

Rebalancing Long-Term Care: The Role of the Medicaid HCBS Waiver Program

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OVERVIEW — *This paper reviews the history and background of the Medicaid home and community-based services (HCBS) waiver program. It describes the eligibility, benefits, and financing structure, as well as the trends in program expenditures over time. The paper considers the contribution of the HCBS waiver program toward improving access to community-based care for Medicaid beneficiaries who are elderly and disabled and discusses the barriers that remain. This paper also summarizes the provisions included in the recently enacted Deficit Reduction Act of 2005 that may further expand Medicaid HCBS and considers how it may continue the process of redefining the concept of long-term care.*

Contents

INTRODUCTION	3
Table 1: Medicaid 1915(c) Waiver Participants and Expenditures by Type of Waiver, 2002	4
THE SHIFT TO COMMUNITY-BASED SERVICES	4
Table 2: Summary of Key Federal Legislation on Home and Community-Based Services Waiver Programs	6
Judicial System Influence	7
Figure 1: Growth in HCBS Waiver Expenditures (in billions)	8
THE INS AND OUTS OF 1915(c)	8
Table 3: Medicaid Provisions That Can Be Waived Under Section 1915(c)	9
Cost Neutrality	10
REBALANCING INSTITUTIONAL AND COMMUNITY-BASED CARE	11
The First Step: Meeting Eligibility Requirements	11
The Next Step: Navigating the Service Delivery System	13
Managing Costs	15
Figure 2: Average Medicaid 1915(c) Waiver Expenditures Per Person Served, by Type of Waiver, 2002	16
Money Follows the Person?	18
SHAPING THE FUTURE OF MEDICAID HCBS	19
The Deficit Reduction Act of 2005	20
Future Needs	21
ENDNOTES	22

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The Medicaid home and community-based services (HCBS) waiver program is the major public financing mechanism for providing long-term care services in community settings. Authorized under section 1915(c) of the Social Security Act, states have used HCBS waiver programs to serve a wide variety of populations, including seniors; people with physical disabilities, HIV/AIDS, mental retardation and developmental disabilities (MR/DD), and traumatic brain injury (TBI); and children who are medically fragile and/or technology-dependent (such as ventilator-dependent due to paralysis). Under the waiver program, states are permitted to provide HCBS to individuals who require the level of care provided in institutional settings [that is, hospitals, nursing homes, or intermediate care facilities for people with mental retardation (ICFs/MR)]. Because of the diversity of the populations served, as well as other factors such as unique state delivery systems, payment structures, and service models, it is difficult to generalize about the programs that have been implemented under the authority of section 1915(c).

HCBS waivers are a diverse group of programs that operate under the same statutory authority. Most states have several HCBS waiver programs, each designed to serve a specific target population. Often, each program is administered by a different subdivision of the state government that may obtain funding from other sources in addition to Medicaid. For example, a state unit on aging may administer an HCBS waiver program for seniors while a developmental disabilities administration may run a waiver program for people with mental retardation.

The proportion of spending for Medicaid beneficiaries receiving HCBS has increased steadily for over ten years. In 1991, HCBS (including waiver programs, personal care, and home health benefits) represented only about 14 percent of Medicaid long-term care expenditures.¹ By 2004, community-based services had increased to 36 percent (\$31.7 billion) of total long-term care spending; two-thirds of that (\$21.2 billion) went specifically to HCBS waiver programs.² There were 263 HCBS waiver programs in operation in 2004.

Every state except Arizona has at least one waiver program serving individuals with MR/DD and one waiver program serving seniors (the aged or aged/disabled) or non-elderly people with physical disabilities.³

These four groups account for over 97 percent of waiver program enrollees and expenditures (Table 1).⁴ In recent years, states also have begun serving adults and children with HIV and AIDS, children with special health care needs, people with TBI, and people with chronic mental illness. However, HCBS waiver programs for these populations have developed at a slower rate than those for people with MR/DD, the aged, and the aged/disabled. The number of people with chronic mental illness served in waiver programs is particularly limited. Because the Medicaid statute specifically excludes coverage of individuals age 22 to 64 placed in “institutions for mental disease,” states considering a HCBS waiver focused on adults with chronic mental illness often find it difficult to achieve the cost neutrality required for 1915(c) waivers.⁵

Increasing the use of HCBS is a high priority for both consumers and payers of services. Most beneficiaries express a strong preference for HCBS. They want to live in their own homes, participate in their communities, and have greater control over their daily decisions. As long-term care costs consume an increasing share of the Medicaid budget, states are pursuing lower-cost alternatives to institutional services. Although it is still somewhat unclear whether HCBS save money in comparison to institutional services, states are working to rebalance resources and programs to increase the proportion of people who receive services in the community.

THE SHIFT TO COMMUNITY-BASED SERVICES

Congress enacted section 1915(c) of the Social Security Act as part of the Omnibus Reconciliation Act (OBRA) of 1981. Until then, comprehensive long-term care services through Medicaid were available only in institutional settings. Although mandatory home health services and optional personal care services were available as Medicaid benefits before OBRA 1981, states had largely restricted their use, only allowing payment for medically oriented types of services, such as skilled nursing care provided in the home.⁶ States also placed limits on the

TABLE 1
Medicaid 1915(c) Waiver Participants and Expenditures by Type of Waiver, 2002

Population	Number of Participants	Expenditures (in thousands)
MR/DD	357,730	\$12,370,641
TBI/SCI	5,924	173,321
Children	7,963	140,388
Physically Disabled	45,506	611,261
Mental Health	2,176	18,139
Aged/Disabled*	376,747	2,830,811
Aged	111,130	686,872
HIV/AIDS	13,657	49,326
	▼	▼
TOTAL	920,833	\$16,880,759

* Individuals who are disabled and age 65 and older.

Source: Martin Kitchener et al., “Medicaid 1915(c) Home and Community-Based Service Programs: Data Update,” Kaiser Commission on Medicaid and the Uninsured, Issue Paper, July 2005; available at www.kff.org/medicaid/7345.cfm.

amount of services that would be covered. In enacting the legislation for HCBS waivers, Congress anticipated that long-term care costs could be contained if services were provided in less expensive home and community-based settings rather than in institutions. The original legislation limited the program to beneficiaries who would otherwise be at risk of institutionalization in nursing homes and ICF/MRs if community-based services were not available.⁷ It also required waiver programs to meet a cost neutrality test in order to ensure that expenditures would be limited.

Growth of the HCBS waiver program was slow at first. In 1982, only six states had received approval for HCBS waivers.⁸ Although it is not uncommon for new programs to take time to develop, one reason for the initial slow growth was a “cold bed” rule that required states to demonstrate that an institutional bed was available for each waiver participant as a means of assuring cost neutrality.⁹ In states that had restrictions on building new nursing home beds, this test was a serious impediment to HCBS waiver growth. The Health Care Financing Administration (HCFA, now the Centers for Medicare & Medicaid Services, or CMS) removed the cold bed requirement in 1994, giving states more flexibility to determine how much waiver programs could grow.

Over the years, Congress also enacted legislation that was designed to stimulate the proliferation of waiver programs. For example, in the late 1980s, Congress broadened the 1915(c) waiver authority, specifically authorizing states to provide waiver services to those who would otherwise be hospitalized and to offer expanded habilitation (prevocational, supported employment, and educational) services to individuals who had previously been institutionalized.¹⁰ (Congress later removed the requirement for previous institutionalization in order to expand access to habilitation services.) Congress has also enacted a number of modifications that made it easier for states to meet the cost neutrality requirements by allowing cost estimates to be made for a specific target population, instead of the institutional population as a whole. Most recently, on February 1, 2006, Congress enacted the Deficit Reduction Act (DRA) of 2005, which adds an option for states to offer HCBS under the Medicaid state plan (that is, without requiring a waiver). Under this new state plan option, states may develop different functional eligibility definitions for institutional care and home and community-based care, making it easier to qualify for HCBS. States will still be able to place limits on the number of participants that receive HCBS, but they will not be required to apply for waiver renewals or to demonstrate cost neutrality to CMS (see Table 2, next page). States are not required to add HCBS to their state plan and will continue to have the option to use waivers to implement HCBS programs.

Under the new state plan option in the DRA, states may determine different functional eligibility definitions for institutional and HCBS care.

TABLE 2
Summary of Key Federal Legislation on
Home and Community-Based Services Waiver Programs

OBRA 1981	Home and community-based services waiver authority enacted at section 1915(c) of the SSA.
COBRA 1985	<p>Provided option to offer expanded habilitation services (prevocational, supported employment, and educational services) to individuals who had previously been institutionalized.</p> <p>Abolished regulatory limit on HCBS expenditures.</p> <p>Changed renewal period from three years to up to five years.</p> <p>Expanded HCBS waiver program to persons who are ventilator dependent, require a hospital level of care, and enter the waiver program from a hospital.</p>
OBRA 1986	<p>Provided option to offer HCBS waiver services to individuals who would otherwise be hospitalized.</p> <p>Added services for persons with chronic mental illness (day treatment, partial hospitalization, psychosocial rehabilitation, and clinic services).</p> <p>Permitted cost estimates specific to an individual with a particular illness/injury when discharged from an institution to the waiver.</p>
OBRA 1987	<p>Section 1915(d) HCBS waiver authority for individuals age 65 and older enacted. (No states currently operate programs under this waiver authority, although it remains in law.*)</p> <p>Eliminated the requirement for a prior institutional stay to make expanded habilitation services available.</p> <p>Allowed waiver of 1902(a)(10)(C)(i)(III) (deeming of income and resources) for the medically needy.</p> <p>Modified cost neutrality requirements to permit waiver costs for persons with MR/DD who had resided in nursing homes to be compared with the typically higher costs that would be incurred in an ICF/MR.</p>
TMRA 1988	Permitted population-specific cost estimates without regard to whether the individual had a prior institutional stay.
OBRA 1990	<p>Permitted states to use ICFs/MR that were terminated from participating in Medicaid for cost comparisons.</p> <p>Permitted coverage of a portion of costs of rent and food for a live-in personal caregiver.</p> <p>Eliminated restriction on number of hours of respite care.</p>
BBA 1997	Removed requirement for prior institutionalization in order to receive supported employment services.
DRA 2005	<p>Permitted states to offer HCBS as a benefit under the Medicaid state plan effective January 1, 2007. States may establish needs-based criteria for determining eligibility for HCBS and use more stringent criteria for institutional care. States may cap the number of individuals that receive HCBS and establish waiting lists.</p> <p>Added new Medicaid state plan option for self-directed personal assistance services (known as cash and counseling) for the elderly and disabled.</p> <p>Authorized a "Money Follows the Person" demonstration to offer enhanced matching funds to states to transition individuals from institutional to HCB settings.</p>

* Only Oregon used this waiver authority. After the cold bed requirement was removed in 1994, Oregon converted its program to a 1915(c) waiver. Spending growth limitations in 1915(d) are tied to growth of the age 65 and older population and are more restrictive than section 1915(c) cost neutrality requirements.

Judicial System Influence

As Congress took legislative action during the 1980s, the states' commitment to reducing their institutional populations grew, largely as a result of legal challenges, skyrocketing institutional costs, and pressure from the advocacy community. A series of class action law suits consistently demonstrated that the civil rights of individuals with MR/DD in (mostly Medicaid-certified) state institutions were being violated. These suits did not specifically affirm the right of individuals in this group to live in the community. But with the help of strong advocacy on behalf of individuals with MR/DD, the class action suits stimulated rapid development of small community-based residences and support services for this group.

The enactment of the Americans with Disabilities Act (ADA) in 1990 had important implications for waiver programs. It required that states provide services in the most appropriate, integrated setting, rather than in institutions. Subsequent court rulings have upheld the rights of people with disabilities to receive care at home or in the community. Most significantly, in *Olmstead v. L.C.* (1999) the Supreme Court upheld the right of people with disabilities to be placed in community settings if such placement is appropriate, is not opposed by the individual in question, and can be accommodated within the resources available.¹¹ Under the ADA, states are obligated to make reasonable modifications in policies, practices, or procedures to avoid discrimination on the basis of disability. However, state responsibility is not unlimited. The court advised that a state could establish compliance with the ADA by demonstrating that it has a comprehensive, effectively working plan for placing qualified persons with disabilities in less restrictive settings as well as a waiting list that moves at a reasonable pace.

Following the *Olmstead* decision, the federal government began to place emphasis on developing effective working plans for moving people from institutions to communities. From 2000 to 2001, HCFA issued a series of letters to state Medicaid directors providing guidance on complying with *Olmstead*. Also in 2000, Congress created the Real Choice Systems Change Grants program. Under this program, CMS has awarded about \$240 million to states to help build the infrastructure necessary for individuals to live in integrated community settings.¹² The grants support activities in four major systems areas: efforts to improve access to existing services and supports; create new services and supports; design, implement, and maintain systems and processes that enable services such as data or quality assurance systems; and improve recruitment, training, and retention of direct service workers. These Systems Change grants have been an important stimulus in the paradigm shift toward HCBS.

The enactment of the Americans with Disabilities Act (ADA) in 1990 had important implications for waiver programs.

In 2001, the Bush administration launched the New Freedom Initiative to further promote community living for seniors and people with disabilities by coordinating existing resources and by modifying policies to create incentives for community integration. As part of the Initiative, the Department of Health and Human Services (DHHS) conducted a self-assessment of existing federal policies, programs, statutes, and regulations to identify barriers that impede community living and to recommend solutions. The assessment resulted in several policy clarifications, including one that permits HCBS waiver programs to cover one-time costs such as security deposits on apartments and utility set-up fees for people who are transitioning from institutions to community living arrangements.

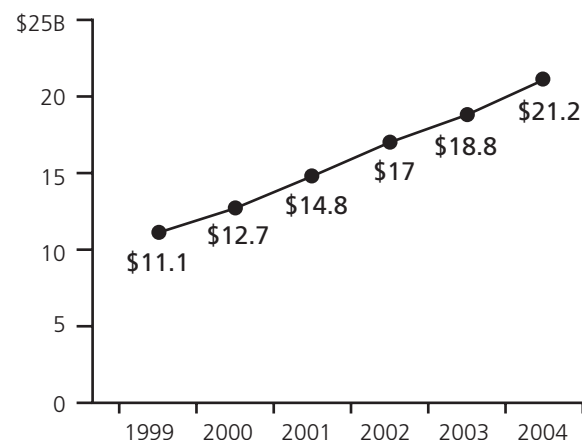
CMS has also provided some additional grant funds to support such transitions. CMS and four academically based partners sponsor an HCBS clearinghouse Web site (www.hcbs.org) for the Community Living Exchange Collaborative. The clearinghouse facilitates sharing of tools, information, and resources across states.

The HCBS waiver program has grown steadily throughout its history, both in terms of the number of participants and in terms of overall spending. Growth in the program has been particularly apparent since 1999 due to the pressures brought by the *Olmstead* decision and the resulting federal emphasis on expanding home and community-based options. The number of participants grew by more than 25 percent between 1999 and 2002, from 689,033 to 920,833.¹³ Expenditures on HCBS waiver programs have almost doubled since 1999, reaching \$21.2 billion in 2004 (Figure 1).¹⁴

THE INS AND OUTS OF 1915(C)

The Medicaid statute requires that “comparable” services are provided to all eligible enrollees across the state.¹⁵ Section 1915(c) permits the Secretary of Health and Human Services to waive these Medicaid requirements (referred to as “comparability” and “statewideness”) for certain populations in order to provide home and community-based care (Table 3, next page).¹⁶ The waivers allow states to provide specific services to targeted populations and also to cap the number of people who receive services. The enrollment limit is established by the state in the approved waiver application and may be adjusted at any time through a waiver amendment. The Secretary may also waive certain Medicaid income and resource rules to further facilitate serving these vulnerable populations. Waivers of income and resource rules permit states to use more liberal income criteria for determining eligibility for HCBS than are used to determine eligibility for other noninstitutionalized Medicaid beneficiaries in the community. States may expand eligibility for HCBS up to the same

FIGURE 1
Growth in HCBS Waiver Expenditures
(in billions)



Source: Steve Eiken, Brian Burtwell, and Eileen Walker, “Medicaid HCBS Waiver Expenditures, FY1999 through FY2004,” memorandum, Medstat, May 9, 2005; available at www.hcbs.org/files/71/3514/HCBSWaivers2004.Doc.

limits used in determining eligibility for institutionalized beneficiaries. However, states may apply more restrictive requirements if they choose, such as not using Medicaid spousal impoverishment provisions which protect a certain amount of a couple’s income and assets so that the non-disabled spouse is not forced into poverty.

Waivers under section 1915(c) are initially approved for three years and may be extended for additional periods of five years. A standard waiver application format developed by CMS is used by states when first applying for or renewing a waiver. The application includes information on the population(s) to be served and the services to be provided. Part of the application requires the state to provide information about the financing of the waiver.

Individuals who participate in HCBS waiver programs receive the full range of services available under the state’s Medicaid plan in addition to a set of supplemental services defined by the state and provided under the waiver. The statute identifies services that may be made available through HCBS waivers—including case management; homemaker and/or home health aide services; personal care services; adult day health, habilitation, and respite care—and permits the Secretary to approve other services at his or her discretion. The standard waiver application contains suggested definitions for over 30 services that states use to design their

TABLE 3
Medicaid Provisions That Can Be Waived Under Section 1915(c)

TITLE XIX PROVISION	STATE PLAN REQUIREMENT	SECTION 1915(C) WAIVER
Section 1902(a)(1)	Statewideness: States must make Medicaid benefits available to all eligible individuals regardless of where in the state they reside.	Permits states to target waiver programs to specific areas of the state where the need is greatest, or where certain types of providers are available. Also used to phase in implementation of programs.
Section 1902(a)(10)(B)	Comparability: States must provide comparable services to all eligible individuals and may not limit services based on diagnosis, type of illness or condition.	Permits states to make waiver services available to specific target populations, for example, elderly or physically disabled, without making them available to the general Medicaid population and to cap the number of participants.
Section 1902(a)(10)(C)(i)(III)	Medically needy income and resource rules applicable in community.	Permits states to provide Medicaid to persons who would otherwise be the eligible only in an institutional setting, often due to the income and resources of a spouse or parent.

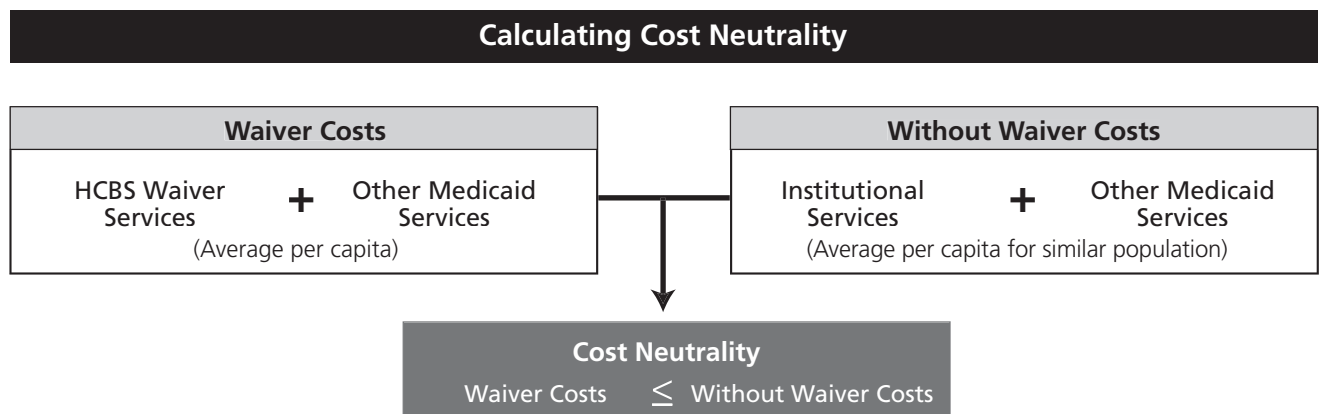
HCBS programs. States are free to adapt, modify, or completely change these definitions to best fit the needs of the program.

The flexibility provided under section 1915(c) has resulted in a great deal of diversity among HCBS waiver program benefits across and within states. Many services that are now part of waiver programs were initially provided exclusively with state or local funding. The waiver enables them to tap into the state-federal matching and reimbursement structure. For example, prior to the enactment of the HCBS waiver authority, services like supported employment for people with developmental disabilities, personal care services, mental health care, and case management services often were not reimbursed as Medicaid services and were provided with state and local funds. The waiver program authority enabled states to shift much of the cost of these services to the federal government in the form of federal Medicaid matching payments.

Cost Neutrality

The statutory requirement that section 1915(c) waivers be “cost neutral” has been a key element of the application and approval process. Cost neutrality means that the average per capita HCBS waiver costs (including the cost of any other Medicaid state plan services furnished to HCBS waiver participants) must be less than or equal to the service costs for a similar population in an institution (including the cost of any other Medicaid state plan services furnished to institutionalized beneficiaries).

While the formula appears straightforward, calculating the cost of services can be complex, particularly in the case of a new program without experience on which to base estimates. A state must project the extent to which waiver program participants will use various services and how much the state will pay for those services. These estimates are then compared to a group of institutionalized individuals with similar needs. Identifying a comparable population can be difficult and, as more people are diverted from institutions, there is a smaller institutional base against which costs can be compared.



Actual expenditures may vary from the estimates provided in the waiver application. For example, costs for a particular participant may exceed the per person costs used to calculate cost neutrality. This is permissible as long as overall program costs (that is, per capita costs multiplied by the number of participants) do not exceed the amount that would have been incurred for program participants in an institutional setting. CMS monitors actual costs relative to projected costs, and states must adjust their projections if cost neutrality limits are exceeded.

REBALANCING INSTITUTIONAL AND COMMUNITY-BASED CARE

States have made significant efforts to accommodate the increasing demand for home and community-based care by rebalancing their long-term care systems. However, despite the progress that has been made toward increasing the proportion of people receiving HCBS, the institutional bias inherent in Medicaid continues to create barriers for people wishing to receive services in the community. At the most fundamental level, the institutional bias stems from the fact that under federal statute, state Medicaid programs must provide nursing home benefits to beneficiaries over age 21, whereas HCBS waiver program services remain an optional Medicaid benefit.¹⁷ Nursing facility care must be made available to all eligible individuals statewide, but states can place limits on the size and number of HCBS waiver programs. As a result, waiver programs are not available to beneficiaries on the same basis as institutional services. Medicaid eligibility rules and procedures, fragmentation and lack of community resources, and fiscal constraints also contribute to the institutional bias and affect states' ability to expand HCBS waiver programs.

National trends in Medicaid program growth show that institutional services are still the primary vehicle for delivering long-term care. However, national trends mask significant differences among states. In Oregon, for example, over 70 percent of Medicaid long-term care spending in 2004 went to HCBS, whereas HCBS represented only 5.2 percent of long-term care expenditures in Mississippi.¹⁸

The First Step: Meeting Eligibility Requirements

Medicaid eligibility rules determine who qualifies to participate in HCBS waiver programs. Applicants must meet both financial and functional eligibility criteria. They must have limited income and assets and be determined to be in need of an "institutional level of care." In addition to these requirements, states determine whether an applicant is in a group targeted by a waiver program (for example, someone age 65 and older or a child who is medically fragile). Both financial and functional eligibility rules can create barriers to access to HCBS; as a result, most people are very poor and very disabled by the time they qualify for services.

In order to receive HCBS, individuals must first meet the financial eligibility requirements for Medicaid. Medicaid financial eligibility for seniors and people with disabilities is based on the rules used to determine eligibility for Supplemental Security Income (SSI). The income threshold changes every calendar year; in 2006, an individual receiving SSI cannot have income that exceeds \$603 per month. However, states can elect to create eligibility groups to cover the elderly and individuals with disabilities at higher income levels. Thirty-three states have elected to allow individuals to qualify for nursing home care at 300 percent of the SSI limit (\$1809 per month in 2006).

The majority of waiver programs (74 percent) use the same, higher income standard for their HCBS waiver programs as is used for institutional services. However, 23 percent set income limits at 100 percent of SSI; the remaining 3 percent of programs set eligibility between 100 and 300 percent of SSI.¹⁹

A study by the American Association of Retired Persons in 2000 revealed that financial eligibility policies in some states contribute to the institutional bias.²⁰ It found that 13 states had more restrictive income eligibility criteria for HCBS waiver participants than for nursing home residents. In addition, four states had more restrictive asset tests (that is, the amount of assets an individual is permitted to retain in order to be eligible) for waiver participants, and 19 states did not use the same spousal impoverishment protections for individuals receiving care through HCBS as opposed to in an institution. These policies create incentives to utilize institutional services in order to avoid impoverishment and to protect spousal assets.

Medicaid financial eligibility determinations for the elderly and people with disabilities are usually done by the same state agency that determines eligibility for Temporary Assistance for Needy Families (TANF) and Medicaid for families and children; the determinations for the elderly and people with disabilities make up only a small portion of the agency's caseload. Federal rules require that financial eligibility determinations be made within 45 days from the date of application (90 days when a disability determination is necessary). However, people who are in need of long-term care services often enter the system upon discharge from a hospital or when a crisis occurs; 45 days may be much too long to wait for a determination and may hinder placement in a community-based setting. As a result, an applicant may be placed in an institutional setting because the nursing homes and ICFs/MR are usually more willing than community-based providers to accept the risk of nonpayment should the applicant be found ineligible for Medicaid.

Some states have addressed this issue by placing responsibility for financial eligibility in the same state agency that provides long-term care

In 2000, 13 states had more restrictive income eligibility criteria for HCBS waiver participants than for nursing home residents.

services so that determinations can be completed more expeditiously. Other states have established “presumptive eligibility” for HCBS waiver programs to ensure that providers receive payment during the eligibility determination period.²¹ For example, the state of Washington has had a state-funded program for several years that allows individuals to receive services while their eligibility is being verified. State officials estimate that it costs less than \$100,000 per year to provide services to people who are ultimately found to be ineligible for Medicaid, but that cost is far exceeded by the savings generated by diverting clients from institutional care.²² States have also expedited eligibility by offering applicants assistance with completing forms and collecting necessary documentation.

Once an applicant is found financially eligible, he or she must meet functional eligibility requirements in order to qualify for enrollment in a HCBS waiver program. This functional determination is generally based on the extent to which an individual is able to perform various activities of daily living (ADLs, which consist of eating, bathing, toileting, dressing, and mobility) or instrumental activities of daily living (IADLs, which include shopping, performing housework, doing laundry, meal preparation, money management, and medication management). The level of assistance needed in completing ADLs and IADLs determines whether the applicant needs an “institutional level of care.” By statute, eligibility for HCBS waiver programs is tied to eligibility for institutional services. Many policymakers, state officials, consumers, and advocates have argued that the need for more costly services could be delayed or avoided if HCBS were made available before an individual’s ADLs and IADLs deteriorate to the point of requiring institutional services. Vermont recently received approval for a long-term care section 1115 demonstration project that will test this theory. It establishes three levels of care, including a “moderate need group” who are at risk but do not yet require the level of care provided in a nursing facility and who will receive a narrow set of Medicaid-funded community-based services.

Although eligibility for the HCBS waiver program remains tied to institutional eligibility, the DRA of 2005 provides states the flexibility to establish different functional eligibility criteria for institutional versus HCBS care in the new state plan option. This flexibility has been long sought by states and the disability community alike.

The Next Step: Navigating the Service Delivery System

Individuals with disabilities and seniors with functional limitations need assistance in areas as diverse as housing, transportation, education, habilitation, light housekeeping and meal preparation, personal assistance, and skilled nursing care. While some services, such as personal care, are needed by people with a variety of disabilities, other services are specific to the type of disability being addressed. In addition, waiver participants

The level of assistance needed in completing ADLs and IADLs determines whether the applicant needs an “institutional level of care.”

often do not fit neatly into a single category. For example, a senior may need mental health services and may also need other general health services related to aging. A person with developmental disabilities who has primarily used habilitation services may need support in managing other health issues as well. People with traumatic brain injuries often do not fall clearly into any one service area.

As might be expected, given the range of populations served and the differing needs of each population, multiple agencies within a state are involved in the delivery of waiver services. Before the HCBS waiver authority existed, many of these separate agencies were created to serve specific populations.

For example, most states have distinct offices that administer programs for the elderly, individuals with MR/DD, and people with mental illness. Lack of coordination among these agencies and with separate housing, education, and transportation agencies creates barriers for people in need of services. These logistical problems can add to the institutional bias; it may be easier for a person in crisis or a person being discharged from a hospital to go to an institutional setting where a range of services can be provided than for families and referral agencies to cobble together the multiple support services needed to keep the person in the community.

States have developed a number of strategies to address the difficulties that Medicaid applicants encounter in navigating the service delivery system. Single point-of-entry systems, or “one-stop shops,” have been implemented in a number of states. One-stop shops may perform a variety of functions, including offering information, performing functional and/or financial eligibility determinations, assisting consumers with completing Medicaid applications, and developing plans of care. Perhaps one of the best-known examples is Oregon’s single point-of-entry system, which merges responsibility for all institutional and community-based care in one state agency.²³ This approach allows for an effective exchange of information about all available options and combines responsibility for assessment, determining eligibility, and care coordination. As a result, Oregon is able to align policies and promote common goals across all programs. Other states have also developed consumer resource centers or hotlines that integrate information about the range of available services.

Another strategy is diversion programs in which caseworkers are assigned to work with discharge planners in hospitals or to go into rehabilitation or nursing facilities shortly after a person is admitted. The caseworkers then assist individuals with planning for placement in the community to ensure that the necessary supports are available. Indiana, for example, mandates a preadmission screening for all individuals seeking placement in a nursing home to make sure the consumer is told about all options for care. Case managers work closely with consumers until home or community-based care is established.

Oregon’s single point-of-entry system merges responsibility for all institutional and community-based care in one state agency.

Some states are also working to develop community capacity in areas where there are provider shortages. A few states have modified their Nurse Practice Acts to make it possible for trained caregivers to perform tasks normally performed by a nurse.²⁴ Consumer-directed care, in which consumers recruit, hire, and supervise their own personal care attendants, is another strategy that states have used to expand the available pool of service providers. Consumers may hire friends and acquaintances or even family members—people who would not usually enter the existing workforce. In Vermont, for example, over half of the personal care delivered through the HCBS waiver program is initiated at consumer direction.²⁵ Through Systems Change Grants, a number of states have also undertaken activities to recruit and train workers.²⁶ For example, Arkansas implemented a public awareness campaign to provide information about the importance of direct care workers and established a Web site and toll-free number for statewide recruitment. Illinois worked to get new legislation passed that increased wages for personal care assistants, and Kentucky developed a curriculum to help train direct service workers.

The DRA of 2005 includes a new Medicaid state plan option under which coverage of self-directed personal assistance services can be included as Medicaid benefits for the elderly and people with disabilities. This expansion of the highly popular “cash and counseling” approach is expected to enable states to expand the use of consumer direction and make community-based care more efficient and accessible.

Managing Costs

Program costs are a significant concern for states working to rebalance their long-term care systems. State budget constraints often drive the extent to which HCBS waiver services are made available. Although a shift away from institutional care is sought by advocates and required by legal actions, both state and federal policymakers have repeatedly raised concerns about potential cost increases that could result from broader availability of HCBS. These concerns stem primarily from what is known as the “woodwork effect,” a phenomenon in which individuals who would not otherwise be willing to apply for institutional care would seek out the more desirable community-based services if they were made widely available through Medicaid. Such increased utilization would be likely to increase program costs and counteract any savings achieved by providing less expensive care in the community. The provision in the DRA of 2005 which permits states to set less stringent functional eligibility criteria for HCBS than for institutional services, potentially increases the number of people who will qualify for HCBS. In its budget estimate for the DRA of 2005, the Congressional Budget Office estimated that the state plan option for HCBS would increase Medicaid spending by \$766 million over five years.²⁷

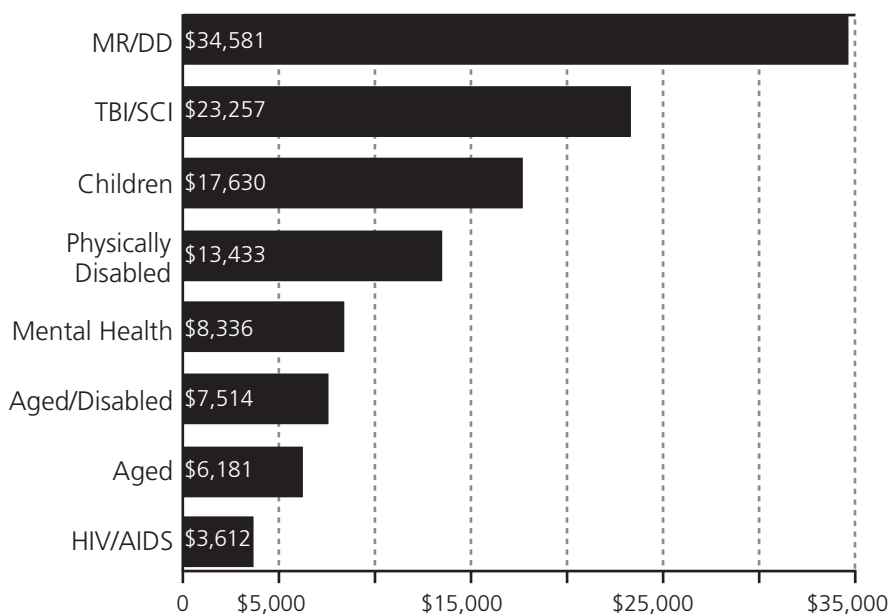
Average HCBS waiver program expenditures in 2002 were \$18,332 per person across all population groups.²⁸ However, the average costs by population varied greatly, from \$3,612 to \$34,581 (Figure 2). The highest costs are for people with mental retardation because of their intensive need for habilitation training and supervision, often on a 24-hour per day basis. In fact, the MR/DD population accounts for almost three-quarters of all HCBS waiver program expenditures (see Table 1).

Although waiver expenditures reported here do not include the costs of other Medicaid state plan services (such as physician visits) incurred in community settings, it appears that, in most cases, HCBS waiver services would be more cost-effective on a per-person basis when compared with institutional costs. One study of residential services for people with MR/DD found that the average annual expenditure in 2002 for ICF/MR residents was \$85,746 as compared to \$37,816 for each HCBS recipient.²⁹ The average annual Medicaid expenditures per beneficiary for nursing home care were \$21,890 in 2001 as compared to \$6,181 for an elderly person with functional deficits in an HCBS waiver program.³⁰

One of the reasons that institutional costs are so much higher than those for HCBS is that the cost of room and board are included in institutional payment rates but not in HCBS rates. Advocates point out that the exclusion of housing costs from federal Medicaid reimbursement for HCBS waiver services further contributes to the institutional bias (see "Housing and the HCBS Waiver Program," next page).³¹

Research findings on the overall cost-effectiveness of HCBS waiver programs have been mixed.³² Some studies have found substantial cost savings. Others have found that, although average costs per recipient were less than institutional costs would have been, the program did not result in savings overall because many waiver participants would not have otherwise entered an institution. One report that conducted an extensive review of the research literature concluded that the woodwork effect seriously impeded the cost-effectiveness of home and community-based

FIGURE 2
Average Medicaid 1915(c) Waiver Expenditures
Per Person Served, by Type of Waiver, 2002



Source: Kitchener et al. for the Kaiser Commission, July 2005

services.³³ The author further suggested that targeted eligibility, limited benefit levels (taking into account availability of informal supports, such as family members), and a strong emphasis on services provided in alternative residential facilities (such as assisted living facilities or small group homes) will increase the chances that HCBS will be cost effective.

It should be noted that the studies examined here were conducted early in the history of the waiver program and there has not been a rigorous evaluation in recent years. However, some analysts believe that the factors influencing cost are not likely to have changed in the intervening years. Although the potential impact of the woodwork effect is difficult to establish, the Government Accountability Office in 2001 estimated that as many as 2.3 million adults living in home or community-based settings are at risk of institutionalization because of their need for assistance with self-care activities.³⁴

Concerns about the woodwork effect on state and federal budgets have led to limitations on the availability of HCBS waiver programs, limitations that often generate strong resistance from the disability community. States use two primary methods to control program costs: caps on the number of participants and caps on spending per participant.

Housing and the HCBS Waiver Program

Medicaid federal financial participation is not available to pay for expenses such as housing, food, and utilities for participants in HCBS waiver programs except in limited circumstances, that is, for out-of-home respite care in state-approved facilities (not private residences) and room and board of a live-in caregiver. Individuals are expected to use their own income and resources (for example, SSI cash assistance benefits and earnings from employment) to meet living expenses. In contrast, room and board costs are embedded in per diem nursing facility and ICF/MR rates. This exclusion complicates the provision of support services in the community. In most communities, SSI payments, which amount to \$603 per month in 2006, are not sufficient to pay for necessary expenses such as rent, food, utilities, and clothing. Waiver participants must usually own their own homes, live in congregate settings, or obtain subsidized Section 8 housing, which is usually scarce.

The room and board exclusion also affects Medicaid eligibility. In a state with a “medically needy” eligibility group, a person whose income exceeds 300 percent of SSI may qualify for Medicaid if he or she has high medical expenses. For example, a person with income at 400 percent of SSI may be able to obtain financial eligibility for Medicaid because the cost of nursing facility care (which includes housing and food) is counted as a medical expense for eligibility purposes. (His or her income would defray some of the Medicaid costs.) In the community, however, the costs of housing for this same person may not be counted toward the medically needy income standard, and he or she may not become eligible for Medicaid as a result.

Many states make non-Medicaid supplementary funding available to assist individuals with expenses for setting up their own living arrangements or rent when their income and resources are not sufficient. For example, both Connecticut and Florida have set aside funds for this purpose.

Caps on spending per participant are set either as a fixed dollar amount or as an average amount so that expenditures for some participants can be higher than average while expenditures for others are lower. These cost control measures can have several effects for consumers. Participants already in waiver slots may be unable to have needed services and supports added to their plans of care, resulting in greater burden on family caregivers or unmet needs for the participant. When services are added to plans of care (or when states are pressured to maintain existing services in the plan of care regardless of whether they continue to be effective), higher spending per participant results. Most states limit appropriations for HCBS waiver services in each year, so greater per-person spending will mean that fewer people can be served. Some analysts have pointed out that caps on per-person spending actually benefit consumers awaiting a waiver slot because more people can be served, albeit at a lower cost per person.

Caps on the number of participants may result in an eligible individual having no alternative other than institutionalization when all waiver program slots are filled. In addition, states have the option to not fill slots that do become available in order to contain costs. Historically, most states have had significant waiting lists for their waiver programs. A recent study found that there were 102 waiver programs with waiting lists of almost 207,000 people in 2004, an increase of almost 49,000 people since 2002.³⁵ The study attributes this increase to the decline in the number of available waiver slots and increased demand due to interest generated by the *Olmstead* decision and the New Freedom Initiative.

Money Follows the Person?

One of the goals of rebalancing efforts, and a key priority for consumers and advocates, is to tie funding to specific individuals and to keep it flexible and available as an individual's needs change, regardless of the setting in which services are delivered. However, state budget processes often do not support the concept of ensuring that the "money follows the person." States generally budget separately for each long-term care service: funding for nursing homes is a separate budget item from waiver program services and, as mentioned previously, may even be administered by a different agency within the state government. This can negatively affect beneficiaries on a number of levels. For example, it may not be possible for a person with physical disabilities residing in a nursing home to receive services in a community setting if the waiver program budget is already committed to other participants, even though Medicaid funds are currently being spent for the nursing home stay for that individual.

To address this concern, a few states have consolidated both institutional and HCBS budgets within the same administrative subdivision. Sometimes known as "global budgeting," the subdivision is given a cap

on total spending as well as administrative flexibility within the spending limit. As waiver program participants' needs and preferences change, the money can more readily follow the person because the funding is redirected administratively.³⁶ For example, Texas, Vermont, and Wisconsin have statutory language that authorizes the transfer of savings from the nursing home budget to the home and community-based care budget. In Oregon, Washington, and Vermont both institutional and HCBS budgets are managed by the same administrative subunit. Legislatures in each of these states set only a total long-term care budget, rather than separate amounts for nursing homes and community-based care.

Budget constraints often prevent states from devoting new funds to the expansion of HCBS, prompting some states to redirect funds from institutions to HCBS programs. For example, states have drastically reduced the populations in large state institutions that serve individuals with MR/DD in favor of supported living in small residential homes and apartments. The population in large ICFs/MR (16 or more beds) decreased from 117,147 in 1988 to 63,834 in 2004.³⁷ Because the vast majority of large ICFs/MR are state-operated, states have the ability to redirect their developmental disability agency budgets toward community-based options. This shift is more complicated for seniors and people with physical disabilities, because they receive institutional services primarily through nursing homes operated by private providers that often have strong political lobbies. Attempts to reduce payments to nursing homes are usually met with powerful opposition.

A few states have devised strategies to divert funds from nursing homes to HCBS. Nebraska and Iowa, for example, have established conversion funds with state-only money that help nursing facilities convert beds to assisted living units. Minnesota enacted legislation that authorized a negotiated adjusted rate to be paid to nursing facilities for closing Medicaid beds and also provided incentives for facilities to close beds temporarily.

Some states also bundle all long-term care services into one capitation rate. This payment is set in a way that provides both resources and incentives for managed care organizations to develop less expensive alternatives to institutional care.³⁸ Capitated programs to date are operating in seven states but are fairly small, and they vary in the type of federal waiver authorizing the program.³⁹

SHAPING THE FUTURE OF MEDICAID HCBS

Almost 70 percent of total Medicaid expenditures go toward services for only about 25 percent of beneficiaries: the elderly and people with disabilities. Long-term care services for these populations are a main driver of overall costs for the Medicaid program. More effective and efficient systems of care for the elderly and people with disabilities have become increasingly essential to the Medicaid program's financial viability.

Although they are not the only mechanism for achieving cost-effective long-term care, HCBS waiver programs may provide a lower-cost alternative to institutional services on a per capita basis and, therefore, are attractive to states looking to control long-term care costs and provide a more desirable setting for beneficiaries.

Despite states' progress toward rebalancing their long-term care systems through the use of innovative strategies such as single point-of-entry systems and global budgeting, many challenges to broad access to HCBS remain. At the root of most of these challenges is financing. Expanded access to HCBS will likely attract a larger number of participants, thus increasing costs. Further, significant differences in the extent to which states fund community-based services raise the question of how well these programs are meeting beneficiaries' needs. One recent study found that 58 percent of dual eligibles (that is, people eligible for both Medicare and Medicaid) living in the community report unmet needs for help with activities of daily living.⁴⁰ The federal government and states must strike a delicate balance between operating waiver programs within very real fiscal constraints and meeting the needs of seniors and people with disabilities.

The Deficit Reduction Act of 2005

Enacted on February 1, 2006, the DRA of 2005 will permit states to offer HCBS as a Medicaid state plan option rather than through a waiver that must be periodically renewed. Effective January 1, 2007, the state plan option may be used to cover eligible individuals up to 150 percent of the federal poverty level with flexibility to set more generous income and resource limits. States may also set more stringent functional eligibility criteria for institutional services than for HCBS and are permitted to provide up to 60 days of presumptive eligibility for HCBS services. As under the current waiver program, states will be able to cap the number of individuals enrolled in the HCBS state plan option and will not be required to make the services available on a statewide basis.

One significant difference from the current waiver authority, however, is that the new law does not include a waiver of the Medicaid comparability requirement. Comparability requires that available services must be equal in amount, duration, and scope for all beneficiaries within a Medicaid eligibility group. States currently use waivers of comparability to target specific services to certain populations. For example, a respite benefit, which provides temporary care while usual caregivers are absent, may be made available to families of individuals with MR/DD but not to those with physical disabilities. It is unclear at this writing how this apparent conflict with states' current ability to design their waiver programs may affect the use of the new state plan option. States may continue to use section 1915(c) and section 1115 programs in addition to the new state plan option.

The law also authorizes a “Money Follows the Person” demonstration project that provides grants to states, beginning in January 2007. States approved to participate in the project would receive an enhanced federal matching rate for providing HCBS for up to 12 months to Medicaid-eligible individuals who move from an institutional setting to a “qualified residence.”⁴¹ The law appropriates \$1.8 billion over five years for these purposes.

Many disability advocates lobbied against the measures contained in the Deficit Reduction Act. They believe that the new authority to cap a state plan service and maintain waiting lists sets a dangerous precedent that weakens existing Medicaid protections. They are concerned that, for example, states will use the new HCBS state plan option that permits caps on enrollment instead of the personal care and rehabilitation benefits that, while optional, must be offered statewide and in the same amount, duration, and scope to all eligible Medicaid beneficiaries when a state elects to provide them.

Expanding access to HCBS is a major policy priority for the disability community. Advocates have long supported a legislative initiative called the Medicaid Community Attendant Services and Supports Act (MiCASSA, S. 401 and H.R. 910), which would provide community attendant (personal care) services as a mandatory Medicaid benefit and would require that services be provided in the most integrated setting appropriate to the needs of the individual.⁴² DRA 2005 includes a new Medicaid state plan option to provide self-directed personal assistance services, which is considered a significant step toward consumer-directed care, but does not make these benefits mandatory.

Future Needs

Long-term care costs are expected to continue to grow as the population ages, placing even greater demands on the long-term care system. Projections indicate that by the year 2020 the percentage of individuals age 65 and older will increase by one-third to 17 percent of the population—nearly 20 million more seniors than in 2000.⁴³ The creativity and innovation needed to address the needs of aging baby boomers may have a significant impact on the future of home and community-based care. The HCBS waiver program and the new HCBS state plan option are likely to play a critical role in meeting current and future seniors’ needs by delivering services in integrated settings that are highly valued by consumers. These programs will continue to require a significant commitment, both philosophical and financial, by the federal government and states in order to truly level the playing field between institutional and home and community-based services.

Many policymakers and advocates would argue that the advantages of home and community-based settings in terms of consumer satisfaction, dignity, quality of life, and reduced family burden are worthwhile at any

cost. However, the challenges involved in maintaining the ability to provide these services to an aging population will be greater than ever. The future success of community-based programs hinges on the ability of states and the federal government to build consumer-friendly, coordinated programs with sufficient provider capacity while keeping costs to a level that is both affordable for taxpayers and effective in meeting beneficiary needs. The provisions contained in the Deficit Reduction Act of 2005 appear to further the goals of expanding access to community-based services, but their impact remains to be seen.

ENDNOTES

1. Kaiser Commission on Medicaid and the Uninsured, "Medicaid and Long-Term Care," fact sheet, March 2005; available at www.kff.org/medicaid/2186-03.cfm.
2. Brian Burwell, Kate Sredl, and Steve Eiken, "Medicaid Long Term Care Expenditures in FY 2004, Medstat, May 11, 2005; available at www.hcbs.org/files/71/3533/2004LTCExpenditures.doc.
3. Although Arizona does not have a section 1915(c) waiver, the state provides similar home and community-based services through its statewide section 1115 demonstration.
4. Martin Kitchener *et al.*, "Medicaid 1915(c) Home and Community-Based Service Programs: Data Update," Kaiser Commission on Medicaid and the Uninsured, Issue Paper, July 2005; available at www.kff.org/medicaid/7345.cfm.
5. The Medicaid statute specifically excludes coverage of individuals aged 22 to 64 placed in "Institutions of Mental Disease" (IMD). Because of this IMD exclusion, the costs of providing institutional care for the mentally ill are generally not borne by the Medicaid program and cannot be incorporated into the baseline expenditures used to assess the budgetary impact of the proposed waiver. Without the fiscal offset gained by avoiding institutional care costs through the provision of HCBS, the cost neutrality requirement imposed on 1915(c) waivers cannot typically be met. Therefore, few waivers focused on mentally ill persons (aged 22 to 64) have been sought or approved. States are permitted to provide home and community-based waiver services to adults with mental illness who had received Medicaid funded care in a nursing facility, and a few states have secured such waivers. As of June 2005, five HCBS waivers were targeted to children with mental illness and one waiver (Colorado) was targeted specifically to adults age 18 and over with mental illness.
6. Title XIX requires states to provide a set of "mandatory" services and permits states to offer additional "optional" services.
7. Individuals who require the level of care provided in a hospital were not eligible for coverage in the HCBS waiver program until the enactment of OBRA 1986 gave states this option.
8. Steven Lutzky *et al.*, "Review of the Medicaid 1915(c) Home and Community-Based Services Waiver Program: Literature and Program Data," The Lewin Group, prepared for the Health Care Financing Administration, June 15, 2000.
9. The cold bed rule was not statutory. HCFA applied the cold bed rule through regulation to implement the statutory cost neutrality requirement for waiver programs.
10. Habilitation services are defined in section 1915(c)(5)(A) of the Social Security Act as services designed to assist individuals in acquiring, retaining, and improving the self-help, socialization, and adaptive skills necessary to reside successfully in home and community-based settings. They are usually provided, for example, to individuals with developmental disabilities who need to learn new skills to live more independently. They are distinct from rehabilitation services which are usually provided to individuals who need to regain skills that are lost as a result of disability or illness.

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11. For more information on *Olmstead vs. L.C.*, see Randy Desonia, "Is Community Care a Civil Right? The Unfolding Saga of the Olmstead Decision," National Health Policy Forum, Background Paper, March 12, 2003; available at www.nhpf.org/pdfs_bp/BP_Olmstead_3-03.pdf.
12. This figure includes awards through September 2005 (written communication, Mary Jean Duckett, Centers for Medicare & Medicaid Services, January 10, 2006). Note that the name change from HCFA to CMS took place in 2001.
13. Kitchener *et al.*, "Medicaid 1915(c) Home and Community-Based Service Programs."
14. Steve Eiken, Brian Burwell, and Eileen Walker, "Medicaid HCBS Waiver Expenditures, FY1999 through FY2004," memorandum, Medstat, May 9, 2005; available at www.hcbs.org/files/71/3514/HCBSWaivers2004.Doc.
15. For more information on the fundamentals of the Medicaid legislation, please refer to "The Basics: Medicaid," National Health Policy Forum, April 27, 2004; available at www.nhpf.org/pdfs_basics/Basics_Medicaid.pdf.
16. Section 1915(c) waiver authority is narrower than the perhaps more well-known section 1115 research and demonstration waiver authority. Only three specific provisions of section 1902 may be waived under 1915(c) authority, whereas section 1115 generally authorizes the Secretary to waive any portion of section 1902. In addition, section 1115 permits federal matching payments for individuals who would not otherwise be Medicaid eligible while section 1915(c) specifically limits eligibility to individuals who would otherwise be eligible for institutional services.
17. Institutional services in an ICF/MR and psychiatric hospital services for individuals under age 22 and over age 65 are optional Medicaid benefits. When the state opts to provide these benefits, they must be offered statewide and meet comparability requirements.
18. Burwell, Sredl, and Eiken, "Medicaid Long Term Care Expenditures in FY 2004."
19. Kitchener *et al.*, "Medicaid 1915(c) Home and Community-Based Service Programs."
20. Enid Kassner and Lee Shirley, "Medicaid Financial Eligibility for Older People: State Variations in Access to Home and Community-Based Waiver and Nursing Home Services," American Association of Retired Persons, April 2000; available at www.aarp.org/research/assistance/medicaid/aresearch-import-534-2000-06.html.
21. Federal matching payments under Medicaid are currently available for periods of presumptive eligibility for children and pregnant women only.
22. Vernon Smith *et al.*, "Making Medicaid Work for the 21st Century: Improving Health and Long-Term Care Coverage for Low-Income Americans," National Academy for State Health Policy, January 2005; available at www.nashp.org/Files/Making_Medicaid_Work_for_the_21st_Century.pdf.
23. Suzanne Crisp *et al.*, "Money Follows the Person and Balancing Long-Term Care Systems: State Examples," Medstat, prepared for CMS, September 29, 2003; available at www.cms.hhs.gov/PromisingPractices/Downloads/mfp92903.pdf.
24. All states have Nurse Practice Acts that govern nursing practice and, in some cases, nursing education. They define nursing, the boundaries of the scope of nursing practice, and the types of licenses required for the practice of nursing.
25. Laura Summer, "Strategies to Keep Consumers Needing Long-Term Care in the Community and Out of Nursing Facilities," Kaiser Commission on Medicaid and the Uninsured, October 2005; available at www.kff.org/medicaid/7402.cfm.
26. Kristen Siebenaler *et al.*, "Real Choice Systems Change Grant Program: Second Year Report (October 1, 2002 – September 30, 2003)," RTI International prepared for the CMS, September 2004; available at <http://new.cms.hhs.gov/RealChoice/downloads/2004report.pdf>.

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27. Congressional Budget Office, "Cost Estimate, S. 1932 Deficit Reduction Act of 2005, Conference Agreement, as amended and passed by the Senate on December 11, 2005," January 27, 2006; available at www.cbo.gov/ftpdocs/70xx/doc7028/s1932conf.pdf.
28. Kitchener *et al.*, "Medicaid 1915(c) Home and Community-Based Service Programs."
29. R. J. Sutcliffe and C. Lakin, "Costs and Outcomes of Community Services for Persons with Intellectual and Developmental Disabilities," University of Minnesota, Research and Training Center on Community Living, Policy Research Brief 15, no. 1, May 2004; available at <http://ici.umn.edu/products/prb/151/151.pdf>. Costs for ICF/MR services as reported here include both large institutions and small community-based residences of 4 to 15 beds. ICF/MR expenditures for only large institutions are significantly higher.
30. "CMS Medicaid Program: Technical Summary," Centers for Medicare & Medicaid Services, updated December 14, 2005; available at www.cms.hhs.gov/MedicaidGenInfo/03_TechnicalSummary.asp. This amount includes state and federal Medicaid expenditures. Most beneficiaries in nursing homes have some income (for example, social security income) that is contributed toward the cost of nursing home care. Beneficiary contributions are not included in average per person Medicaid expenditures reported here.
31. For more information on housing and HCBS, see Gary Smith *et al.*, "Understanding Medicaid Home and Community Services: A Primer," George Washington University Center for Health Policy Research prepared for the U.S. Department of Health and Human Services, Office of Disability, Aging and Long-Term Care Policy (USDHHS/ASPE), October 2000; available at <http://aspe.hhs.gov/daltcp/reports/primer.htm>.
32. Lutzky *et al.*, "Review of the Medicaid 1915(c) Home and Community-Based Services Waiver Program: Literature and Program Data."
33. Pamela Doty, "Cost-Effectiveness of Home and Community-Based Long-Term Care Services," USDHHS/ASPE, Washington DC, June 2000; available at <http://aspe.hhs.gov/daltcp/reports/costeff.htm>.
34. General Accounting Office (GAO), "Long-Term Care: Implications of the Supreme Court's *Olmstead* Decision Are Still Unfolding," GAO-01-1167T, testimony of Kathryn G. Allen before the Special Committee on Aging, U.S. Senate, September 24, 2001; available at www.gao.gov/new.items/d011167t.pdf.
35. Kitchener *et al.*, "Medicaid 1915(c) Home and Community-Based Service Programs." See figure 9 on page 9 for information on the growth of waiting lists.
36. For more information on global budgeting see Leslie Hendrickson and Susan Reinhard, "Global Budgeting: Promoting Flexible Funding to Support Long-Term Care Choices," Rutgers Center for State Health Policy, November 2, 2004; available at www.hcbs.org/moreInfo.php/topic/210/sby/Date/doc/998/State_Policy_in_Practice..._Global_Budgeting:_Prom.
37. Robert Prouty, Gary Smith, and K. Charlie Lakin, "Residential Services for Persons with Developmental Disabilities: Status and Trends Through 2004," University of Minnesota, Research and Training Center on Community Living, July 2005; available at <http://rtc.umn.edu/risp/index.html>.
38. Charles Milligan Jr., "Money Follows the Person: Reducing Nursing Home Expenditures to Expand Home and Community-Based Services," prepared for Community Living Exchange at Rutgers/NASHP, Issue Brief, January 2005; available at www.hcbs.org/moreInfo.php/topic/210/sby/Date/doc/1170/Money_Follows_the_Person:_Reducing_Nursing_Facilit.
39. States with capitated long-term care programs include: Arizona, Florida, Massachusetts, Minnesota, New York, Texas, and Wisconsin.
40. Harriet L. Komisar, Judith Feder, and Judith D. Kasper, "Unmet Long-Term Care Needs: An Analysis of Medicare-Medicaid Dual Eligibles," *Inquiry*, 42, no. 2 (October 2005): 171-182.

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41. A qualified residence is defined as a home that is owned or leased by an individual or a family member, an apartment with an individual lease, or a community residence in which no more than four unrelated people reside.
42. A summary of MiCASSA is available at www.adapt.org/casaintr.htm.
43. GAO testimony, "Long-Term Care: Implications."



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