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

Executive Summary

Prepared by

Ellen O'Brien
Georgetown University Health Policy Institute

for

The Kaiser Commission on Medicaid and the Uninsured

November 2005

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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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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.

1330 G Street NW, Washington, DC 20005
Phone: (202) 347-5270, *Fax:* (202) 347-5274
Website: www.kff.org/KCMU

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