

medicaid
and the uninsured

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Medicaid as a Long-term Care Program:
Current Benefits and Flexibility

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The design of Medicaid's benefits package reflects the health and long-term care needs of the 50 million low-income individuals it covers. The populations served by Medicaid not only have a broad range of health and long-term care needs; they also have more significant health problems and face higher financial barriers to care than other Americans. Over a third of Medicaid beneficiaries (36%) report that their health status is fair or poor, compared to just 12% of people enrolled in private insurance plans, and over a quarter had a serious illness or health problem in the past year.¹ Low-income individuals typically subsist on tight family budgets, often just meeting their basic needs such as housing, food, and transportation.² Individuals with disabilities and the elderly often live with multiple chronic conditions that require ongoing access to a range of health services that are not widely available, such as costly prescription medications, special equipment, and supportive services.

Under current Medicaid law, states have broad discretion in designing their Medicaid programs to serve these populations:

- States have the discretion not to participate in the program at all. Federal Medicaid rules apply only to states that elect to receive guaranteed federal matching payments for the cost of health and long-term care services furnished to their low-income populations.
- States have the discretion to cover – or not to cover – “optional” population groups and “optional” services, like prescription drugs. If they choose to cover these groups, like individuals with high long-term care expenses (the “medically needy”), and services, they receive federal matching funds for the resulting costs. Approximately 65 percent of all Medicaid spending is on such populations and benefits.³
- States have the discretion to limit the scope of the benefits that they do cover, whether those benefits are “mandatory,” like nursing facility services, or “optional,” like personal care services.
- States have the discretion to impose “nominal” cost-sharing requirements on some populations with respect to some benefits (e.g., low-income elderly beneficiaries for outpatient prescription drugs).
- States have the discretion to impose prior authorization and other utilization control requirements with respect to the services that they cover (e.g., establishing severity criteria for admission to nursing facilities).⁴ With the exception of services to children, states have the discretion to adopt restrictive definitions of “medical necessity” for the purposes of determining that a payment will be made for a covered service.

- States have the discretion to purchase the benefits they cover from providers on a fee-for-service basis, from managed care plans on a capitation basis, or through a combination of payment structures. While some states buy some long-term care services for some populations on a capitation basis, most Medicaid long-term care services are purchased on a fee-for-service basis. (One type of capitation arrangement, the Program for All-inclusive Care (PACE), is discussed in more detail below).
- States have the discretion to set payment rates for almost all of the benefits they purchase on a fee-for-service basis at a level lower than the cost incurred by the provider in furnishing the service to a Medicaid patient. For example, Medicaid payments for nursing facility services are frequently lower than Medicare payments for nursing facility services on behalf of residents with comparable functional limitations.
- States have the discretion to purchase home- and community-based services for particular groups of Medicaid beneficiaries who at risk of institutional care. As discussed in more detail below, federal matching funds for these services are available only under a waiver from the Secretary of Health and Human Services (HHS) based on a showing of budget neutrality to the federal government.
- States also have the discretion to request from the Secretary of Health and Human Services (HHS) waivers of most federal Medicaid rules for purposes of demonstrating innovations in benefits design while continuing to receive federal Medicaid matching funds. A number of states have obtained waivers for statewide demonstrations affecting benefits and cost-sharing, including waivers that eliminate all long-term care coverage for certain populations.⁵ The Administration has signaled its willingness to entertain similar requests from other states.⁶

Faced with sharp declines in revenues, state policymakers are expressing a strong interest in even greater “flexibility,” particularly with respect to benefits and cost-sharing.⁷ This has triggered a debate over the extent to which the current minimum federal Medicaid requirements should be further relaxed and what the implications of such changes would be for the health status of the low-income populations that Medicaid serves. The fiscal context for minimum federal requirements is that, nationally, the federal government pays more than half of the costs of Medicaid services; in FY 2003, it will spend an estimated \$46.5 billion on Medicaid long-term care services alone.⁸

The purpose of this issue brief is to inform this debate by identifying those areas in which current federal Medicaid law does not extend unlimited discretion to states. Though the “flexibility” debate spans the breadth of the program, from eligibility to benefits and cost-sharing to administration,⁹ this brief focuses on just one subset of “flexibility” issues: the current federal benefits and cost-sharing rules that apply with respect to long-term care. (A companion issue brief examines state “flexibility” in the context of Medicaid’s acute care benefits).¹⁰ Specifically, it discusses the minimum requirements that states must meet in order to receive federal Medicaid matching funds for the costs of the long-term care benefits they purchase. It also discusses the options

states have under current law and the waivers that states may obtain from federal rules relating to Medicaid coverage of long-term care services. Although the brief describes the federal rules within which states establish their benefits packages, and the ways in which these rules can be waived, it does not provide a state-by-state listing of services covered or cost-sharing imposed.¹¹

Minimum Federal Benefits Requirements

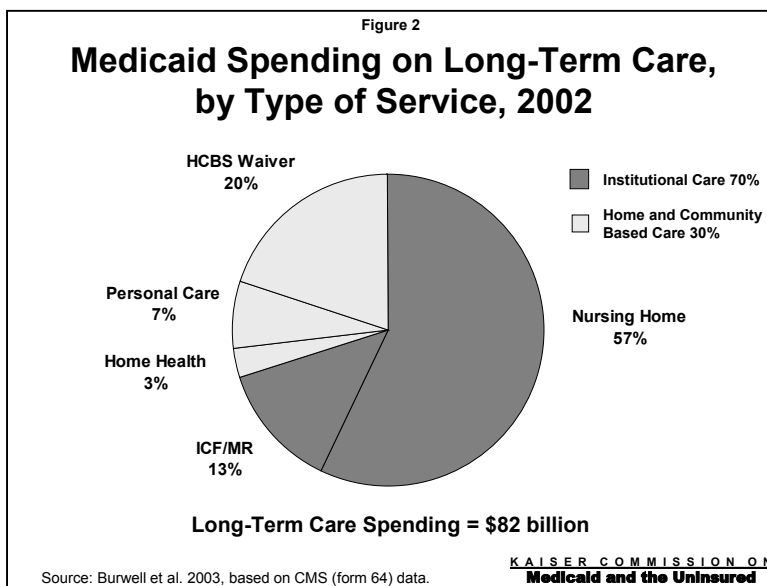
There are five basic rules in federal Medicaid law that governs the design of a state's Medicaid benefits package with respect to long-term care services. These rules are intended to ensure that, in all states, low-income Americans eligible for Medicaid receive coverage for a benefits package of a minimum scope, and that the scope of benefits offered by any particular state does not vary depending on an individual's medical condition or place of residence. These rules are aimed at making coverage affordable for the low-income population served, ensuring that services are adequate, and promoting fairness in the distribution of benefits financed with federal funds. These rules are supplemented by general prohibitions (not discussed in this issue brief) against discrimination on the basis of race or ethnicity, disability, or gender in programs of federal financial assistance.¹²

Mandatory Benefits. Medicaid is an individual entitlement program.¹³ That is, low-income Americans who qualify are entitled to have payment made on their behalf, when medically necessary, for a defined set of benefits. This defined set of benefits includes, at a minimum, so-called "mandatory" benefits that all states electing to participate in Medicaid must offer to most groups of beneficiaries. States may elect to expand this minimum benefits package with one or more "optional" benefits, and all states have chosen to do so. As a result, Medicaid benefits packages vary substantially from state to state. Figure 1 shows the statutory "mandatory" and "optional" benefits categories related to long-term care services under current federal law.¹⁴ As is evident, most of the long-term care benefits categories are "optional."

Figure 1: Medicaid Long-term Care Statutory Benefits Categories ¹⁵

<u>“Mandatory” Items and Services</u>	<u>“Optional” Items and Services</u>
<i>Institutional Services</i>	<i>Institutional Services</i>
Nursing facility (NF) services for individuals 21 or over	Inpatient hospital and nursing facilities services for individuals 65 and over in an institution for mental diseases (IMD)
	Intermediate care facility for individuals with mental retardation (ICF/MR) services
	Inpatient psychiatric hospital services for individuals under age 21
<i>Noninstitutional Services</i>	<i>Noninstitutional Services</i>
Home health care services for individuals entitled to NF services	Home health care services
	Case management services
	Personal Care Services
	Prescription Drugs
	Respiratory care services for ventilator-dependent individuals
	Private duty nursing services
	Hospice care
	Services furnished under a PACE program
	Home- and community-based (HCBS) services (under waiver, subject to federal budget-neutrality requirements)

This imbalance between the number of “mandatory” noninstitutional services and the number of “optional” noninstitutional services has contributed to the criticism that Medicaid has an “institutional bias.” And in fact, of the \$82.1 billion that the federal and state governments spent on long-term care services in FY 2002, about 70 percent was paid to institutions (Figure 2). However, more Medicaid beneficiaries (2.1 million in 2001) receive noninstitutional services than receive institutional care (1.8 million).¹⁶ This is not to say that all Medicaid beneficiaries now residing in nursing facilities or ICFs/MR are appropriately placed; clearly there are cases where individuals are institutionalized only because they are unable to obtain Medicaid coverage for needed services in the community. The Federal law limitations on the availability of Medicaid coverage for home and community-based services are discussed below.



Amount, Duration, and Scope. While all participating states must cover all mandatory benefits, a mandatory benefit in one state need not be identical to a mandatory benefit in another. For example, one state might cover an unlimited number of medically necessary inpatient days in a hospital, while another might impose a limit on the number of days, as in Florida and Oklahoma (45 and 15 days per year, respectively).¹⁷ In all states, however, each “mandatory” benefit must be more than a benefit in name only. In technical terms, it must be “sufficient” in “amount, duration, and scope” to reasonably achieve its purpose.¹⁸ This same requirement applies to any “optional” services, like prescription drugs, that a state chooses to cover. The Centers for Medicare & Medicaid Services (CMS) has never defined with precision what amount, duration and scope is minimally “sufficient” for each mandatory benefit. Instead, CMS has left this issue to state discretion, ultimately to be resolved by the federal courts.¹⁹

Comparability. Whatever amount, duration, and scope limits, if any, a state imposes on a particular mandatory or optional service, the service as so limited may not vary among individual beneficiaries, whether those beneficiaries are in mandatory or optional eligibility groups. Technically, this is referred to as the “comparability” requirement.²⁰ For example, a state may not limit eligible parents to 21 days of inpatient hospital services per year while offering unlimited inpatient hospital coverage to elderly or disabled individuals receiving Supplemental Security Income (SSI) benefits. Similarly, a state may not offer unlimited prescription drug coverage to elderly individuals receiving SSI while imposing a 5-prescription per month limit on individuals with disabilities receiving SSI.

Non-Discrimination. Federal Medicaid law precludes states from limiting coverage for any particular mandatory service solely on the basis of diagnosis, type of illness, or condition.²¹ Again, CMS has not defined this requirement with any specificity,

but federal courts have on occasion ruled on the issue.²² On its face, the rule precludes states from implementing benefits design policies that would, for example, specifically exclude eligible individuals with Alzheimer’s from coverage for nursing facility services while providing these same benefits to other groups.

Statewideness. State Medicaid programs may not vary the mandatory or optional benefits they offer by place of residence.²³ The purpose of this “statewideness” requirement is to ensure that benefits, whether mandatory or optional, do not vary from locality to locality, depending on, for example, the amount a locality is able or willing to contribute toward the state’s share of program costs or on the partisan political orientation of the locality or its elected officials.²⁴ The “statewideness” requirement does not guarantee that an individual beneficiary will actually receive covered services in the community in which he or she resides; that is determined by the availability and accessibility of providers. “Statewideness” does, however, mean that a state Medicaid program cannot offer unlimited coverage for nursing facility services in urban counties that contribute toward the costs of the program while limiting coverage to, say, 60 days per year in rural counties that are unwilling or unable to make a contribution.

Minimum Federal Cost-Sharing Requirements

Cost-sharing refers to out-of-pocket payments that individuals enrolled in Medicaid are required to make in connection with the furnishing of a covered service. Cost-sharing may include deductibles, copayments, or coinsurance requirements. (Cost-sharing does not include premiums, the payment of which enables an individual to qualify for coverage; cost-sharing applies only when an individual has already established eligibility for coverage). The purpose of cost-sharing requirements is to deter unnecessary utilization of covered services, thereby reducing the costs of coverage for the Medicaid program. The imposition of cost-sharing on low-income populations, however, can deter both the use of needed as well as unnecessary services.²⁵

Note that, in the context of long-term care services, federal Medicaid policy often requires out-of-pocket payments by applicants and beneficiaries in forms other than conventional cost-sharing – i.e., deductibles, copayments, or coinsurance. In the case of applicants, there are some eligibility pathways – notably the optional “medically needy” pathway – that have the effect of postponing coverage until an individual has spent a portion of his or her income on health care. Individuals seeking to qualify for Medicaid as “medically needy” must “spend-down” in order to establish eligibility – i.e., incur medical expenses in amounts that, when subtracted from their incomes, reduce their net incomes to the state-established eligibility level.²⁶

In the case of individuals who have established their eligibility for Medicaid benefits – whether as “medically needy” or through some other eligibility pathway – and who reside in an institution (e.g., nursing facility, ICF/MR), federal regulations require that much of the individual’s monthly income be applied to the cost of care, thereby

reducing the amount that the Medicaid program must pay. Certain expenses, such as a personal needs allowance of at least \$30 and a maintenance needs allowance for a spouse living in the community, are deducted from the beneficiary's income, and the remainder is paid to the institution.²⁷ 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.²⁸

Federal Medicaid law limits state flexibility to impose conventional cost-sharing – deductibles, co-payments, or coinsurance -- on low-income Medicaid beneficiaries in four ways. First, certain categories of beneficiaries are exempt from any cost-sharing requirements. Second, certain acute care services are not subject to cost-sharing. Third the cost-sharing that states may impose must be “nominal.” Finally, participating providers may not withhold services from beneficiaries who cannot afford the deductible, copayment, or coinsurance requirement.

Federal Medicaid law exempts several categories of beneficiaries from cost-sharing entirely, two of which are pertinent here.²⁹ One category is inpatients in hospitals, nursing facilities, or intermediate care facilities for the mentally retarded (ICFs/MR) who, as a condition of eligibility, are required to apply most of their income to the cost of care. The other is terminally ill individuals receiving hospice care. In the former case, as noted before, the beneficiary is already sharing substantially in the cost of care, and imposition of additional cost-sharing requirements would serve no useful purpose. In the latter case, the purpose of the exemption is to avoid deterring terminally ill individuals from using hospice benefits.³⁰

With respect to all non-exempt groups of beneficiaries and types of services, states have the discretion to impose “nominal” cost-sharing. Under CMS regulations, which have not been revised since 1983:

- a “nominal” deductible is \$2 per month per family,
- a “nominal” copayment may range from 50 cents to \$3.00, depending on the amount of the state's payment for the item or service, and
- a “nominal” co-insurance requirement is five percent of the state's payment rate for the item or service.³¹

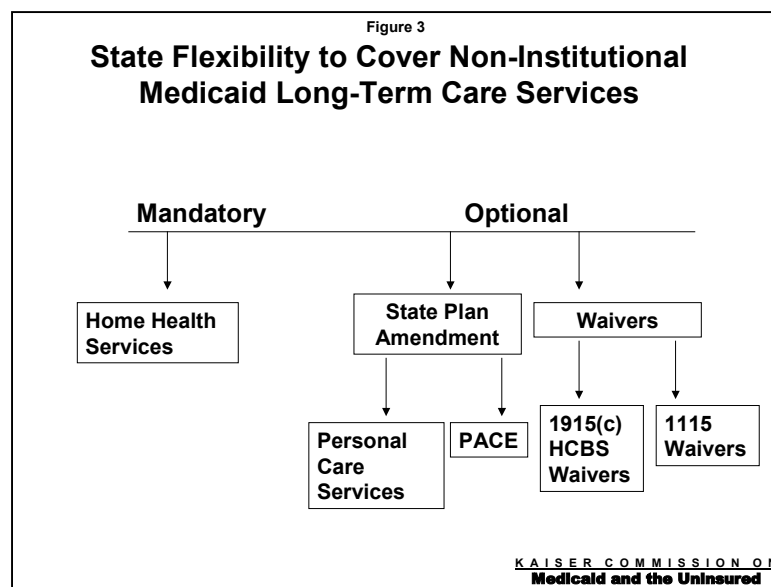
Cost-sharing, whether in the form of deductibles, copayments, or coinsurance, is commonly collected by providers at the point of service. Providers are not required to participate in Medicaid, but if they do so they must accept the amounts that Medicaid pays for a service as payment in full. Medicaid programs will generally deduct from their payment rates the amount of any cost-sharing imposed on the service, assuming that the provider will collect the amount directly from the beneficiary. Since Medicaid beneficiaries are by definition poor or near-poor, many may be unable to pay some or all of the required amount. Under federal Medicaid law, participating providers may not withhold covered items or services from beneficiaries who are unable to pay.³² As a

legal matter the beneficiaries remain liable to the provider for the allowed cost-sharing amount, but as a practical matter these sums are often uncollectible. In these circumstances, cost-sharing requirements operate as reductions in provider reimbursement rates and have the effect of discouraging providers from participating in the program.³³

Flexibility to Cover Non-institutional Long-Term Care Services

As noted in Figure 1, states are required to cover just one non-institutional long-term care benefit: home health services. This benefit, in turn, has three mandatory elements: (1) part-time or intermittent nursing services; (2) home health aide services provided by a home health agency meeting Medicare participation requirements; and (3) medical supplies, equipment, and appliances suitable for use at home. States also have the option, as part of this benefit, to cover physical therapy, occupational therapy, or speech pathology and audiology services provided by a home health agency.³⁴ Medicaid beneficiaries may qualify for home health services whether or not they require institutional care or have been discharged from a hospital or nursing home.³⁵ And, unlike Medicare, Medicaid policy does not require the beneficiary to be homebound in order to qualify for home health services.

Beyond the mandatory home health services benefit, states have broad discretion in designing non-institutional Medicaid long-term care benefit packages for different populations (e.g., frail elderly, individuals with mental retardation, individuals with chronic mental illness, etc.). This flexibility takes a number of forms: optional service categories like personal care services and PACE programs; home and community-based services (HCBS) waivers; and section 1115 demonstration waivers. The large majority of Medicaid spending on non-institutional long-term care occurs through the HCBS waivers; in FY 2001, total federal and state Medicaid spending on HCBS waivers was \$14.2 billion, compared to \$5 billion on personal care services and \$2.8 billion on home health services.³⁶ The following sections discuss each of these types of flexibility (Figure 3).



Personal Care Services. There is no single definition for the term “personal care services.” The term is generally used to describe individualized assistance with activities of daily living (ADLs) such as bathing, toileting, dressing, eating, and transferring from a bed to a chair. It can also extend to assistance with the instrumental activities of daily living (IADLs) such as personal hygiene, light housework, shopping, meal preparation, and money management. In either case, the general purpose of the services is to enable individuals with long-term care needs – whether frail elderly or individuals with disabilities – to maintain their independence and remain in the community. Personal care services do not include physician or nursing services or other medical care.

States that want to cover personal care services through Medicaid have the choice of offering them as an optional service, as a service under a HCBS waiver, or both. There are two important differences. First, as in the case of other optional services, states that offer personal care services as an optional service must make them available to all individuals in the state who meet the financial and non-financial eligibility criteria. In contrast, under an HCBS 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. This discussion focuses on personal care services as an optional service; personal care in the context of the HCBS waiver is discussed below.

States that elect to cover personal care services as an optional benefit have broad latitude in defining its scope. Federal regulations require only that the services be (1) authorized by a physician or under a state-approved service plan, (2) provided by a qualified individual who is not a member of the beneficiary’s family, and (3) furnished in the beneficiary’s home or other location specified by the state.³⁷ Given this latitude, it is not surprising that the scope of tasks covered, the functional eligibility criteria for receiving such services, the coverage limits (e.g., number of hours per month), and the provider qualifications vary from state to state.³⁸ As of 2000, over half the states (27) offered personal care services as an optional benefit.³⁹ In 2001, federal and state Medicaid spending on the personal care services benefit totaled \$5 billion, with roughly half a million beneficiaries served.⁴⁰

Program of All-inclusive Care for the Elderly (PACE). PACE services are unique among the Medicaid optional long-term care benefits categories. PACE services are not just an institutional service or just a non-institutional service; beneficiaries enrolled in PACE programs may receive both types of long-term services, as well as all acute care services covered by their state’s Medicaid program with no cost-sharing. In addition, PACE services are not purchased on a fee-for-service basis, like personal care services, but rather on a capitation basis. As of September 2003, there were 28 approved PACE programs operating in 17 states (CA, CO, FL, KS, MD, MA, MI, MO, NY, OH, OR, PA, SC, TN, TX, WA, and WI).⁴¹ Just as coverage of long-term care services through PACE programs is optional with states, so enrollment in PACE programs is voluntary for beneficiaries. (Beneficiaries who enroll agree to receive all of

the acute and long-term care services to which they are entitled under their state's Medicaid plan through the PACE program). As of December 2002, there were 8171 individuals in the 28 programs.

PACE programs are designed to manage the care of the frail elderly – i.e., individuals age 55 or older who are eligible who are certified as needing nursing home care. These individuals may be eligible for Medicare only, for Medicaid only, or for both Medicare and Medicaid. In 2000, the typical enrollee was “an 81-year-old widow, living alone or with relatives, with several chronic medical conditions and, more likely than not, suffering some degree of cognitive impairment.”⁴² PACE programs are paid on a capitation basis. In the case of dually eligible enrollees, PACE programs are paid a monthly capitation payment by both Medicare and Medicaid; in the case of enrollees eligible for Medicaid but not Medicare, only the state Medicaid agency makes a capitation payment; and in the case of an enrollee eligible for Medicare only, that individual pays privately the equivalent of the Medicaid capitation payment. About 2/3 of PACE program revenues come from Medicaid, about 1/3 from Medicare.⁴³ In exchange for monthly capitation payments, PACE programs furnish both institutional and non-institutional services to their enrollees, ranging from case management, adult day health services, personal care services, and physician care to hospitalization and nursing home care. The financial incentive for each PACE program is to reduce the use of expensive hospital and nursing home care; evaluations have found that they do so by substituting less expensive preventive and supportive services.⁴⁴

The Federal Medicaid statute requires that PACE programs furnish, either directly or through contractual arrangements with other providers, a wide range of acute and long-term care services to their enrollees. Specifically, in the case of enrollees dually eligible for Medicare and Medicaid, all items and services covered under Medicare and all items and services covered under the state's Medicaid program must be furnished “without any limitation or condition as to amount, duration, or scope.”⁴⁵ In addition, enrollees in PACE programs are exempt from any deductibles, copayments, coinsurance, or other cost-sharing that would otherwise be required of a beneficiary under Medicare or their state Medicaid program. PACE programs must provide covered services to enrollees through “a comprehensive, multidisciplinary health and social services delivery system, which integrates acute and long-term care services pursuant to regulations.”⁴⁶

Home and Community-Based Services (HCBS) Waivers. Under section 1915(c) of the Social Security Act, the Secretary of HHS has the authority to “waive” certain federal requirements to enable states to cover home and community-based services for individuals at risk of institutionalization in a hospital, nursing home, or intermediate care facility for individuals with mental retardation (ICF/MR).⁴⁷

HCBS waivers accomplish a number of policy objectives. First, they allow states to cover on a fee-for-service basis certain non-institutional services for which they could otherwise not receive federal Medicaid matching funds (e.g., adult day health services, habilitation services and respite care). Second, they allow states to limit coverage of

services for which they could otherwise receive federal matching funds – e.g., personal care services – to particular populations (e.g., individuals with developmental disabilities) in particular areas of the state. Finally, they allow the federal government to limit its financial exposure for coverage of non-institutional long-term care services under Medicaid because states must demonstrate budget neutrality in order to receive a waiver. If all HCBS services could be offered as an optional benefit (as is the case with personal care services), states would not be required to show federal budget neutrality. The Bush Administration has identified HCBS waivers as one of two policy tools available to states under its “Independence Plus” initiative (the other is the section 1115 demonstration waiver authority described below).⁴⁸

As summarized in Figure 4, eight categories of services can be covered under an HCBS waiver. These are: case management; homemaker/home health aide services; personal care services; adult day health services; habilitation services; respite care; and day treatment and other partial hospitalization services, psychosocial rehabilitation services, and clinic services for individuals with chronic mental illness. Finally, HCBS waivers may include other services requested by the state, such as in-home supports, special communication services, minor home modifications, and transportation for non-medical purposes. However, states may not make direct cash payments to beneficiaries to enable them to purchase services directly. In addition, states may not use federal funds under HCBS waivers to pay for room and board.

Figure 4: Medicaid Home- and Community-Based Services Options

<u>Optional Service Category</u>	<u>Optional Service Elements</u>
<p><i>Home health care services</i> (must include (1) nursing care on a part-time or intermittent basis, (2) home health aide service provided by a home health agency, and (3) medical supplies, equipment, and appliances suitable for use in the home)</p>	<p>Physical therapy, occupational therapy, or speech pathology and audiology services provided by a home health agency</p>
<p><i>Personal care services</i></p>	<p>Services furnished by an individual who is not a member of the beneficiary’s family Case management services</p>
<p><i>Home and Community-Based (HCBS) Waiver Services</i> (no payment for room and board; federal budget neutrality required)</p>	<p>Homemaker/home health aide services Personal care services Adult day health services Habilitation services Respite care Day treatment or partial hospitalization, psychosocial rehabilitation services, and clinic services for individuals with chronic mental illness Other services requested by the state as the Secretary may approve (other than room and board)</p>

Every state (except Arizona) has multiple HCBS waivers targeted at a wide range of populations at risk of institutional care: the frail elderly; individuals with physical disabilities; individuals with mental retardation and developmental disabilities; medically fragile or technology-dependent children; individuals with HIV/AIDS; and individuals with traumatic brain injury.⁴⁹ As may be expected, the types of services covered under these waivers vary from population to population and from state to state.⁵⁰ In some states, HCBS waivers may be used to respond to the 1999 Supreme Court decision, *Olmstead v. L.C.*, holding that “unjustified institutional isolation of persons with disabilities is a form of discrimination” that violates the Americans with Disabilities Act.⁵¹

Section 1115 Demonstration Waivers

Although states have considerable discretion in Medicaid long-term care benefits design, some states have sought additional flexibility. Under section 1115 of the Social Security Act, the Secretary of HHS has the authority to waive many federal statutory requirements for the purposes of testing “experimental, pilot, or demonstration project(s) which, in the judgment of the Secretary, (are) likely to assist in promoting the objectives of (the Medicaid statute)” while allowing a state to continue receiving federal Medicaid matching funds. By administrative interpretation, section 1115 waivers must be budget neutral.⁵² As of May 2003, 24 states were operating section 1115 demonstration waivers.⁵³

Section 1115 demonstration waivers offer additional flexibility to states with respect to Medicaid long-term care services. One state uses this waiver authority to operate the largest capitated long-term care program in the nation. Under its Arizona Long-Term Care System (ALTCS), Arizona furnishes both institutional and home and community-based services to roughly 40,000 Medicaid-eligible frail elderly, individuals with physical disabilities, and individuals with developmental disabilities.⁵⁴

Section 1115 demonstration waivers are also being used to enable states to test the provision of “consumer-directed” services by individuals with disabilities – i.e., services that are purchased directly by the client rather than by a private or public agency on behalf of the client. Under its “Independence Plus” initiative, the Bush Administration has encouraged states to provide consumer-directed services through either section 1115 demonstration waivers or HCBS waivers. The section 1115 waiver authority gives states more flexibility than does the HCBS waiver authority. Under the section 1115 waivers, states can enroll individuals who are not at risk for institutional care, and they can allow beneficiaries to receive cash payments with which to purchase services directly. In contrast, under the HCBS waiver authority, states can only enroll individuals who meet the criteria for institutional care, and they can not make cash payments directly to beneficiaries (a third party must manage the payment for services).⁵⁵ As of September 2003, one state (Florida) had received a section 1115 “Independence Plus” waiver. (New Hampshire, South Carolina, and Louisiana have also received in “Independence Plus” waiver but under the HCBS waiver authority).⁵⁶

Conclusion

States enjoy considerable discretion under current law to administer their Medicaid programs. State policymakers are requesting additional “flexibility,” particularly with respect to benefits and cost-sharing design. In the case of long-term care coverage, states are currently required to cover nursing facility services and home health services, but they have the discretion to cover a broad range of other institutional and non-institutional services with federal financial assistance. With respect to non-institutional services, the policy choices available to states include personal care services, PACE programs, home and community-based services (HCBS) waivers, and section 1115 demonstration waivers allowing direct cash payments to beneficiaries. Given the vulnerability of the low-income elderly and individuals with disabilities who qualify for long-term care services under Medicaid, any changes in the scope of long-term care services that Medicaid covers or in the way in which Medicaid buys these services should be based on a careful analysis of the experience under current law.

Endnotes

¹ Kaiser/Commonwealth 1997 Survey of Health Insurance.

² Hudman, J. and M. O'Malley. *Health Insurance Premiums and Cost-Sharing: Findings from the Research on Low-Income Populations*. (Washington, DC: The Kaiser Commission on Medicaid and the Uninsured): March 2003.

³ Holahan and Bruen, *Medicaid "Mandatory" and "Optional" Eligibility and Benefits* (July 2001), Figure 11, www.kff.org/content/2001/2256/2256.pdf.

⁴ For a detailed discussion of the variation among states in level-of-care criteria for eligibility for Medicaid coverage of nursing facility services, see J. O'Keeffe, *People with Dementia: Can They Meet Level-of-Care Criteria for Admission to Nursing Homes and Home and Community-Based Waiver Programs?*(August 1999), AARP Public Policy Institute, www.aarp.org.

⁵ See S. Gill and C. Mann, *Section 1115 Waivers at a Glance: Summary of Recent Medicaid and SCHIP Waiver Activity* (April 2003).

⁶ See S. Gill, J. Guyer, and C. Mann, *Section 1115 Medicaid and SCHIP Waivers: Policy Implications of Recent Activity* (June 2003).

⁷ In testimony to the Congress in March of 2003, Governor Jeb Bush of Florida urged that states (among other things) be allowed to (1) provide "different coverage for different populations to meet different needs...[that] might include a core package of benefits, a long-term care package, and a supplemental package for lower income individuals with specific chronic health conditions;" (2) "design benefit packages that look more like commercial models;" (3) "...encourage Medicaid beneficiaries to be active participants in the program by ... sharing in the cost of their care and helping to control program costs;" and (4) "...encourage choice through private health insurance, supplementing costs when necessary." *Testimony of Governor Jeb Bush on Medicaid Reform*, before the Subcommittee on Health of the House Committee on Energy and Commerce (March 12, 2003) pp. 10-11.

⁸ Congressional Budget Office, *Fact Sheet for CBO's March 2003 Baseline Medicaid and the State Children's Health Insurance Program* (March 2003).

⁹ Mann, C., "The Flexibility Factor: Finding the Right Balance," *Health Affairs* (January/February 2003), pp. 62 - 76.

¹⁰ Schneider, A. and R. Garfield, *Medicaid as a Health Insurer: Current Benefits and Flexibility* (July, 2003).

¹¹ For a state-by-state listing of categories of services covered as of November 2002, see Centers for Medicare & Medicaid Services, *Medicaid At-a-glance 2002: A Medicaid Information Source*, pp. 7-11, <http://cms.hhs.gov/states/maag2002.pdf>.

¹² 42 CFR 430.2.

¹³ Medicaid is also an entitlement to states. See Schneider, Rousseau, and Wachino, *Medicaid Financing* (forthcoming).

¹⁴ For a more extensive discussion, see Kaiser Commission on Medicaid and the Uninsured, *The Medicaid Resource Book* (July 2002), Chapter II: Medicaid Benefits, p. 49 – 80, www.kff.org.

¹⁵ Transportation services are not a statutory benefits category. However, states are required to ensure necessary transportation for beneficiaries to and from providers, 42 C.F.R. 431.53, and federal Medicaid matching funds are available for transportation expenses, 42 C.F.R. 440.170(a).

¹⁶ M. Kitchener, et al., *Medicaid Home and Community-Based Services, Program Data, 1992-2001*, Kaiser Commission on Medicaid and the Uninsured, Forthcoming, Fall 2003.

¹⁷ Health Management Associates for the National Conference of State Legislatures, unpublished survey results (March 2003).

¹⁸ 42 CFR 440.230(b). This "sufficiency" requirement applies to "optional" as well as "mandatory" services

¹⁹ See cases cited in Perkins, J. and S. Somers, *An Advocate's Guide to the Medicaid Program* (June 2001), Section 4.6, note 76, www.healthlaw.org.

²⁰ Section 1902(a)(10)(A)(B) of the Social Security Act, 42 USC 1396a(a)(A)(10)(B), 42 CFR 440.240(b)(1) requires that state Medicaid plans provide that the services available to any individual in a categorically needy eligibility group be "equal in amount, duration, and scope for all recipients within the group." This "comparability" requirement also applies to individuals covered as medically needy; however, the amount, duration, and scope of the services available to the medically needy may be smaller than that of the services available to the categorically needy.

²¹ 42 CFR 440.230(c).

²² See cases cited in Perkins, J. and S. Somers, *An Advocate's Guide to the Medicaid Program* (June 2001), Section 4.6, note 77, www.healthlaw.org.

²³ Section 1902(a)(1) of the Social Security Act, 42 USC 1936a(a)(1), 42 CFR 431.50.

²⁴ Since its enactment in 1965, the Medicaid program has given states the discretion to delegate eligibility determinations and other administrative functions to counties and localities, as well as to require localities to contribute a portion of the state share of spending. Some states, including California and New York, have take up one or both of these options.

²⁵ Hudman, J. and M. O'Malley. *Health Insurance Premiums and Cost-Sharing: Findings from the Research on Low-Income Populations*. (Washington, DC: The Kaiser Commission on Medicaid and the Uninsured): March 2003.

²⁶ For a detailed explanation of "spend down," see Crowley, J., *Medicaid Medically Needy Programs: An Important Source of Medicaid Coverage* (January 2003), Appendix 1, www.kff.org

²⁷ 42 CFR 435.725 and 42 CFR 435.733 (post-eligibility treatment of income of categorically needy institutionalized individuals); 42 CFR 435.832 (post-eligibility treatment of income of medically needy institutionalized individuals).

²⁸ 42 CFR 435.726, 42 CFR 435.735.

²⁹ The other two categories exempt from any cost-sharing are (1) children under 18 with respect to all services, and (2) pregnant women with respect to any services relating to pregnancy or any other medical condition that may complicate the pregnancy. The purpose of these two exemptions is to ensure, as a matter of public health policy, that low-income children and pregnant women are not deterred from using needed services.

³⁰ Office of Technology Assessment, U.S. Congress. *Benefit Design in Health Care Reform: Background Paper—Patient Cost-sharing*, OTA-BP-H-112 (Washington, DC: U.S. Government Printing Office):

September 1993; Roemer, M. et al. "Copayments for Ambulatory Care: Penny-Wise and Pound-Foolish." *Medical Care*, 13(6): 457-66; Helms, J., J. Newhouse, and C. Phelps. "Co-payments and Demand for Medical Care: The California Medicaid Experience." *Bell Journal of Economics*. 9:192-208.

³¹ 42 CFR 447.50 – 447.59. The regulations also contain an exception to deter misuse of hospital emergency rooms. In the case of non-emergency outpatient services furnished in a hospital ER, a state may impose a deductible or copayment up to twice the "nominal" amount if the state shows that beneficiaries "have actually available and accessible to them alternative sources of non-emergency, outpatient services." 42 CFR 431.57.

³² Section 1916(e) of the Social Security Act, 42 USC 1396o(e), 42 CFR 447.15.

³³ For a discussion of the impact of unpaid Medicare cost-sharing requirements on the willingness of physicians to provide home visits or office hours to low-income Medicare beneficiaries that might help avoid premature nursing home placement, see Sheldon Hersh, M.D., *Dually Eligible People with Medicare and Medicaid* (February 26, 2003), Slide 15, www.nacdep.org/show/pptnotes.pdf.

³⁴ 42 CFR 440.70.

³⁵ 42 CFR 441.15(c).

³⁶ M. Kitchener, et al., *Medicaid Home and Community-Based Services, Program Data, 1992-2001*, Kaiser Commission on Medicaid and the Uninsured, Forthcoming, Fall 2003.

³⁷ 42 CFR 440.167.

³⁸ Mollica R., and Kassner E. *Personal Care Services: A Comparison of Four States* (March 2001), AARP Public Policy Institute, www.aarp.org.

³⁹ *Understanding Medicaid Home and Community-Based Services: A Primer*, US Department of Health and Human Services, Office of the Assistant Secretary for Planning and Evaluation, October 2000.

⁴⁰ M. Kitchener, et al., *Medicaid Home and Community-Based Services, Program Data, 1992-2001*, Kaiser Commission on Medicaid and the Uninsured, Forthcoming, Fall 2003.

⁴¹ National PACE Association, *PACE Census and Capitation Rate Information, 2002/03* (unpublished). This figure does not include so-called "Pre-PACE" programs in seven states (HI, IL, MA, NM, NY, PA, VA) which capitates for Medicaid services only, and which bill for Medicare services on a fee-for-service basis.

⁴² National PACE Association, *PACE Enrollee Characteristics*, <http://www.natpaceassn.org/content/research/profile/profile3.asp>.

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- ⁴³ National PACE Association, *PACE Revenues and Expenditures*, <http://www.natlpacessn.org/content/research/profile/profile6.asp>.
- ⁴⁴ For a summary of evaluations of PACE Demonstration Projects, see <http://www.chausa.org/LONGTERM/LTPACE.ASP>.
- ⁴⁵ Section 1934(b)(1)(A)(i) of the Social Security Act, 42 U.S.C. 1396u-4(b)(1)(A)(i).
- ⁴⁶ Section 1934(b)(1)(C) of the Social Security Act, 42 U.S.C. 1396u-4(b)(1)(C).
- ⁴⁷ Accompanying this flexibility in benefits design is the option for states to make Medicaid eligibility standards for HCBS waiver services comparable to those for institutional services. Without this pathway, qualified individuals (or their families) might face strong financial incentives for institutional placement. See Enid Kassner and Lee Shirey, *Medicaid Financial Eligibility for Older People: State Variations in Access to Home and Community-Based Waiver and Nursing Home Services* (April 2000), AARP Public Policy Institute, www.aarp.org.
- ⁴⁸ Crowley, J., *An Overview of the Independence Plus Initiative to Promote Consumer-Direction of Services in Medicaid*, The Kaiser Commission on Medicaid and the Uninsured (forthcoming Fall 2003).
- ⁴⁹ For a listing of HCBS Waivers by type and by state, see www.cms.gov/medicaid/1915c/proginfo.asp.
- ⁵⁰ *Promising Practices in Home and Community-Based Services*, US Department of Health and Human Services, The Centers for Medicare and Medicaid Services, www.cms.gov/Medicaid.
- ⁵¹ *Olmstead v. L.C.*, 199 S. Ct. 2187 (1999); Sara Rosenbaum, *The Olmstead Decision: Implications for Medicaid* (March 2000), www.kff.org. *Olmstead* requires that states develop “comprehensive working plans for placing qualified persons with disabilities in the most integrated setting appropriate” and to maintain a “waiting list that moves at a reasonable pace.” Health Care Financing Administration, Letter to State Medicaid Directors, January 14, 2000, available at <http://www.cms.hhs.gov/states/letters/smd1140b.asp>, accessed on June 20, 2003.
- ⁵² For background on section 1115 waivers and Medicaid, see Mann, C., *The New Medicaid and CHIP Waiver Initiatives* (February 2002), www.kff.org/content/2002/4028/4028.pdf; Lambrew, J., *Section 1115 Waivers in Medicaid and the State Children’s Health Insurance Program* (July 2001), www.kff.org/content/2001/4001/4001.pdf. Under section 1916(f) of the Social Security Act, 42 U.S.C. 1396o(f), the Secretary’s ability to waive federal cost-sharing requirements is more constrained than his ability to waive federal benefits requirements.
- ⁵³ Kaiser Commission on Medicaid and the Uninsured, unpublished analysis of section 1115 waivers based on information from the Centers for Medicare & Medicaid Services, May 2003.
- ⁵⁴ Kronick, R., and Dreyfus T. *Capitated Payment of Medicaid Long-Term Care for Older Americans: An Analysis of Current Methods* (March 2001), AARP Public Policy Institute, www.aarp.org.
- ⁵⁵ Crowley, J. *An Overview of the Independence Plus Initiative to Promote Consumer Direction of Services in Medicaid*. (Washington, DC: The Kaiser Commission on Medicaid and the Uninsured): Forthcoming, Fall 2003.
- ⁵⁶ Crowley, J. *An Overview of the Independence Plus Initiative to Promote Consumer Direction of Services in Medicaid*, (Washington, DC: The Kaiser Commission on Medicaid and the Uninsured): Forthcoming, Fall 2003.

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