

medicaid  
and the uninsured

## Medicaid and Long-Term Care

*Prepared by*

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Kaiser Commission on Medicaid and the Uninsured

May 2004

# kaiser commission medicaid and the uninsured

**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 bipartisan group of national leaders and experts in health care and public policy.**

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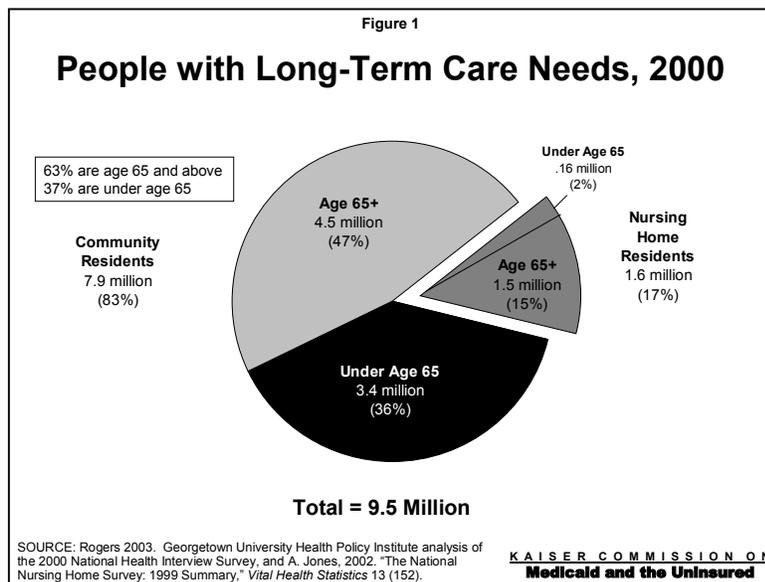
Kaiser Commission on Medicaid and the Uninsured

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## Table of Contents

Introduction.....	1
Overview of Medicaid Long-Term Care.....	5
Issues in Medicaid Long-Term Care.....	13
Medicaid eligibility is limited.....	13
Reducing Medicaid’s institutional bias and increasing access to community-base care.....	15
Expanding consumer direction.....	16
Concerns persist about the quality of nursing home and home and community-based care.....	17
State efforts to control long-term care costs.....	18
Growing demand for long-term care.....	19
Conclusion.....	20

Nearly 10 million Americans need long-term services and supports to assist them in life's daily activities. Tasks that most people take for granted – getting dressed, getting to the bathroom, walking, shopping, preparing meals -- are often impossible or difficult for people with disabling physical or mental conditions to accomplish on their own. For some people, these needs are lifetime needs. Children born with severe physical impairments, developmental disabilities, or a degenerative disease often need care throughout their lives. Teenagers and adults who incur traumatic injuries, such as spinal cord injuries, may need care for decades. The elderly also often need some long-term care services due to decreasing mobility and cognitive functioning that often comes with aging, with needs ranging from simple assistance with bathing and dressing and meal preparation, to more extensive services for those who are disabled by a serious illness, such as a stroke or Alzheimer's disease. In 2000, there were an estimated 9.5 million people with long-term care needs in the U.S., including 6 million elderly and 3.5 million nonelderly [Figure 1].

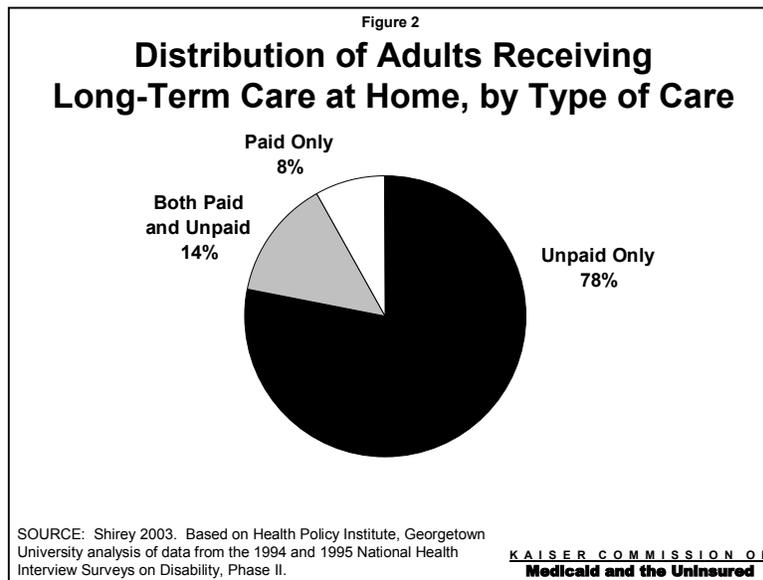


Most Americans (85 percent) have health insurance coverage to protect against the risk of high medical care costs. Although these insurance arrangements fail to provide universal coverage, leaving nearly 43 million uninsured, there is no similar system of insurance to cover the costs of long-term care services. Some long-term care needs are met by some health insurance plans, but, in general, health insurance plans cover preventive, primary, and acute care services and provide only limited coverage of long-term care services (e.g. nursing home and home health care) often as “post-acute” benefits following a hospital stay. Medicare, for example, provides a substantial amount of assistance for some people with chronic and disabling conditions, primarily through its home health benefit, but those receiving services must also have a need for skilled nursing care or therapy services. Medicare also provides coverage for nursing home care, but covers only 100 days of care in a nursing facility for those recently discharged from the hospital (and who need skilled nursing care or rehabilitative therapy). Medicaid provides long-term care services to both elderly and nonelderly persons with disabilities,

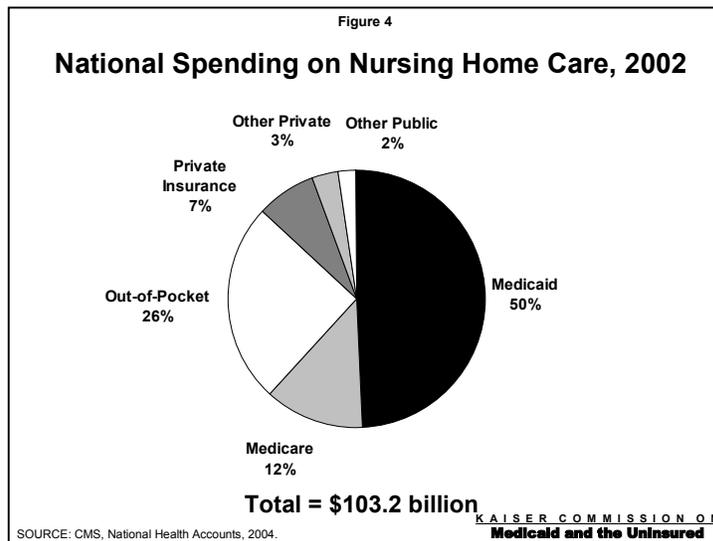
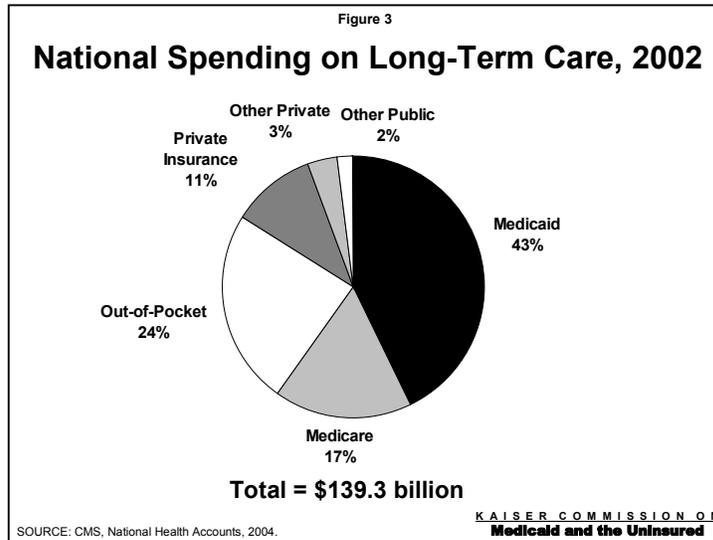
but Medicaid’s protections are limited to the poor or to those who have become poor due to high out-of-pocket spending on medical or long-term care. Nevertheless, Medicaid is the primary source of financing for long-term care and accounts for the large majority of public spending on long-term care. Other federal (e.g. the Older Americans Act, the Rehabilitation Act, and Social Services Block Grants) and state-funded programs also typically supplement Medicaid.

### How do people who need long-term services and supports get and pay for the care they need?

Circumstances vary; both in terms of care needs and ability to pay for that care. Very often, people who need long-term care rely almost exclusively on care provided by family and friends in their own home. Nearly 80 percent of adults receiving long-term care at home rely exclusively on unpaid help [Figure 2]. When families cannot do the whole job—because very intensive care is needed, or because caring has become too physically or emotionally draining—families often turn to more formal arrangements (paid in-home care, or nursing home or other institutional care), and draw on their own financial resources to pay for that care. A few rely on private long-term care insurance to pay for care. For others, Medicare provides coverage of in-home skilled nursing care and other home health services. A minority, but typically those with substantial disabilities, very high costs, and modest incomes, relies on public financing for long-term care available through the Medicaid program.



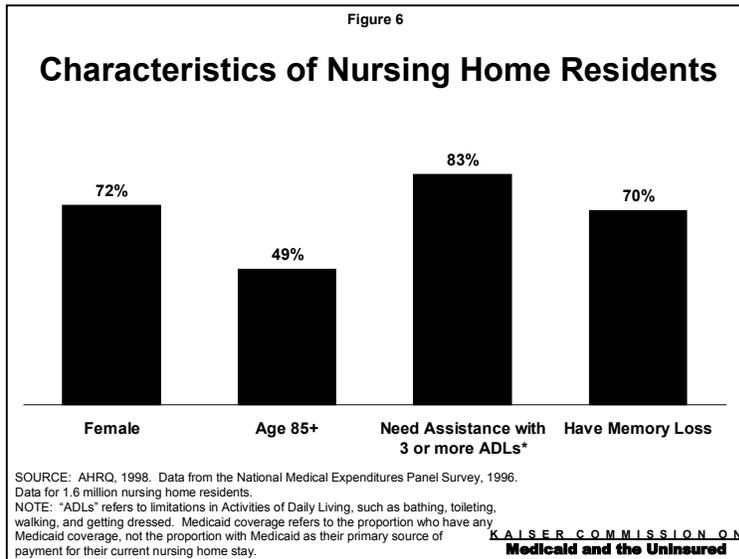
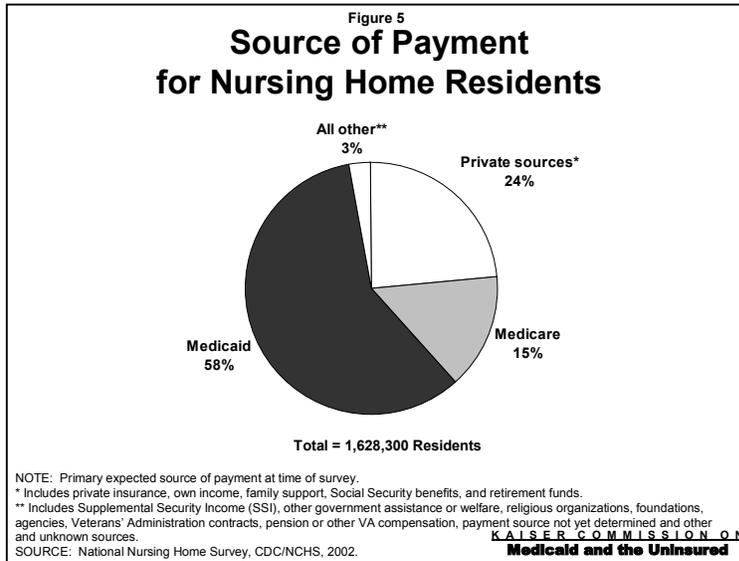
In 2002, a total of \$139 billion was spent on long-term care in the U.S. for people of all ages, with \$103.2 billion spent on nursing home care and \$36.1 billion spent on care in the community. Of total national spending on long-term care, Medicaid accounted for 43 percent of spending [Figure 3]. Medicaid paid for a slightly higher share of nursing home care (50 percent) [Figure 4], and Medicaid accounted for 23 percent of total spending on home health care services, while Medicare accounted for 32 percent.



Medicaid is the main source of funding for people in institutions, including those in nursing homes and people in Intermediate Care Facilities for Individuals with Mental Retardation (ICFs/MR).<sup>1</sup> Nearly 60 percent of those in nursing homes have Medicaid as their primary source of payment [Figure 5]. Those in nursing homes typically have severe physical or cognitive impairments, they tend to be over age 80, female, and

<sup>1</sup> The ICF/MR benefit is an optional Medicaid benefit that provides funding for "institutions" (of 4 or more beds) that provide "active treatment" to people with mental retardation. Currently, all 50 States have at least one ICF/MR facility serving about 129,000 people with mental retardation and other conditions nationwide. Many ICF/MR residents have conditions in addition to intellectual or developmental disabilities; many are non-ambulatory, have seizure disorders, behavior problems, mental illness, or visual or hearing impairments (CMS, ICF/MR Program Information Site, [www.cms.hhs.gov/medicaid/icfmr/icfbkgd.asp](http://www.cms.hhs.gov/medicaid/icfmr/icfbkgd.asp))

without a spouse in the community [Figure 6]. Most have few choices available to them, and the need for continuous care and monitoring makes remaining in the community unaffordable and impractical.



## Overview of Medicaid Long-Term Care

Medicaid is a means-tested entitlement program financed by federal and state governments and administered by the states. Medicaid covers long-term care services for both elderly and nonelderly individuals both in institutional settings (nursing homes and intermediate care facilities for people with mental retardation and developmental disabilities (ICFs-MR)), and in homes and other community-based settings (adult day care facilities, for example). Only nursing home care and home health care for people who would otherwise qualify for institutional care are mandatory benefits under Medicaid. In addition, states have the option of providing additional optional long-term care benefits through state plan amendments or waivers.

Long-term care involves providing a range of supportive services that may assist individuals with performing activities of daily living and instrumental activities of daily living. These range from providing assistance with eating, dressing, and toileting to assisting with managing a home, preparing food, and using the telephone. The bulk of long-term care spending is concentrated on institutional care and reflects the high cost of providing these services. A smaller share of Medicaid spending is devoted to community-based care. Over the past two decades, spending on community-based care has been increasing and as more people with long-term care needs receive home and community-based services, however, the proportion of Medicaid spending on home health and personal care services is likely to rise.

Federal Medicaid law requires that the states provide certain services to everyone covered by the program. Such mandatory services, particularly important for those with long-term care needs, include institutional services for adults and home health care services for individuals entitled to nursing facility care [Figure 7]. Medicaid law also defines optional services that states can elect to provide. The loss of optional services includes a broad range of long-term care related services, such as case management, personal care services, home and community-based waiver services, and ICF/MR services. Many of these services, including case management and personal care services, are not typically covered in private health insurance policies.

Figure 7

<u>“Mandatory” Items and Services</u>	<u>“Optional” Items and Services</u>
<p style="text-align: center;"><i>Institutional Services</i></p> <ul style="list-style-type: none"> <li>• Nursing facility (NF) services for individuals 21 or over</li> </ul> <p style="text-align: center;"><i>Non-Institutional Services</i></p> <ul style="list-style-type: none"> <li>• Home health care services (for individuals entitled to nursing facility care)</li> </ul>	<p style="text-align: center;"><i>Institutional Services</i></p> <ul style="list-style-type: none"> <li>• Inpatient/nursing facility services for individuals 65 and over in an institution for mental diseases (IMD)</li> <li>• ICF/MR services</li> <li>• Inpatient psychiatric hospital services for individuals under age 21</li> </ul> <p style="text-align: center;"><i>Non-Institutional Services</i></p> <ul style="list-style-type: none"> <li>• Home health care services</li> <li>• Case management services</li> <li>• Prescription Drugs</li> <li>• Respiratory care services for ventilator-dependent individuals</li> <li>• Personal care services</li> <li>• Private duty nursing services</li> <li>• Hospice services</li> <li>• Services furnished under a PACE program</li> <li>• Home- and community-based services</li> </ul>

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In addition to the approximately one million people who received institutional services under Medicaid in fiscal year 2000, just over 2 million received care in their homes and communities--728, 000 received home health care services, about 833,000 received care under HCBS waivers, and 558,000 received personal care services (**Figure 8**).

<b>Figure 8. Medicaid Long-Term Care Services</b>				
	<b>Mandatory or Optional?</b>	<b>Financial Eligibility</b>	<b>Benefits</b>	<b>Statewide Coverage</b>
<b>Nursing Home Care</b>	Mandatory for individuals 21 and over	Must be eligible for Medicaid	Provides, in a facility that meets federal requirements, skilled nursing care and rehabilitation services	Yes
<b>Intermediate Care Facilities for Individuals with Mental Retardation</b>	State option (50 states)	Must be eligible for Medicaid	Provides, in a protected residential setting, ongoing evaluation, planning, 24-hour supervision, coordination, and integration of health or rehabilitative services to help each individual function at his/her greatest ability	Yes
<b>Home Health Care</b>	Mandatory for individuals age 21 and over who would otherwise be entitled to institutional care	Must be eligible for Medicaid	May provide nursing therapy, home health aides, medical supplies, and equipment  Limits on services are allowed	Yes
<b>Personal Care</b>	State option (27 states)	Must be eligible for Medicaid	Usually includes assistance with activities of daily living and homemaker/chore services. In some states includes cuing/ supervisory services, transportation services, and nursing care  Limits on services allowed	Yes
<b>Home- and Community-Based Services Waivers</b>	State may seek a waiver from the Secretary of HHS. Waivers must be "cost effective": the cost of caring for an individual under the waiver must be less than or equal to the cost of institutional care	Under Medicaid, individuals "at risk" of institutional care are eligible	Case management, adult day care, home health aide, personal care habilitation, assisted living services, and respite care.  Limits on services allowed	Not required  Can target certain geographical areas and/or specific population groups

Those who need long-term care must meet financial and categorical eligibility criteria to qualify for Medicaid. Medicaid is limited to certain groups of low-income Americans, including families with children, people with disabilities, and the elderly who meet strict income and asset limits. For the elderly and people with disabilities with long-term care needs these limits are often tied to the Supplemental Security Income (SSI) program—\$552 per month in 2003—but limits can be higher in states that supplement Medicaid.

Most states also allow the “medically needy”—those with large medical or long-term care bills that reduce their income to the required level—to participate in Medicaid. People whose assets are less than a specified level (\$2,000 for individuals, \$3,000 for couples) can qualify for Medicaid if the cost of nursing home care (or other medical care) exceeds their incomes—that is, they may spend down to a state-set eligibility standard. These criteria are usually quite stringent; most states set their medically needy income level at or below SSI levels. This program is optional for states, however, and 15 states (plus the District of Columbia) do not have medically needy programs (Crowley 2003).

In states that do not have medically needy programs, individuals needing nursing home care can be covered under the “300 percent rule”. Under this option, individuals with income up to 300% of SSI (\$1,656 per month in 2003), can qualify for institutional care. To assist those very modest income elderly with incomes above the limits in these income cap states, the Medicare Catastrophic Coverage Act created a vehicle for putting excess income in trust. Income cap states must allow those with incomes above the cap to qualify for Medicaid if they put their excess income in a trust, known as a “Miller Trust.” However, states may recover funds in the trust after the person’s death.

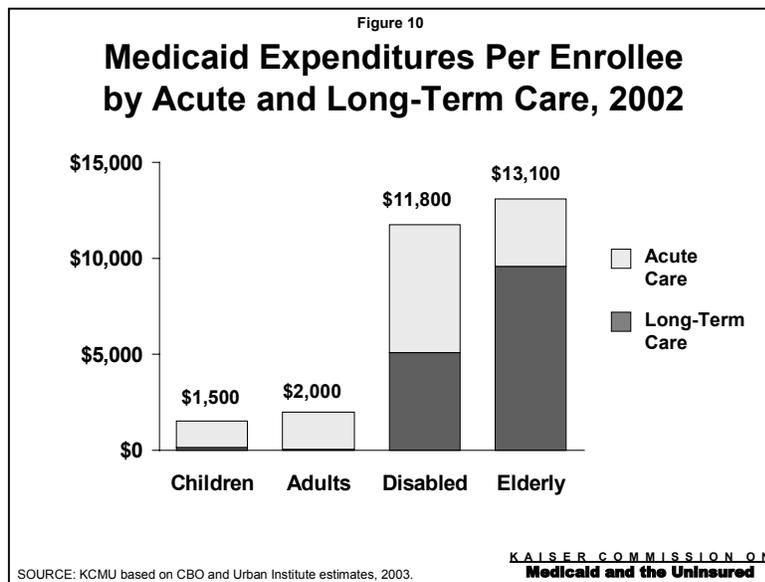
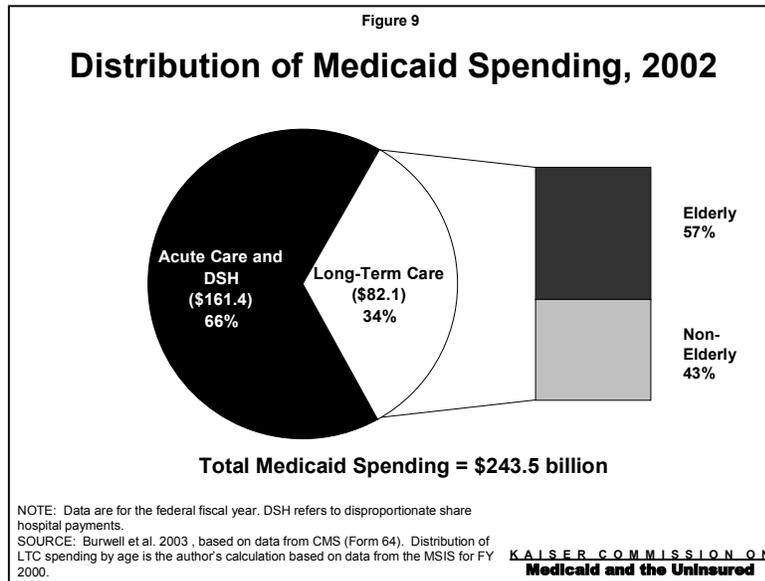
Nursing home residents who qualified as medically needy or through the 300 percent rule must apply the majority of their monthly income toward the cost of care, thereby reducing the amount that the Medicaid program must pay. Medicaid nursing home residents may keep only a small personal needs allowance (between \$30-\$90 per month) to pay for items that are not covered by Medicaid, such as clothing, books, toiletries, or telephone service. Medicaid beneficiaries receiving home and community-based services are also 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 themselves at home than if they were in an institution, where Medicaid covers room and board.

States are required to allow nursing home residents with spouses living in the community to disregard a certain amount of income for the support of the community-residing spouse. States must allow the spouse who remains in the community to keep a certain amount of income and assets. States may set their own income limits but must allow a community spouse to keep between —\$1,492 and \$2,265 per month in 2003—In addition, a community spouse is allowed to keep half of the couple’s joint assets (at least \$8,132 and no more than \$90,660) (Friedland 2003, p. 56).

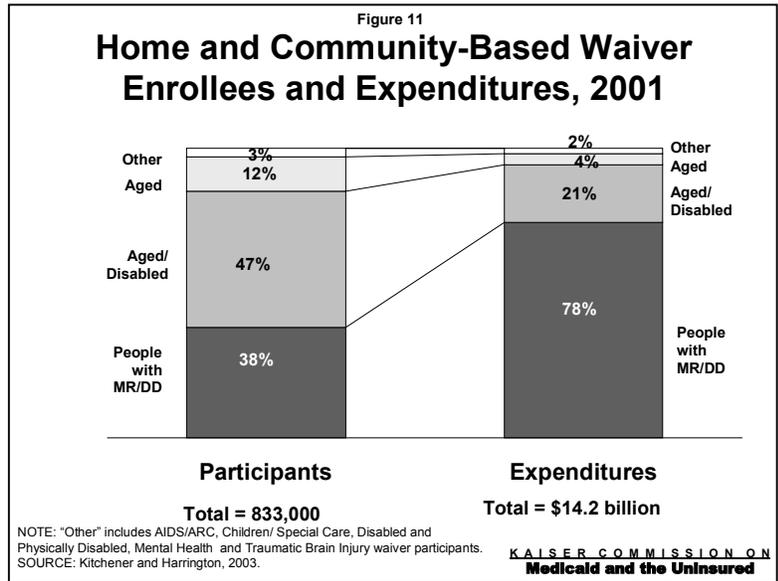
Although mandatory for nursing home residents, states are not required to offer spousal impoverishment protections to home and community-based service waiver program participants. Consequently, a substantial number of states (19) fail to offer the spouses of waiver participants the full level of income and/or asset protection afforded the spouses of nursing home residents. Thirteen states protect neither the income nor assets of spouses of waiver participants, and an additional 6 states protect the assets but not the incomes of the community spouses of waiver participants (Kassner and Shirey 2000, p. ii).

## Spending

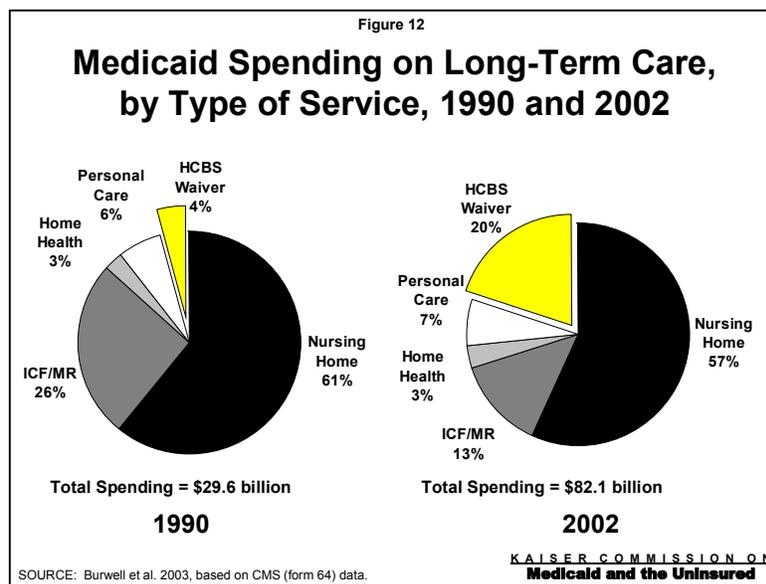
Although less than 10 percent of Medicaid beneficiaries use long-term care services, long-term care accounts for about one-third of total Medicaid spending (\$82.1 billion of total Medicaid spending of \$243.5 billion in 2002). Spending on the elderly accounted for about 57 percent of that spending, with the remaining 43 percent spent on those under 65 (including people with disabilities with Medicaid, and some children and adults)<sup>1</sup> [Figure 9]. Long-term care accounts for 70 percent of spending per elderly enrollee and 45 percent of spending per disabled enrollee [Figure 10].



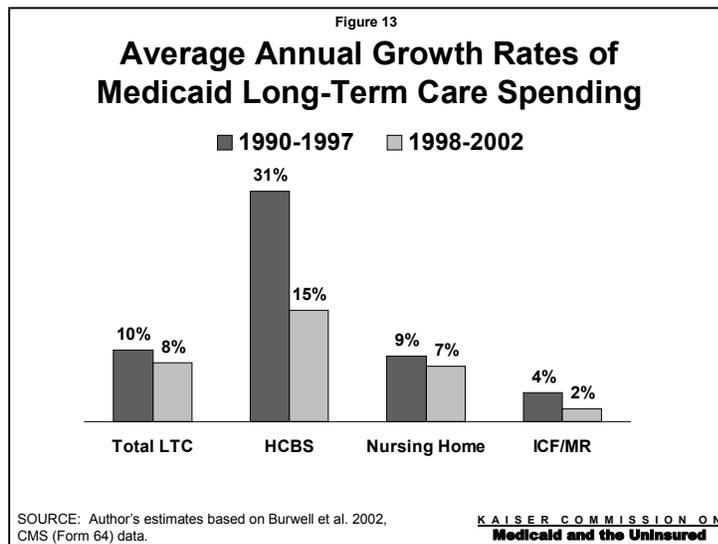
The home and community-based waiver program accounts for the largest share of all non-institutional long-term care spending in Medicaid (66 percent in 2002); spending on home health care (a mandatory benefit) constituted 10 percent compared to 22 percent for personal care services (an optional benefit) of total Medicaid home and community-based spending in 2002. Within the waiver program, individuals with MR/DD account for 38 percent of participants, but nearly 80 percent of waiver spending [Figure 11].



Within long-term care, spending on home and community-based care services has grown from \$1.2 billion in 1990 to \$16.4 billion in 2002 increasing at an average rate of 25 percent per year. With spending on institutional services growing at a much more moderate pace, spending on institutions dropped from 87 percent of the total Medicaid long-term care budget in 1990 to 70 percent in 2002 [Figure 12].

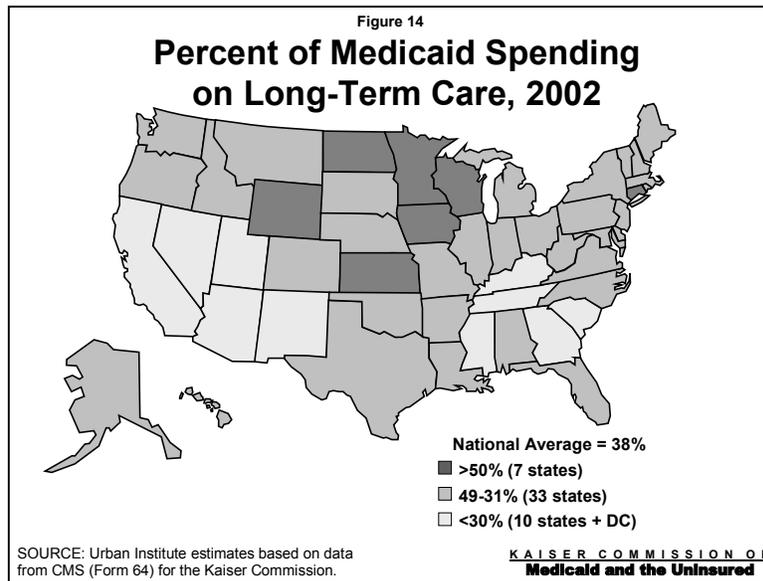


However, spending on long-term care has declined as a share of overall Medicaid expenditures. In 1988, for example, long-term care accounted for about 45 percent of all Medicaid expenditures (Eiken and Burwell, 2001) compared to about 35 percent in 2002. Some of this drop in the share of Medicaid spending that goes toward long-term care is due to the rapid growth in enrollment of children who rely on Medicaid for health insurance and typically do not use long-term care services. However, spending on long-term care has slowed. Since 1997, the growth in long-term care spending, most especially spending on waiver services, has slowed markedly. HCBS spending grew at a 31 percent average annual rate between 1990 and 1997, and then slowed to a 15 percent annual rate of growth after 1997 [Figure 13].



## State Variation

State Medicaid programs vary enormously. Although states must adhere to certain federal rules in order to receive federal matching payments under Medicaid, they also have considerable flexibility to set eligibility levels, determine which services will be covered, and set payment rates, with important consequences for who gets access to services, the amount of service they receive and the level of spending on acute and long-term care services. Long-term care also varies as a share of total Medicaid spending. Long-term care accounts for more than 50 percent of Medicaid spending in six states (AK, CO, NY, OR, VT, WY), and less than 20 percent of total spending in 8 states (IL, IN, IA, MS, OK, OH, PA, TN) [Figures 14 and 15].



In part, these differences reflect the different economic capacities of states to finance Medicaid long-term care (despite differences in the federal matching rate), but they also reflect differences in states' willingness to finance that care. As a result, people with similar incomes, assets, and long-term care needs may have very different experiences depending on where they live. The average Medicaid long-term care expenditure per elderly beneficiary ranges from over \$14,000 in Connecticut and New York, to less than \$5,000 in South Carolina, Mississippi, and Oklahoma (Urban Institute 2004).

States also vary in the extent to which they cover home and community-based long-term care. In some states, a significant share of resources is devoted to home and community-based services. Expenditures for home and community-based care (including home health, waiver services and personal care) varied from a high of 11% of total Medicaid expenditures in Louisiana to 63% in New Mexico [Figure 15].

**Figure 15. Medicaid Long-Term Care Spending, 2002**

State	Long-Term Care Spending (In millions)	Long-Term Care as a Share of Medicaid Spending	Spending as a Share Of Total Medicaid Long-Term Care		
			Nursing Facilities	ICF-MR	Home Care
<b>TOTAL U.S.</b>	<b>\$93,219</b>	<b>38%</b>	<b>56%</b>	<b>12%</b>	<b>32%</b>
Alabama	\$1,078	35%	68%	6%	27%
Alaska	\$210	31%	47%	0%	53%
Arizona	\$973	28%	57%	12%	32%
Arkansas	\$827	36%	71%	4%	26%
California	\$7,945	29%	54%	8%	38%
Colorado	\$870	37%	45%	2%	53%
Connecticut	\$1,920	54%	54%	11%	35%
Delaware	\$231	36%	60%	14%	26%
Washington, D.C.	\$293	28%	67%	27%	6%
Florida	\$3,154	32%	60%	10%	30%
Georgia	\$1,502	23%	58%	7%	35%
Hawaii	\$247	33%	69%	4%	28%
Idaho	\$303	39%	44%	18%	38%
Illinois	\$2,864	32%	54%	24%	22%
Indiana	\$1,729	39%	62%	22%	17%
Iowa	\$1,526	59%	71%	14%	16%
Kansas	\$981	53%	54%	7%	39%
Kentucky	\$1,087	29%	61%	9%	30%
Louisiana	\$1,903	38%	71%	19%	11%
Maine	\$550	38%	42%	9%	49%
Maryland	\$1,323	36%	69%	5%	26%
Massachusetts	\$2,854	36%	52%	7%	42%
Michigan	\$2,468	33%	74%	2%	25%
Minnesota	\$2,376	53%	40%	9%	52%
Mississippi	\$791	27%	60%	23%	18%
Missouri	\$2,043	38%	61%	11%	29%
Montana	\$256	44%	55%	6%	39%
Nebraska	\$668	49%	62%	7%	31%
Nevada	\$219	27%	60%	14%	27%
New Hampshire	\$471	45%	64%	0%	36%
New Jersey	\$3,571	46%	67%	13%	20%
New Mexico	\$509	29%	33%	4%	63%
New York	\$15,728	43%	47%	15%	38%
North Carolina	\$2,329	33%	40%	18%	42%
North Dakota	\$290	62%	61%	18%	21%
Ohio	\$4,539	47%	62%	21%	18%
Oklahoma	\$964	41%	52%	11%	37%
Oregon	\$913	35%	27%	1%	73%
Pennsylvania	\$5,788	47%	72%	9%	20%
Rhode Island	\$483	35%	90%	2%	41%
South Carolina	\$981	29%	43%	18%	39%
South Dakota	\$263	48%	67%	7%	27%
Tennessee	\$1,587	27%	60%	16%	24%
Texas	\$4,366	32%	43%	19%	39%
Utah	\$291	29%	37%	19%	44%
Vermont	\$227	34%	41%	1%	59%
Virginia	\$1,850	48%	67%	13%	20%
Washington	\$1,810	35%	48%	7%	45%
West Virginia	\$616	39%	55%	8%	37%
Wisconsin	\$2,315	55%	61%	10%	29%
Wyoming	\$138	50%	42%	9%	50%

NOTE: Home care includes Personal Care, HCBS Waiver, and Home Health. Nursing facilities include mental health institutions. Due to rounding, columns may not add up to 100%.

Source: Urban Institute estimates based on data from CMS (Form 64) for the Kaiser Commission.

## **Issues in Medicaid Long-Term Care**

Medicaid provides health and financial security to 4 million people with long-term care needs. Nevertheless, there are a number of concerns about how the program works, and a number of ways in which Medicaid long-term care could be improved to expand access to care and improve the quality of the services provided. Key concerns relate to:

- Medicaid eligibility is limited
- Reducing Medicaid's institutional bias and increasing access to community-based care
- Expanding consumer direction
- Concerns persist about the quality of nursing home and home and community-based care
- State efforts to control long-term care costs
- Growing demand for long-term care

### **▪ Medicaid eligibility is limited**

Few Americans have insurance to protect them from the high cost of long-term care. Medicaid is usually the only source of financial assistance, but eligibility is limited to the very poor or those with large expenses. Many elderly persons enter nursing homes as private pay clients, spend their available life savings, and then apply for medical assistance under Medicaid after their assets are depleted. Thus, because Medicaid eligibility is means-tested and not insurance, Medicaid provides assistance only after the elderly have spent down their assets and have applied almost all of their monthly income from social security or pensions toward the cost of care.

In 2000, an estimated 40 percent of nursing home residents had Medicaid as their primary source of payment at admission to the nursing home (those who are poor or who have already spent down due to high medical expenses). In a sample of current residents, however, 60 percent had Medicaid as their primary expected source of payment (CDC/NCHS 2002), suggesting that a significant proportion of those with extended nursing home stays eventually spend down to Medicaid eligibility levels. Research studies confirm that approximately 20 percent of current residents spend down at some point during their stays. Those who stay in the nursing home for a long period of time are more likely to eventually spend down to Medicaid. About one-third of nursing home residents who used long-term care services for one to three years spent down, and about half of those with a nursing home stay of more than three years spent down their income and assets to Medicaid eligibility levels (Weiner, Sullivan and Skaggs 1996).

Federal Medicaid law attempts to discourage individuals from transferring savings and other countable resources to adult children, siblings, or others in order to satisfy the Medicaid resource test and qualify for nursing home coverage. It does so by imposing, for a specified period of time, an exclusion from nursing home coverage upon those

individuals who engage in such transfers. The period of exclusion from Medicaid coverage is related to the amount of resources transferred, the average monthly cost of nursing home care in the state, and the date on which the transfer was made. Even with the “look back” provisions, there is still a perception among some administrators and policy makers that many middle and higher income elderly seek to obtain Medicaid coverage by divesting their assets (artificially impoverishing themselves) to qualify for Medicaid, instead of applying their assets to for the cost of long-term care. There is little empirical evidence to support these assertions, and the extent of abuse remains unknown since very few of the elderly have a trust (Taylor, Sloan and Norton 1999). Although 4 in 10 elderly people in the community could potentially qualify for Medicaid by using a trust, fewer than 1 in 10 had a trust. Avoidance of probate and controlling assets after death appear to be stronger motivations for trust creation among the elderly than achieving Medicaid spend down. The asset levels of elderly people likely to need nursing home care are typically low to begin with and federal legislation (OBRA 1993) placed greater restrictions on asset transfers (Schneider, Fennel and Keenan 1999).

A related criticism of Medicaid long-term care programs is that the availability of the medically needy pathway discourages the middle income elderly from adequately preparing for their future long-term care needs, either by saving or by purchasing private long-term care insurance. Proponents of expanded private financing argue that if incentives to purchase insurance were expanded, Medicaid long-term care costs would fall. At the very least, Medicaid coverage could be postponed until private long-term care insurance benefits were exhausted or used to supplement private insurance. Although efforts have been made to promote the purchase of private long-term care insurance (LTCI) in several states, these plans have had limited success and it is doubtful they would have much impact on the growth of Medicaid long-term care spending.

To help expand sale of LTCI and relieve burdens on Medicaid, four states have a public-private partnership under which people who purchase a state-approved long-term care insurance policy can keep more of their assets and still qualify for Medicaid long-term care (CA, CT, IN, NY). The Partnership for Long-Term Care began in 1988 with funding from the Robert Wood Johnson Foundation. Currently, the program is funded by the participating states through Medicaid state plan amendments. The Partnership for Long-Term Care provides an alternative to spending down or transferring assets by forming a partnership between Medicaid and private long-term care insurers (Meiners 2003a). Under the Partnership plan, if the policyholder receives long-term care and exhausts the benefits of their private LTCI policy, he or she can then receive benefits under Medicaid using more liberal eligibility rules that protect an amount of assets equal to the benefits payable under the policy. For example, if a person buys a policy that provides \$50,000 worth of long-term care services, they can receive Medicaid long-term care and keep \$50,000 of assets, rather than the \$2,000 in assets that Medicaid eligibility typically requires. Few partnership policies have been purchased<sup>2</sup>, however, despite a substantial effort to promote them (Wiener 2003, p.117).

Even if sales of private long-term care insurance expand and insurance plays a more important role in long-term care financing in the future, there is considerable doubt about the extent to which expanded insurance coverage will reduce Medicaid spending.

- **Reducing Medicaid’s institutional bias and increasing access to community-based care**

Access to community-based alternatives to institutional long-term care has historically been limited under Medicaid. All states are required to provide institutional services, but they are generally not required to provide home and community-based services. Since states most often provide home and community-based services as optional benefits or through waivers, funding and eligibility have been limited. Consequently, despite the substantial growth in home and community-based care, many states have waiting lists for services (Harrington, 2003).

To reduce the institutional bias in Medicaid, most states have used the flexibility allowed under federal law to provide community-based care. However, many states have been reluctant to expand home and community-based services for fear of rising costs. To limit their exposure, many states provide home and community-based services through waivers instead of as an optional service. There are important differences between providing services as an optional benefit or through a waiver. States that offer optional services must make them available to all individuals in the state who meet the financial and non-financial eligibility criteria. In contrast, under a waiver, states can limit the number of otherwise qualified individuals it will cover. Secondly, under a HCBS waiver, individuals must be at risk of institutional care; under the optional service approach, individuals need only be residing in the community.

Individuals with disabilities and their advocates—especially advocates for persons with mental disabilities—have long argued that Medicaid’s “institutional bias” interferes with their rights under the Americans with Disabilities Act to receive care in the “least restrictive setting.” In July 1999, the U.S. Supreme Court ruled, in *Olmstead v. L.C.*, that the unnecessary segregation of persons with disabilities is a violation of the Americans with Disabilities Act of 1990, creating an expectation that home and community-based care would become the standard for long-term care in Medicaid in the future as states seek to comply with the decision. By the end of 2000, 37 states had task forces or workgroups to develop comprehensive plans or papers that could serve as blueprints for change. However, states are facing the most challenging fiscal environment since World War II that has resulted in many states to pull back from their original implementation schedules (Fox-Grage, Folkemer, and Lewis 2003, p. 2). Although progress has slowed, planning and design activity continues due to assistance from Systems Change Grants and pressure created by legal challenges filed by people with disabilities (Desonia 2003, p. 12).

One obstacle facing nursing homes residents who want to move back to the community is housing. Because Medicaid does not pay for housing other than institutional care, and in most cases these individuals have depleted their savings, it is difficult for these

individuals to find affordable housing. Developing new models to integrate housing and long-term care services is important. One example is a 2001 joint HUD-CMS demonstration project, which allocates fifty Section 8 housing slots to each of ten states for individuals being discharged from nursing homes (Milne et. al., 2004).

The Bush Administration has proposed a number of projects under its “New Freedom Initiative” intended to remove barriers to community living for people with disabilities. The goal of the initiative is to promote full access to community life: facilitating states’ efforts to expand home- and community-based services; expanding access to assistive technologies, educational opportunities, homeownership, and transportation; and helping people with disabilities who want to work get into and stay in the workforce. The initiative calls for states to implement the Olmstead decision and for workforce integration through the Ticket to Work and Work Incentives Act of 1999. As part of the New Freedom Initiative, the Administration has announced a number of new waivers and budget proposals to promote home and community-based care for people with disabilities.

Expanding home and community-based services has been restricted due to limited resources, particularly in light of the budget problems states have faced over the last several years. It is unlikely that states will be able to increase access to home and community-based services without additional federal dollars. Some states favor shifting a larger share of the costs of long-term care to the federal government by increasing the federal matching payments for long-term care. Others would like to change home and community-based services from a state option into a waiver program.

- **Expanding consumer direction**

Under the New Freedom Initiative, the federal government, since 2000, has awarded states \$40 million in “Real Choice System Change Grants” to support state efforts to expand or improve community long-term care support systems to help people with disabilities or long-term care needs live and participate in community life. To further the goals set forth in the New Freedom Initiative, the Bush Administration, in fall 2002, announced the Independence Plus Waiver Initiative. The Independence Plus waiver program is an expansion and modification of the previously approved “Cash and Counseling” waivers that were first established in 1996 and allow individuals to hire, fire, train, and supervise personal assistance attendants.

As of September 2003, 4 states (Florida, Louisiana, New Hampshire, and South Carolina) have enacted Independence Plus waivers (Crowley 2003b). While these waivers provide important opportunities for improving the quality of and satisfaction with Medicaid home and community-based services, critical policy issues, such as whether the individual budgets are adequate to meet the needs of the beneficiary, what happens when an individual is faced with a change in health status and needs emergency services or equipment, and whether the scope of services subject to consumer direction under these waivers are too broad to be handled by an individual budget. There are also concerns about the quality of services delivered and the potential for the misuse of

funds on behalf of an incapacitated beneficiary. To ensure adequate quality of care there needs to be a balance between personal independence, consumer protection and the appropriate use of public funds. These issues must be resolved in order for this initiative to successfully meet the needs of the beneficiaries who wish to direct their own care.

- **Concerns persist about the quality of nursing home and home and community-based care**

Over the past 15 years, the quality of care and quality of life for residents of the nation's nursing homes has improved significantly, but problems remain. Nursing home reform legislation passed in 1987 altered the standards to which nursing homes are held, established new survey methods, and improved enforcement mechanisms (Jost 1989, Hawes 1996). These reforms have had a real impact on quality, with substantial reductions in the inappropriate use of physical restraints and psychotropic drugs, reductions in bad practices such as the use of indwelling urinary catheters, and increases in good practices, such as more comprehensive care plans and more widespread provision of activities for residents (Hawes 1996). However, quality problems remain in a significant proportion of the nation's nursing homes, and enforcement mechanisms are weak and underutilized in many states. A 1998 report by the U.S. General Accounting Office that documented serious deficiencies in California nursing homes led to a new round of Congressional hearings on nursing home quality and renewed efforts to improve the effectiveness of survey and enforcement and quality measurement (U.S. GAO 1998).

One issue that has received attention is the adequacy of nursing home staffing levels and the relationship between staffing and quality. Many studies show a positive relationship between nurse staffing levels and better care outcomes. CMS and an expert panel by the Hartford Institute for Geriatric Nursing put forth recommendations on the level of nursing staff necessary to guarantee resident safety. Both sets of recommendations present higher staffing levels than federal and, in many cases, state staffing requirements. Recent survey findings show that actual medial staffing levels in nursing homes are higher than state minimum standards and much higher than federal requirements, however, they are still lower than both the CMS and Hartford Panel recommendations (Harrington 2002).

Poor quality of care has also been linked to low payment rates in Medicaid. The Boren Amendment established federal standards requiring that states' nursing home payments be "reasonable and adequate to meet the cost incurred by efficiently and economically operated facilities in order to provide care and services in conformity with applicable State and Federal laws, regulations, and quality and safety standards." However, Boren was widely criticized for increasing nursing home costs and jeopardizing other parts of the Medicaid program.<sup>3</sup> With its repeal in the 1997 Balanced Budget Act, states were given more freedom to set payment rates,<sup>4</sup> raising concerns that Boren's repeal may result in a reduction in the rates paid for publicly financed residents and may reduce access to and the quality of care for Medicaid patients. What the repeal of these federal

standards has actually meant for access and quality of care in the nation's nursing homes has not yet been studied.

It is generally assumed that the quality of home and community-based care is better than nursing home quality because clients, have greater control over services, have family and other community supports, are less isolated than residents of nursing homes, and tend to be more satisfied with the services they receive. However, since clients are physically dispersed it is more difficult to monitor quality and hold providers accountable. Quality assurance activities tend to be limited, financed exclusively by states (unlike nursing home survey and certification which is financed by the federal government), and home care quality measures are much less developed than measures of nursing home quality. States attempt to ensure quality of care in HCBS waiver programs through monitoring activities, consumer complaint programs, and licensing, certification, and regulatory requirements. However, a 2003 GAO report found that Medicaid HCBS waivers do not have sufficient oversight and the quality of beneficiary care is not adequately monitored (U.S GAO 2003).

As with nursing homes, the federal government does not set minimum standards for payment rates for home and community-based long-term care services. Stakeholders assert that low payments make it difficult to recruit and retain high quality workers to care for elderly and disabled Medicaid beneficiaries.

- **State efforts to control long-term care costs**

Long-term care accounts for a substantial share of total Medicaid spending. On average, however, Medicaid spending on long-term care has grown at about the same rate as acute care spending in recent years (approximately 8 percent per year between 1992 and 2002). Moreover, in 2002, Medicaid long-term care spending grew much more slowly than overall Medicaid spending—at an 8.5 percent rate compared to acute care, which grew by 13.5 percent (the sixth consecutive year that spending growth in the program accelerated).<sup>5</sup> Between fiscal years 2002 and 2004, at least nineteen states took action to reduce long-term care spending. These reductions took the form of revised reimbursement policies for nursing homes, tightening eligibility criteria to qualify for home and community-based services, reducing the number of home and community-based service waiver slots, eliminating or scaling back medically needy programs and reducing benefits (Smith et al, 2003). Some states have also sought to reduce their costs by taking a more aggressive approach to asset transfer and estate recovery. Spending reductions have affected those using community-based care services as well as those needing nursing home care.

One approach that some states have pursued, and many assert is necessary, is to better integrate acute and long-term care delivery and financing. Those who need long-term care often have multiple chronic conditions and also have significant needs for acute care services. When acute and long-term care services are not well integrated or managed, the use of services may be higher, and the quality of care lower, than it would otherwise be. Since Medicare and Medicaid financing streams are not integrated, many

argue that providers have financial incentives to shift patients between settings and payors. Despite the interest in this approach to cost containment and quality improvement, there is not a great deal of evidence of cost savings and some reason to be concerned about how “integration” would affect access to health care services under Medicare and Medicaid.

There have been several efforts to integrate acute and long-term care services, such as the Program of All-Inclusive Care for the Elderly (PACE), Social Health Maintenance Organizations (SHMOs) and Minnesota Senior Health Care Options (MSHO). In Minnesota, Medicare funds are blended with Medicaid funds through a Medicare waiver that allows health plans to integrate delivery and financing of a full range of medical and long-term care services. The Minnesota program has not been replicated by other states because of concerns that the program interferes with Medicare beneficiaries’ freedom of choice of providers. The PACE program also combines Medicare and Medicaid funded services. Social HMOs in Medicare added a limited chronic care benefit to cover a range of home and community-based services in Medicare HMOs. Although PACE and SHMOs are viewed as promising models, they have not been widely replicated or attracted large number of enrollees.

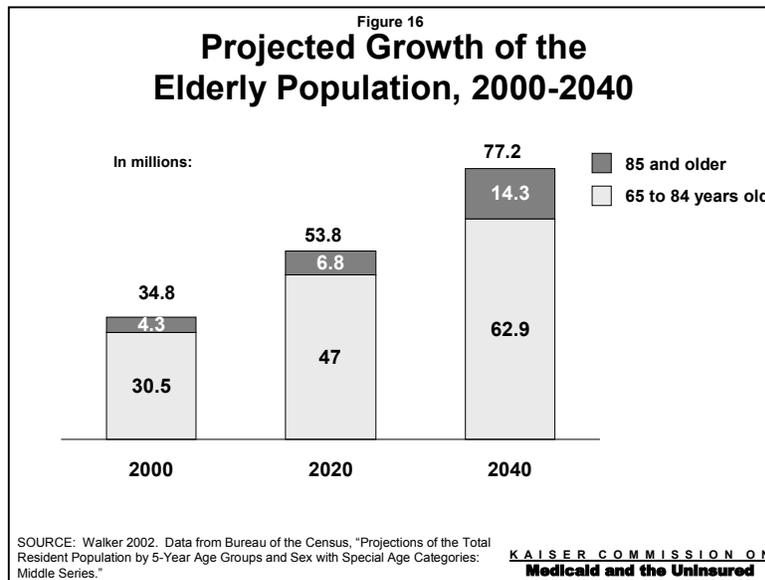
States are also grappling with how to finance care for the over 7 million dual eligibles, the low-income elderly and persons with disabilities who are enrolled in both Medicaid and Medicare. States have called on the federal government to assume greater fiscal responsibility for this population (NGA, 2003). Dual eligibles account for a small share of total Medicaid enrollment but more than 40 percent of Medicaid expenditures for medical services (Bruen and Holahan, 2003). While Medicare covers basic health services, including physician and hospital care, dual eligibles rely on Medicaid to pay Medicare premiums and cost sharing, and to cover critical benefits Medicare does not cover, such as long-term care. Starting in 2006, coverage of prescription drugs for dual eligibles will shift from Medicaid to Medicare. However, states are required to finance a large share of the cost of providing the Medicare Part D prescription drug benefit to full dual eligibles through payments to the federal government. Although it will likely be some time before states are able to fully evaluate the effect of the new Medicare law on their Medicaid budgets, it is clear that financing coverage of dual eligibles will continue to pose a challenge to fiscally-pressed Medicaid programs.

- **Growing demand for long-term care**

The demand for long-term care is projected to grow significantly over the next several decades, especially after 2030 when the baby-boom generation begins to reach age 85. By 2040, growth in the over 85 population – the population most likely to need long-term care services—is projected to more than triple from about 4 million to about 14 million (Walker 2002, p. 10) [**Figure 16**].

Although disability rates among the elderly are falling, there has been a rise in the disability rates among the non-elderly (Lakdawalla, Bhattacharya, and Goldman 2004). One explanation for the change in disability rates is the improved medical treatments

that are able to extend the lives of the frail elderly and persons with disabilities. Despite the improvements in the well being of the elderly, there are still a substantial number of elderly who continue to be at risk of living in poverty. According to a recent Employee Benefit Research Institute (EBRI) report, most retirees in 2030 will not have enough income and assets to cover even basic expenditures or any expenses related to a nursing home stay or services from a home health provider (VanDerhei and Copeland 2003). Due to the change in disability rates and the economic welfare of the elderly, the demand for long-term care services is expected to continue to increase and will cause the overall cost of providing long-term care services to rise.



In the absence of broader long-term care reform, Medicaid will continue to be the major source of financing for long-term care. However, as states continue to face serious fiscal problems and there are concerns that the major entitlement programs (Social Security and Medicare) will grow and eventually account for a large piece of the federal budget (Walker 2002, p. 1), the major issue facing Medicaid is how to continue to provide coverage for long-term care for low-income and vulnerable populations who rely on this program in the face of intense pressures to limit public spending. Although improvements in the health of the elderly may offset some of the effects of the aging population, they will not be enough to substantially reduce the burdens on Medicaid.

## Conclusion

Gaps in existing insurance arrangements result in financial burdens for individuals who need long-term care, burdens on caregivers, and needs for services that go unmet. Ironically, changes in medical care that have improved its effectiveness—such as shorter hospital stays, the increased use of outpatient procedures, and the substitution of home care for institutional care—have shifted responsibility from paid providers toward unpaid providers, increasing burdens on family caregivers.

Medicaid is the single largest source of financing for long-term care and accounts for the large majority of public financing for long-term care. However, there are a number of problems with the way Medicaid works for people with long-term care needs: eligibility based on a welfare model limits access for those with limited ability to afford care on their own; low provider payments limit access to services; and issues around quality of care persist. But there have also been some important improvements in the Medicaid long-term care program, notably in the quality of nursing home care and in access to home and community-based services. Further opportunities for improvement exist — the main focus now being the expansion of home and community-based services — and are on the agenda of state and federal policy makers. Fiscal challenges, however, limit efforts to expand access to care and put Medicaid's existing long-term care protections at risk. A number of states have proposed or implemented policies that would restrict eligibility for services, reduce payment rates, or cut benefits. These changes threaten access to care and the quality of care for Medicaid's most vulnerable beneficiaries.

Barring significant policy changes, such as adding long-term care services to Medicare or creating a new program to assist with long-term care, Medicaid is likely to be the major source of financing for long-term care in three to four decades from now as the baby boomers begin to turn 85. Improvements in the financial wellbeing of the elderly and declining disability rates may offset some of this increased demand, but Medicaid's long-term care protections will need to be maintained and improved to assure the health and quality of life for the nation's elderly and persons with disabilities who need long-term care.

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<sup>1</sup> Includes nursing home, ICF-MR, home health and personal care, but excludes HCBS spending—not available by age.

<sup>2</sup> Through 2002, 140,000 policies have been sold and 116,000 policies remain in force; 1,397 policyholders have received services payments (Meiners 2003b).

<sup>3</sup> "State Medicaid officials overwhelmingly came to oppose the amendment as impossible to operationalize, believing that they were forced by the courts to spend too much on nursing homes at the expense of other services" (Wiener and Stevenson 1998, p. 1).

<sup>4</sup> In its place is a new section of the Medicaid Act which requires states to (a) use a public process for determining rates, (b) publish proposed and final rates, the methodologies underlying the rates, and justifications for the rates, and (c) give interested parties a reasonable opportunity for review and comment on the proposed rates, methodologies, and justifications.

<sup>5</sup> The Congressional Budget Office explains that the 2002 increase "resulted from a combination of higher prices and rising enrollment and utilization. Rising unemployment—along with state and federal actions in recent years to expand Medicaid eligibility and benefits, increase payment rates to providers, and conduct outreach—has increased both enrollment and costs (CBO 2003). Most notably, spending for outpatient prescription drugs, which accounted for about 9 percent of Medicaid spending in 2002, jumped by 18 percent (after rising by roughly 20 percent in each of the previous three years). States also expanded their use of financing mechanisms related to Medicare's upper payment limit (UPL), which generated additional federal payments.

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