kaiser commission on medicaid and the uninsured

Long-Term Care: Understanding Medicaid's Role for the Elderly and Disabled

Prepared by

Ellen O'Brien
Georgetown University Health Policy Institute

for

The Kaiser Commission on Medicaid and the Uninsured

November 2005

THE HENRY J. KAISER FAMILY FOUNDATION

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The Kaiser Commission on Medicaid and the Uninsured provides information and analysis on health care coverage and access for the low-income population, with a special focus on Medicaid's role and coverage of the uninsured. Begun in 1991 and based in the Kaiser Family Foundation's Washington, DC office, the Commission is the largest operating program of the Foundation. The Commission's work is conducted by Foundation staff under the guidance of a bi-partisan group of national leaders and experts in health care and public policy.

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Executive Summary

Medicaid today plays a critical role for people with long-term care needs. With expenditures of $86.3 billion in 2003, Medicaid is the single largest source of financing for long-term care, providing services to the elderly, working age adults and children with disabilities. Despite Medicaid's importance to people who need long-term care, Medicaid also has significant limitations. Medicaid's benefits are provided unevenly across the nation and stringent means-testing forces people who need care to impoverish themselves to receive assistance. This paper provides a review of how Medicaid works for people with long-term care needs and describes the fiscal challenges that states currently face and that Medicaid may face in the future as the population ages.

Key facts about Medicaid and long-term care include the following:

Medicaid is the Nation's Primary Source of Financing for Long-Term Care

- **Medicaid is the single largest source of financing for long-term care.** With payments of $86.3 billion in 2003, Medicaid accounted for nearly half (47.4 percent) of the nation's spending on long-term care services.

- **Medicaid is an important source of payment for both the elderly and the nonelderly with long-term care needs.** Estimates of long-term care spending for different age groups are hard to come by, but the Congressional Budget Office estimates that Medicaid paid for about a third of the long-term care spending on the elderly in 2004, including a third of all nursing home costs. The CBO also reports that Medicaid paid for a much larger share, an estimated 60 percent, of the long-term care spending of nonelderly persons with disabilities in 1998.

- **People who need long-term care services are diverse.** They include the elderly with physical and cognitive impairments, as well as children and nonelderly adults. People with disabilities in Medicaid include children and adults with mental retardation and developmental disabilities, the severely mentally ill, people with traumatic brain injuries and spinal cord injury, adults with debilitating illness such as Parkinson's disease and multiple sclerosis, people with AIDS, and children born with severe physical and cognitive impairments (mental retardation, cerebral palsy, multiple sclerosis, epilepsy, muscular dystrophy, hearing loss or deafness, and blindness, for example).

Medicaid Eligibility is Limited

- **Medicaid is limited to poor and low-income people and those who become poor paying for care.** With limited exceptions, states must cover the elderly and people with disabilities who receive income support through the SSI program. However, states can extend benefits to higher income people who would otherwise qualify for SSI, and states can also expand eligibility through medically needy programs and special income rules for people residing in institutions. Most elderly and disabled people who qualify for Medicaid become eligible through a mandatory, welfare-related pathway. In 2001, 85 percent of

disabled children in Medicaid were part of a mandatory eligibility group, as were roughly three quarters of disabled adults. The elderly are more likely to apply for Medicaid when they need nursing home care. Consequently, a somewhat larger share of the elderly qualifies through an optional category such as the special income rule.

Medicaid Provides a Wide Range of Long-Term Care Benefits

- **State Medicaid programs provide a wide range of long-term care services needed by people of all ages.** These include comprehensive long-term care services provided in institutions—nursing homes and intermediate care facilities for the mentally retarded—as well as a wide range of services and supports needed by people to live independently in the community—home health care, personal care, medical equipment, rehabilitative therapy, adult day care, case management, home modifications, transportation, and respite for caregivers. Through these varied long-term care benefits, states provide services to millions of people annually. In 2002, more than 1.8 million Medicaid beneficiaries received long-term care services while living in institutional facilities during the year, including nursing homes (1.7 million) and ICFs-MR (129,000), about 920,000 received care under HCBS waivers, 722,000 received home health care services, and 683,000 received services under Medicaid's optional personal care benefit.

- **Medicaid has long been accused of having an "institutional bias," but there has been substantial growth in Medicaid spending on community-based long-term care services over the past decade, and a significant shift in the distribution of Medicaid long-term care resources from institutional to home- and community-based services.** Between 1994 and 2004, spending on home and community-based services increased from $8.4 billion to $31.6 billion, rising from 19 percent to 36 percent of Medicaid long-term care spending. The shift was primarily due to the rapid growth in HCBS waiver spending which today accounts for nearly two-thirds of all Medicaid long-term care spending in the community.

Medicaid Spending on Long-Term Care Varies by State

- **States vary widely in the resources they devote to long-term care.** Medicaid spending on long-term care in 2004 ranged from a high of $833 per state resident in New York to just about $100 per resident in Utah and Nevada. Similarly, Medicaid spending per enrollee varies widely. Medicaid nursing home spending per elderly beneficiary varied from a high of nearly $15,000 in Connecticut to about $2,600 in California and Maine in 2001. Spending on home and personal care ranged from a high of $7,145 per disabled enrollee in Connecticut to less than $250 in the District of Columbia, Hawaii, and Mississippi in 2001.

- **Inequities in access to long-term care services have profound impacts on the health and wellbeing of the frail elderly and nonelderly people with disabilities.** Waiting lists for home and community-based services prevent financially eligible individuals from receiving services, leading to inappropriate institutionalization and unmet needs. One recent study of frail elderly applicants for a Medicaid HCBS waiver in Connecticut found that the elderly applicants who did not participate in the waiver program "appear to get by in the community" through a combination of informal care, use of Medicare home care, and going

without needed services. Their ability to manage in the community, however, was limited. The elderly who applied for but did not receive waiver services were far more likely than those who received HCBS to enter a nursing home within six months following their assessment for waiver services.

Policymakers are Seeking Strategies to Reduce Medicaid Spending Growth

- **Long-term care spending has grown slowly in recent years, but remains a target for efforts to close state and federal budget gaps.** Spending on long-term care ($91 billion in 2003) accounts for about a third of all Medicaid spending nationally. Spending on nursing home care represents the single largest category of Medicaid spending (about 17 percent), surpassing spending on inpatient hospital care and payments to managed care plans. In theory, states have significant flexibility to reduce spending on long-term care services in Medicaid. Unlike acute care, where the majority of Medicaid spending is for mandatory services for mandatory groups, the vast majority of all Medicaid spending for long-term care (85 percent) is "optional"—payments for optional services or enrollees. Although states have sought to reduce payments to providers, limit optional benefits and reduce eligibility for the elderly and people with disabilities, long-term care has not been the primary target of cost containment efforts. Long-term care for the elderly may be targeted for reductions in the current federal budget debate which seeks $10 billion in Medicaid savings to help address the growing federal budget deficit.

- **Medicaid is at the center of discussions about how to address future long-term care challenges, but opinions differ sharply about what Medicaid's role should be.** Continuing increases in health care costs, population aging, and growing demands for long-term care are expected to contribute to growing, and, some argue, "unsustainable" public spending burdens. An older but more affluent nation will be able to afford to spend some share of increased national income to maintain and expand Medicaid's (and Medicare's) benefits for people who need long-term care. However, current policy debates focus on slowing the growth of entitlement spending rather than on improving long-term care protections.

- **If Medicaid is to remain the nation's long-term care safety net, pressing financing, service delivery, and quality challenges will need to be addressed.** Because the future growth in demand for Medicaid services is likely to be unevenly distributed across states, long-term care financing may pose a serious challenge to the current federal-state structure in Medicaid. A number of program and policy initiatives implemented over the past decade seek to enhance the cost-effective delivery of long-term care services and improve the quality and satisfaction with services. These include efforts to reform Medicaid long-term care by "rebalancing" long-term care services, implementing consumer-directed service delivery models, and "integrating" acute and long-term care services in Medicare and Medicaid. Improving service delivery models especially for the community-dwelling elderly, for whom options are lacking in many states, will remain a priority. However, savings from more cost effective approaches may not be sufficient to offset the gap in states' abilities to finance future long-term care needs. Another option would be to federalize home and community-based services by expanding the federal financing to cover 100 percent of all community-based long-term care. This policy would go a long way toward relieving burdens on states,

improving equity, and addressing unmet needs for care. Another option would be to expand Medicare's role in long-term care. Medicare already provides universal health coverage to the elderly and has large expenditures for skilled nursing and home health care.

Medicaid's long-term care services are a critical source of support for millions of poor and low-income people. The long-term care system we have today is primarily financed by Medicaid, and without significant policy changes, Medicaid is likely to be the major source of long-term care coverage in the future. In the absence of a universal, social insurance program for long-term care, expanded private insurance and savings will not be adequate to address all long-term care risks and needs for all people. The low- and modest-income elderly will remain at risk of impoverishment due to long-term care needs, and private insurance will not likely address the needs of either nonelderly persons with disabilities or the low- and modest-income elderly. Medicaid will likely remain the nation's safety net for the poor and the middle class with long-term care needs, but Medicaid has important gaps and inequities that should be addressed to assure that elderly and nonelderly people with disabilities have access to the long-term care services that are needed to assure their health and wellbeing.

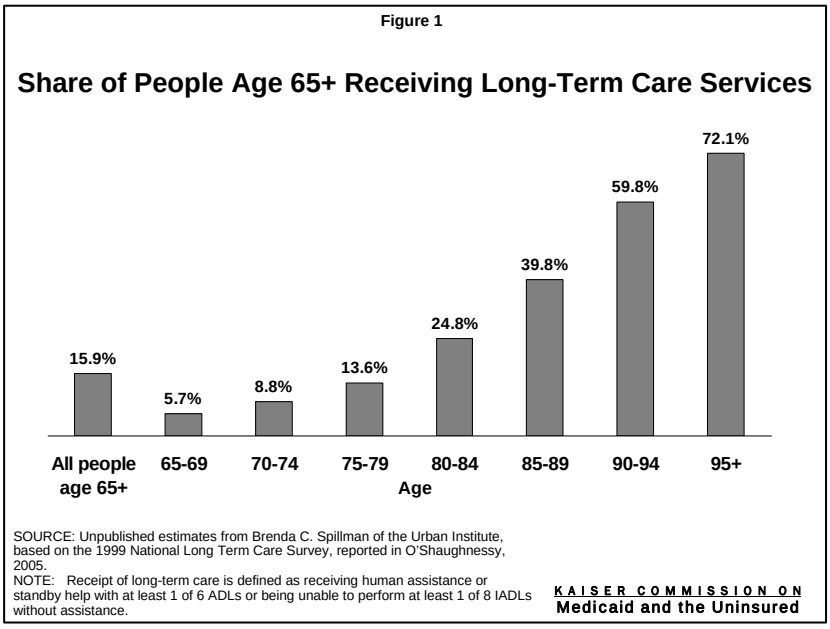
OVERVIEW OF LONG-TERM CARE

Long-term care refers to the services and supports that people need when their ability to care for themselves has been reduced by a chronic illness or disability. Long-term care affects the old and the young; people may need care over a lifetime, or care needs may be limited to a relatively brief period of several months or years. Needs for care also range considerably. People with long-term care needs may need only some supportive services around the home, help with everyday tasks such as bathing or preparing meals, or they may have complex medical needs requiring around-the-clock care and supervision. Only a small fraction of those who need long-term care reside in nursing homes or other institutions; most live in their own homes, and a growing number live not in nursing homes or their own home, but in congregate settings where they receive some supportive services.

Who needs long-term care?

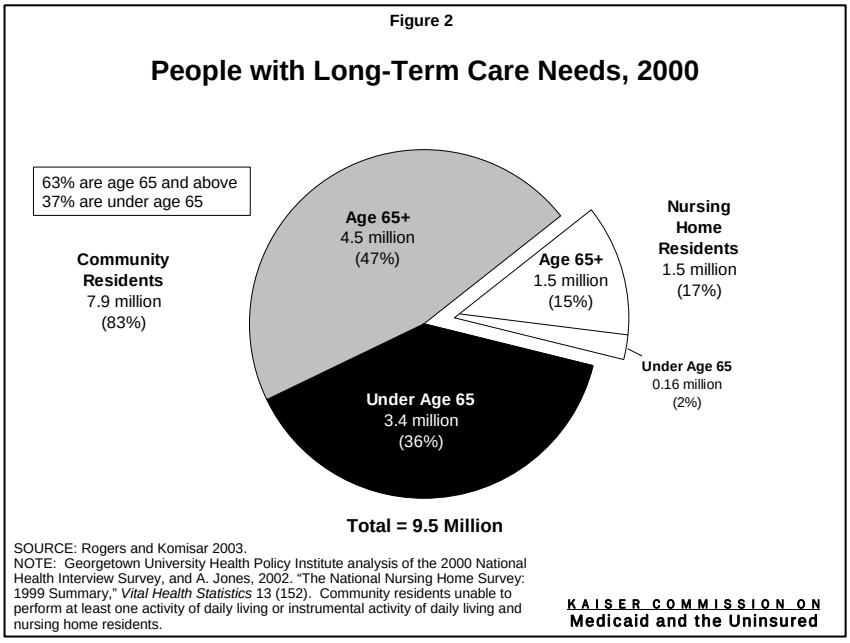
About 10 million people need long-term care in the United States, including 6 million elderly and roughly 4 million children and working age adults. The need for long-term care is often measured in terms of the extent to which an individual needs assistance or supervision in performing basic "activities of daily living" (ADLs), such as bathing, dressing, toileting, or eating, or "instrumental activities of daily living" (IADLs) such as shopping, cleaning, or managing money. People who have limitations and need assistance or supervision with any ADLs or IADLs are said to have long-term care needs. Long-term care needs are often a consequence of aging, most often affecting those age 85 and above, about half of whom have some need for long-term care. About 6 percent of people age 65 to 69 received some long-term care services in 1999, with rates climbing among the oldest old. Nearly three quarters of people age 95 and above received some long-term care services in 1999. [Figure 1]

Figure 1



Disabling conditions affect the nonelderly as well, including children born with disabilities such as mental retardation or cerebral palsy, and teenagers and adults who sustain spinal cord or brain injuries or who are impaired by diseases such as multiple sclerosis or Parkinson's disease. Although only a relatively small proportion (1.4 percent) of people under age 65 have significant physical or cognitive impairments which leave them dependent on others for personal care and support, they account for a large share of the long-term care population. Nearly 40 percent of community residents who need long-term care services are working-age adults or children [Figure 2].

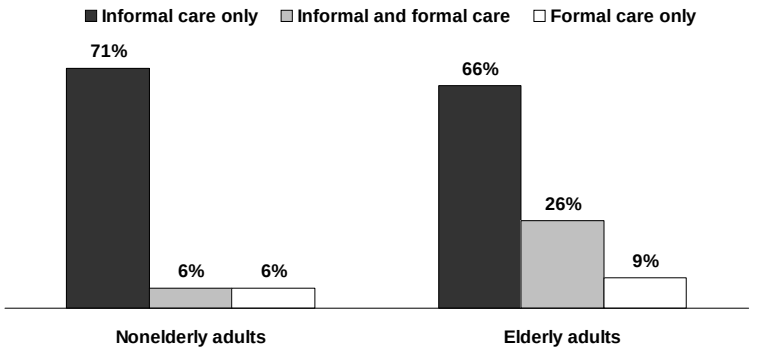
Figure 2



Where do people receive long-term care?

People who need long-term care receive services in a variety of settings, including: their own homes; other community settings, such as adult day care centers, assisted living facilities, board and care homes, and other congregate living facilities; and nursing homes. Most people who need long-term care live at home and in the community, and get by with the assistance of family caregivers. Even when needs are substantial, families provide the bulk of care to children and adults with disabilities. Among the elderly living in the community with long-term care needs, more than two-thirds rely exclusively on informal, unpaid care provided by family members – usually a spouse or a daughter. A small proportion (less than 10 percent) relies exclusively on assistance from formal (paid) caregivers—personal assistants or home care aides, and about a quarter rely on a combination of paid and unpaid assistance. Among nonelderly adults with long-term care needs, family supports play an even larger role. More than 70 percent of nonelderly adults with long-term care needs rely exclusively on informal care; only 12 percent rely exclusively on paid care or receive a mix of paid and unpaid assistance. [Figure 3]

Figure 3



SOURCE: National Long Term Care Survey, reported in *Older Americans 2004: Key Indicators of Wellbeing*, available at: http://www.agingstats.gov/chartbook2004/healthcare.html; and, 1994 National Health Interview Survey, Disability Supplement, reported in William Spector, et al. *Characteristics of Long-Term Care Users,* Prepared for the Institute of Medicine.

NOTE: Data for the elderly refer to Medicare enrollees age 65 and above who report receiving personal care from a paid or unpaid helper for a chronic disability. Data for the nonelderly excludes 18 percent of adults with long-term care needs under age 65 for whom type of care is "unknown."

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Just 17 percent of people with long-term care needs receive those services in institutional settings. The disabled elderly are more likely than nonelderly people with disabilities to reside in nursing homes. But even among the elderly who receive long-term care services, the large majority (75 percent) receives care in the community; only 25 percent receive care in nursing homes.

The elderly in the community tend to be healthier and less disabled than the elderly living in nursing homes; nevertheless, a large number of people with substantial needs are living in their own homes or receiving care in other community settings. More than one million elderly individuals needing assistance with 5 or more ADLs live in nursing homes, and roughly the same number of people (with similar levels of impairment) receive long-term care services in their own homes or in the community.[1] What separates the nursing home from the community population is not so much level of impairment, but the presence of family or social supports. Nursing home residents generally lack family or social supports, or have families who have provided substantial care to a disabled person at home, but are no longer able to provide the amount and kind of care needed without assistance.

[1] People with 5-6 ADLs account for the large majority of nursing home residents (69%), or 1.09 million; the are a much smaller share of the community-dwelling population with long-term care needs (25%), but the populations are roughly equal in size (1.05 million live in the community). Calculated based on estimates from Brenda Spillman reported in O'Shaughnessy, C. 2005. "Long-Term Care: What Direction for Public Policy? Testimony Before the House Committee on Energy and Commerce". Washington, D.C.: Congressional Research Service., p. 6.

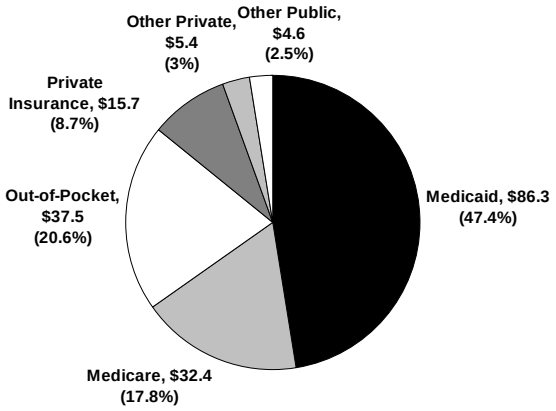
Who pays for long-term care?

When long-term care needs persist for months and years, paid services can quickly deplete available resources for all but the very wealthy. A year of care in a nursing home is estimated to cost $70,000 on average across the nation, but most of the elderly—and especially those at greatest risk of nursing home entry—lack the financial resources to afford that care for more than a few weeks or months. Only about a third of the elderly in the community have enough resources (money in checking or savings accounts, individual retirement accounts, etc.) to pay for a year or more of nursing home care, and about a third have such limited resources (less than $5,000) that they could not pay for a month of care. Among those at high risk of nursing home use—those over age 85 with no spouse and some functional or cognitive limitation—assets available to pay for care are even more limited. Most of the elderly in this high risk group (two-thirds) have less than $5,000 in available assets (Lyons, Schneider, and Desmond 2005). Similarly, care for a child or nonelderly adult with a disability would quickly impoverish most middle-class families.

Nevertheless, most people use their own resources to pay for formal long-term care services when they are needed. Estimates of the sources of payment for nursing home care over the lifetime use of the elderly (that is, all nursing home services used by people from age 65 forward) suggest that a substantial proportion of the elderly with any nursing home use (44 percent) paid their own way. In total, in 2003, people with long-term care needs and their families paid $37.5 billion out-of-pocket on long-term care in 2003, accounting for roughly 21 percent of all long-term care spending. [Figure 4]

Figure 4

National Spending on Long-Term Care, 2003
(in billions)



Total = $181.9 billion

SOURCE: CRS Analysis of data from the National Health Accounts, Centers for Medicare and Medicaid Services. Includes unpublished data from CMS on Medicare and Medicaid expenditures for hospital-based nursing home and home health care, and data from Medicaid expenditures under HCBS Waivers.

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Private insurance plays only a small role in long-term care financing. Private health insurance plans typically cover only a limited period of home health care and nursing home care for people who are recovering from an illness or injury. Private insurance policies that explicitly cover long-term care services are held by only a small fraction of older workers and retirees and account for a small share of spending. In 2002, a trade associate for the insurance industry (America's Health Insurance Plans) reported that $1.4 billion was paid in claims under private long-term care insurance policies (reported in Desonia 2004). Sales of private long-term care insurance policies have increased in recent years, but the market is limited for a number of reasons: policies are unaffordable for many older people looking to buy them, benefits offered provide inadequate protection against future risks, and many who might purchase a policy are turned down by insurers because they have medical conditions that may put them at risk of needing long-term care (Merlis 2003). In total, $16 billion in long-term care services was covered by private insurance policies, accounting for 8.7 percent of total spending. [see Figure 4 above]

The nation's public health insurance programs, Medicare and Medicaid, together made payments of $118.7 billion for long-term care services, accounting for 65 percent of total spending on long-term care. Medicare, which provides health insurance coverage to nearly all of the elderly and certain people with disabilities, makes substantial payments for home health care and skilled nursing facility care—$32.4 billion in 2003. But Medicare's coverage for home care and nursing home care is closely tied to the need for acute care. Medicare pays for only 100 days of nursing home care for people who have recently been hospitalized, and Medicare's home care benefits are also limited, with personal care services available only if skilled services—like nursing and rehabilitative therapy—are also needed.

People with substantial long-term care needs and limited ability to pay for care often turn to Medicaid, the single largest source of financing for all long-term services. The federal-state Medicaid program provides a long-term care safety net for those who are poor or who become poor paying for care. Medicaid pays for long-term care for the elderly and people with disabilities, but beneficiaries must have very limited assets and must apply nearly all of their income toward the cost of care. With payments of $86.3 billion in 2003, Medicaid accounted for nearly half (47.4 percent) of the nation's spending on long-term care services.

Medicaid is an important source of payment for both the elderly and the nonelderly with long-term care needs. Estimates of long-term care spending for different age groups are hard to come by, but the Congressional Budget Office (CBO) estimates that Medicaid paid for about a third of the long-term care spending on the elderly in 2004, including a third of all nursing home costs.[2] The CBO also reports that Medicaid paid for a much larger share, an estimated 60 percent, of the long-term care spending of nonelderly persons with disabilities in 1998 (Congressional Budget Office 2004, pp. 3 and 17).

[2] Similar estimates were made in 1993. Those estimates suggested that Medicaid paid for 35 percent of long-term care for the elderly; the elderly and their families paid 42 percent out-of-pocket, and Medicare and private insurance 19 percent and 1 percent, respectively. Reported in (Wiener and Stevenson 1997, p. 2).

MEDICAID'S ROLE

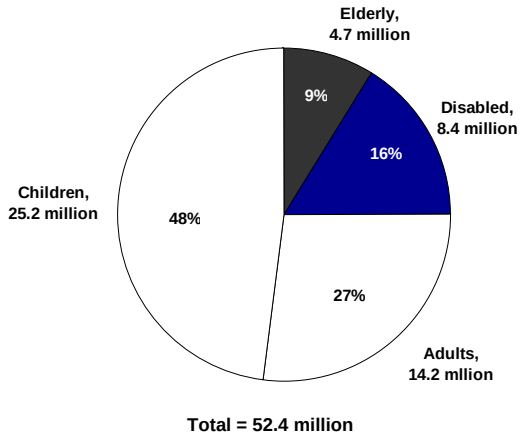
Medicaid is the federal-state program of medical assistance for certain poor and low-income people, including families with children, the elderly, and the disabled. Medicaid plays different roles for its beneficiaries: it pays for comprehensive health care services, provides financial assistance with Medicare's cost sharing for poor and low-income Medicare beneficiaries, and pays for long-term care services for the elderly and children and adults with disabilities. Medicaid is a long-term care safety net for poor and low-income people, as well as those who become poor paying for care. However, unlike insurance, Medicaid does not protect income and assets of those who incur catastrophic long-term care costs. It provides assistance once catastrophe strikes—once nearly all available private resources have been applied to the cost of care.

Who qualifies for Medicaid and how?

Medicaid is a means-tested program that provides benefits to certain people who meet strict income and asset rules. People who need long-term care must meet categorical, financial, and functional eligibility criteria to receive Medicaid-funded long-term care services. They must be elderly or disabled (meet a state or federal definition of disability)[3], have limited financial resources, and meet level-of-care criteria for long-term care services. Nationwide, of the 52.4 million people enrolled in Medicaid in 2003, about 4.7 million (9 percent) were elderly and 8.4 million (16 percent) qualified on the basis of disability [Figure 5].

Figure 5

Distribution of Medicaid Enrollees, by Eligibility Group 2003



SOURCE: KCMU estimates based on CBO and OMB data, 2004.

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People with disabilities in Medicaid are a diverse group. They include children and adults with mental retardation and developmental disabilities, the severely mentally ill, people with traumatic brain injuries and spinal cord injury, adults with debilitating illness such as Parkinson's disease and multiple sclerosis, people with AIDS, and children born with severe physical and

[3] Children, pregnant women, and some parents may not have undergone a disability determination process but may have long-term care needs and meet the Medicaid categorical eligibility criteria.

cognitive impairments (mental retardation, cerebral palsy, multiple sclerosis, epilepsy, muscular dystrophy, hearing loss or deafness, and blindness, for example).

There are a number of different ways of meeting Medicaid's financial eligibility criteria, and elderly and nonelderly people with long-term care needs often take different paths to Medicaid eligibility. The majority of the disabled in Medicaid arrive at eligibility via a "welfare-related pathway." The elderly primarily enroll in Medicaid once they need nursing home care and after they have spent down their income and assets. They qualify through a "medically needy" or "spend-down" pathway. For people who need long-term care, Medicaid eligibility is complex calculation with rules that vary widely across states.

Welfare-related pathways

With limited exceptions, states are required to provide Medicaid coverage to individuals enrolled in the Supplemental Security Income program (SSI).[4] SSI is a federal program that provides monthly cash payments to people with limited incomes and resources who are age 65 or older, blind, or disabled. Elderly and disabled people who qualify for SSI have incomes below the federal poverty (in 2005, the threshold was about 73 percent of the federal poverty level), but states can extend Medicaid coverage to elderly and disabled people with incomes up to 100 percent of poverty.

In general, both SSI and Medicaid benefits are available to people with low income and very few assets. Countable assets must fall below SSI thresholds ($2,000 for an individual, $3,000 for a couple) and countable income must below the SSI benefit rate ($579 for an individual, and $869 for a couple in 2005).[5] People with assets above the Medicaid eligibility threshold may "spend down" those assets – reduce them to the $2,000/$3,000 threshold—by paying off debts such as a home mortgage, making home improvements, purchasing household goods, buying a car, or paying for medical care or long-term care. However, assets cannot be reduced by simply giving them away, making gifts to adult children, for example. Assets that must be "spent down" include checking and savings accounts, stocks and bonds, and other liquid financial assets, such as funds in individual retirement accounts. A limited number of assets, however, are excluded from this requirement. People on Medicaid may retain a small life insurance policy, funds set aside for funeral expenses, household goods, an automobile regardless of value if it is used for transportation, and certain income-producing property. The single most important countable asset for most elderly people who need long-term care is a home. The home is excluded (and the equity in the home need not be spent down to reduce assets to the Medicaid threshold) so long as it serves as their principal place of residence for the Medicaid applicant, spouse or certain other close relatives. However, states are allowed to place liens on homes to recoup the costs of care from the estate of a Medicaid beneficiary once he or she has died (ASPE 2005).

[4] Eleven states, so-called "209(b)" states for the section of the 1972 Social Security Act amendments in which the option was enacted, use a more restrictive eligibility standard than the SSI standard a state may use a definition of disability as restrictive as the one they used in January 1972. These states (Connecticut, Hawaii, Illinois, Indiana, Minnesota, Missouri, New Hampshire, North Dakota, Ohio, Oklahoma, Virginia) use more restrictive income and/or asset thresholds to determine Medicaid eligibility for the elderly and people with disabilities.

[5] Parents' income is considered when determining the eligibility of children. That is, some of the income of parents is "deemed" available to meet the basic needs of children.

Although beneficiaries can retain certain assets, states seek to recover private assets upon the Medicaid beneficiary's death (exceptions are made when estate recovery would create undue hardship for a surviving spouse or other family members). Since 1993, states have been required to seek to recover the cost of Medicaid benefits paid (including nursing home and home and community-based services, hospital and prescription drug costs) from the estates of certain individuals, including those in nursing homes. Most states seek to recover from assets in probate estates including individually owned bank accounts, other financial accounts (including the personal needs accounts managed by nursing homes), cash, a home owned solely by the Medicaid beneficiary, real property other than the home, and potential recoveries from pending lawsuits. States recovered a total of $347.4 million in 2003, about one half of one percent of total long-term care spending. Most recoveries (74 percent) came from real property, and nearly all real property recoveries (96 percent) involved beneficiaries' homes (Karp, Sabatino, and Wood 2005), p. 54).

Other eligibility pathways

Because income eligibility limits for SSI are very low, most states use a special income rule for institutionalized individuals or allow nursing home residents to spend down to Medicaid eligibility. Most states offer a medically needy option for people who need long-term care, but the criteria states use are very stringent—below the income thresholds for SSI. People who need assistance with long-term care costs must spend down their incomes to the state's "medically needy income level" which is set, in most states, at or below SSI levels. States without medically needy programs may use higher income limits for people in institutions than for people in the community.[6] Under this option, the so-called "300 percent rule," states can use an income threshold up to 300 percent of the SSI income limit (3 times $579, or $1,737 per month in 2005) in determining eligibility for people living in institutions. As of October 2001, 38 states used the special income rule.

Until recently, people with modest incomes above these thresholds could not qualify for Medicaid even if their incomes were inadequate to cover the cost of care. To assist those very modest income elderly, OBRA 1993 created an arrangement under which people with excess income could place that income in trust, known as a "Miller Trust," and receive Medicaid. However, states may recover funds in the trust after the person's death.

Nursing home residents who qualified as medically needy or through the 300 percent rule are expected to apply their available income toward the cost of their own nursing home care, thereby reducing the amount that the Medicaid program must pay. Medicaid beneficiaries living in nursing homes may keep only a small personal needs allowance (out of their monthly income) to cover personal care items not covered by Medicaid, such as clothing, books, toiletries, or telephone service). Federal rules require states to reserve at least $30 of a beneficiary's monthly income, but some states supplement the federal minimum personal needs allowance with state funds (Stone 2002).

[6] As of October 2001, 12 states did not offer a medically needy option. The 209(b) states must offer a medically needy program or they must allow individuals to spend down to the cash assistance level. Institutionalized individuals who reduce their assets to and spend income down to eligibility levels that are typically substantially below the federal poverty rate, (e.g. 75% in Indiana, 62% in Ohio) may qualify for Medicaid (Crowley 2003).

Medicaid eligibility rules are more generous for nursing home residents who have a spouse who remains in the community. States are required to set aside specific amounts of income and assets to maintain a community spouse. The spousal impoverishment protections require states to disregard the income of the community spouse, and to supplement it if necessary to reach a minimum monthly income threshold. None of the income streams in a community spouse's name are treated as income for the purposes of Medicaid eligibility. However, if the community spouse's income falls below the state standard, income may be transferred from the nursing home resident spouse to the community spouse. A community spouse is allowed to keep half of the couple's joint assets subject to minimum and maximum thresholds. Federal law requires states to allow a community spouse to keep at least $19,020 and as much as $95,100 in 2005 (Centers for Medicare and Medicaid Services 2005). Most states allow the community spouses of Medicaid nursing home residents to keep resources in excess of the federal minimum.

Functional eligibility criteria

People who need long-term care must also meet level-of-care criteria to receive long-term care services in Medicaid. These criteria vary—they are more restrictive (require a greater level of impairment) for institutional services and home and community based-waivers, and tend to be less restrictive (require a lower level of functional impairment) for services provided under Medicaid's home health benefit and optional personal care services benefit.

Federal law sets out only a very few parameters within which states must operate. States are primarily responsible for developing level-of-care criteria and assessment tools to determine eligibility for Medicaid's institutional and community-based long-term care services. States choose different criteria and weight them differently based on who they are trying to serve and how the various benefits fit into their overall long-term care system. Perhaps the most significant federal requirement is that states must limit HCBS waiver services to people who meet the institutional level of care criteria.[7] States that impose very stringent institutional care criteria will consequently limit their ability to serve people with disabilities through waiver programs.

To be eligible for nursing home care, for example, an elderly or disabled person must have a need for nursing home care above the level of room and board as defined by the states. Federal law states that institutional services must be medically necessary, but there is no federal definition of this term and states are free to define it broadly—states need not use medical service criteria; they may define "medically necessary" services as those that promote optimal health and functioning.[8]

Level-of-care criteria explicitly describe the type and level (severity) of functional limitations or needs that a person must have to be admitted to an institutional setting. States usually include measures of need for assistance with ADLs or IADLs, as well as need for other services

[7] HCBS waiver participants must also meet the targeting criteria set out in the approved waiver (i.e. states can target to certain age groups, categorical eligibility groups, people with diagnoses such as traumatic brain injury, MR/DD or physical disability), and other criteria such as the ability to receive services safely in a community setting.
[8] In the case of ICF-MR services, the person must have mental retardation or a related condition and be found to need various supports to maintain or improve function.

including nursing and medical services. States' level-of-care criteria are complex, comprising multiple measures of functional needs and nursing needs, which states weigh and combine in different ways to arrive at a determination of eligibility for service. For example, nearly all states consider ADL limitations when making a level of care determination, but states vary in how they implement these criteria—they may assess whether hands-on or physical assistance is needed, whether supervision or stand-by help is needed, whether prompting or cueing is needed, or they may use some combination of these criteria and may establish levels of impairment and place prospective clients into different groups reflecting their priority for service.

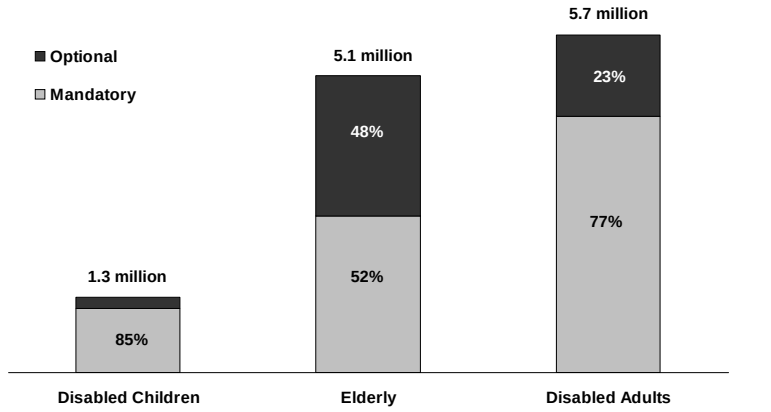
As a result of differences in how states set these criteria, a person with functional and cognitive impairments who meets the level of care threshold in one state may not meet the service threshold in another state. For example, in 7 states a person who meets either an ADL criterion or a supervision criterion is eligible for nursing home or home and community-based waiver services (CT, DE, MN, NH, NJ, NY, OR). However, in another 6 states meeting a supervision criterion is not sufficient to be found eligible for nursing home or home and community-based waiver services—although meeting an ADL criterion is (IL, KS, MS, NC, SC, WA). And, in another 6 states, an individual must meet both an ADL and a supervision criterion to be eligible for these services (CO, IN, MA, MO, NE, NV, NM) (O'Keefe 1999).

In the case of home health care and personal care, states have more flexibility to set level of care criteria. For home health care in Medicaid, there is a general federal requirement that services be medically necessary, but states may not limit services to people who need skilled care (as is required for Medicare home health care), nor may they limit services to people who are homebound. For personal care services provided as an optional benefit, there are no federal statutory or regulatory provisions regarding the type or level of impairment a person should have to receive benefits. The only federal requirement is that states must make the service equally available to all beneficiaries who satisfy the criteria that have been set. Because of this freedom, there is tremendous variation in how states set level of care criteria for the personal care services optional benefit (Smith et al. 2000).

Eligibility status of Medicaid enrollees

Although states can expand Medicaid eligibility for people who have long-term care needs through medically needy programs and special income rules, most elderly and disabled people in Medicaid arrive at eligibility through the SSI program or another mandatory pathway. In 2001, 85 percent of disabled children in Medicaid were part of a mandatory eligibility group, as were roughly three quarters of disabled adults. In contrast, just under half of the elderly in Medicaid arrived through an optional category, such as spend down or the Special Income Rule (Sommers, Ghosh, and Rousseau 2005). [Figure 6]

Figure 6



SOURCE: Sommers, Ghosh, and Rousseau, 2005. Urban Institute estimates based on FFY data from MSIS 2001 and CMS 64 reports.

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Children with disabilities may have difficulty qualifying through medically needy programs (available in 33 states) because Medicaid "deems" family income to be available to children living in the community. Only when there is a major health crisis, such as a hospitalization, will they be able to incur medical liabilities of a sufficient amount to reduce their income to the medically needy level (through the spend-down process) (Ellwood 1990). However, some children with disabilities are not included in the "disability" category. Since income eligibility thresholds for children are relatively high, some children with disabilities may enroll on the basis of family income, rather than seeking a determination of disability through SSI.

Effects of Medicaid's spend down requirements

Medicaid's stringent eligibility rules require people who need long-term care to spend down all of their assets (except $2,000) and contribute nearly all of their income to the cost of care. Many frail elderly people in the community have already spent their retirement savings supporting themselves in retirement and paying for care in the community—and thus qualify for Medicaid at admission to the nursing home. They must, however, contribute their entire income (except for a small personal needs allowance) to the cost of care. Many others with modest savings above Medicaid's resource thresholds must spend down their available assets before they can qualify for assistance. Because this process is both frightening and demeaning, many refuse to seek services—even when they have resources at or near Medicaid eligibility levels.

The concern more often raised about Medicaid's means-tested eligibility criteria, however, is that a not insignificant number of Medicaid applicants have transferred assets, or sheltered their income or assets in trusts, to make themselves appear poor enough to qualify for Medicaid. Medicaid rules seek to prevent transfers by restricting eligibility for those who make transfers "at less than fair-market value." Eligibility workers examine financial records over a three-year lookback period prior to application to determine whether unapproved transfers have been made. Applicants are declared ineligible for Medicaid long-term care coverage if there is evidence of

inappropriate transfers.[9] For example, if a Medicaid applicant makes transfers of $10,000 during the three-year look back window, the individual incurs a penalty period (a period of ineligibility for Medicaid) equal to the number of weeks or months of nursing home care that could have been purchased with those funds, with the penalty period beginning on the date the transfer was made. If the average Medicaid payment for a month of nursing home care is $5,000, a two-month period of ineligibility, beginning on the date of the transfer, would be imposed.

During this period of ineligibility, an individual would need to use private resources to pay privately for care (perhaps seeking assistance from family members), or would have to forego nursing home care, relying on informal care or paid care at home. Since most people seek nursing home care only when it is no longer possible to be cared for safely at home, they would undoubtedly face unmet needs. People who are already in the nursing home when eligibility for Medicaid is denied would remain in the nursing home, and cost burdens would be shifted to providers who would either have to absorb this uncompensated care or attempt to transfer patients without a source of payment to a hospital.

Many critics complain that the existing rules permit Medicaid applicants to use resources that should have been used to pay for care to buy a car or undertake home renovations, shifting the burden to Medicaid and taxpayers. Although some point to the large number of elder law attorneys who make their living doing "Medicaid planning" for the elderly and their families, no data are available to indicate how many nursing home residents on Medicaid may have transferred assets or the value of those transfers. Empirical studies that are available suggest that transfers by the middle class elderly, when they do happen, are relatively modest (in comparison to the cost of nursing home care), and are rarely motivated by a desire to qualify for Medicaid. Those with relatively modest assets, and who are at risk of nursing home entry, tend to preserve their assets to meet future needs (O'Brien 2005).

Despite these concerns, states can and do use less stringent methodologies for determining available resources, allowing elderly and disabled applicants to retain more of their assets. States can also offer expanded allowances for people who are in the nursing home and are likely to return home, and for those receiving home and community-based services (Summer 2005).

What long-term care services does Medicaid cover?

State Medicaid programs provide a wide range of long-term care services needed by people of all ages. These include comprehensive long-term care services provided in institutions—nursing homes and intermediate care facilities for the mentally retarded—as well as a wide range of services and supports needed by people to live independently in the community—home health care, personal care, medical equipment, rehabilitative therapy, adult day care, case management, home modifications, transportation, and respite for caregivers.

To participate in Medicaid, states are required to provide nursing home care and home health care to categorically eligible beneficiaries age 21 and over. They may choose to extend those benefits to the "medically needy" and people with disabilities younger than 21. All other long-

[9] This three-year look-back window is extended to five years in the case of transfers to trusts. Periods of ineligibility may be reduced or eliminated if it can be demonstrated that transfers were made for purposes other than establishing Medicaid eligibility, or if denying Medicaid eligibility would create "undue hardship."

term care services in Medicaid are "optional." States may choose whether or not to offer targeted case management, personal care, and ICF/MR and other services needed by people with long-term care needs (and whether to extend those benefits to the medically needy) [See Appendix Table 1 for brief descriptions of these benefits].

Whether optional or mandatory, these benefits are federal entitlements that must meet certain criteria for adequacy. The services must be "adequate in amount, duration and scope" to provide the care beneficiaries need, payments to providers must be adequate to assure access to care, and the benefits must be offered statewide to all beneficiaries who are determined to have a need for service. For example, if states offer the optional personal care benefit, they must serve all Medicaid beneficiaries who meet the eligibility standard.[10]

States, however, are afforded a fair amount of latitude in designing these benefits. For home health care and nursing home or ICF-MR services, states can use traditional cost containment tools—medical necessity guidelines, utilization management tools, and payment incentives—to control utilization and spending. However, states may set coverage limits, and these limits may be imposed regardless of need. If states elect to provide personal care, they can cap the number of hours of personal care assistance a person may receive and may place a cap on individual spending. That is, states are not required to provide a sufficient level of personal care to assure that a person can live safely in the community (Doty 2000).[11]

In addition to the home care benefit and the personal care services option, states have a third major option for covering long-term care services in the community. States may cover home and community based services through waivers of certain statutory requirements under section 1915(c) of the Social Security Act. Under waivers, states may offer a comprehensive package of long-term care services and supports to people with substantial needs who are eligible to receive care in institutions, providing comprehensive services that allow Medicaid beneficiaries to live in their own homes or in small group residential settings in the community. The most frequently provided services are personal care, habilitation (services to assist individuals in developing skills necessary to reside successfully in home and community-based settings, needed by people with mental retardation and developmental disabilities), case management, adult day health, respite care. Other services that are cost effective and necessary to avoid institutionalization may also be covered. Medicaid may pay for home modifications and necessary equipment and pay one-time transitional expenses (e.g. a security deposit to secure an apartment) for people leaving institutions.

HCBS waiver programs support innovative service delivery models, but 1915(c) waivers also permit states to adopt strategies to limit the use and cost of services in ways that depart significantly from traditional Medicaid policies. States may restrict waiver services to certain age groups, or to people with certain kinds of disabilities (such as the elderly, people with spinal cord injuries, or people with AIDS). Eligible individuals are not entitled to receive waiver

[10] The need for assistance with activities of daily living is the criterion most commonly used to assess functional eligibility for the personal care benefit. Other assessment criteria include need fore assistance with IADLs, the presence of medical conditions, evidence of cognitive impairment and the need for a certain number of hours of assistance. Most states use a system that takes one or more criteria into account (Summer and Ihara 2005).
[11] States may not set an aggregate cap on spending for all personal care services.

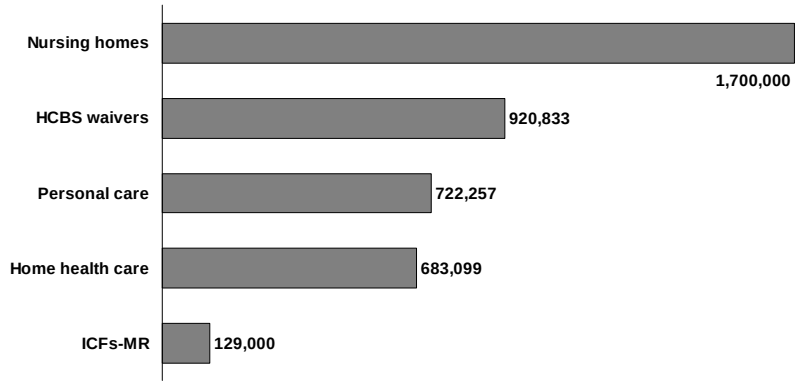
services and may be placed on a waiting list. States also seek to contain costs by using per capita or aggregate spending limits. States may seek to waive the Medicaid "state-wideness" requirement, thus limiting eligibility to people living in certain parts of the state, though few states employ this strategy (Reester, Missmar, and Tumlinson 2004).

Although most Medicaid long-term care services are optional for states, they are essential for people with disabilities and most states offer them. All states and the District of Columbia operate home- and community-based waiver programs, all states provide care in ICFs-MR, and all except one provide targeted case management.[12] Thirty states and the District of Columbia offer personal care services through the state option. [See Appendix Table 1]

Through these varied long-term care benefits, states provide services to millions of people annually. More than 1.8 million Medicaid beneficiaries receive long-term care services while living in institutional facilities, including nursing homes (1.7 million) and ICFs-MR (129,000), about 920,000 thousand receive care under HCBS waivers, 722,000 receive home health care services, and 683,000 receive services under Medicaid's optional personal care benefit. [Figure 7] States vary in the resources they devote to long-term care, however, and how they structure their programs.

Figure 7

Number of Medicaid Beneficiaries Receiving Long-Term Care Services, by type of service



SOURCE: Kitchener and Harrington 2005 (number of users of community-based long-term care services, 2002), *Health Care Financing Review, Statistical Supplement, 2003* (for number of nursing home users, 2001), CMS ICF-MR webpage (for number of users of ICFs-MR).

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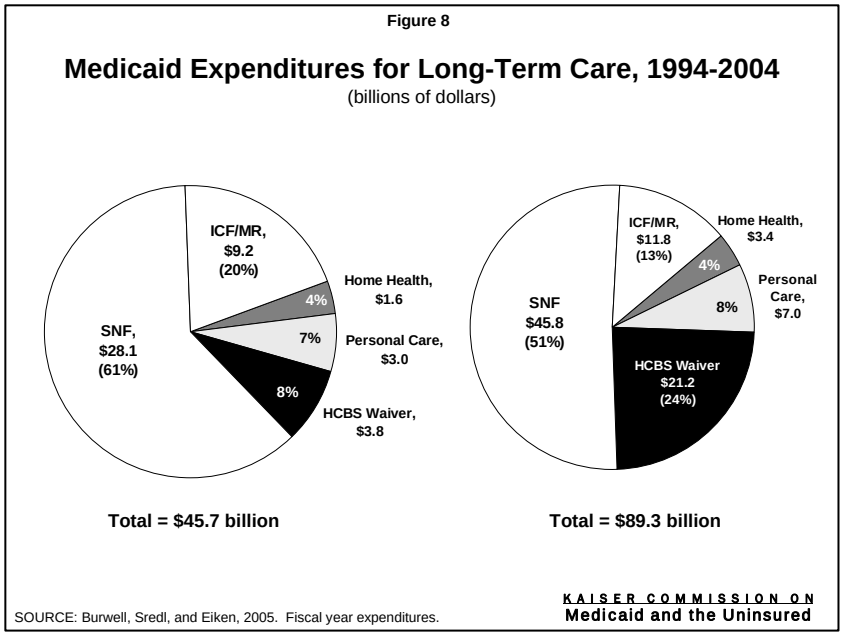
Service delivery trends: the growth of home and community-based long-term care

When Medicaid began in the mid-1960s, states primarily paid for long-term care services in institutions. With the addition of the personal care services option in the mid-1970s and the HCBS waiver in the early 1980s, however, states have had more flexibility to provide long-term

[12] States offering a targeted case management benefit as of January 2003. Based on a survey by Health Management Associates completed for the National Conference of State Legislatures and the Kaiser Commission on Medicaid and the Uninsured (www.kff.org/medicaidbenefits/targetedcasemgt.cfm).

care services in people's homes and communities. Over the past decade, most especially, there has been substantial growth in Medicaid spending on community-based long-term care services, and a significant shift in the distribution of Medicaid long-term care resources from institutional to home- and community-based services. Between 1994 and 2004, spending on home and community-based services increased from $8.4 billion to $31.6 billion, rising from 19 percent to 36 percent of Medicaid long-term care spending. The shift was primarily due to the rapid growth in HCBS waiver spending which today accounts for nearly two-thirds of all Medicaid LTC spending in the community. [Figure 8]

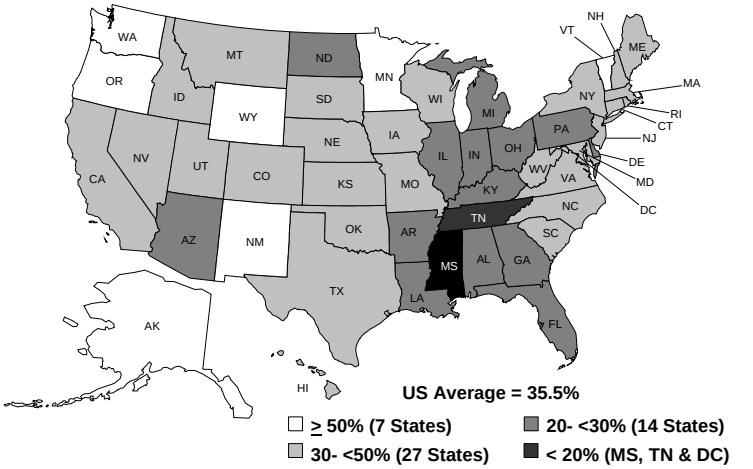


Changes in rules surrounding waivers in the mid-1990s allowed states to expand their waiver programs. Federal authorities, for example, eliminated the "cold bed" rule, which required states to demonstrate that an HCBS waiver participant would otherwise have filled an institutional bed but for the services provided under waivers. Continuing advocacy and the Supreme Court's decision in *Olmstead v. L.C.* has put pressure on states to provide services in the least restrictive setting possible, however budget pressures on the federal and state levels have restrained the growth of community-based care (Kaiser Commission on Medicaid and the Uninsured 2004).

Despite this shift, most states devote most of their Medicaid LTC resources to providing institutional services to people with substantial needs. Only seven states devote more than half of their spending to community-based care. Three states—Alaska, New Mexico, and Oregon—devote more than 60 percent of Medicaid long-term care spending to community-based services. [Figure 9 and Table 1 below, p. 23] Moreover, states that do spend significant amounts on home and community-based care tend to rely on waivers, and provide only small amounts of personal care through a state option.

Figure 9

Spending on Home and Community-Based Services as a Share of Total Medicaid Long-Term Care Spending, 2004



SOURCE: Medstat, 2005.

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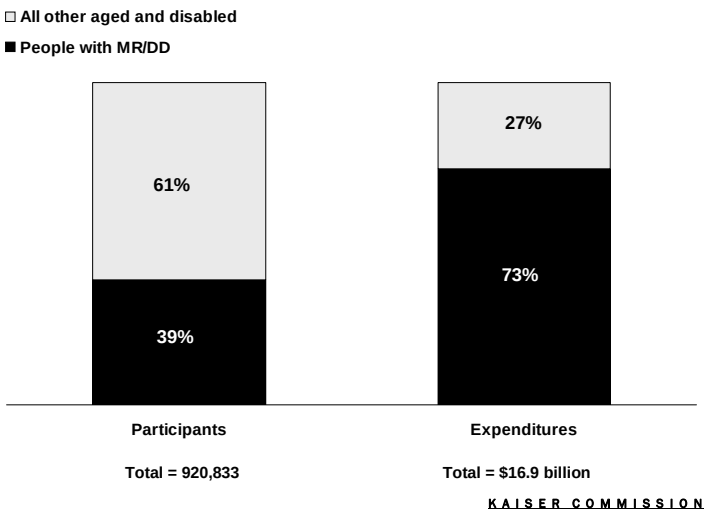
The most substantial progress toward community-based services has been made for the nonelderly disabled in Medicaid, and especially for people with mental retardation and developmental disabilities (MR/DD). HCBS waivers have been used to provide services to many groups—the mentally retarded, people with spinal cord injuries or traumatic brain injuries, people with AIDS, the mentally ill, the elderly, and the physically disabled. People with MR/DD however, are roughly 40 percent of people served under waivers, but account for nearly three-quarters of waiver spending. [Figure 10]

Figure 10

HCBS Waiver Enrollees and Expenditures, 2002



SOURCE: Kitchener and Harrington, 2005.

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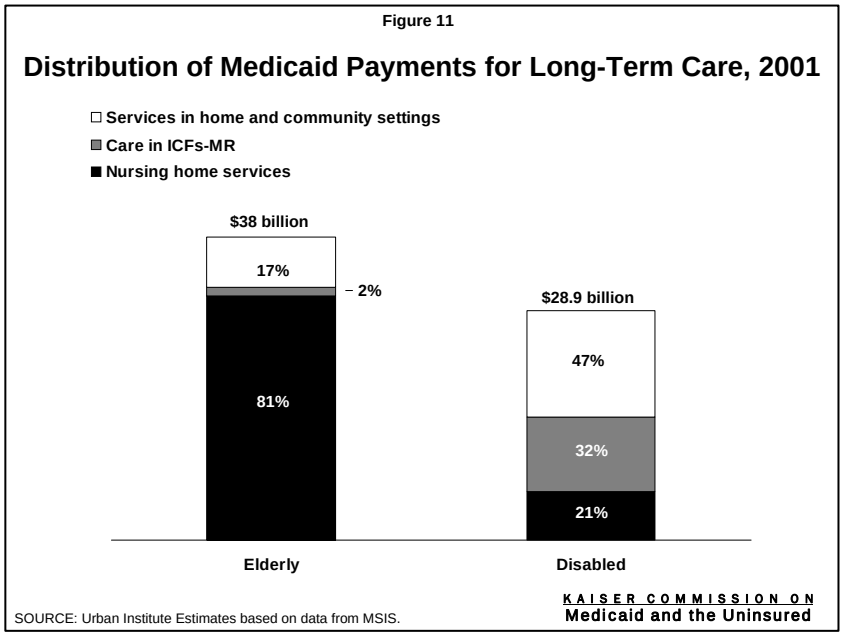
Pressure from parents, families, and other advocates to deinstitutionalize the mentally retarded, together with states' ability to convert previously state-funded programs to Medicaid-based financing, fueled the growth in community-based long-term care spending for people with MR/DD in Medicaid. A shift toward home-based care and placement in smaller, community-based ICFs-MR (with six or fewer beds) has occurred as states have converted their service programs for the developmentally disabled to Medicaid-based financing. Consequently, most states (38 in fiscal 2004) spend at least half of their long-term care budgets for the MR/DD population on home and community-based long-term care services. Eight states have effectively eliminated institutional placements, with 90 percent of Medicaid long-term care funds for people with MR/DD being spent in the community (Burwell, Sredl, and Eiken 2005a).

Looking at the broader population of people with disabilities in Medicaid, the availability of community-based services is somewhat more limited than it is for people with MR/DD. For the nonelderly disabled in Medicaid, just under half (47 percent) of all long term care spending in 2001 was for care in the community; 21 percent for nursing home care, 32 percent was for care in ICFs-MR. [Figure 10] Many children and adults with physical and cognitive impairments may not get the community services they need to live independently. States have an obligation to make reasonable modifications, however, and the proportion using institutional services has declined (Vladeck 2003).

In most states, the expansion of community-based services for the elderly in Medicaid has proceeded more slowly. The large majority of Medicaid long-term care spending for elderly (83 percent) is for nursing home care. [Figure 11] In only four states—New Mexico, Oregon, Alaska, and Washington—does spending on care in the community for the aged and disabled (excluding people with MR/DD) exceed the amount spent on institutions (Burwell et al. 2005a).

Figure 11



SOURCE: Urban Institute Estimates based on data from MSIS.

Fear of rising costs remains the single most important barrier to the expansion of community-based long-term care services for the elderly in Medicaid. Most states seek to limit their expenditures on community-based services for the elderly by relying on HCBS waivers, capping enrollment and limiting services and individual spending. Many impose restrictive financial eligibility criteria that limit the eligible pool of disabled elderly, but make it difficult for people to remain in their homes and communities. [Box 1] Other barriers to community–based care for the elderly include lack of alternative residential settings (such as assisted or congregate living and adult foster care homes), separate points of entry into institutional and home-based long-term care systems, separate systems for eligibility determination (both financial and functional), and separate budgets for community-based and institutional long-term care.

BOX 1

Financial eligibility rules and Medicaid's institutional bias

Restrictive financial eligibility rules contribute to the so-called "institutional bias" in Medicaid, forcing people who could otherwise remain at home to seek care in institutions. Financial eligibility for waiver participants is typically more generous than for Medicaid's personal care and home care benefits. States may apply the same eligibility standards to people receiving long-term care services in the community that they apply to people residing in nursing homes or other institutions. In practice, however, many states use more restrictive income thresholds for waiver participants than nursing home residents. States that extend eligibility to 300 percent of SSI for nursing home residents may cap income eligibility for waiver participants at 100 percent of SSI. Many states also use more restrictive financial criteria for married couples under waivers; they may not offer the spouses of waiver participants the full level of income and/or asset protection afforded the spouses of nursing home residents. Medicaid beneficiaries receiving home and community-based services, like nursing home residents, are required to apply a portion of their income to the cost of care, although states may allow them to retain more of their income to maintain a home.

Expanding HCBS: current policy directions

To address these barriers, some states have changed policies and practices with the goal of developing integrated service delivery systems and expanding community-based care (Summer 2005). For example, states have expanded the use of alternative residential settings or assisted living in their Medicaid programs.[13] As of October 2002, 41 states had approval to cover services in residential settings (such as board and care homes or congregate housing/assisted living). More than 102,000 Medicaid beneficiaries received services in these settings (Mollica 2002).

[13] States can provide long-term care services in residential settings, such as private homes that serve a few (5 or 6) residents (adult foster care homes) or congregate care settings (which serve 6 to 200), and can use either the personal care option or HCBS waivers to provide services in these settings O'Keefe, J., C. O'Keefe, and S. Bernard. 2003. "Using Medicaid to Cover Services for Elderly Persons in Residential Care Settings: State Policymaker and Stakeholder Views in Six States". Washington, D.C.: U.S. Department of Health and Human Services, Office of the Assistant Secretary for Planning and Evaluation..

States have also implemented policies to allow "money to follow the person," consolidating funding streams into a single budget appropriation for long-term care and creating the ability to move funds from a nursing home budget to the home and community based services budget. (Crisp et al. 2003). Some states sought to redesign their delivery systems to transition or divert people from institutional settings, and have created plans to reduce waiting lists for community services (Summer 2005).

The federal government has provided financial and technical assistance to states in their efforts to expand community options. Successful efforts in some states to undertake systematic reforms to expand community-based care and "rebalance" long-term care systems have benefited from federal grants for "systems change," a clearer federal policy on the availability of federal funding for community transitions, and expanded opportunities for consumer direction of long-term care services through the Independence Plus Initiative. The Congress is also considering legislation for a five-year "Money Follows the Person" demonstration program under which the federal government will pay the full first-year cost (with no state matching payment required) for a package of home and community-based services for eligible individuals who moved from institutions into the community.

Gaps and inequities in the long-term care safety net

The quality of the Medicaid long-term care safety net varies enormously from state to state, and even within states. States vary in the restrictiveness of the eligibility rules they apply and in mix and amount of service, and quality of services, they provide. States make different decisions about the restrictiveness of income and asset tests, what services financially eligible beneficiaries will receive, may seek to limit the number of nursing home beds, limit community-based care by limiting waiver slots, and make varying decisions about the amount and intensity of services, payments for those services, and quality oversight.

As a result, states vary widely in the resources they devote to long-term care. A very broad measure of states' willingness and ability to pay for long-term care services—spending per state resident—reveals a more than eight-fold variation: Medicaid spending on long-term care in 2004 ranged from a high of $833 per state resident in New York to just about $100 per resident in Utah and Nevada. [See Table 1 below]. Looking at measures of long-term care spending per elderly or disabled Medicaid enrollee reveals similar spending variation within the pool of state residents covered by the Medicaid program. For example, nursing home spending per elderly Medicaid beneficiary varied from a high of nearly $15,000 in Connecticut in 2001 to just about $2,600 in California and Maine (national average nursing home spending per elderly Medicaid beneficiary was $5,997 in 2001). Similarly, spending on all home and community-based long-term care services for persons with disabilities in Medicaid ranged from a high of $7,145 per disabled enrollee in Connecticut to less than $250 in the District of Columbia, Hawaii, and Mississippi in 2001 (national average spending per disabled enrollee for these services was $1,922 in 2001).[14]

[14] Author's calculations based on analysis of MSIS data for 2001 from the Urban Institute (http://www.kff.org/medicaid/kcmu070805oth.cfm). Expenditures are per enrollee, not per elderly or disabled user of nursing home care or personal care services. "Home and personal care" includes home health, personal care, targeted case management, HCBS, and private duty nursing.

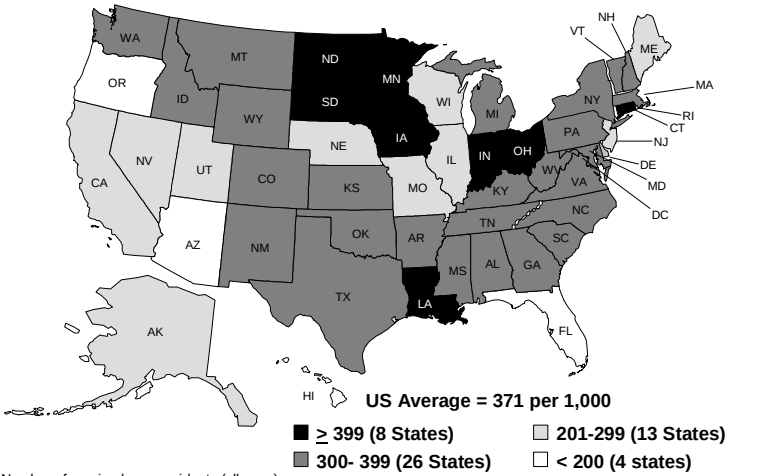
As these data suggest, states' decisions can have a profound impact on whether a person with long-term care needs is eligible for services, and, if eligible, the, amount, frequency and mix of services they may receive. Individuals with very similar needs in different states may have very different experiences in Medicaid (United States General Accounting Office 2002, Summer 2003). State policies and practices matter, as does the discretion of local case managers who screen Medicaid-eligible individuals to determine what services they qualify for based on their level of disability. Case managers have discretion to customize care plans based on an individual's needs and preferences, and the availability of unpaid care provided by family members or other informal caregivers (U.S. GAO 2002, p. 2). Since states often limit the number of people served in waiver programs, many state waiver programs have long waiting lists. State officials responding to a 2005 HCBS waiver program survey reported that more than 206,000 people in 32 states were on waiting lists for services, with waiting times of 10 to 20 months (Kitchener et al. 2005).

Access to institutional care also varies widely. The number of people living in nursing homes (per 1,000 elderly age 85 and above) varies from more than 400 per 1,000 in eight states to substantially less than half that rate in four states (National Center for Health Statistics 2004).[15] [Figure 12] The wide variation in the number of nursing home beds in parts of the country is not related to variation in the number of old people who might use them, but to different market factors, such as the generosity of Medicaid payments for nursing home care. Medicaid payments for nursing home care tend to fall below private pay rates, leading to concerns about access to care and quality of care for Medicaid beneficiaries. The average Medicaid reimbursement per day of care in 2002 was $118, while the average private pay rate (for urban areas) was $158. The extent of this "Medicaid shortfall" varies across states and localities (Gibson, et al 2004). Many states have also sought to limit the construction of new nursing homes or addition of new nursing beds to reduce Medicaid long-term care spending growth. Although occupancy rates have fallen in recent years, some Medicaid patients in some areas may still have difficulty finding a nursing home bed. [See Appendix table 2 for state data on nursing home beds and occupancy]. In some areas, home and community-based services may fill in the gap, but in others, limits on home care may lead to overall unmet needs for long-term care.

[15] The eight states with the highest rates of nursing home use (among the elderly age 85 and above) are: Louisiana (484/1,000), Connecticut (410), Minnesota (408), Indiana (416), Iowa (419), North Dakota (401), and South Dakota (404)). The four states with the lowest rates of nursing home use are: including Oregon (143), Colorado (169), Arizona (169), Hawaii (185), and Florida (196).

Figure 12

Nursing Home Residency Rates, 2002



NOTE: Number of nursing home residents (all ages) per 1,000 residents age 85 and above.
SOURCE: Health United States 2004, NCHS

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Medicaid and the Uninsured

Impact of safety net gaps

These inequities in access to long-term care services have profound impacts on the health and wellbeing of the frail elderly and nonelderly people with disabilities. Waiting lists for home and community-based services prevent financially eligible individuals from receiving services, leading to inappropriate institutionalization and unmet needs. One recent study of frail elderly applicants for a Medicaid HCBS waiver in Connecticut found that the elderly applicants who did not participate in the waiver program "appear to get by in the community" through a combination of informal care, use of Medicare home care, and going without needed services. Their ability to manage in the community, however, was limited. The elderly who applied for but did not receive waiver services were far more likely than those who received HCBS to enter a nursing home within six months following their assessment for waiver services (Long et al. 2005).

Other research documents that there are substantial unmet needs for long-term care services among the low-income elderly, and that the level of unmet need is higher in states where the use of formal (paid) care is lower. Nearly 60 percent of elderly dual eligibles (eligible for both Medicare and Medicaid) in six states reported unmet needs for long-term care, resulting in significant consequences for their health and well-being. A large proportion of those with unmet needs for assistance reported that they had wet or soiled themselves (56 percent), fallen out of a bed or chair (48 percent), or been unable to bathe or shower (42 percent). A smaller, but still significant proportion (18 percent) reported that they went hungry because they lacked the assistance they needed (Komisar, Feder, and Kasper 2005).

Table 1. Medicaid Long-Term Care Expenditures by State, Ranked by Per Capita Spending, FY 2004

STATE	FY 2004 expenditures (in millions)	Spending per state resident	LTC as a share of Medicaid spending	Average annual growth rate 2001-2004	Distribution of Medicaid Long-Term Care Spending	
					Institutional (%)	Home and community-based* (%)
New York	$16,023	$833.37	38.9%	5.7%	56.6%	43.4%
Connecticut	$2,029	$579.26	50.9%	3.3%	62.6%	37.4%
Washington DC	$305	$550.93	24.9%	6.4%	88.3%	11.7%
Minnesota	$2,458	$482.01	45.5%	8.7%	44.1%	55.9%
Rhode Island	$519	$480.46	31.6%	6.7%	57.9%	42.1%
Pennsylvania	$5,886	$474.47	42.1%	4.6%	77.7%	22.3%
North Dakota	$286	$450.50	57.8%	4.5%	77.5%	22.5%
Massachusetts	$2,858	$445.39	32.9%	5.8%	64.6%	35.4%
Maine	$583	$442.69	28.6%	12.4%	53.1%	46.9%
Alaska	$283	$431.69	31.8%	21.8%	37.9%	62.1%
Vermont	$249	$400.24	31.0%	9.3%	42.3%	57.7%
Ohio	$4,547	$396.84	40.4%	7.7%	78.4%	21.6%
West Virginia	$689	$379.46	35.3%	9.0%	61.2%	38.8%
Nebraska	$617	$353.04	42.3%	2.2%	68.2%	31.8%
New Hampshire	$450	$346.62	38.7%	7.9%	61.8%	38.2%
Wisconsin	$1,889	$342.83	41.8%	1.4%	60.6%	39.4%
New Jersey	$2,912	$334.83	36.2%	-3.0%	68.4%	31.6%
Wyoming	$166	$328.59	44.3%	13.9%	46.6%	53.4%
New Mexico	$625	$328.55	28.1%	15.1%	32.4%	67.6%
Iowa	$946	$320.37	41.9%	7.8%	68.9%	31.1%
Delaware	$264	$317.91	33.2%	10.5%	71.0%	29.0%
Montana	$286	$308.71	42.5%	9.9%	64.2%	35.8%
North Carolina	$2,496	$292.21	30.1%	7.0%	61.2%	38.8%
Louisiana	$1,304	$288.90	25.7%	-8.0%	77.6%	22.4%
Kansas	$778	$284.56	40.1%	-4.3%	53.1%	46.9%
Missouri	$1,632	$283.57	26.7%	-0.9%	64.5%	35.5%
Arkansas	$779	$283.00	29.9%	6.4%	78.5%	21.5%
Indiana	$1,765	$282.94	34.4%	10.5%	73.3%	26.7%
South Dakota	$218	$282.68	38.0%	-2.7%	63.0%	37.0%
Mississippi	$791	$272.57	23.1%	7.0%	94.8%	5.2%
Maryland	$1,489	$267.89	31.6%	12.0%	62.3%	37.7%
Oklahoma	$923	$261.87	35.8%	4.4%	63.2%	36.8%
Washington	$1,583	$255.26	29.5%	3.5%	45.3%	54.7%
Illinois	$3,226	$253.78	30.9%	7.7%	73.4%	26.6%
Tennessee	$1,492	$252.94	21.2%	7.5%	82.7%	17.3%
Kentucky	$1,044	$251.84	24.2%	3.7%	70.3%	29.7%
Georgia	$2,145	$242.90	23.5%	25.0%	75.2%	24.8%
Alabama	$1,076	$237.57	29.5%	5.1%	74.6%	25.4%
Michigan	$2,401	$237.43	29.1%	0.2%	71.8%	28.2%
Hawaii	$299	$236.66	32.6%	12.4%	63.7%	36.3%
Oregon	$808	$224.88	31.2%	-9.0%	29.5%	70.5%
South Carolina	$917	$218.53	23.3%	5.2%	69.4%	30.6%
Idaho	$304	$218.28	31.4%	5.6%	59.2%	40.8%
Florida	$3,457	$198.69	27.2%	9.3%	74.0%	26.0%
Colorado	$910	$197.84	34.3%	5.8%	51.5%	48.5%
California	$6,732	$187.56	24.0%	5.0%	55.4%	44.6%
Texas	$4,077	$181.29	26.0%	7.4%	64.0%	36.0%
Virginia	$1,256	$168.45	31.9%	7.6%	68.3%	31.7%
Utah	$272	$114.06	21.6%	4.2%	58.7%	41.3%
Nevada	$240	$102.64	23.1%	13.7%	69.9%	30.1%
Arizona	$31	$5.39	0.6%	27.1%	74.9%	25.1%
United States	**$89,315**	**$304.18**	**31.6%**	**5.4%**	**64.5%**	**35.5%**

Source: Brian Burwell, Kate Sredl, and Steve Eiken, Medicaid Long-Term Care Expenditures in FY 2004, May 11, 2005. Cambridge, MA: Medstat. Available at: http://hcbs.org/files/71/3542/2004LTCExpenditures.pdf

Note: Expenditures per capita is total long-term care spending in Medicaid divided by the total state population.

MEDICAID LONG-TERM CARE: A STATE AND FEDERAL BUDGET ISSUE

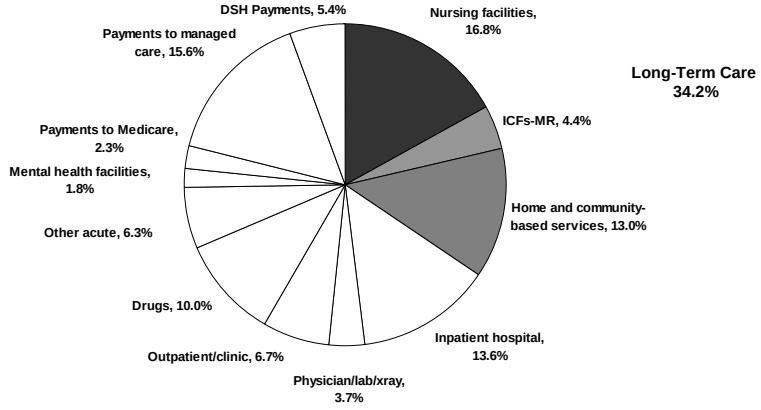
Although Medicaid long-term care programs fail to reach many who need care, Medicaid spending remains a target for reduction for both state government and the federal governments. Medicaid expenditures are shared by the federal government and states, with federal spending accounting for 57 percent of Medicaid spending and states contributing 43 percent.[16] Medicaid is the second largest item in state budgets and growing health care costs are often blamed for squeezing those budgets and reducing the ability to fund other priorities. Federal policy makers faced with growing budget deficits have also sought ways to control Medicaid spending growth.

Medicaid spending trends

Spending on long-term care ($91 billion in 2003) accounts for about a third of all Medicaid spending nationally. Spending on nursing home care represents the single largest category of Medicaid spending (about 17 percent), surpassing spending on inpatient hospital care and payments to managed care plans. [Figure 13] Spending on long-term care varies across states, however. Long-term care represents more than 50 percent of spending in North Dakota (58 percent), and Connecticut (51 percent) and less than quarter of Medicaid spending in Tennessee (21 percent), Nevada, South Carolina, and South Dakota (23 percent). [See Table 1 above].

Figure 13

Medicaid Spending by Service, 2003



Total = $266.1 billion

SOURCE: Urban Institute estimates based on data from CMS (Form 64), prepared for the Kaiser Commission on Medicaid.

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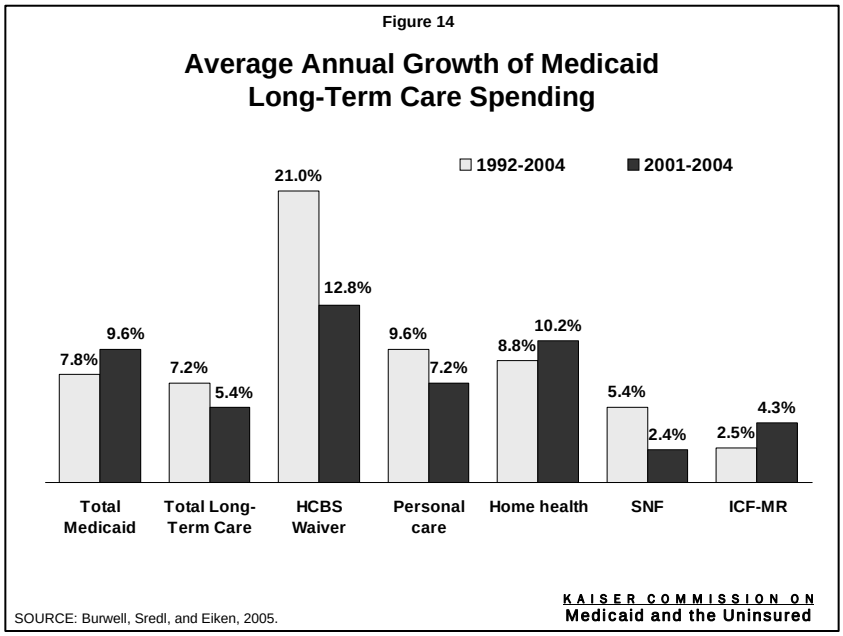
[16] The federal government's contribution ranges from 50 in the highest income states to 77 percent in the poorest (*Medicaid: A Primer*, Kaiser Commission on Medicaid and the Uninsured, Washington, D.C., July 2005).

Over the past 12 years, Medicaid long-term care spending has grown at a moderate rate (7.2 percent per year between 1992 and 2004), but somewhat more slowly than overall Medicaid spending (7.8 percent per year on average) (Burwell, Sredl, and Eiken 2005b). [Figure 14] Long-term care spending has been driven by rapid growth in spending under HCBS waivers as states have sought to "rebalance" long-term care systems. Spending on HCBS waivers grew 21 percent per year on average between 1992 and 2004, followed by growth in spending on personal care, which increased nearly 10 percent per year on average, and spending on home health, which grew at an average annual rate of about 9 percent per year. In contrast spending on institutional services has grown much more slowly—5.4 percent per year for nursing facility services, and only 2.5 percent per year for ICF-MR services.



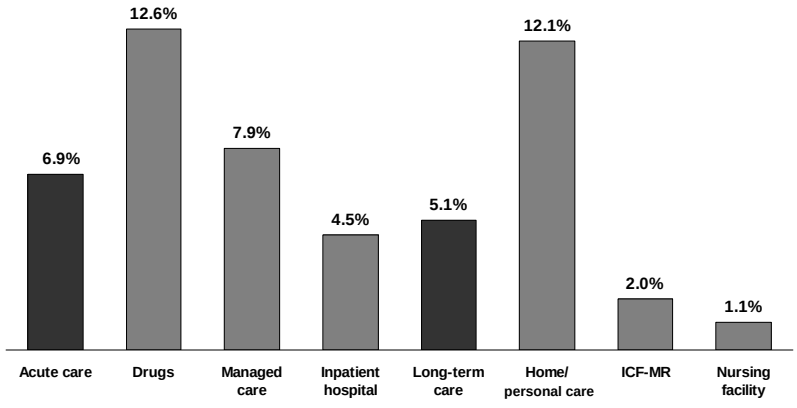
Most recently, spending on long-term care has slowed significantly, growing at an average annual rate of only 5.4 percent between 2001 and 2004, due to both lower nursing home spending and much slower growth in the spending under HCBS waivers. [Figure 14] Spending under HCBS waivers continues to grow faster than other long-term care services, but at a much more modest 12.8 percent annual rate. Spending on nursing facility services grew very slowly between 2001 and 2004, at just 2.4 percent per year.[17]

[17] See Holahan and Ghosh (2005) for a discussion of the impact of upper payment limit on NF spending.

On average across the nation, growth in long-term care spending has been modest because enrollment growth among the elderly and disabled has been modest (in comparison to enrollments of children and parents in Medicaid) and because expenditures per enrollee have grown very slowly for the institutional services that account for the bulk of spending. Spending per beneficiary receiving nursing home care increased by just 1.1 percent per year between 2000 and 2003, and spending per enrollee for ICF-MR services was similarly modest at 2.2 percent per year. Overall, long-term care spending per enrollee grew at 5.1 percent per year due to the much higher rate of spending growth per enrollee for home and community-based services (12.1 percent per year) (Holahan and Ghosh 2005). Spending per enrollee for acute care services has grown somewhat faster, at 6.9 percent per year on average, with spending on prescription drugs increasing faster than any other service, at 12.6 percent per year. [Figure 15]

Figure 15

Average Annual Growth of Medicaid Spending Per Enrollee, 2000-2003



SOURCE: Holahan and Ghosh, 2005.
NOTE: Home/personal care includes home health services, home and community-based waiver services, personal care and related services.

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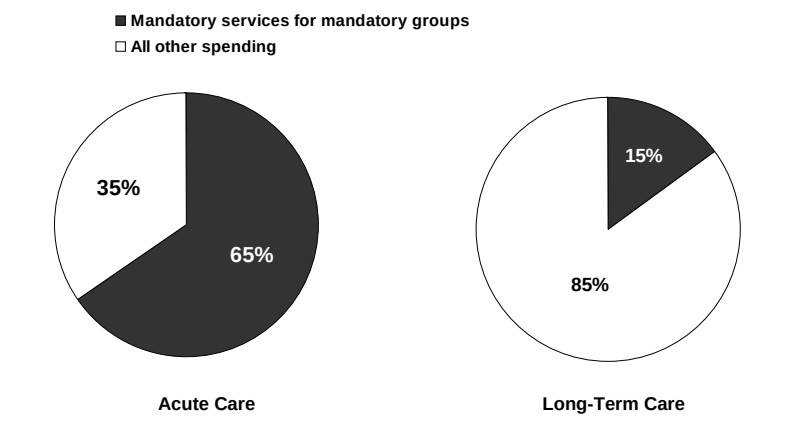
Recent state cost containment efforts

The economic slowdown and recession which began in 2000 has produced record budget shortfalls in many states. States, including many that reduced tax rates in the 1990s, have faced slow, no or negative revenue growth at the start of the next decade, and escalating Medicaid costs as well. Medicaid spending grew by a third between 2000 and 2003 (Holahan and Ghosh 2005). Since most states also have balanced budget requirements, many sought means to reduce Medicaid spending growth, including spending on long-term care.

In theory, states have significant flexibility to reduce spending on long-term care services in Medicaid. Unlike acute care, where the majority of Medicaid spending is for mandatory services for mandatory groups, the vast majority of all Medicaid spending for long-term care (85 percent) is "optional"—payments for optional services or enrollees. [Figure 16] States have sought to reduce payments to providers, limit optional benefits, and reduce eligibility for the elderly and people with disabilities, but long-term care has not been the primary target of cost containment efforts.

Figure 16



SOURCE: Sommers, Ghosh, and Rousseau, 2005.
NOTE: Urban Institute estimates based on FFY data from MSIS 2001 and CMS 64 reports. Total expenditures do not include DSH payments, administrative costs, or accounting adjustments.

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In fiscal years 2004 and 2005, about 28 states froze or cut payments to nursing homes and a number of states restricted the number of available slots in waiver programs, decreased benefits covered under waivers, instituted waiting lists, or used other means to limit caseload and expenditure growth. States also cut benefits, focusing on reducing or eliminating optional services. Many of these cuts have affected the long-term care population, including limits on therapy services, targeted case management, and personal care services (Smith et al. 2005).

States have not been likely to reduce income eligibility for seniors and people with disabilities, although two states (Oregon and Oklahoma) eliminated their medically needy programs in 2003, and in fiscal year 2006, Mississippi and Florida have plans to reduce eligibility for the aged and disabled. States have pursued more targeted measures, such as changing disability criteria, spend down and asset transfer criteria, and spousal impoverishment criteria, that will affect the number who are eligible (Smith et al. 2003). This year, New Hampshire lawmakers authorized changes estate recovery policies and penalties for asset transfers as part of strategy to reduce long-term care spending. In addition, the state of Vermont received federal approval for a five-year waiver that will give the state greater flexibility in running its Medicaid program in exchange for a cap on federal funding. The state proposes to reduce long-term care spending growth by providing HCBS to people who are at risk of institutionalization in the future but do not currently meet the eligibility criteria for nursing home care.

Although only a small share of state budget-driven policy actions were directed at controlling long-term care spending, the changes that were made may have significant impacts on beneficiaries and providers. Despite a significant slowdown in long-term care spending growth, states are likely to continue to target benefits and eligibility for reduction this year. Federal policy changes that are currently under consideration may also adversely affect state Medicaid programs.

Medicaid long-term care and the current federal budget debate

As it seeks to reduce the rapid growth of the federal budget deficit, the Congress has set a goal of reducing Medicaid spending by $10 billion over the next five years (2006-2010). Although the ultimate size of Medicaid spending reductions and the direction of reform are yet to be determined, long-term care—specifically, nursing home services for the "middle class" elderly—is seen as an important source of savings.

A proposal in the President's budget would require states to extend the lookback period for asset transfers from three to five years, and would increase the amount of time that states must withhold Medicaid eligibility when asset transfers occur. Penalty periods for inappropriate transfers would begin on the date an applicant applied for Medicaid, rather than on the date the transfer was made. Such a policy, would, in theory, increase private payments by the elderly and thus reduce the amount Medicaid spends on their care.

Since little is known about how many elderly nursing home residents seek to divest assets, cost estimates are necessarily tenuous. The Office of Management and Budget estimates that federal Medicaid outlays would be reduced by $4.5 billion between 2006 and 2015—a reduction of less than two-tenths of one percent in projected federal Medicaid expenditures. State expenditures would also be reduced by an estimated $3.4 billion.[18]

Far more modest changes to asset transfer policies are contained in the fiscal year 2006 budget reconciliation package passed by the Senate Committee on Finance. Most significantly, proposals to extend the look back period and implement harsher penalties were excluded from the Finance Committee's proposal. The CBO estimates that the proposed asset transfer restrictions will result in federal Medicaid savings of $335 million over the next five years (CBO 2006). However, as budget reconciliation moves forward, it is possible that House budget proposals will contain the more restrictive eligibility policies put forward by the Administration.

Medicaid's restrictive eligibility rules, spend down and estate recovery requirements, and complex application process deter many who may need care from seeking assistance. Longer lookback periods and harsher penalties may create a further deterrent and may, in fact, increase spending out of private funds. However, these changes are also likely to place greater administrative burdens on people applying for assistance, and the states and localities responsible for making eligibility determinations, making it much more difficult for some people who are eligible to access the services they need. The proposed policy may help slow the growth of burgeoning budget deficits, but the policy seems destined to hurt many with very modest means.

[18] See Office of Management and Budget (OMB), *Major Savings and Reforms in the President's 2006 Budget*, February 11, 2005, p. 188 (http://whitehouse.gov/omb/budget/fy2006/pdf/savings.pdf). The 2006 Budget proposes to curb asset transfers by making it impossible for Medicaid applicants to circumvent Medicaid penalties. Under current law, individuals who make inappropriate transfers are subject to a penalty period that delays their Medicaid eligibility by the number of weeks (or months, or years) of nursing home care that could have been purchased had the transfer not been made. Under the proposed policy, the penalty period for inappropriate transfers would start on the date of eligibility for Medicaid nursing home services or the date of transfer, whichever occurs later.

MEDICAID AND FUTURE LONG-TERM CARE CHALLENGES

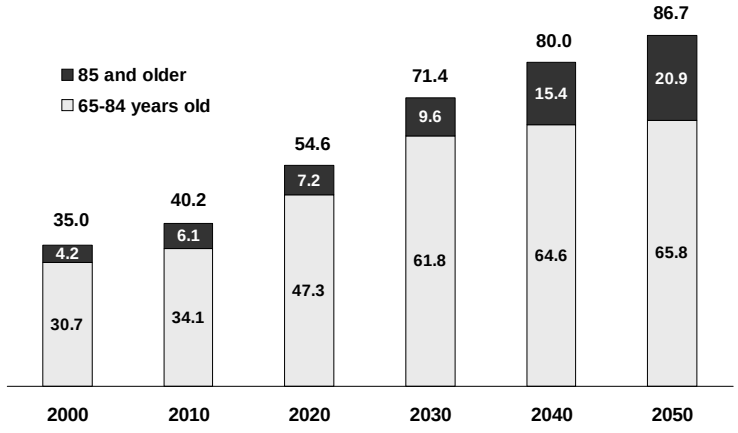
Burdens on Medicaid are expected to grow in the coming decades: continuing increases in health care costs, population aging, and growing demands for long-term care are expected to contribute to growing, and, some argue, "unsustainable" public spending burdens. An older but more affluent nation will be able to afford to spend some share of increased national income to maintain and expand Medicaid's (and Medicare's) benefits for people who need long-term care. But current policy debates focus on slowing the growth of entitlement spending rather than on improving long-term care protections. The fundamental question for the future is how best to assure access to affordable long-term care for all people who need it.

Population aging and its impact on public budgets

By demographers' accounts, most American communities will look much grayer in 30 or 40 years. The elderly will account for a growing share of the U.S. population and the "oldest old," those age 85 and above, are projected to double by 2030 (when they will number about 10 million, and comprise 1.5 percent of the population) and quadruple by 2050 (when they will number 20 million and account for 4.8 percent of the population) [Figure 14].

Figure 17

Projected Growth of Population Age 65 and Above, 2000-2050
(in millions)



SOURCE: U.S. Census Bureau, 2004, "U.S. Interim Projections by Age, Sex, Race, and Hispanic Origin," Table 2a, census.gov/ipc/www/usinterimproj/natprojtab02a.pdf.

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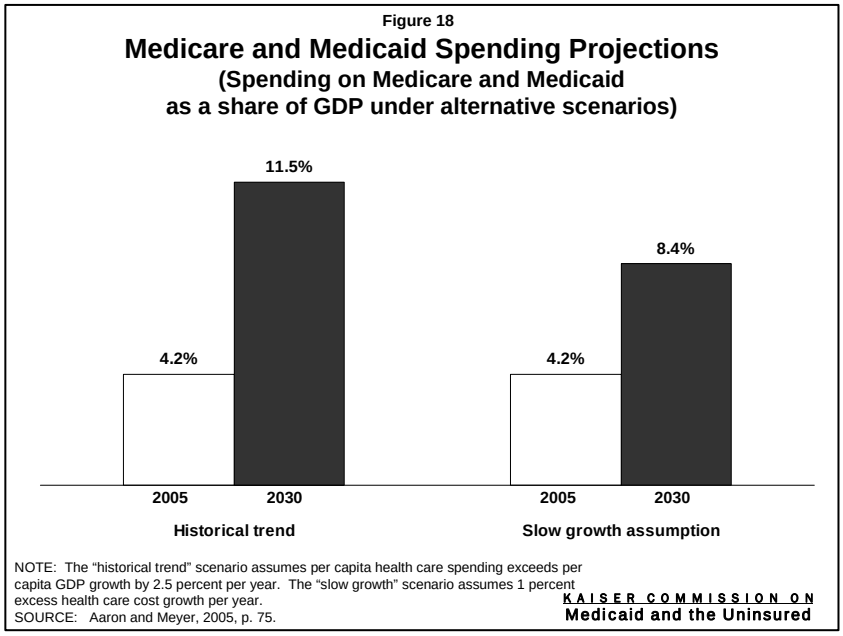
Population aging and longer life expectancies are likely to increase demand for nursing home services and other long-term care services in the decades ahead, as trends toward smaller families, higher divorce rates, and higher opportunity costs for caregiving reduce the availability of informal care. Declining disability rates among the elderly may help offset some of the increased demand for formal services, but the net result will be increased pressure on the public programs that currently finance long-term care. Medicaid costs are projected consume a larger share of state budgets, and combined Medicare and Medicaid spending are expected to consume

a larger share of the nation's economy (Aaron and Meyer 2005, p. 83). Under varying assumptions about the growth of health care spending, spending on Medicare and Medicaid is projected to grow from 4.2 percent of GDP today, to somewhere between about 8.4 percent and 11.5 percent of GDP in 2030 (depending on whether the estimator uses a slow growth or historical trend assumption to predict future spending) (Aaron and Meyer 2005, p. 75). [Figure 15] Such projections are highly uncertain, and the intervening decades allow more than enough time to identify program and financing changes to meet these needs more effectively. However, many argue that policy changes need to be made now to shift more responsibility to private individuals and reduce public responsibilities.



For those concerned with federal budgets, these spending trends mean larger budget deficits or unacceptably large tax increases. Efforts to reduce long-term care spending in Medicare and Medicaid are seen as part of the solution.[19] The primary focus of current policy debates about the future of long-term care is on reducing public spending while promoting personal preparedness through private long-term care insurance and/or increased saving for future needs.

For those who view long-term care primarily as a budget problem, the solution is to reduce public outlays. However, efforts to reduce federal spending on long-term care through Medicare and Medicaid may help address federal budget gaps, but they will not solve the nation's long-term care challenges. Restricting Medicaid is unlikely to substantially increase savings for long-

[19] Long-term care may be a relatively small part of the problem. In 1999, the CBO projected that total long-term care spending for the elderly (both public and private) would grow modestly as a share of gross domestic product (GDP), rising from 1.3 percent of GDP in 2000 to 1.5 percent of GDP in 2040 (in inflation-adjusted terms (2000 dollars) from $123 billion to $346 billion) (cited in Congressional Budget Office. 2004. "Financing Long-Term Care for the Elderly". Washington, D.C., p. 15) . The projections depend on assumptions about levels of impairment among the elderly, the use of paid and unpaid services, and growth in the price of long-term care services.

term care needs or purchases of private long-term care insurance (O'Brien 2005). Nor are efforts to restrict Medicaid likely to reduce the demand for nursing home care. One recent paper estimates that restricting Medicaid eligibility would do little to change the proportion of the elderly residing in nursing homes. The demand for nursing home care, the authors conclude, is relatively inelastic—that is, fairly unresponsive to the financial incentives that the program presumably creates. What would change is who pays for that care and who will have access to care. The costs and burdens will be shifted to individuals who need long-term care and their families, and perhaps to providers, through increased bad debt or charity care (Grabowski and Gruber 2005). The primary accomplishment will have been to shift from a relatively progressive financing scheme to one that places the greatest burdens on those with the least ability to pay. Long-term care needs will still need to be met, formal services will be needed, and burdens will increasingly be shifted to individuals and families.

Expand private long-term care insurance

Another set of policy options would alleviate fiscal pressure by improving the functioning of the market for private long-term care insurance. This strategy is less likely than public cutbacks to reduce access, but it is unlikely to significantly improve access or equity. For example, some have suggested that enhanced regulation of the private long-term care insurance market, through enhanced protections and standardization, may improve the insurance products and expand their purchase. Incentives for the purchase of private long-term care insurance, through tax credits could help make policies more affordable.

Expansions of the existing Medicaid Partnership program have also been proposed. Four states currently operate long-term care insurance "partnership" programs. Under special Medicaid rules, people who purchase designated long-term care insurance policies may qualify for Medicaid without spending down all of their available assets. Purchasers protect a certain amount of assets through insurance, though they must still contribute their available income to the cost of care once they are enrolled in Medicaid. Under various proposals, Partnership programs could be expanded nationwide. However, in the four states that currently operate Partnership programs, take up has been limited and its impact on Medicaid spending is not yet known.

In a quarter century, a somewhat larger proportion of the elderly *will* be wealthy enough to pay for long-term care out of their own resources, and a smaller proportion will be poor enough to qualify for Medicaid more or less automatically. But, just as today, that will leave a large proportion of elderly "tweeners"—in between financial self-sufficiency and automatic eligibility for Medicaid—who will remain vulnerable to impoverishment due to needs for long-term care. They will have accumulated modest resources, but will be at-risk of spend down.[20] Private long-

[20] One study estimates that the share who are financially independent (unlike ever to rely on Medicaid for long-term care) will increase from 27percent today to 38 percent in 2030. The percentage of the elderly who will likely depend on Medicaid ("Medicaid bound") will decline from 45 percent today to 29 percent in 2030, and the number of elderly in between (or "tweeners" with liquid assets between liquid assets between $70,000 and $210,000) are projected to increase from 28 percent of the elderly today to 33 percent in 2030. (The projections are based on assumptions about economic growth, wage growth, long term care cost growth of one percent per year in real, inflation-adjusted terms) Knickman, J. R. and S. K. Snell. 2002. "The 2030 Problem: Caring for Aging Baby Boomers." *Health Services Research* 37(4):849-84.

term care insurance may provide meaningful coverage for some of these elderly, but for many of modest means it will remain unaffordable. Nor will private insurance address the needs of children and working age adults disabled from birth or from illness or injury. Expanding tax subsidies for the purchase of private long-term care insurance will increase public spending and are likely to benefit higher income rather than lower income people.

Future Challenges for Medicaid

In the absence of a universal, social insurance program for long-term care, expanded private insurance and savings will not be adequate to address all long-term care risks and needs for all people. The low- and modest-income elderly will remain at risk of impoverishment due to long-term care needs, and private insurance will not likely address the needs of the nonelderly persons with disabilities. Medicaid will likely remain the nation's safety net for the poor and the middle class with long-term care needs, and will face ever more pressing financing, service delivery, and quality challenges.

The nation may well be able to afford to spend more on long-term care for an aging population, but what may be affordable for the nation as a whole may not be affordable for some states, raising an important challenge for Medicaid (Merlis 1995). States have a more limited capacity than the federal government to raise revenues, are subject to constitutional balanced budget requirements, and vary significantly in their abilities to finance care for the poor. Since growth in demand for Medicaid services is likely to be unevenly distributed across states, long-term care financing may pose a serious challenge to the current federal-state structure in Medicaid.

On average across the nation, the ratio of elderly people to working age adults is projected to change from about 1 in 5 in 2002, to 1 in 3 in 2025—an increase of 66 percent. But the changes in this ratio will differ across states, with some states well below the projected average (California, Connecticut, the District of Columbia, and Massachusetts), and some states far above. In many states, the ratio is projected to increase by more than 75 percent, and in a few (Colorado, Utah, Oregon), it is projected to more than double. All states will be challenged to meet increasing long-term care needs. However, states that currently spend relatively little on long-term care are experiencing the most rapid growth in their elderly populations and may be least well-equipped to meet the demand through expanded state financing (Merlis 2004).

A number of program and policy initiatives implemented over the past decade seek to enhance the cost-effective delivery of long-term care services and improve the quality and satisfaction with services. These include efforts to reform Medicaid long-term care by "rebalancing" long-term care services, implementing consumer-directed service delivery models, and "integrating" acute and long-term care services in Medicare and Medicaid.[21] However, experiments with models of service delivery and financing that integrate acute and long-term care have not yet demonstrated that there are more cost effective approaches that can solve the nation's long-term

[21] Medicare pays primarily for acute care, while Medicaid provides assistance with Medicare's cost sharing and provides long-term care benefits to some poor and middle income Medicare beneficiaries. It is often suggested that more services could be provided if Medicare and Medicaid's acute care and long-term care benefits were more effectively managed. According to some, more effective management of the substantial expenditures at stake requires integrating the funding streams to provide appropriate financial incentives for more effective management of care.

care financing dilemmas. Improving service delivery models especially for the community-dwelling elderly, for whom options are lacking in many states, will remain a priority. And, a key challenge for states will be to assure cost effective delivery of those services while assuring quality and oversight.

To truly address the shortfalls in states' ability to meet future long-term care needs, fully federalized financing could replace Medicaid as the primary source of financing for long-term care, and provide much needed assistance to people who would never qualify for Medicaid's means-tested assistance. In the absence of a shift to full-scale social insurance model, the current balance of state and federal responsibilities may have to be adjusted to assure that long-term care services are provided adequately and equitably across the nation. One option would be to federalize home and community-based services by expanding the federal financing to cover 100 percent of all community-based long-term care. This policy would go a long way toward relieving burdens on states, who would still share in the cost of institutional services, and toward addressing current gaps and unmet needs for care.

CONCLUSION

Medicaid's long-term care services are a critical source of support for millions of poor and low-income people. The long-term care system we have today is primarily financed by Medicaid, and without significant policy changes, Medicaid is likely to be the major source of long-term care coverage in the future. Medicaid, however, has important gaps and inequities. Medicaid is not an option for many; for those who do qualify, Medicaid does not provide insurance protection against large financial losses, but requires impoverishment. Eligibility and benefits are limited in many states, and waiver programs may not be available to all who need them and are financially eligible for them. Efforts to address these gaps are needed. Medicaid eligibility policies could be revised to make the program's means-testing less harsh. Federal financing could be expanded to make it easier for states to provide community-based services for people with long-term care needs. Barring major changes in the structure of long-term care financing, improving Medicaid's long-term care protections for people of modest means is likely to be a key part of any future strategy for meeting the long-term care needs.

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Appendix Table 1. Medicaid Long-Term Care Services

Benefit	Description of services	Type of benefit	Number of states* offering
Nursing facility services	A nursing facility must provide skilled nursing care and related services for residents who require medical or nursing care, rehabilitation services, and health-related care and services for injured, disabled or sick persons.	Mandatory benefit	51
Intermediate care facility for the mentally retarded (ICF-MR)	Services provided in facilities (of 4 or more beds) meeting federal criteria. ICFs-MR must be primarily for the diagnosis, treatment, or rehabilitation of the mentally retarded or persons with related conditions. In a protected residential setting, must provide ongoing evaluation, planning, 24-hour supervision, and coordination and integration of health or rehabilitative services to help each individual function at his or her greatest ability.	Optional benefit	51
Home health services	Includes intermittent or part-time nursing services, home health aide services, case management, and medical supplies and equipment for use in the home. States have the option of providing physical, occupational, speech therapies. Home care patients need not meet the nursing home level-of-care criteria, and states may not limit to beneficiaries who need skilled care. Services must be medically necessary, and must be ordered by a physician.	Mandatory benefit	51
Personal care	Personal care is defined broadly to include hands-on assistance with ADLs—tasks people would normally do for themselves if they did not have a disability. States typically provide help with bathing, dressing, toileting, eating, transferring, ambulation, as well as shopping, housekeeping, and meal preparation in the personal care benefit. But states have discretion to define the specific services they will provide and may place limits on the hours of service provided or cap total beneficiary spending. Eligibility criteria are typically less restrictive than criteria for nursing home admission, and the benefit is less medically oriented than the home health benefit. States may permit professionals other than physicians to authorize services (e.g. nurses, case managers, social workers). Services need not be nurse-supervised, and may be provided both in the home and outside a person's home. Many states allow services to be directed by the consumer or by a family member.	Optional benefit	31
Targeted case management	Helps individuals gain access to needed medical, social, educational and other services; includes assistance with gaining access to housing and other supports, in addition to Medicaid services. Targeted case management services are not furnished in accordance with Medicaid state-wideness or comparability requirements. States can target case management services according to medical condition, age, institutional status, geographic area or other characteristics. To fund case management for individuals transition to community-based long-term care services (under waivers, for example), the target population must include institutionalized individuals.	Optional benefit	50
Home and community-based services waivers (1915(c) waivers)	States may provide HCBS under waivers as an alternative to institutional care. Services covered often include case management, homemaker and home heath aide services, personal care, adult day health, respite care, habilitation services (designed to assist individuals in developing the skills necessary to reside successfully in a community-based setting), and prevocational, educational, and supported employment services, home modifications, and community transition services (certain up-front costs needed to establish a community household for people moving out of a Medicaid-funded institution). Other services that are cost effective and necessary to avoid institutionalization may also be covered. Waiver participants must meet the functional and level-of-care criteria for institutionalization, but many limit waiver eligibility by age, medical condition (e.g. MR/DD, AIDS, traumatic brain injury, spinal cord injury, physically disabled), geographic location, or other criteria.	Optional waiver	51

* Includes the District of Columbia.
SOURCE: Number of states offering benefit as of January 1, 2003 and October 1, 2004 reported in the Medicaid Benefits Online Database, Kaiser Commission on Medicaid and the Uninsured, (www.kff.org/medicaid/benefits/index.jsp).

Appendix Table 2. Nursing Home Beds, Occupancy Rate, Resident Rate, 2002.

STATE	Nursing Homes	Residents	Occupancy Rate	Resident Rate
Alabama	230	96,369	89.3	364.9
Alaska	15	649	79.4	211.2
Arizona	134	13,115	79.4	169.1
Arkansas	247	18,179	72.1	371.3
California	1,347	106,384	81.6	226.0
Colorado	224	16,351	80.3	307.9
Connecticut	252	28,734	91.9	410.0
Delaware	42	3,942	83.7	333.5
District of Columbia	21	2,817	90.5	298.9
Florida	704	70,761	85.6	196.4
Georgia	362	36,337	91.2	379.9
Hawaii	45	3,780	93.6	185.7
Idaho	82	4,780	75.5	242.6
Illinois	848	81,147	74.7	392.3
Indiana	545	40,988	76.1	416.9
Iowa	463	28,720	77.8	419.1
Kansas	376	21,117	79.0	391.7
Kentucky	303	22,741	88.7	371.1
Louisiana	321	29,674	77.3	483.5
Maine	121	6,995	90.7	279.5
Maryland	245	25,621	86.8	348.4
Massachusetts	499	48,304	89.4	385.8
Michigan	431	41,541	84.3	266.5
Minnesota	425	37,374	92.2	407.9
Mississippi	204	15,872	88.2	356.4
Missouri	538	37,831	69.2	367.4
Montana	102	5,815	77.3	351.0
Nebraska	230	14,082	82.7	396.4
Nevada	44	4,182	79.9	203.9
New Hampshire	83	7,120	90.3	356.6
New Jersey	360	44,605	86.7	299.5
New Mexico	82	6,286	84.1	243.5
New York	674	113,628	93.0	337.1
North Carolina	415	37,278	88.0	322.6
North Dakota	84	6,234	94.1	401.1
Ohio	994	80,677	76.6	422.6
Oklahoma	373	22,350	68.4	383.2
Oregon	145	9,065	70.2	143.2
Pennsylvania	757	82,411	88.0	318.4
Rhode Island	97	8,910	87.9	392.4
South Carolina	176	16,117	89.2	291.7
South Dakota	112	6,878	82.1	404.1
Tennessee	339	34,051	89.5	392.1
Texas	1,139	84,980	70.3	332.5
Utah	90	5,399	72.1	224.2
Vermont	44	3,279	90.5	304.5
Virginia	277	27,199	84.5	283.8
Washington	267	20461	82.5	219.8
West Virginia	137	10157	90.2	305.1
Wisconsin	407	37,095	84.6	359.6
Wyoming	39	2518	82.3	346.2
United States	**16,491**	**1,458,236**	**82.4**	**317.5**

Source: *Health, United States, 2004*, U.S. Department of Health and Human Services, Centers for Disease Control and Prevention, National Center for Health Statistics, Table 113, p. 322.

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