an applicant's primary place of residence.

### **Eligibility Criteria: Group Two**

Medicaid law also allows states to enroll people with higher income into Medicaid and receive either institutional services, such as nursing home care, or a usually comprehensive benefit package of home and community-based services under section 1915(c) waiver programs, if they require the level of care that is offered in a nursing home, hospital, or ICF/MR. Under these rules, people may have income up to a specified level established by the state, but no greater than 300% of the maximum Supplemental Security Income (SSI) payment applicable to a person living at home. A number of states also allow persons to place income in excess of the special income level in an income-only trust, often referred to as a Miller Trust, and still qualify for Medicaid through the special income rule. Following the individual's death, the state becomes the beneficiary of amounts in this trust. People who qualify under this eligibility pathway must also meet the state's asset test, as described above.

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<sup>13</sup> Under section 209(b) of the Social Security Act, some states apply more restrictive criteria to income, resources, and/or disability than is used by the SSI program and thus do not confer eligibility for all SSI beneficiaries.

<sup>14</sup> State practices for counting assets vary significantly. Under Section 1902(r)(2) of the Social Security Act, states are granted flexibility to modify these rules. This provision grants states permission to use more liberal standards for computing resources (and income) than are specified under SSI. Most states use Section 1902(r)(2) to ignore or disregard certain types or amounts of assets (and income), thereby extending Medicaid to individuals with assets too high to otherwise qualify under the specified rules for that eligibility pathway.

## **Other Requirements**

Persons who qualify for Medicaid through certain eligibility groups are required to apply their income above specified amounts toward the cost of their care. The amounts they may retain vary by setting. For example, Medicaid beneficiaries in a nursing home may retain a personal needs allowance. Persons receiving services in home and community-based settings may retain a maintenance needs allowance. All income amounts above these levels, including what may be available in a Miller Trust, must be applied toward the cost of their care.<sup>15</sup> Special rules apply to the spouses of persons who seek Medicaid coverage for LTC services, allowing these spouses to retain higher amounts of income and assets than allowed under general Medicaid rules.

## **Services**

States make available a broad range of institutional and home and community-based services to certain Medicaid enrollees. States are required to offer some of these services, while states are not required to offer others. For those services that are offered, states define them differently, using criteria that places limits on the amount, duration, and scope of the benefits. States may also restrict benefits to persons who demonstrate medical necessity for the benefit. For the most part, services that states make available are offered to all enrollees who demonstrate need; exceptions are made for certain long-term care services that are made available on a more limited basis to selected individuals. The following describes Medicaid's LTC services:

### **Mandatory Services:**

- **Nursing Facility Care.** Federal law requires that Medicaid programs provide coverage for nursing facility care for beneficiaries aged 21 and over. Such care includes room and board, skilled nursing care and related services, rehabilitation, and health-related care. States may also cover therapeutic services, such as physical therapy, occupational therapy, and speech pathology and audiology services.
- **Home Health Care Services.** Federal law requires that states provide home health services to persons entitled to nursing facility coverage under a state's Medicaid plan. Home health services must be medically necessary and authorized by a physician as part of a written care plan. Services covered vary by state and include intermittent or part-time nursing services, care by home health aides, and medical supplies and appliances for use in the home, among others.

### **Optional Services:**

- **Personal Care Services.** States have the option to cover personal care services for Medicaid beneficiaries who need assistance with ADLs and IADLs. The Medicaid statute defines personal care as services furnished to an individual at home or in another location (excluding institutional settings) that are either authorized by a physician, or at state option, under a plan of care. Services may include assistance with bathing, dressing, eating, toileting, personal hygiene, light housework, laundry, meal preparation, and grocery shopping, among others.

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<sup>15</sup> For more detailed information on eligibility for LTC, see CRS Report RL33593, *Medicaid Coverage for Long-Term Care: Eligibility, Asset Transfers, and Estate Recovery*, by Julie Stone.

States also have the option to cover self-directed personal care in which beneficiaries take on more responsibility for hiring and firing workers and establishing worker schedules and job responsibilities.<sup>16</sup>

- **Intermediate Care Facilities for People with Mental Retardation (ICFs/MR).** States have the option to provide coverage of institutional care to people with mental retardation and developmental disabilities in ICFs/MRs. Services include room and board and a wide range of specialized health and rehabilitative services to assist those with mental retardation and developmental disabilities to function at optimal levels.<sup>17</sup>
- **Nursing Facility Services for Persons Under Age 21.** States have the option to cover nursing facility care for persons under age 21. Such care includes room and board, skilled nursing care and related services, rehabilitation, and health-related care. States may also cover therapeutic services, such as physical therapy, occupational therapy, and speech pathology and audiology services.
- **Inpatient Hospital Services and Nursing Facility Services for Persons Aged 65 and Older in Institutions for Mental Diseases.**<sup>18</sup> States have the option to offer such inpatient and nursing facility services under the direction of a physician for the care and treatment of recipients with mental diseases.
- **Case Management Services or Targeted Case Management.**<sup>19</sup> States may offer care coordination services to assist individuals who reside in community settings or are transitioning to a community setting, in gaining access to needed medical, social, educational, and other services. Case Management also includes the development and implementation of a care plan and a comprehensive assessment and periodic reassessment of individual needs.
- **Respiratory Care for Persons Who Are Ventilator-Dependent.**<sup>20</sup> States may offer such services on a part-time basis in the recipient's home by a respiratory therapist or other health care professional trained in respiratory therapy to individuals who are medically dependent on a ventilator for life support at least six hour per day, among other criteria.
- **PACE (All-Inclusive Care for the Elderly).** PACE programs combine Medicare and Medicaid services under one common administrative/clinical provider, often based at adult day or community centers, but also frequently include home service referrals. PACE beneficiaries receive all their health, medical, and social services through a network of health professionals contracted by the PACE program. In addition, an interdisciplinary team, including physicians, nurses, physical therapists, social workers, and other professionals, develop and monitor care plans for enrollees.

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<sup>16</sup> For more detailed information on self-directed care, see archived CRS Report RL32219, *Long-Term Care: Consumer-Directed Services Under Medicaid*, by Karen Tritz.

<sup>17</sup> Some states cover persons in large facilities while increasingly more states, in an effort to expand the availability of home and community-based services for this population, are covering persons in small residential ICF/MRs.

<sup>18</sup> This benefit is not exclusively used for LTC purposes.

<sup>19</sup> This benefit is not exclusively used for LTC purposes.

<sup>20</sup> This benefit is not exclusively used for LTC purposes.

- **Transportation.**<sup>21</sup> States have the option to cover expenses for transportation for an individual and his or her attendant, if necessary, and other related travel expenses determined necessary to secure medical examinations and treatment for a recipient.
- **Home and Community-Based Services State Plan Option.**<sup>22</sup> This Medicaid option allows states to cover one or more home and community-based benefits for certain individuals with LTC needs. States are not required to make services available on a statewide basis. This benefit is limited to individuals whose incomes do not exceed 150% of the federal poverty level and who meet a state-determined level of need criteria. If states cover this option, the needs-based criteria must be less stringent than that used for institutional care eligibility. States may limit the number of individuals served. Services are limited to homemaker/home health aide, personal care, adult day health, habilitation, respite care, day treatment or other partial hospitalization services, psycho-social rehabilitation services, and clinic services for individuals with chronic mental illness. The Secretary may not approve other state-requested services on a case-by-case basis as possible under 1915(c) waivers (see below).
- **Medicaid Home and Community-Based 1915(c) Waivers.** Section 1915(c) of the Social Security Act gives states the option to extend a broad range of home and community-based services to selected populations of individuals with the level-of-care needs that would otherwise be offered in Medicaid-covered institutions, such as a nursing home, ICF/MR, or a hospital. Services that states may choose to offer under the section 1915(c) waiver include case management, homemaker/home health aide, personal care, adult day health, habilitation, respite care, rehabilitation, day treatment or other partial hospitalization services, psychosocial rehabilitation services, and clinic services (whether or not furnished in a facility) for individuals with chronic illness. States have flexibility to offer additional services if approved by the Secretary of the Department of Health and Human Services (DHHS). Section 1915(c) waivers may not cover room and board.<sup>23</sup> To date, all states have chosen to make these waivers available to targeted populations. Waivers have been used to cover persons aged 65 or older who would otherwise meet the state's eligibility criteria for nursing home care. They are also used to cover individuals with mental retardation and developmental disabilities, persons under age 65 with physical disabilities, persons with HIV/AIDS, persons who are medically fragile or technologically dependent, and persons with mental illness. States may limit access to these waiver programs by capping enrollment. As of 2007, states have extended section

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<sup>21</sup> This benefit is not exclusively used for LTC purposes.

<sup>22</sup> For additional information, see CRS Report RS22448, *Medicaid's Home and Community-Based Services State Plan Option: Section 6086 of the Deficit Reduction Act*, by Cliff Binder.

<sup>23</sup> Spending limitations are placed on states under the waivers' statutory cost-effectiveness requirements. These requirements specify that the average annual expenditures per capita for waiver clients may not exceed average annual Medicaid spending on institutional residents (including expenditures on nursing home care, hospital care, physician services, and all other Medicaid spending for those persons). States may apply the per capita expenditure limit to each individual, or apply the limit as an aggregate cap across all waiver participants. (This calculation includes the costs of other Medicaid state plan services that the individual may be eligible for, such as inpatient hospital costs.)

1915(c) waiver coverage to an estimated 1 million people (of all ages) nationwide.<sup>24</sup>

## **Medicare**

Medicare also plays a role in paying for LTC servicers, although on a much more limited scale than the Medicaid program. Medicare finances care in skilled nursing facilities (SNFs) and home health services for persons who need skilled nursing care on a part-time or intermittent basis, or physical or speech therapies. These benefits also provide limited access to personal care services both in the home health setting and in the SNF for certain beneficiaries on a short-term basis. Significant confusion and debate has ensued among policy makers and stakeholders over the classification of these benefits into post-acute and/or LTC benefit categories. This is likely because Medicare and Medicaid cover stays in nursing homes<sup>25</sup> as well as visits by home health agencies,<sup>26</sup> yet the scope of their coverage is generally different. Unlike Medicaid, Medicare is not intended to be a primary funding source for LTC for persons who need assistance with chronic conditions.

### *Home Health Services*

Medicare covers visits by a home health agency when such services are required because an individual is confined to his or her home and needs skilled nursing care on an intermittent basis or physical therapy or speech language therapy. After establishing such eligibility, the continuing need for occupational therapy services may extend the eligibility period. Covered services include part-time or intermittent nursing care, physical or occupational therapy or speech language pathology services, medical social services, home health aide services, medical supplies, and durable medical equipment. The services must be provided under a plan of care established by a physician, and the plan must be reviewed and updated by the physician at least every 60 days. As long as the beneficiary qualifies, home health services may be provided for an indefinite period of time. There is no beneficiary cost-sharing for home health services (though some other Part B services provided in connection with the visit, such as durable medical equipment, are subject to cost-sharing charges).

### *Skilled Nursing Facility (SNF) Services*

This program covers up to 100 days of post-hospital care for persons needing continued skilled nursing or rehabilitation services on a daily basis. The SNF stay must be preceded by a hospital stay of at least three days, and the transfer to the SNF must occur within 30 days of the hospital

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<sup>24</sup> Per conversation with CMS in January 2007.

<sup>25</sup> Medicare and Medicaid have different coverage rules regarding nursing homes. Whereas Medicaid covers long-term custodial care in a nursing home in every state, Medicare does not cover such care.

<sup>26</sup> The home health benefits under Medicare and Medicaid can serve persons for short or long duration, yet the goals of each program's coverage are generally different (with some state expectations for Medicaid's home health benefit). Medicare's home health benefit is intended to cover post-acute rehabilitation after an injury or hospitalization. Depending on a state's rules, Medicaid's home health benefit can be used for this purpose as well. Medicare can also cover skilled care at home for a longer duration, with the approval of a physician (e.g., regular visits by a registered nurse for individuals who are ventilator-dependent or require the long-term use of a feeding tube.) Depending on a state's rules, Medicaid may do this as well. Unlike Medicare, however, states may also use their home health benefit to cover long-term personal care services.

discharge. The program does not cover nursing care if only custodial care is needed (e.g., when a person needs assistance with bathing, walking, or transferring from a bed to a chair). To be eligible for Medicare-covered SNF care, a physician must certify that the beneficiary needs daily skilled nursing care or other skilled rehabilitation services that are related to the hospitalization, and that these services, as a practical matter, can be provided only on an inpatient basis. There is no beneficiary cost-sharing for the first 20 days. Days 21-100 are subject to daily coinsurance charges (\$133.50 in 2009).<sup>27</sup>

## Other Public Payers

Federal and state governments also pay for LTC services through a variety of other programs and grants. **Table 1** provides brief summaries of these programs.

**Table 1. Other Public Programs for LTC Services**

Program	Services	Eligibility	Administering Agency
Older Americans Act	Homemaker, chore and transportation services, congregate and home-delivered nutrition services, and caregiver support services, among others.	Targets older people who are in greatest social and economic need, with particular attention to low-income older individuals, including those who are low-income minority, have limited English proficiency, reside in rural areas, and/or are at risk for institutional placement	Administration on Aging
Veterans Health Administration (VHA)	Includes nursing home care (community living centers, community nursing homes, and state veterans homes), domiciliary care, medical, rehabilitative, respite, and hospice services; and home and community based care in non-institutional settings, such as home based primary care, respite care, home hospice care, community residential care, purchased skilled home care, adult day health care, and homemaker/home health aide services.	VHA pays for nursing home (NH) care for veterans who require NH care and have either at least a 70% service-connected disability, who are rated 60% (or more) service-connected and who are unemployable or are considered permanently disabled, or who need NH care for a service-related disability. If space and resources are available VA may also provide VA NH care to other veterans who do not fall into the categories listed above. Eligible persons may choose to receive their LTC services outside of NHs. All veterans enrolled in VA's health care system are eligible for home and community based long-	Department of Veterans Affairs, Veterans Health Administration (VHA)

<sup>27</sup> For additional information, see CRS Report RL33921, *Medicare's Skilled Nursing Facility Payments*, by Julie Stone.

<b>Program</b>	<b>Services</b>	<b>Eligibility</b>	<b>Administering Agency</b>
		term care services. Clinical indicators and conditions help determine the need for these services.	
Social Services Block Grant (SSBG)	Largely foster care services and protective services for children. May include homemaker services, congregate and home-delivered meals, adult day care, and transportation, among others	May include LTC populations, as defined by each state.	Department of Health and Human Services, Administration for Children and Families
Department of Housing and Urban Development (HUD) Supportive Services Programs - Multi-family Service Coordinators, Resident Opportunities and Self-Sufficiency (ROSS) Service Coordinators, and Congregate Housing <sup>a</sup>	Services available to residents may include the arrangement of transportation, meal services, housekeeping, personal care, medication management, and visits from nurses or other health care professionals. Some HUD supportive services programs are available to all residents, while others target those residents with limitations in activities of daily living (ADLs).	Residents of HUD-assisted housing who are either "elderly," defined as residents aged 62 or older, or who meet the definition of "person with disabilities" are eligible for services. Not all HUD-assisted facilities, even those dedicated to elderly residents and residents with disabilities, receive Service Coordinator or Congregate Housing funds.	Department of Housing and Urban Development (HUD) Offices of Multifamily Housing (Service Coordinators and Congregate Housing) and Public and Indian Housing (ROSS Service Coordinators)
Developmental Disabilities Assistance and Bill of Rights Act (DD Act)	Supported living; case management; residential habilitation with 24 hour supervision; day habilitation services; transportation; specialized medical equipment and supplies; skilled nursing; behavioral services; mental health services; dental and vision services, among others.	Selected persons with developmental disabilities.	U.S. Department of Health and Human Services, Administration for Children and Families, Administration on Developmental Disabilities
State Vocational Rehabilitation (VR) Programs	Counseling and guidance; assessment; vocational training; post-secondary education; assistance with living expenses; personal assistance services; and job placement.	Individuals with physical or mental impairment that results in a substantial impediment to employment and who require VR services to achieve an employment outcome. If a state is unable to serve all eligible individuals, priority must be given to servicing individuals with the most significant disabilities.	US Department of Education, Office of Special Education and Rehabilitation Services
Centers for Independent Living (CILs)	An array of independent living services, such as information and referral; independent living skills training; peer counseling;	Individuals with disabilities and their informal caregivers.	US Department of Education, Office of Special Education and Rehabilitation Services

Program	Services	Eligibility	Administering Agency
	and individual and systems advocacy.		
Assistive Technology Act	Any item, piece of equipment, or product system, whether acquired commercially, modified, or customized, that is used to increase, maintain, or improve functional capabilities of individuals with disabilities. Can range from relatively low tech items, such as canes, walkers, magnifying glasses, or dressing aids to more high tech equipment such as computer screen readers or power wheelchairs.	Certain states that improve the provision of assistive technology to individuals with disabilities of all ages and their families.	US Department of Education, Office of Special Education and Rehabilitation Services

**Notes:** This list describes the major payers of LTC services but may not be comprehensive.

- a. Many of these programs focus on assessment and referral to outside community service organizations. Other HUD programs directly support the linkage of supportive services for elderly households residing in HUD-assisted properties.

## Private Sources of Financing for LTC

Individuals who do not meet the categorical, financial, and functional eligibility criteria for Medicaid and who do not qualify for services funded under other public programs either purchase private insurance or pay for LTC services directly out-of-pocket. Other private funds pay for LTC services on a relatively small scale.

### Private LTC Insurance

Private LTC insurance (LTCI) provides financial protection for persons needing assistance with ADLs, IADLs, and cognitive impairments against the risk of the potentially high cost of LTC. LTCI policies pay benefits to cover certain LTC services for persons who have paid premiums and qualify to receive such care. Care in a variety of settings may be covered by a LTCI policy, including nursing homes or assisted living facilities, or the individual’s own home through home health. Policies may also cover respite care for caregivers, homemaker and chore services, and medical equipment, among others.

LTCI policies may be sold to an individual or a group as part of an employer-sponsored policy. There are currently about 6-7 million policies active (often called “in-force”).<sup>28</sup> The premiums charged for LTCI vary by age at purchase, with higher premiums charged to those purchasing at

<sup>28</sup> Estimates by Marc Cohen reported in Testimony Before the U.S. House Committee on Energy and Commerce Subcommittee on Oversight and Investigation: Long-Term Care Insurance: Are Consumers Protected for the Long-Term? July 24, 2008.



older ages. This age differential reflects the higher risk of needing LTC services at advanced ages. One study has estimated that over two-thirds of individuals who turn age 65 will require LTC services at some point before they die.<sup>29</sup>

The private LTCI market has undergone significant changes in the past three decades. The employer-sponsored market has grown as a share of total LTCI sales and the overall market has become more concentrated in terms of the number of companies selling the product. Further, a number of newer product lines have been introduced that combine LTCI with other retirement and life-insurance products.<sup>30</sup>

## **Out-of-Pocket Spending**

Out-of-pocket expenditures include both direct payments of LTC services, and deductibles and co-payments for services that are primarily paid for by another source. Direct payments for LTC services could include private pay nursing facilities or home health services if no other third parties cover such services. Out-of-pocket payments may also include, however, copayments under Medicare's limited LTC benefit. They also include copayments of any private health insurance plans that provide limited short-term skilled nursing and home health care coverage.

Individuals who do not have insurance that covers LTC services, who have exhausted their private health insurance benefits, and/or LTCI, and who do not qualify or have access to a sufficient number of services under public programs and continue to need assistance with LTC must pay the full cost of care directly out-of-pocket or forgo care.

The magnitude of out-of-pocket costs will depend on the setting, intensity (including the skill level of the provider), and the duration of LTC services. For example, the setting of care can include care provided in one's own home, in a community-residential care setting such as an assisted living facility, or in an institutional setting such as a nursing home. For those receiving care at home, the cost will also vary depending on the skill level of the paid caregiver. In 2009, the cost of personal unskilled care at home (such as bathing, dressing, and transferring) was \$19 an hour, whereas skilled care from a visiting nurse was \$46 an hour.<sup>31</sup> In addition, the annual cost of care will also vary by intensity and duration of care. Assuming care is provided three hours a day, seven days a week, the annual cost for unskilled care would be about \$20,750 in 2009. Assisted living facilities that provide hands-on personal care for those who are not able to live by themselves (but do not yet require constant care provided by a nursing home) cost on average \$33,900 annually in 2009. Nursing home care, on the other hand, generally costs more, in that it provides LTC assistance 24 hours a day and includes the cost of room and board. In 2009, the annual cost of a nursing home stay was \$66,886 for a semi-private room and \$74,208 for a private room.<sup>32</sup> These estimates are national averages and can vary widely by geographic region.

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<sup>29</sup> Kemper, P., H.L. Komisar, and L. Alecxih, "Long-Term Care Over An Uncertain Future: What Can Future Retirees Expect?" *Inquiry* 42, Winter 2005-2006.

<sup>30</sup> See CRS Report R40601, *Factors Affecting the Demand for Long-Term Care Insurance: Issues for Congress*, by Janemarie Mulvey.

<sup>31</sup> Genworth Financial 2009 Cost of Care Survey, April 2009.

<sup>32</sup> *Ibid.*

## **Other Private Funds**

Other private funds generally include philanthropic support, which may be direct from individuals or obtained through philanthropic fund-raising organizations such as the United Way. Support may also be obtained from foundations or corporations.

## **LTC Issues for Congress**

Concern about the way LTC is financed and delivered has drawn congressional attention for several decades. Exacerbating this concern is the aging of the U.S. population, which will put increased strains on federal and state budgets that pay a significant share of the formal LTC service provided in the United States. The first wave of the baby boom generation (born between 1946-1964 and approximately 80 million in size) is beginning to retire. This generation is expected to live longer than previous generations, increasing their likelihood of needing LTC services. In addition, advances in medicine and technology have enabled younger persons with disabilities to live longer and more independent lives with the assistance of publicly funded services. Whereas these demographic changes are positive, they also have important implications for the financing and delivery of LTC services in the future. The following discusses some of the major LTC issues affecting our current system.

## **Barriers to Public and Private Coverage**

The number of persons who can access publicly funded LTC services varies greatly across the country. For example, an individual may qualify for a comprehensive service package of Medicaid LTC services in a one state, qualify for a more limited package in a second state, and not qualify at all in a third state. Further, the reach of other public programs that cover LTC is often limited by eligibility restrictions, funding, and the number of services available. So, although public programs have successfully met the LTC needs for many, significant unmet need persists.

Relying on the private LTCI, to date, also has limitations. After 15 years of strong growth in the market, the share of the older population with a private LTC insurance policy is relatively small. Currently, less than 10% of the population aged 50 and older owns a LTC insurance policy.<sup>33</sup> One of the key factors affecting the demand for private LTC insurance is cost. Higher costs reflect individuals purchasing at older ages, increased preferences for more comprehensive benefit packages (including inflation adjustments and longer durations of coverage), and improved claims data used to more accurately price policies. Additional barriers to purchasing a policy, even among those who can afford them, include the complexity of the product and that some are not able to purchase a policy because of the insurers' underwriting requirements that may disqualify them because of pre-existing conditions.<sup>34</sup>

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<sup>33</sup> Feder, Judith, Harriet L. Komisar and Robert B. Friedland, 2007, "Long-Term Care Financing: Policy Options for the Future," Washington, DC: Georgetown University.

<sup>34</sup> See CRS Report R40601, *Factors Affecting the Demand for Long-Term Care Insurance: Issues for Congress*, by Janemarie Mulvey.

In the absence of public financing or private LTC insurance, the cost of paying for LTC directly out-of-pocket can often exceed an individual's or family's annual income and, in some cases, their savings. Many must rely on family or friends, or forgo care altogether.

Disagreement among Members of Congress persists regarding the appropriate roles of the public and private sectors in the financing of LTC. Whereas some Members of Congress assert that public programs should be expanded to shield greater numbers of individuals and families from financial hardship, others assert that the private sector should play a larger role; others want to see a larger role for both.

## **Strain on Federal, State, and Local Budgets**

Growing costs of both medical and LTC services combined with increasing enrollment have put increased financial pressures on both federal and state programs. From a federal perspective, the key source of funds for Medicare skilled nursing facility benefits is the Medicare Hospital Insurance (HI) Part A Trust Fund. Recent projections show that this trust fund will become insolvent in 2017, two years earlier than was projected in 2008.<sup>35</sup>

Medicaid, funded jointly by the federal and state governments, will also face fiscal pressures. Under current law, spending on Medicaid is expected to substantially outpace the rate of growth in the U.S. economy over the next decade.<sup>36</sup> In CBO's baseline, Medicaid's growth rate is expected to increase annually at about 7% annually from 2010 through 2019.<sup>37</sup> State spending for Medicaid is expected to increase by 4.4% in the governors' recommended budgets for FY2009—more than four times the rate of growth in other parts of the budget.<sup>38</sup> At the same, slow growth in the economy and declining housing values have reduced state revenues. The Government Accountability Office had projected that under current policies state and local governments would begin to face growing fiscal challenges even before the recent downturn had materialized.<sup>39</sup>

## **Better Coordinating Care Across Medicaid, Medicare, and Other Public Programs**

About 8.8 million Medicare beneficiaries are simultaneously enrolled in Medicaid.<sup>40</sup> These individuals receive most of their acute care services through Medicare, including home health and skilled nursing facility care when appropriate, and their non-Medicare-covered acute care and long-term care benefits under Medicaid. These dually enrolled individuals and other Medicaid

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<sup>35</sup> See 2009 Hospital Insurance (HI) and Supplementary Medical Insurance (SMI) Trustees' Report and CRS Report RS20173, *Medicare: Financing the Part A Hospital Insurance Program*, by Patricia A. Davis.

<sup>36</sup> Centers for Medicare and Medicaid Services, Press Release, *Medicaid Spending Projected to Rise Much Faster Than the Economy*, October 17, 2008.

<sup>37</sup> Congressional Budget Office, *The Budget and Economic Outlook: Fiscal Years 2009 to 2019*, January 2009.

<sup>38</sup> National Governors Association, *The Fiscal Survey of States*, June 2008.

<sup>39</sup> Government Accountability Office, *State and Local Governments: Growing Fiscal Challenges Will Emerge During the Next 10 Years*, January 2008.

<sup>40</sup> Holahan J, D Miller and D. Rousseau, "Dual Eligibles: Medicaid Enrollment and Spending for Medicare Beneficiaries in 2005," Kaiser Commission on Medicaid and the Uninsured, Washington, DC, February 2009.

enrollees may also be eligible to receive LTC services paid for by other public programs, such as the Older Americans Act.

People enrolled in or eligible for services from multiple programs may face challenges in determining which program will cover which needed services. This sometimes leads to the fragmentation or duplication of services delivered, over- or under-utilization of needed services, missed opportunities to reduce dependency on institutional services, the maximization of payment from another payer (e.g., Medicaid maximizing Medicare's home health payments before Medicaid will pay), and inappropriate emergency room visits, among others.

Congress, states, and the Department of Health and Human Services have explored various ways to improve the integration of service delivery systems across multiple programs. Various integrated managed care models have been established across the country. Still, a substantial unmet need remains. Better coordination across payers may improve efficiency, result in cost-savings, and even improve beneficiary satisfaction for those persons whose health care needs can be met through a more seamless process.

## **Better Coordinating Care Across Provider Settings**

Significant public expense is dedicated to persons with LTC needs as they transition across LTC settings (e.g., from a nursing facility to a community-based residence to receive an array of home and community-based services) and between LTC and acute- and post-acute-care settings (e.g., from a nursing facility to a hospital to a nursing facility). Each public program makes separate payments to individual providers for covered services, even though these providers may be delivering care to an individual for the same or related conditions. This approach to provider payments encourages each provider to attempt to maximize its revenue while an individual is under its care and does not encourage the management of an individual's care as he or she moves across provider settings.

Although some care coordination is funded within the LTC system (e.g., Medicaid pays for care coordination under section 1915(c) home and community-based waivers and under some Medicaid state plans), significant unmet needs exists. Some policy makers and others have suggested that certain payment reforms could provide financial incentives to individual providers, provider networks, and/or interdisciplinary teams of trained individuals (e.g., doctors, nurses, therapists, social workers, nutritionists) to manage episodes of care across provider settings for individuals.

## **Medicaid Spending Still Dominated by Institutional Care**

Medicaid spending for LTC continues to be dominated by institutional care rather than home and community-based services, despite consumer preferences for the latter. This spending trend finds its origins in a Medicaid statute that has *required* states to make nursing facility care available to certain Medicaid enrollees since the program's establishment in 1965, while giving states the *option* to extend a comprehensive package of home and community-based services as an alternative to such care. In more recent years, however, Congress has amended the Medicaid statute to expand the options available to states to provide access to home and community-based services under Medicaid. Today, the combination of waiver authority and Medicaid state plan optional benefits allows states considerable flexibility to shift this spending bias away from institutional care and toward home and community-based services. Although some states have

done just this, many have not. Concern that improving access to home and community-based services would add additional pressures on already strained state budgets is a major reason why some states have not been more aggressive. Pressure to maintain current levels of institutional spending, a lack of coordination among state agencies responsible for administering services, and limitations in the availability of home and community-based providers are among some of the barriers states may face in accomplishing this objective.

## **Navigating the Current LTC System Is Complex**

The financing and delivery system is composed of multiple services funded through a myriad of private, federal, and state programs. Accessing and arranging formal care services, delivered through multiple providers, can be confusing for individuals and their families, particularly for vulnerable populations and those with significant physical and/or mental disabilities. This results in fragmented and uncoordinated care for many beneficiaries attempting to navigate the system. Some policy makers have expressed interest in streamlining this system so as to improve access to needed care among the elderly and younger persons with disabilities.

## **Limited Supply of the LTC Workforce**

Shortages in the supply of qualified LTC workers pose a significant challenge to the nation's ability to meet the growing demand for LTC services and to meet quality standards and/or expectations for this care. Currently, many nursing homes experience high worker turnover rates and difficulties attracting qualified staff to care for the current supply of residents. Among home and community-based providers, finding qualified staff is also difficult, particularly in rural areas, where the supply of workers is often limited. Developing methods to increase the supply of staff and to adequately train them in both settings so as to meet the growing demand for LTC is a major challenge facing Congress and the nation.

## **Limited Access to Affordable Housing**

The limited funding available for affordable and accessible housing has left many individuals with LTC needs with difficulties in securing affordable and accessible housing in the community. Medicaid pays exclusively for services and does not cover room and board for community-based living. Although some federally funded housing programs finance some LTC services, such as meals and transportation, significant unmet need exists for some low-income populations. As the demand for assistance with LTC services grows, so too will pressure on federal and state governments and on Congress to identify and determine the appropriate amount of payment for a mix of community-based services and housing assistance.

## **Guaranteeing Quality Can Be Challenging**

Federal and state governments continue to struggle to identify ways to ensure that the services LTC beneficiaries receive, whether in institutions or home and community-based settings, guarantee beneficiaries' safety, promote their highest level of functioning and independence, and are free from abuse or harm. Under the current system, no assurance can be provided that public dollars will purchase services of high quality. For example, despite decades of effort on behalf of federal and state governments to improve the quality of care delivered in nursing homes, reports of quality violations are prevalent. To date, little is known about the quality of services delivered

in home and community-based settings under Medicaid and other publicly funded programs, partly because these services are delivered on a one-on-one basis in private homes and partly because advanced monitoring systems are still not in place in many states. Some work is currently being done to develop quality assurance systems in the Medicaid program in home and community-based settings. It is likely, however, that monitoring and improving quality will continue to be a challenge for federal and state governments as well as for the Congress in years to come.

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