Home and Community-Based Services Under Medicaid

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Summary

Medicaid is the largest public payer of home and community-based long-term care (LTC) services in the country. This is primarily because federal and state governments, the two sources of funding for Medicaid, have devoted significant efforts over the past several decades to expanding Medicaid's offering of home and community-based services (HCBS) for persons with disabilities and to reducing reliance on institutional care, often referred to as rebalancing.

Despite relatively high spending on LTC nationally, however, significant variation exists in the proportion of each state's Medicaid HCBS spending versus institutional care. In part, this variation is due to the enormous flexibility allowed to states under Medicaid law concerning which populations with LTC needs to cover and which services to offer them. As a result of this flexibility, no two state Medicaid LTC programs look alike.

The health reform law (the Patient Protection and Affordable Care Act, PPACA, P.L. 111-148) gives states new options to expand their coverage of HCBS and provides them with financial incentives to do so. States will be faced with decisions about whether to take up any of these new options given other pressing demands on state budgets. Members of the 112th Congress may want to know whether and how states take up these new options and may want to evaluate whether the significant variation in state spending on HCBS versus institutional care meets Congress's policy goals. A discussion about the increasing financial strain of Medicaid's institutional and HCBS spending on state and federal budgets will likely be part of this debate.

This report looks at (1) the history of the Medicaid program as it relates to state flexibility in offering HCBS; (2) basic eligibility rules for accessing HCBS under Medicaid; (3) the existing Medicaid state plan and waiver authorities that states may use to offer HCBS; (4) the variation in state spending on HCBS versus institutional LTC care; and (5) challenges states face in expanding their HCBS programs.

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Introduction

The aging of the population and increasing life expectancy of people with disabilities have drawn attention to the adequacy of Medicaid as a long-term care (LTC)[1] safety net for some time. Among the major topics of interest is the extent to which Medicaid-financed home and community-based services (HCBS)[2] meet the preferences of Medicaid beneficiaries with LTC needs.

Also at issue is cost. Medicaid is the largest public payer of HCBS in the country.[3] This is primarily because federal and state governments, the two sources of funding for Medicaid, have devoted significant efforts over the past several decades to expanding Medicaid's offering of HCBS for persons with disabilities and to reducing reliance on institutional care, often referred to as rebalancing.[4] Despite relatively high spending nationally, however, significant variation exists in the proportion of HCBS spending versus institutional care across states and by population group. Further, at the forefront of public debate is the increasing financial strain of Medicaid on state and federal budgets in general, and HCBS and other LTC spending in particular.

The health reform law (the Patient Protection and Affordable Care Act, PPACA, P.L. 111-148) gives states new options to expand their coverage of HCBS and provides them with financial incentives to do so. Members of the 112th Congress may want to know whether and how states take up these new options and to evaluate whether the significant variation in state spending on HCBS versus institutional care meets Congress's policy goals.

In addition, as the demand for LTC grows, states and the federal government may be asked to further modify Medicaid to better meet the needs and preferences of low-income persons with LTC needs. To meet these preferences, states could be asked to continue to rebalance their programs so as to either prevent or delay individuals with disabilities from entering LTC institutions. PPACA provides states with additional options and financial incentives to do this. Congress may choose to do more in this regard.

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[1] Long-term care refers to a broad range of health and social services needed by people who are limited in their 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 long-term care affects people of all ages—children born with disabling conditions, working-age adults with inherited or acquired disabling conditions, and the elderly with chronic conditions or illnesses.

[2] HCBS includes a broad range of LTC services that help persons with LTC needs remain either at home or in a residential community setting while maintaining or restoring the highest level of functioning and independence possible. Examples of services and supports include home health aides, personal care, case management, private-duty nursing, assistive devices, adult day health care, respite care, and rehabilitation, among others.

[3] In addition to Medicaid, a number of other federal programs finance home and community-based care for distinct groups of persons with disabilities. One federal authority that offers social and supportive services to the elderly in home and community-based settings is the Older Americans Act (OAA). Other programs, such as the Social Services Block Grant program (SSBG, under Title XX of the Social Security Act) provide some support services in the community for the elderly and other groups. The U.S. Department of Health and Human Services (DHHS) also uses its grant-making and waiver authority to address some of the challenges states face in their efforts to prepare their LTC programs to better care for people in the community. State and local governments also pay for a range of social services.

[4] Medicaid also covers institutional care for individuals with LTC needs. Institutional care refers to services and room and board delivered in nursing facilities (NFs, also referred to in this report as nursing homes), intermediate care facilities for the mentally retarded (ICF/MRs), institutions for mental disease (IMDs), and hospitals.

Given competing demands for state and federal dollars, policymakers will be faced with decisions about how much of their limited resources they want to spend on LTC in general, and on HCBS in particular. To the extent that Americans highly value health and personal choice for individuals with disabilities of all ages, they may be willing to devote more public resources to these programs, but doing so implies increasingly difficult tradeoffs between home and community-based LTC for individuals with disabilities and other goods, services, and functions for other populations and purposes.

Given these tradeoffs, Congress and/or states may decide that no additional funds can be spared for HCBS. If so, they may turn their attention to how existing funds can best be spent. Congress and states will want to decide how much flexibility to give states, what new or modified services are desirable, and how to allocate funds across distinct groups of needy populations.

This report looks at (1) the history of the Medicaid program as it relates to state flexibility in offering HCBS; (2) basic eligibility rules for accessing HCBS under Medicaid; (3) the existing Medicaid state plan and waiver authorities that states may use to offer HCBS; (4) the variation in state spending on HCBS versus institutional LTC care; and (5) challenges states face in expanding their HCBS programs.

Historical Perspective on Medicaid LTC Authorities and Rebalancing

States choosing to modify their Medicaid LTC programs to expand their offerings of HCBS have historically faced significant challenges. In the early years, the primary challenge to offering HCBS was a statutory requirement, included in the original 1965 law, specifying that certain Medicaid eligibles be entitled to nursing home care.

In more recent decades, federal authority has expanded to assist states in increasing and diversifying their Medicaid HCBS offerings. With the addition of the HCBS waiver[5] to Medicaid law in 1981, and subsequent statutory amendments that created new Medicaid state plan[6] benefit options, states now have a broad range of benefit options to select from when designing their HCBS programs. PPACA further adds to the range of options available to states that want to pursue rebalancing.

Below is a brief history of Medicaid's institutional care authority and a description of the evolution of the range of HCBS options made available to states. A discussion of PPACA's changes to Medicaid law regarding HCBS is also included.

[5] In general, waivers allow states to operate programs outside of traditional Medicaid rules. HCBS waivers are described in greater detail later in this report.

[6] The Medicaid state plan (also referred to as the state plan) refers to the part of the Medicaid program that generally follows, with exceptions, the program benefit rules outlined in Medicaid statute, including a broad range of mandatory and optional benefits. Waivers, on the other hand, allow states the opportunity to provide benefits outside of some of these rules.

Institutional Care

Prior to the enactment of Medicaid in 1965, homes for the aged and other public institutions were financed by a combination of direct payments made by individuals with their Old Age Assistance benefits[7] and vendor payments made by states with federal matching payments on behalf of individuals. The Kerr-Mills Medical Assistance to the Aged (MAA) program (enacted in 1960 under P.L. 86-778) allowed states to provide medical services, including skilled nursing care,[8] to persons who were not eligible for Old Age Assistance cash payments, thereby expanding the coverable population.

In 1965, when Kerr-Mills was incorporated into the new federal-state Medicaid program, Congress created an entitlement to skilled nursing facility care for beneficiaries age 21 and older, requiring all states to offer it as a mandatory benefit under the expanded program. It also gave skilled nursing facility care the same priority status as hospital and physician services. Amendments in 1967 allowed states to provide care in "intermediate care facilities" for persons who did not need skilled nursing home care, but needed more assistance than room and board alone. In 1987, Congress eliminated the distinction between skilled nursing facilities and intermediate care facilities (effective in 1990) in the Medicaid program. Medicaid law now refers to all of these facilities as nursing facilities.[9]

These early legislative developments helped stimulate growth in the nursing home industry. A significant increase in the number of nursing homes was seen during the 1960s—from 1960 to 1970, the number of homes more than doubled, from around 9,600 to almost 23,000, and the number of beds more than tripled, from 331,000 to more than 1 million.[10] Since 1970, the count of nursing homes nationwide has declined, but the number of beds has significantly increased. For example, in 2008, the total number of nursing homes nationwide totaled 15,730 while the number of beds totaled 1.7 million.[11]

Under current law, Medicaid institutional LTC includes, but is not limited to the following classifications:

- *Nursing Facility Care.* Nursing facility care is a mandatory service for Medicaid beneficiaries age 21 and over and is available in all states. States have the option to cover nursing home care for persons under age 21. Services include 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. To be eligible, an individual must meet the state-defined level-of-need criteria.
- *Intermediate Care Facilities for People with Mental Retardation (ICFs/MR).* Institutional care provided to people with mental retardation and developmental

[7] Old Age Assistance gave cash payments to poor elderly. This was the original version of Social Security benefits established under Title I of the Social Security Act in 1935 (P.L. 74-271).

[8] Nursing services often provided by a registered nurse or licensed practical (vocational) nurse.

[9] Omnibus Reconciliation Act of 1987 (P.L. 100-203).

[10] U.S. Congress, Senate Special Committee on Aging, Developments in Aging, 1970, Report 92-46, Feb. 16, 1970, Washington, cited from the American Nursing Home Association Fact Book, 1969-1970.

[11] National Center for Health Statistics, *Health, United States. 2009: With Special Feature on Medical Technology*, Hyattsville, MD, Table 119, 2010, http://www.cdc.gov/nchs/data/hus/hus09.pdf#119.

disabilities is an optional benefit under state Medicaid plans; however, most states cover this care. Services include room and board and a wide range of specialized therapeutic services to assist those with mental retardation and developmental disabilities to function at optimal levels. ICF/MRs must offer "active treatment" defined by regulation as aggressive, consistent implementation of a program of specialized and generic training, treatment, health and related services directed toward acquisition of behaviors necessary for the client to function with as much self-determination and independence as possible, and the prevention or deceleration of regression or loss of optimal functional status.[12] To be eligible, an individual must have a developmental disability and meet a state-defined level-of-need criteria.

- *Institutions for Mental Disease (IMDs).* IMD coverage for individuals age 65 and older with mental diseases is an optional benefit under state Medicaid plans. Services include diagnosis and treatment, including medical attention, nursing care and related services. States may cover such services for individuals age 65 and older and individuals who are in hospitals or nursing facilities that are institutions for mental diseases. To be eligible, individuals must meet a state-defined level-of-need criteria.

Home and Community-Based Services (HCBS)

Home care services also received some congressional attention in Medicaid's original authorizing statute. Under the 1965 law, home health care was established as one of the optional services that states could provide. In 1968, three years after Medicaid was established, Congress amended the law to require states to provide home health care to persons entitled to skilled nursing facility care as part of their state Medicaid plans (effective in 1970). Federal law requires that home health services be medically necessary and authorized by a physician as part of a written care plan. Services covered under this benefit vary by state and may include care by nurses and home health aides, medical supplies, medical equipment, and certain appliances delivered to Medicaid beneficiaries in their homes. States may also cover therapeutic services, such as physical therapy, occupational therapy, and speech pathology and audiology services.

Over time, Congress allowed states to cover other types of HCBS as optional benefits under the Medicaid state plan. For example, the personal care benefit[13] became an optional Medicaid benefit in 1978 (see **Table 1**). To enable states to make improvements in the management of care for their LTC beneficiaries and other groups, Congress added case management[14] as an optional benefit in 1986 (see **Table 1**).

[12] 45 CFR 483.440

[13] Designed to provide assistance inside or outside the home with activities of daily living (ADLs), instrumental activities of daily living (IADLs), and/or 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.

[14] Intended to provide assistance with gaining access to needed medical, social, education, and other services.

During the 1970s, the U.S. Department of Health, Education and Welfare (now DHHS) devoted increased attention to alternatives to nursing home care through a variety of federal research and demonstration efforts.[15] These efforts were undertaken not only to find ways to offset the high costs of nursing facility care, but also to respond to the desires of persons with disabilities to remain in their homes and in community settings, rather than in institutions. However, it was not until 1981 that Congress took significant legislative action to expand HCBS when it authorized the Medicaid section 1915(c) home and community-based waiver program (see **Table 2**).

In 1999, the U.S. Supreme Court ruled on a landmark case for people with disabilities, *Olmstead v. L.C.*[16] The Court held that institutionalization of people who could be cared for in community settings was a violation of Title II of the Americans with Disabilities Act (ADA).[17] This case prompted federal administrative and legislative activities to encourage efforts to provide expanded HCBS to persons with disabilities.[18] Since this time, every state has taken up the section 1915(c) waiver option or a comparable waiver under the authority of section 1115 of the Social Security Act,[19] to offer HCBS to certain LTC beneficiaries.

More recently, in the Deficit Reduction Act of 2005 (DRA, P.L. 109-171), Congress approved a variety of new options for states to modify the way they implement HCBS under the Medicaid program. Among other provisions, Congress established two new optional Medicaid benefits that allow states to cover certain HCBS. One gave states the option to establish a new waiver-like HCBS state plan option (i.e., Section 1915(i) of the Social Security Act) without requiring a Secretary-approved waiver for this purpose (under Sections 1915(c) or 1115 of the Social Security Act). Specifically, the benefit provides states the option to offer limited or comprehensive packages of benefits to targeted populations of individuals so as to delay and/or prevent their need for a higher and more expensive institutional level-of-care. It also provided for a new state plan option that allows states to offer consumer-directed personal care services. Among other things, these new options incorporated elements of the state flexibilities allowed under Medicaid waivers into Medicaid state plan benefits, giving states the option to offer HCBS while containing spending. In addition, DRA established new grants to help expand adult day care services into rural areas under the Program for All-Inclusive Care for the Elderly (PACE), an integrated Medicaid and Medicare program, and authorized additional grant funding to states to conduct demonstration projects to increase the use of and expand the states' capacity to provide HCBS.

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[15] U.S. General Accounting Office, *Home Health Care Benefits Under Medicare and Medicaid*, July 9, 1974, http://archive.gao.gov/f0302/094820.pdf.

[16] 527 U.S. 581 (1999).

[17] Specifically, the Court held that the Americans with Disabilities Act (ADA) requires states to transfer individuals with mental disabilities from institutions to less confining community settings when a state treatment professional has determined the latter is appropriate, the community setting is not opposed by the individual with a disability, and the placement can be reasonably accommodated by the state. A January 2000 Health Care Financing Administration (now Centers for Medicare and Medicaid Services) notice to state Medicaid directors indicated that the decision was applicable to all individuals with disabilities, not just those with mental disabilities. See CRS Report RS20588, *Olmstead v. L.C.: Implications and Subsequent Judicial, Administrative, and Legislative Actions*, by Melinda DeAtley and Nancy Lee Jones.

[18] See CRS Report R40106, *Olmstead v. L.C.: Judicial and Legislative Developments in the Law of Deinstitutionalization*, by Emily C. Barbour.

[19] Under section 1915(c) authority, Medicaid generally provides a comprehensive benefit package of home and community-based services to individuals who require the level-of-care offered in an institution. Some states also use the waiver authority in section1115 (Research and Demonstration Projects) to cover HCBS services.

The Patient Protection and Affordable Care Act provided a number of new options under Medicaid for states to further their rebalancing efforts. First, PPACA established a four-year incentive payment program, referred to in the law as Balancing Incentive Payments (BIP). BIP allows qualifying states to receive bonus payments for increasing their share of Medicaid LTC spending on HCBS while reducing their share of Medicaid LTC spending on institutional care. To receive payments, states will be required to meet certain target-spending percentages. Specifically, if the state's spending for HCBS in FY2009 is less than 25% of total LTC spending, the state must achieve a 25% target on HCBS by October 1, 2015, to receive bonus payments. Such states will receive a federal medical assistance percentage (FMAP)[20] increase of 5 percentage points on eligible medical assistance payments. Other states will be required to reach a target of 50% by October 1, 2015, to qualify for these incentive payments. Such states will receive an FMAP increase of 2 percentage points for eligible payments. In no case may the aggregate amount of payments made by the Secretary to states exceed $3 billion. The incentive period begins October 1, 2011, and ends on September 30, 2015.

PPACA also added a new authority under Medicaid law that states may use to offer personal attendant care and/or pay for transition costs for an individual moving from an institution to a community setting, including such costs as a first month's rent and utilities, bedding, and basic kitchen supplies, among others. Personal care attendants provide assistance with activities of daily living (ADL) and/or instrumental activities of daily living (IADL) to individuals with a significant disability. Further, attendants must be qualified to deliver such services and may include family members (as defined by the Secretary). Specifically, beginning October 1, 2011, states can offer home and community-based attendant services as an optional benefit to Medicaid beneficiaries whose income does not exceed 150% of the federal poverty level, or if greater, the income level applicable for an individual who has been determined to require the level-of-care offered in a hospital, nursing facility, ICF/MR, or IMD. States that choose this option will receive an increased FMAP of 6 percentage points for these services (see **Table 1**).

PPACA also significantly expanded the section 1915(i) HCBS state plan option established under DRA. Among other changes to this statutory authority, PPACA increased the amount of income individuals may have to qualify for the benefit and added new flexibility for states to target different benefit packages to specific populations of individuals with LTC needs. PPACA also granted states the option to establish a new eligibility pathway for certain qualifying beneficiaries who met the benefit's financial and needs-based criteria.

Eligibility for Medicaid Coverage of HCBS

Medicaid is means-tested and limits coverage for LTC to only those persons who meet the program's categorical, financial, and level-of-need (also referred to as level-of-care or medical necessity criteria) eligibility criteria. Medicaid coverage of LTC is intended to serve as a safety

[20] Financing for Medicaid is shared by the federal government and the states. The federal share for most Medicaid expenses for benefits is determined by the federal medical assistance percentage (FMAP). FMAP rates are based on a formula that provides higher federal reimbursement to states with lower per capita income relative to the national average (and vice versa). FMAPs have a statutory minimum of 50% and a maximum of 83%, although some Medicaid services receive a higher federal match rate. FY2010 FMAPs ranged from a high of 75.67% in Mississippi to a low of 50.00% in 10 other states. In February 2009, with passage of the American Recovery and Reinvestment Act of 2009 (ARRA), states received temporary enhanced FMAP rates for nine quarters beginning with the first quarter of FY2009 and running through the first quarter of FY2011 (December 31, 2010).

net for persons who cannot afford the cost of institutional care or HCBS. Generally, enrollees apply most of their income to the cost of their care, offsetting some portion of Medicaid spending for those individuals.

Categorical eligibility requirements relate to the age or other characteristics of an individual. Persons age 65 and over, certain persons with disabilities, children and their parents, and pregnant women are among the categories of individuals who may qualify for Medicaid. For the most part, persons who apply to Medicaid for coverage of LTC services and supports fall into the category of persons with disabilities, children, or individuals age 65 and over.[21]

Financial eligibility requirements include limits on the amount of income and assets individuals may possess (often referred to as standards or thresholds) before enrolling in Medicaid. These limits vary by eligibility pathway. There are numerous eligibility pathways that low-income persons with disabilities, children and persons age 65 and over may use to qualify for Medicaid. The specific income and asset limitations that apply to each eligibility group are set through a combination of federal parameters and state definitions. Consequently, standards vary considerably among states, and different standards apply to different population groups within a state.

In addition to meeting categorical and financial requirements, access to LTC is limited to individuals meeting the state's level-of-need criteria. Such criteria evaluates an individual's need for a particular service, or package of services, based on a functional, cognitive and/or diagnostic assessment of an individual's capacity for self-care. In general, states establish a level-of-need assessment to determine eligibility for institutional care. This criteria is also used to determine eligibility for HCBS services offered under waivers (discussed later in this report) for individuals who would otherwise require institutional care. States use other, often, less stringent criteria to determine eligibility for other HCBS benefits offered by under a state Medicaid plan.

State Options to Provide HCBS

Medicaid statute and other provisions in the Social Security Act offer states two broad authorities under which to offer HCBS to beneficiaries with LTC needs, either through a Medicaid state plan benefit or through a waiver program. The Medicaid state plan refers to the part of the Medicaid program that generally follows, with exceptions, certain program benefit rules outlined in Medicaid statute. These rules require states to cover certain benefits under the traditional Medicaid state plan program (i.e., mandatory benefits) and gives states the option to cover others (i.e., optional benefits). With respect to state plan benefits, federal law requires states to meet the following guidelines (with some exceptions):

- Each service must be sufficient in amount, duration, and scope to reasonably achieve its purpose. States may place appropriate limits on a service based on such criteria as medical necessity or functional level-of-care;
- Within a state, services available to certain groups of enrollees must be equal in amount, duration, and scope. These requirements are called the "comparability rule";

[21] Starting in 2014, an additional category of eligibles will be added to mandatory coverage under Medicaid. This category will be comprised primarily of childless adults.

- With certain exceptions, the amount, duration, and scope of benefits must be the same statewide, also referred to as the "statewideness rule"; and
- With certain exceptions, beneficiaries must have "freedom of choice" among health care providers or managed care entities participating in Medicaid.

Certain waivers, on the other hand, allow states to provide benefits outside of some of these rules. For example, waivers allow states to extend services that are, among other things, neither comparable across groups nor statewide. The most commonly used waiver authority states use to provide HCBS to Medicaid beneficiaries is the section 1915(c) authority. Individuals served under this waiver live in community-based setting but require the level-of-care offered in an institution. Some states also use the waiver authority in section 1115 (Research and Demonstration Projects) to cover HCBS services.

Together, these benefit and waiver authorities constitute an inventory of options states have in designing their HCBS benefit packages for LTC beneficiaries. Each of the HCBS state plan waiver benefits and programs are described below and the differences between authorities are outlined in **Table 1** and **Table 2**.

Home and Community-Based State Plan Services

Below is a summary of the wide array of HCBS state plan services that states may cover under their Medicaid programs. Each state may also determine the amount, duration or scope of these particular services. Among the options described below, the only state plan service that participating Medicaid states are required by federal law to cover are home health and transportation. All other HCBS state plan services are optional.

Home Health State Plan Mandatory Benefit

Medicaid law requires states to cover home health services for certain eligible persons age 21 and older who are entitled to, but not necessarily eligible for,[22] nursing facility coverage under a state's Medicaid plan. To be eligible, individuals must already be enrolled in Medicaid and meet the state's definition of need for home health services. Home health services must be medically necessary and authorized by a physician as part of a written care plan.

The definition of Medicaid's home health benefit is significantly flexible so as to allow for a range of skilled and unskilled services delivered to beneficiaries in their homes. Services covered vary by state and may include care by nurses and home health aides,[23] as determined by a person's medical condition. Services may include nursing, home health aides, medical supplies, medical equipment, and appliances suitable for use in the home. States may also provide therapeutic services, such as audiology and physical or cognitive therapy, under this benefit.

[22] Beneficiaries are entitled to the home health benefit when they meet certain categorical eligibility criteria. Certain medically needy individuals and/or persons age 21 and older residing in states that offer nursing home coverage to these groups are also entitled to the state's home health benefit. However, beneficiaries may only receive the home health benefit if they meet the state's needs-based criteria for home health. Source: Janet O'Keeffe, Gary Smith, and Letty Carpenter, et al., *Understanding Medicaid Home and Community Services: A Primer*, Office of the Assistant Secretary for Planning and Evaluation, U.S. Department of Health and Human Services, Washington, DC, October 2000.

[23] Home health aides assist with ADLs and IADLs.

Some states use this benefit primarily to extend skilled nursing and therapy care to Medicaid beneficiaries. In addition, some states use Medicaid's home health benefit to cover homemaker and other personal care services, services similar to those allowed under Medicaid's personal care state plan benefit.

Medical Transportation and Other Transportation

States must provide a minimum transportation benefit that ensures transport for Medicaid recipients to and from providers, such as to medical doctor visits. States may also provide a transportation benefit beyond these minimum requirements to enable recipients of HCBS services to gain access to waiver and other non-medical community services, activities, and resources specified by the plan of care.

Case Management and Targeted Case Management Services

States may offer a free-standing case management benefit 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. The case management benefit can be offered separately from the other services the state offers, such as the section 1915(c) waivers (described later in this memorandum). Case management includes the development and implementation of a care plan and a comprehensive assessment and periodic reassessment of a beneficiary's needs. Examples include service/support planning, monitoring of services, and assistance to persons with obtaining other non-Medicaid benefits, such as food stamps, energy assistance, and emergency housing.

States choosing to offer the case management benefit must make it available on a statewide basis. States also have the option to offer a targeted case management benefit to a specified beneficiary subpopulation within a specific geographic area. Like the case management benefit, states can use targeted case management to assist such individuals in gaining access to needed medical, social, educational and other services. To be eligible for either benefit option, Medicaid beneficiaries must meet the state-defined criteria for that benefit.

Respiratory Care for Persons Who Are Ventilator-Dependent

States may offer respiratory care for persons who are ventilator-dependent for life support for at least six hours per day. Such services assess and treat breathing disorders, such as asthma, emphysema, and chronic obstructive pulmonary diseases and are provided on a part-time basis in the recipient's home by a respiratory therapist or other health care professional trained in respiratory therapy.

Options to Provide Personal Care as a Stand-alone Benefit

Personal care attendants provide assistance with activities of daily living (ADL) and/or instrumental activities of daily living (IADL) to individuals with a significant disability. States are permitted to cover personal care services, including personal care attendant services, under a variety of optional statutory authorities such as (1) the personal care state plan benefit; (2) self-directed personal care state plan benefit; and (3) home and community-based services state plan benefit (Section 1915(i)). Below is an explanation of these statutory authorities. Although states

have significant flexibility to determine the amount and scope of these benefits, each statutory authority includes a unique set of rules governing the way in which a state may extend this benefit to Medicaid beneficiaries.

States may also use the HCBS waiver (sections 1915(c), (d), and (e)) and the section 1115 research and demonstration waivers to offer personal care.

Personal Care Option

Services offered under the personal care option may include assistance with ADLs and IADLs. For persons with cognitive impairments, such services may include cuing along with supervision. Services may be furnished to an individual at home or in another location (such as a workplace or senior center, but excluding hospital, nursing facility or ICF/MR, or institution for mental diseases) to enable beneficiaries to participate in community activities.

Personal care services must be authorized by a physician, or at state option, otherwise authorized under a plan of care. Medicaid-approved personal care providers may include family relatives, except legally responsible relatives such as spouses. Further, the provision of personal care services may be directed by the people receiving them, including the individual's supervision and training of their personal attendants. To be eligible, Medicaid beneficiaries must meet the state's definition of need for personal care services.

Self-Directed Personal Assistance State Plan Option (Section 1915(j) of the Social Security Act)

Under Section 1915(j) of the Social Security Act, states are given the choice of covering self-directed personal care services (excluding room and board) through a state plan option. This option gives states more flexibility than the personal care state plan option and eliminates the need to seek waiver authority to provide personal care through a self-directed delivery model.

Under this benefit, self-directed personal care services can be made available to only those Medicaid enrollees who would otherwise be (1) entitled to the state's personal care state plan option, if the state offers this benefit; or (2) receiving services under a state's HCBS waiver. The state may offer this self-directed personal assistance services state plan option on a less than statewide basis, and may limit the number of persons served, features that are not permitted under the personal care state plan option or under state plan services in general.

This self-directed program must allow beneficiaries to exercise choice and control over the budget, planning, and purchase of their services. Other requirements include an assessment of the beneficiary's needs, the availability of a support system to counsel beneficiaries, a written service plan, an individualized budget, and appropriate quality assurance and risk management.

Community First Choice Option (Section 1915(k) of the Social Security Act)

PPACA established a new Medicaid state plan option in which states can offer consumer-directed personal care attendant services under a new statutory authority, and receive an increased federal match rate of 6 percentage points for doing so. Beginning October 1, 2011, states can offer home and community-based attendant services as an optional benefit to Medicaid beneficiaries whose income does not exceed 150% of the federal poverty level, or if greater, the income level

applicable for an individual who has been determined to require the level of care offered in a hospital, nursing facility, or intermediate care facility for the mentally retarded (ICF/MR), or an institution for mental disease.

Services offered through this benefit option may include, among others, home and community-based attendant services and supports to assist eligible individuals in accomplishing ADLs, IADLs, and health-related tasks. Such services must be delivered under a person-centered plan of care in which attendants are selected, managed, and dismissed by the individual (or his or her representative). Services and supports may also include expenditures for transition costs, such as from a nursing home to the community. Such costs might include the first month's rent and utilities, bedding, and basic kitchen supplies, among others. Further, attendants must be qualified to deliver such services and may include family members (as defined by the Secretary).

To obtain approval from the Secretary to offer this benefit, states must (1) collaborate with a state-established Development and Implementation Council; (2) provide these services on a state-wide basis and in the most integrated setting, as is deemed appropriate to meet the needs of the individual; (3) in the first full fiscal year of operation, maintain or exceed the preceding fiscal year's level of state Medicaid expenditures for individuals with disabilities or elderly individuals; and (4) establish and maintain a comprehensive, continuous quality assurance system, among other requirements.

HCBS State Plan Option (Section 1915(i) of the Social Security Act)

Section 1915(i) of the Social Security Act allows states to extend packages of community-based LTC services to Medicaid beneficiaries without requiring a Secretary-approved waiver for this purpose. PPACA amended section 1915(i) to modify and expand this state plan option, as described below.

Eligibility

Federal law imposes certain limitations on the characteristics of beneficiaries who may obtain section 1915(i) services in a state. States may extend this state plan option to those Medicaid beneficiaries whose income does not exceed 150% of the federal poverty level and who meet a state's needs-based criteria. The needs-based criteria must be less stringent than the criteria states use to determine eligibility for institutional care in a nursing facility, intermediate care facility for the mentally retarded (ICF/MR), or hospital. States may also extend eligibility to those with income up to 300% of the State Supplemental Income (SSI) benefit rate who are receiving HCBS services under a home and community-based waiver authorized under sections 1915(c), (d) or (e) of the SSA, or under Section 1115 of SSA (research and demonstration projects).

In addition, states may create a new section 1915(i) eligibility pathway into Medicaid to increase access to the 1915(i) benefits for people who need a lower level-of-care than is provided in an institution. States may also choose to extend full Medicaid benefits to this new eligibility group.

Targeting

States may use section 1915(i) authority to offer different packages of services to different target groups of beneficiaries. States can elect to target the provision of HCBS to specific populations and to vary the type, amount, duration or scope of the benefits for each of these populations.

Such elections will be for five-year periods (i.e., an initial five-year period and five-year renewal periods). Enrollment and/or the provision of services can be phased-in (as long as the phase-in is accomplished prior to the end of the initial five-year period). States may not cap the number of persons eligible for this benefit.

To help states contain enrollment, Medicaid law allows states to modify their needs-based criteria, without obtaining prior approval from the Secretary, if actual enrollment exceeds states' projected enrollment, and certain other requirements are met. If a state makes its needs-based criteria more stringent, such individuals must continue to be eligible until such time as they no longer meet the state's former needs-based criteria.

Benefits

In the design of each benefit package, states may choose from a list of services. The list includes case management, home-maker/home health aide and personal care, adult day health, habilitation, respite care, day treatment or other partial hospitalization, psychosocial rehabilitation, and clinic services (whether or not furnished in a facility) for individuals with chronic mental illness. In addition, states may seek approval from the Secretary to offer other services, with the exception of room and board.

Home and Community Care for Functionally Disabled Elderly Individuals (Section 1929)

To be eligible for this benefit, Medicaid beneficiaries must have functional disabilities, be age 65 or over, and be eligible for Medicaid coverage in the community because they have low income and resources, or, if they live in a state with a medically needy eligibility program, because they have incurred large medical expenses that deplete their income and resources.[24] Services that states may cover include homemaker/home health aide services, chore services, personal care, nursing care, respite care, training for family members in managing the individual, adult day care, day treatment or other partial hospitalization, psychosocial rehabilitation service, and clinic services for persons with chronic mental illness, and other services approved by the Secretary.

Federal matching payments to each participating state may not exceed 50% of the aggregate amount that would have been spent to provide Medicare skilled nursing facility services to persons receiving home and community-based care under this optional benefit. To the extent that a state electing this optional benefit fails to maintain levels of nonfederal expenditures for home and community-based care for functionally disabled elderly individuals (excluding 1915(c) waiver services and Medicaid home health and personal care), a state's federal matching payments are reduced by the amount it no longer spends.

[24] Generally, states are not permitted to apply the more liberal financial standards that states may use for persons served under section 1915(c) waiver programs unless they discontinue their wavier programs and provide coverage to such waiver participants under the new optional benefit.

PACE (Program All-Inclusive Care for the Elderly)

To improve the delivery of home and community-based services and to reduce institutionalization among the dual eligibles[25] age 55 and older with LTC needs, Congress authorized the Program for All-Inclusive Care for the Elderly, as a demonstration program, in 1986. The Balanced Budget Act of 1997 (P.L. 105-33) then established PACE as a permanent option under both Medicaid and Medicare. PACE is a voluntary Medicaid and Medicare integration program for duals with LTC needs who receive services in adult day or adult day health centers.

PACE providers receive capitated payments from both Medicaid and Medicare to provide a comprehensive package of covered benefits to individuals age 55 and older who require the level-of-care offered in a nursing home. PACE providers assume the risk for expenditures that exceed the revenue from their capitation payments.

Covered services include primary care, hospital care, medical specialty services, prescription drugs, nursing home care, emergency services, home care, physical and occupational therapy, adult day care, recreational therapy, meals, dentistry, nutritional counseling, social services, and transportation, among others. Under PACE, an interdisciplinary team of physicians, nurses, physical therapists, social workers, and other professionals provide all needed health, medical, and social services, often in adult day care settings.

PACE is intended to provide seamless coordinated care to certain low-income individuals aged 55 and older who would otherwise require nursing home care.

[25] Individuals enrolled in both Medicaid and Medicare.

Table 1. HCBS State Plan Benefits

	Home Health Benefit	Medical Transportation and Other Transportation	Case Management Services or Targeted Case Management (TCM)	Respiratory Care for Persons Who Are Ventilator-Dependent	Personal Care Benefit	1915(j) Self-Directed Personal Care	1915(k) Community First Choice Option	1915(i) HCBS State Plan Option	Other HCBS State Plan Benefits	PACE
Summary of Services/ Benefits	Services may include skilled nursing care, therapy (physical, speech, occupational), and home health aides, among others.	Transportation to and from doctors appointments, clinics, and non-emergency hospital care.	Individualized care and connects individuals to services and supports.	Services assess and treat breathing disorders, (e.g., asthma, emphysema, chronic obstructive pulmonary diseases.)	Personal care attendant.	Self-directed personal care services.	Personal care attendant. May cover transition costs (e.g., first month's rent, utilities, bedding, kitchen supplies) such as from a nursing facility to the community.	May include case management, home-maker/home health aide and personal care, adult day health care, habilitation, respite care, among others States can offer different benefit packages to different populations.	May include, rehabilitation, private duty nursing, therapies (physical, speech, occupational), home modifications and other adaptive services, family and caregiver supports, and social supports.	HCBS are provided for certain low-income individuals aged 55 and older who would otherwise require nursing home care. Care delivered by an interdisciplinary team (mostly in a day care setting).
Optional or Mandatory	Mandatory	Mandatory	Optional	Optional	Optional	Optional	Optional	Optional	Optional	Optional

	Home Health Benefit	Medical Transportation and Other Transportation	Case Management Services or Targeted Case Management (TCM)	Respiratory Care for Persons Who Are Ventilator-Dependent	Personal Care Benefit	1915(j) Self-Directed Personal Care	1915(k) Community First Choice Option	1915(i) HCBS State Plan Option	Other HCBS State Plan Benefits	PACE
Eligibility Pathway into Medicaid	No, must already be enrolled in Medicaid.	No, must already be enrolled in Medicaid.	No, must already be enrolled in Medicaid.	No, must already be enrolled in Medicaid.	No, must already be enrolled in Medicaid.	No, must already be enrolled in Medicaid.	No, must already be enrolled in Medicaid.	Yes, income below 150% of the SSI benefit rate and meet needs-based criteria. States may extend full Medicaid benefits to these individuals.	No, must already be enrolled in Medicaid.	No
Benefit Eligibility	Entitled to but not necessarily eligible for nursing facility coverage Must be authorized by a physician as part of a written care plan.	State establishes criteria for benefit eligibility.	State establishes criteria for benefit eligibility.	Must be dependent upon a ventilator for life support for at least 6 hours a day.	State establishes criteria for benefit eligibility.	Enrollees who would otherwise be entitled to the state's personal care state plan option if the state has one; or receiving services under a state's HCBS waiver plan.	Medicaid enrollees with income less than 150% of FPL, or If income is 150% of FPL or greater, the income level of state's institutional level-of-care. Must also meet the state's needs-based criteria.	Beneficiaries with income less than 150% of FPL and who meet state's needs-based criteria Beneficiaries with income up to 300% of the SSI benefit rate and receiving HCBS under an HCBS or 1115 waiver.	State establishes criteria for benefit eligibility.	Individuals must reside in a PACE service area, be certified by a state as eligible for nursing home care, and meet the state's financial institutional eligibility criteria.

	Home Health Benefit	Medical Transportation and Other Transportation	Case Management Services or Targeted Case Management (TCM)	Respiratory Care for Persons Who Are Ventilator-Dependent	Personal Care Benefit	1915(j) Self-Directed Personal Care	1915(k) Community First Choice Option	1915(i) HCBS State Plan Option	Other HCBS State Plan Benefits	PACE
Self-Directed by beneficiary	Requires a waiver approved by the Secretary	Requires a waiver approved by the Secretary	Requires a waiver approved by the Secretary	Requires a waiver approved by the Secretary	Requires a waiver approved by the Secretary	Yes. Beneficiaries exercise choice and control over the budget, planning, and purchase of services.	Yes. Must be delivered under a person-centered plan care plan in which attendants are selected, managed, and dismissed by the beneficiary (or his or her representative).	Optional. Must be consistent with the assessment of capabilities, preferences, needs, etc. and include a service plan.	Different rules apply to each benefit.	Yes. Patients participate in decision making.
Tools to Limit Enrollment	State defines eligibility criteria	State defines eligibility criteria	State defines eligibility criteria	State defines eligibility criteria	State defines eligibility criteria	May be offered on a substate basis, and may limit the number of persons served	State defines level-of-need eligibility criteria	Allows states to limit eligibility by modifying the needs-based criteria	State defines eligibility criteria	Sites are limited by geographic area and enrollment caps.
FMAP	Regular state FMAP	Regular state FMAP	Regular state FMAP	Regular state FMAP	Regular state FMAP	Regular state FMAP	6% enhanced FMAP	Regular state FMAP	Regular state FMAP	Regular state FMAP
Must seek Secretary's approval for renewal	No	No	No	No	No	No	No	Every five years	No	No

Source: CRS analysis of title XIX of the Social Security Act.

Waivers

States may also use waivers to extend HCBS to individuals with disabilities of all ages residing in community-based settings. Such waivers are referred to by their statutory reference and include, section 1915(c), (d) and (e) HCBS waivers and section 1115 research and demonstration projects. These waiver options are described below.

Section 1915(c) HCBS Waivers

To grant states additional flexibility to offer a broad range of home and community-based long-term care services as an alternative to institutional care, Congress authorized the use of the HCBS waiver program under section 1915(c) of the Social Security Act in 1981. To date, most states have chosen to make these waivers available to targeted populations (other states have used section 1115 waivers for similar purposes).

Section 1915(c) gives states the option to extend a broad range of home and community-based services to selected populations of individuals with the level-of-need that would otherwise be offered in Medicaid-covered institutions, such as a nursing home, ICF/MR, or a hospital. Under an HCBS waiver, the Secretary of DHHS is permitted to waive Medicaid's "statewideness" requirement to allow states to cover HCBS services in a limited geographic area. The Secretary may also waive the requirement that services be comparable in amount, duration, or scope for individuals in particular eligibility categories. States may use this waiver to limit the number of individuals served and target certain populations, such as persons with mental retardation and developmental disabilities, persons under age 65 with physical disabilities, individuals with HIV/AIDS, persons who are medically fragile or technologically dependent, and individuals with mental illness. States may limit access to these waiver programs by capping enrollment. For HCBS waivers to be approved, states also must meet other requirements, such as a cost-effectiveness test, under which average Medicaid expenditures for waiver participants do not exceed costs that would have been incurred if these individuals resided in institutions.

The statute specifies a broad range of services that states may provide to participants in the waiver. Examples of such services include case management, homemaker/home health aide, personal care, adult day health, habilitation, respite, 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, as well as other services that the Secretary may approve. States have flexibility to offer additional services if approved by the Secretary. Section 1915(c) waivers may not cover room and board.

When states offer the same service under section 1915(c) that that they offer under their Medicaid state plan, the state is generally using the approved waiver service to supplement those services offered under the state plan. For example, if a state offers personal care under its 1915(c) waiver and also offers it as an optional benefit under the Medicaid state plan, then the waiver personal care service is used to add into the personal care state plan benefit. For states that do not offer these benefits under their state plan, the 1915(c) waiver may provide the only access to such benefits for individuals with LTC needs.

Section 1915(d) Waivers for the Elderly

Under section 1915(d) of Medicaid law, states may provide comprehensive HCBS to targeted elderly persons at risk of needing nursing home care. Like section 1915(c) waivers, states are authorized to request waivers of Medicaid statewideness, comparability, and financial eligibility requirements to target services toward individuals whom they believe can be served effectively in the community. States can provide case management, homemaker/home health aide services, personal care, adult day health services, respite care, and other medical and social services that can contribute to the health and well-being of individuals and their ability to reside in the community. Section 1915(d) waiver authority differs from the section 1915(c) authority in two respects. First, the target population is limited to persons 65 years of age and older who, without home and community-based care, would require nursing home care that would be paid for by Medicaid. Second, the budget neutrality test for 1915(d) waivers establishes a cap or ceiling on the total amount that states may spend for LTC services under Medicaid.

Section 1915(e) Home and Community-Based Waivers for Certain Children

Section 1915(e) of the Social Security Act allows states to cover home and community-based care for children who are infected with the acquired immunodeficiency syndrome (AIDS) virus or who are drug dependent at birth and who may remain in hospitals indefinitely because of problems in finding an alternative placement. Like section 1915(c) waivers, states are authorized to request waivers of Medicaid statewideness and comparability requirements. Specifically, the law allows states to provide services to such children, as well as to any children with AIDS, who (1) are under age 5, (2) are receiving or are expected to receive federally funded adoption or foster care assistance, and (3) would be likely, in the absence of waivered services, to require the level of care provided by a hospital or nursing facility. Services that states may provide under this waiver program include nursing care, physicians' services, respite care, prescription drugs, medical devices and supplies, transportation, and any other service requested by the state and approved by the Secretary. To gain approval from the Secretary, the state must demonstrate that the costs of this program will not exceed the costs for the same individuals in the absence of this waiver.

Section 1115 Research and Demonstration Projects

Section 1115 of the Social Security Act provides the Secretary with broad authority to conduct research and demonstration projects under several programs authorized by the Social Security Act, including Medicaid. Under Section 1115, the Secretary may waive Medicaid requirements contained in Section 1902 (including but not limited to what is known as freedom of choice of provider, comparability of services, and state-wide access).[26] The Secretary may also use the Section 1115 waiver authority to provide Federal Financial Participation for costs that are not otherwise matched under Section 1903 of the Social Security Act.[27] States must submit proposals

[26] Freedom of choice refers to a requirement that Medicaid beneficiaries have the freedom to choose a provider. Comparability refers to a requirement that services be comparable in amount, duration, and scope for persons in particular eligibility groups. A waiver of the statewideness requirement allows states to provide services in only a portion of the state, rather than in all geographic jurisdictions.

[27] Section 1903 describes the conditions under which federal financial participation is available. Section 1115(a)(2) stipulates that expenditures under a waiver are eligible for matching under Section 1903.

outlining terms and conditions for proposed waivers to CMS and reserve approval before implementing these programs.

Unlike regular Medicaid, CMS waiver guidance specifies that waiver costs are budget neutral to the federal government over the life of the waiver program. To meet the budget neutrality test, estimated spending under the waiver cannot exceed the estimated cost of the state's existing Medicaid program under current law program requirements. For example, costs associated with an expanded population (e.g., those not otherwise eligible under Medicaid), must be offset by reductions elsewhere within the Medicaid program. Several methods are used by states to generate cost savings for such waivers: (1) limiting benefit packages for certain eligibility groups; (2) providing targeted services to certain individuals so as to divert them from full Medicaid coverage; and (3) using enrollment caps and cost-sharing to reduce the amounts states must pay.

Waiver projects are generally approved for a five-year period, however, states may seek up to a three-year extension for their existing waiver program under the same special terms and conditions (STC), and an additional extension(s) under revised STC for the continuation of a waiver project operating under an initial three-year extension.[28]

Some states use section 1115 waivers, either in addition to or in lieu of section 1915(c) waivers, to provide HCBS to targeted populations of beneficiaries. The use of 1115 waivers offers states more flexibility than do section 1915(c) waivers in the design of the HCBS benefit package, the organization of payments for services, and/or the delivery of care. For example, some states have used 1115 waivers to provide HCBS services to beneficiaries under managed care. Other states have used such waivers to allow for the direct payment by states to beneficiaries or their representatives. A state may get approval for these practices and a variety of other self-directed activities under a Section 1115 waiver, including (1) changing the Medicaid eligibility requirements (e.g., allowing an individual to have more income and still qualify for Medicaid); or (2) waiving the requirement that the state only pay those agencies, or practitioners, that have provider agreements with the state.

[28] The approval process associated with each type of extension is defined in statute at Section 1115(e) and at Section 1115(f) respectively.

Table 2. Waivers for HCBS

	1915(c)	1915(d)	1915(e)	1115
Targeted Populations Covered	Persons who would otherwise require institutional care that would be covered by Medicaid	Same as 1915(c)	Children under age 5, who are infected with AIDS or who are drug dependent at birth, and who are eligible for adoption or foster care assistance, and who would otherwise require institutional care that would be covered by Medicaid	States have flexibility to select target populations
Eligibility Pathway into Medicaid	Yes, if meets institutional eligibility rules and an enrollment slot is available	Same as 1915(c)	Same as 1915(c)	Subject to state and Secretary discretion
Medicaid requirements authorized to be waived	Statewideness, comparability requirements, and income and resource rules that apply to persons receiving services in the community	Same as 1915(c)	Same as 1915(c)	Medicaid requirements contained in Section 1902 (including freedom of choice of provider, comparability of services, and state-wide access), among others
Covered Services	Case management, homemaker/home health aide, personal care; adult day health, habilitation services, respite care, day treatment or other partial hospitalization, psychosocial rehabilitation, and clinic services for the chronically mentally ill, and other services approved by the Secretary	Case management, homemaker/home health aide, personal care, adult day health, respite care, and other medical and social services that can contribute to the health and well-being of individuals and their ability to reside in the community	Nursing care, respite care, physicians' services, prescribed drugs, medical devices and supplies, transportation, and other services approved by the Secretary	Subject to state and Secretary's discretion
Optional or Mandatory	Optional	Optional	Optional	Optional
Tools to Limit Enrollment	May cap enrollment and maintain waiting lists	Same as 1915(c)	Same as 1915(c)	Subject to state and Secretary discretion

	1915(c)	1915(d)	1915(e)	1115
Budget /Cost Limitations	Average per capita expenditures for persons receiving waiver services cannot exceed expenditures that would have been incurred for these individuals in the absence of the waiver. For this cost-effectiveness test, states must estimate the number of Medicaid certified nursing home beds and beds in other institutions participating in the program that could serve waiver participants	Total long-term care spending (for nursing facility care, home health, private duty nursing, personal care, and home and community-based care provided under other waiver authorities) cannot exceed the amount spent for these services in a base year, adjusted for changes in the costs of services and for changes in the size of the state's population aged 65 and over	Average per capita expenditures for persons receiving waiver services cannot exceed expenditures that would have been incurred for these individuals in the absence of the waiver	Estimated spending under the waiver cannot exceed the estimated cost of the state's existing Medicaid program under current law program requirements
Must seek Secretary approval for renewal	An initial term of three years, renewable for five-year periods	Same as 1915(c)	Same as 1915(c)	Every five years

Source: CRS analysis of title XIX of the Social Security Act.

Spending on HCBS Versus Institutional Care

Spending on institutional care has dominated Medicaid's LTC financing for decades, leading many to describe federal and state LTC spending as having an institutional bias. In recent years, Medicaid has steadily increased its financing of HCBS as an alternative to institutional care. Further, states' adoption of section 1915(c) HCBS waivers,[29] starting in the early 1980s, in addition to state take-up of other state plan and waiver options, resulted in an increase in the proportion of Medicaid LTC spending on HCBS at the national level. As shown in **Figure 1**, in 1993, Medicaid spending on HCBS, primarily on the waiver but also on home health and personal care, represented 16% ($6.7 billion) of Medicaid's total LTC spending ($42.1 billion). For the same year, Medicaid expenditures on institutional care, primarily on nursing homes, represented 84% ($35.4 billion) of total LTC spending.[30] In 2008, Medicaid spending on HCBS represented 43% ($45.4 billion) of all Medicaid LTC expenditures ($106.4 billion), while spending on institutional care represented 57% ($61.0 billion).[31]

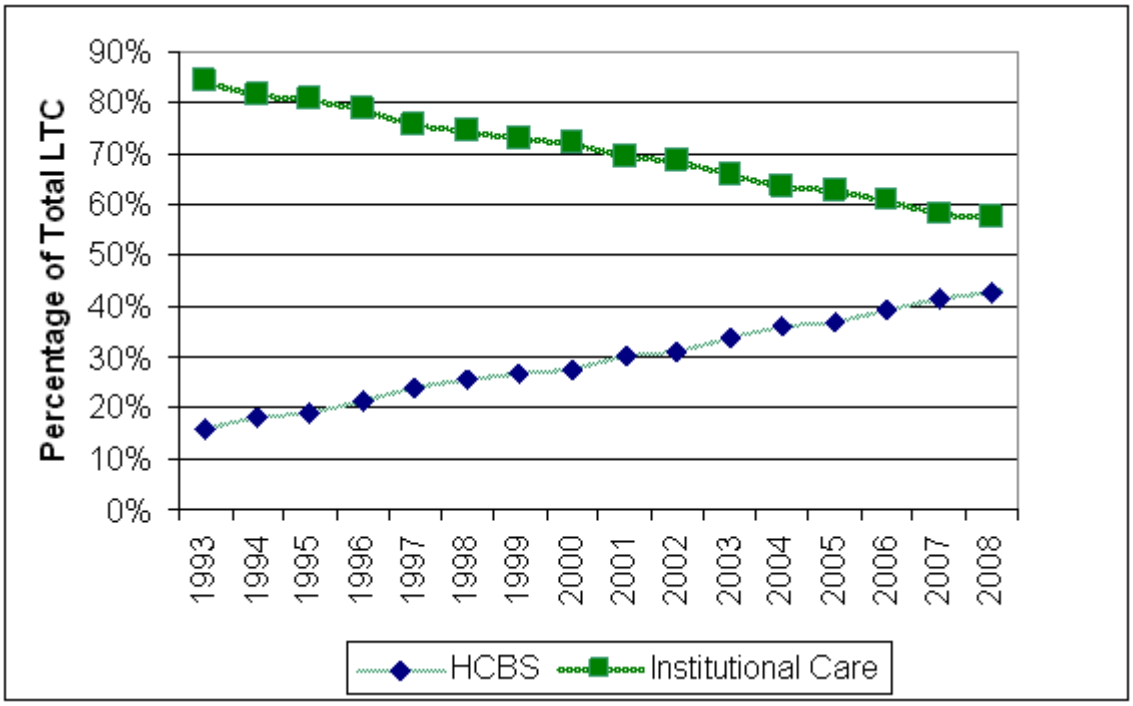
[29] Section 1915(c) HCBS waivers provide authority for the Secretary of Health and Human Services to waive certain Medicaid provisions as an alternative to institutional care to targeted populations on a less than statewide basis.

[30] Brian Burwell, Kate Sredl, and Steve Eiken, *Medicaid Long-Term Care Expenditures in FY 2005*, Thomson Medstat, Cambridge, MA, July 5, 2006.

[31] Burwell et al., *Medicaid LTC Expenditures in FY 2008*, Thomson Reuters, Cambridge, MA, December 1, 2009.

Figure 1. Total Federal and State Medicaid HCBS and Institutional Care Expenditures as a Percentage of LTC Spending

1993-2008

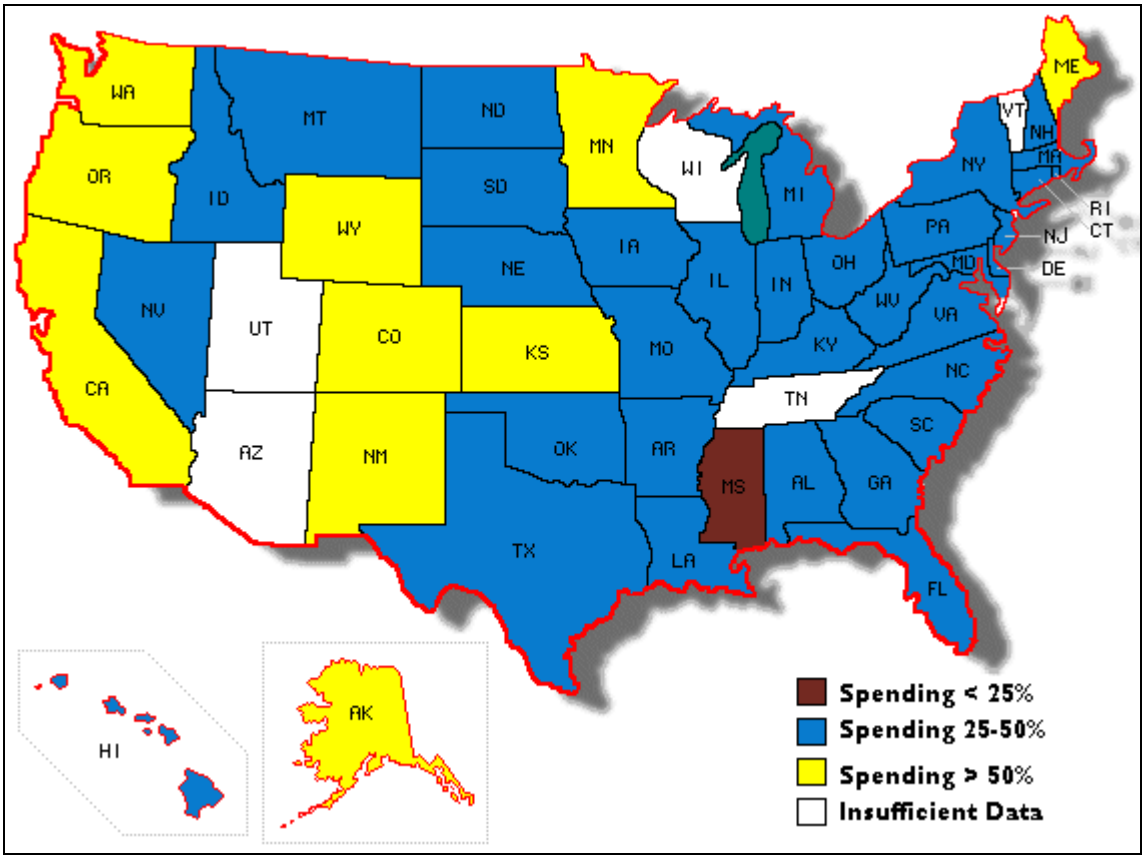


Source: Brian Burwell, Kate Sredl, and Steve Eiken, *Medicaid Long-Term Care Expenditures in FY 2005*, Thomson Medstat, Cambridge , MA, July 5, 2006; and Brian Burwell, Kate Sredl, and Steve Eiken, *Medicaid Long-Term Care Expenditures in FY 2008*, Thomson Medstat, Cambridge , MA, December 1, 2009.

Although national spending on HCBS has increased over time, significant variation exists at the state level. **Figure 2** illustrates state-by-state Medicaid spending on HCBS as a proportion of total Medicaid LTC expenditures for 2008. The three states with the largest percentage of spending on HCBS were New Mexico (75%), Oregon (81%), and Minnesota (66%). The three states with the lowest percentage of spending on HCBS were New Jersey (30%), Indiana (29%), and Mississippi (14%). Nine states spent 50% or more of their LTC dollars on HCBS, thirty-six states and D.C. spent between 25 to 50%, and only one state, Mississippi, spent less than 25%.

Figure 2. HCBS Expenditures as a Proportion of LTC Expenditures, by State

2008



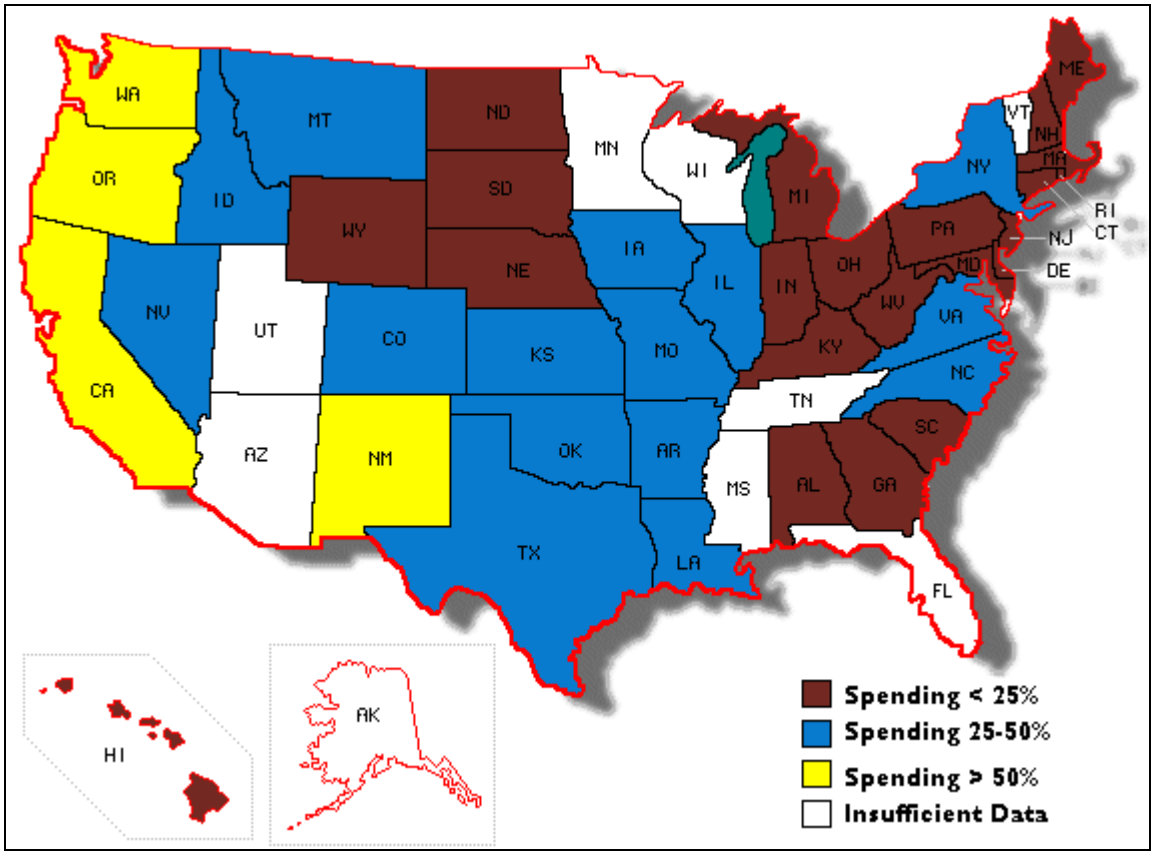
Source: Burwell et al., Medicaid LTC Expenditures in FY 2008, Thomson Reuters, Dec. 1, 2009.

Notes: The data submitted by the following states were insufficient to include them in this analysis: Arizona, Tennessee, Utah, Vermont, and Wisconsin.

Not only does spending vary by state but it varies by population group as well. **Figure 3** shows the proportion of LTC dollars spent on HCBS versus institutional care for people age 65 and older and younger non-elderly adults with disabilities (AD) for FY2008. The share of Medicaid LTC expenditures on HCBS for the AD population was greatest in New Mexico at 64% of expenditures. The share of Medicaid LTC expenditures on HCBS for the AD population was lowest in North Dakota at 9%. Four states spent 50% or greater, 16 states and D.C. spent between 25% and 50%, and 22 states spent less than 25%.

Figure 3. HCBS Expenditures as a Proportion of LTC Expenditures for the Aged and Non-elderly Adults with Physical Disabilities, by State

2008



Source: Burwell et al., Medicaid LTC Expenditures in FY 2008, Thomson Reuters, Dec. 1, 2009.

Notes: The data submitted by the following states were insufficient to include them in this analysis: Arizona, Florida, Minnesota, Mississippi, Tennessee, Utah, Vermont, and Wisconsin.

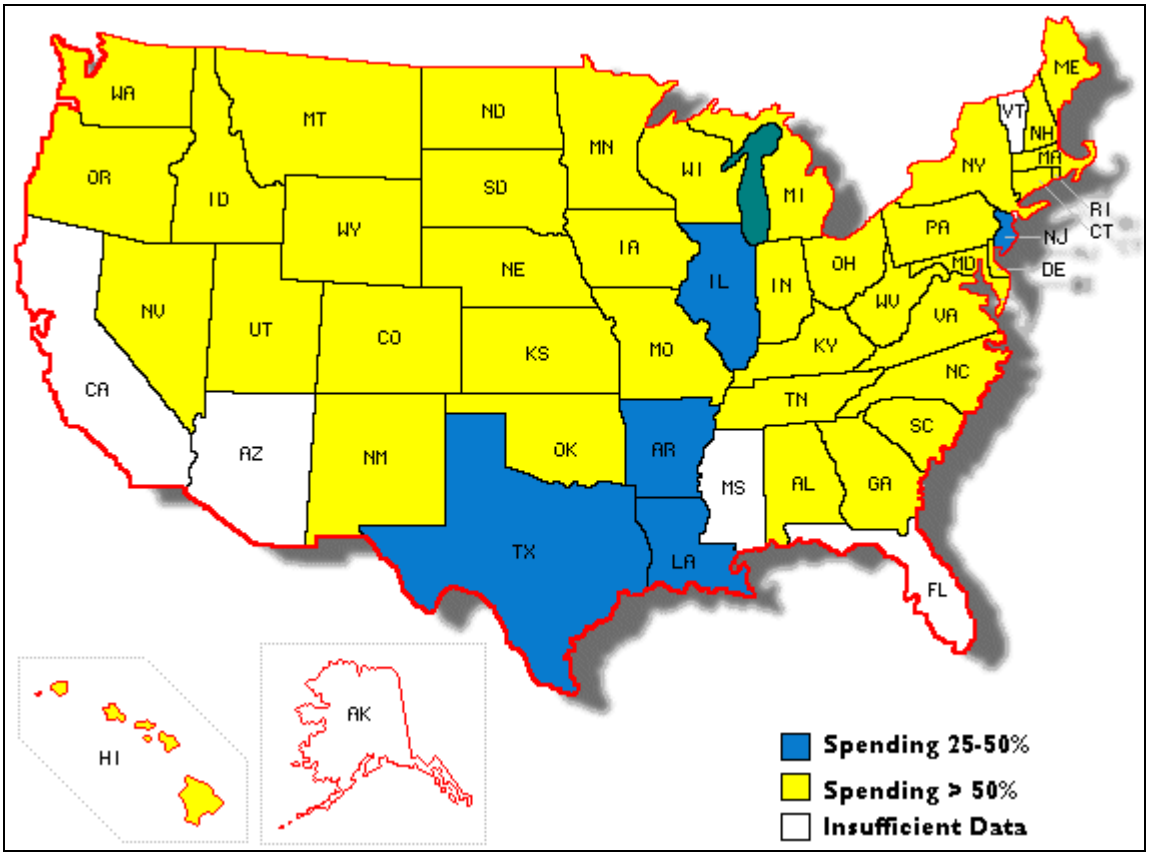
States' share of Medicaid LTC spending for persons with developmental disabilities (DD) on HCBS is dramatically different. As shown in **Figure 4**, a large majority of states spent more than 50% of their LTC dollars for the DD group on HCBS. This represents a significant shift from the 1970s and 1980s, during which state spending on institutions for the DD population was much higher. To make this shift, states relied heavily on the section 1915(c) HCBS waiver (discussed earlier in this report).[32] In 2008, 39 states spent more than 50% of their Medicaid LTC dollars for the DD population on HCBS. Only five states spent less than 50%, and no states spent below 25%. Further, as of FY2008, Oregon's Medicaid LTC spending for the DD population was entirely on HCBS, paying for no institutional care for this population at all. In FY2008, the two other states with the largest proportion of spending of their Medicaid LTC dollars for the DD population on HCBS, were New Hampshire (98%) and Rhode Island (96%). Conversely, Illinois

[32] From FY1993 to FY2008, HCBS waiver programs had an average annual growth rate of 17%. Federal and state Medicaid spending for HCBS waivers grew from $2 billion to approximately $30 billion. Source: Burwell et al., Medicaid LTC Expenditures in FY2008, Thomson Reuters, December 1, 2009. Burwell et al., Medicaid LTC Expenditures in FY 2005, Thomson Reuters, July 5, 2006.

spent the lowest share of Medicaid LTC dollars for the DD population on HCBS. In FY2008, it spent 42% of its Medicaid LTC DD dollars on HCBS.

Figure 4. HCBS Expenditures as a Proportion of LTC Expenditures for Persons with Developmental Disabilities, by State

2008



Source: Burwell et al., Medicaid LTC Expenditures in FY 2008, Thomson Reuters, December 1, 2009.

Notes: The data submitted by the following states were insufficient to include them in this analysis: Alabama, Arizona, California, Florida, Mississippi, and Vermont.

Challenges to the Expansion of HCBS

Although some states have taken the lead in picking up the above described HCBS state plan and waiver options and, thus, shifting a share of their LTC dollars toward HCBS, others have lagged behind (see spending section of this report). As noted earlier, heavy reliance on institutional care in some states is, in part, a result of the statutory mandate to provide such care. Other factors also play a part. Among them is the fact that federal initiatives to support states' take-up of HCBS state plan and waiver services have been designed to maximize state flexibility. As a result, states have many choices and each state has chosen differently. Consequently, variation across state Medicaid programs reflects differences in states' desires to serve more individuals with LTC needs in the community. It also reflects the varied economic, political, and geographic circumstances within each state.

Further complicating rebalancing are the following factors: (1) state budget constraints and uncertainty about how the expansion of HCBS could impact these budgets; (2) the existing provider system can sometimes be oriented toward serving persons in institutional settings; and (3) not all persons with LTC needs who want to remain in the community have access to affordable and accessible housing. The following discussion provides additional insights into these challenges.

Strain on Federal and State Budgets

Accompanying the recent economic recession is an increase in Medicaid enrollment nationwide. Between December 2007 and December 2009, for example, national level enrollment in Medicaid increased by 6 million. In FY2010, average Medicaid enrollment across states grew by 8.5%. And, Medicaid is expected to continue to grow on average by 6.1% in FY2011. Further, while state revenue has declined, total Medicaid spending has increased to cover the costs of growing enrollment, among other things. In FY2010, for example, Medicaid spending nationally grew by 8.8% on average. In FY2011, Medicaid spending is expected to increase by 7.4% over FY2010 levels.[33]

As many states experience budget shortfalls in 2011,[34] they will be asked to make decisions about how and whether to expand access to HCBS. Yet, many states face uncertainty about how such expansions would impact their bottom lines. This question often centers around the cost-effectiveness of HCBS. Broad disagreement persists among stakeholders about the savings that might occur if a Medicaid program were to invest in a broader array of HCBS for more individuals. Some states maintain that more access to HCBS can reduce the rate of increase in often more costly nursing home care because it can delay or even prevent the need for this care. Further, the substitution of HCBS for nursing home care for persons with lower levels of care needs can lower Medicaid's per capita costs, especially because Medicaid does not cover room and board in the community as it does for nursing home care.

However, others assert that substitution can also increase per capita state (and federal) costs for persons with relatively high need levels because caring for individuals who require a higher intensity of care in community settings cannot usually achieve the same economies of scale as facility-based settings. Others claim that individuals who are eligible but not currently enrolled avoid Medicaid in some states because of the programs' emphasis on institutional care. If Medicaid were to offer a more attractive benefit package of HCBS, some policymakers worry that enrollment would substantially grow and result in unwieldy and unpredictable program expenditures.

To date, studies attempting to evaluate the cost-effectiveness of HCBS have had mixed results. In general, some show increased costs.[35] Another study, by The Hilltop Institute, found that a HCBS waiver for older persons in Maryland was cost-effective for Medicaid when it served individuals who would have otherwise been cared for in a Medicaid-funded nursing home. In fact, costs in

[33] Kaiser Commission on Medicaid and the Uninsured, *State Fiscal Conditions and Medicaid*, Medicaid Facts, Washington, DC, October 2010, http://kff.org/medicaid/upload/7580-07.pdf.

[34] Ibid.

[35] The National Channelling Demonstration was a federally sponsored demonstration program that tested the effectiveness of delivering home and community-based services in six states as compared to institutional care. http://aspe.hhs.gov/daltcp/reports/chansum.htm.

the Maryland nursing home totaled $4,835 per person during a 12-month period in 2006 whereas costs totaled $2,780 per person in Maryland's Older Adult Waiver group.[36] Yet the same study also found that Medicaid would save money by not providing waiver services to individuals who would not otherwise have entered a Medicaid-covered nursing home.[37] Without access to either, Medicaid beneficiaries would likely rely on family members, Medicare, LTC insurance or other insurance for payment of care when available, or forgo needed care rather than enter a nursing home.

In general, many studies thus far have been largely limited by their narrowness in scope. For the most part, studies have not taken into account the impact that not covering room and board in home and community-based setting may have on family caregivers and out-of-pocket expenditures. In addition, with some exceptions, such as in The Hilltop study mentioned above, most studies do consider how serving people in the community rather than in Medicaid-covered institutions may affect spending by other public payers, such as Medicare, the Supplemental Security Income (SSI) program, and the Food Stamps program, among others.

Provider Orientation Toward Institutional Care

In some cases, incentives in the LTC system encourage heavier reliance on institutional care than on HCBS. Anecdotal information[38] suggests that hospital personnel are more likely to discharge persons needing LTC services to nursing facilities, rather than to home and community-based settings, which are sometimes seen by discharge planners as riskier choices for people with complex and high care needs. Nursing homes provide 24-hour care and regular access to nursing, personal aide, and therapy services, such as physical, occupational, and speech therapists. Discharges to a home care setting can vary by the amount of accessible care and are subject to the availability of qualified caregivers. Discharge planners often view transfers to nursing homes as easier to manage because they require coordination with just one entity, the nursing home, whereas transfers to a person's home, for a person with LTC needs, can require the discharge planner to coordinate referrals with multiple providers. Further, some states do not provide prompt access to services under section 1915(c) waiver services, making it faster to obtain care in nursing homes and other institutions.[39] Discharges to home care settings in rural areas are often even more risky because they may require reliable transportation services to bridge long distances between providers and clients.

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[36] A. Tucker, K. Johnson, and Y. Huang, et al., *Examining the Medicare Resource Use of Dually Eligible Medicaid Recipients*, The Hilltop Institutue, UMBC, Baltimore, MD, January 30, 2010. Tucker A. and Johnson K., *Cross-Payer Effects on Medicare Resource Use: Lessons for Medicaid Administrators*, The Hilltop Institute, UMBC, Baltimore, MD, May 15, 2010.

[37] A. Tucker, K. Johnson, and Y. Huang, et al., *Examining the Medicare Resource Use of Dually Eligible Medicaid Recipients*, The Hilltop Institutue, UMBC, Baltimore, MD, January 30, 2010. Tucker A. and Johnson K., *Cross-Payer Effects on Medicare Resource Use: Lessons for Medicaid Administrators*, The Hilltop Institute, UMBC, Baltimore, MD, May 15, 2010.

[38] Information is based on interviews with state officials in 2000 and 2001, providers and advocates as part of a CRS 10-state study of state long-term care systems funded in part by grants from the Jewish Healthcare Foundation and the U.S. Department of Health and Human Services, Health Resources and Services Administration, Office of Rural Health Policy.

[39] Pennsylvania Intra-Governmental Council on Long-Term Care, *Home and Community-Based Services Barriers Elimination Work Group*, Report, Harrisburg, PA, April 2002, http://www.adrc-tae.org/tiki-download_file.php?fileId=26486.

Finally, another desirable reason to refer individuals with LTC needs to nursing homes rather than HCBS providers is because of the likely assistance they will receive from the nursing home staff in applying to Medicaid after depleting their financial resources on their care. People living in the community, however, may not get the same assistance with this process. For persons with mental impairments, the challenge of discharging to the community, arranging for providers, and identifying adequate informal caregivers can be even more complex.

Limited Availability of Affordable and Accessible Housing

The limited funding available for affordable and accessible housing has made it difficult for many low-income elderly and people with disabilities who have LTC needs to secure housing in the community. Medicaid pays exclusively for services and does not cover room and board for community-based living. Without access to affordable and accessible housing, some individuals with LTC needs look to nursing homes to meet both their care and shelter needs.

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