

medicaid
and the uninsured

**Recent Growth in Medicaid Home and
Community-Based Service Waivers**

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

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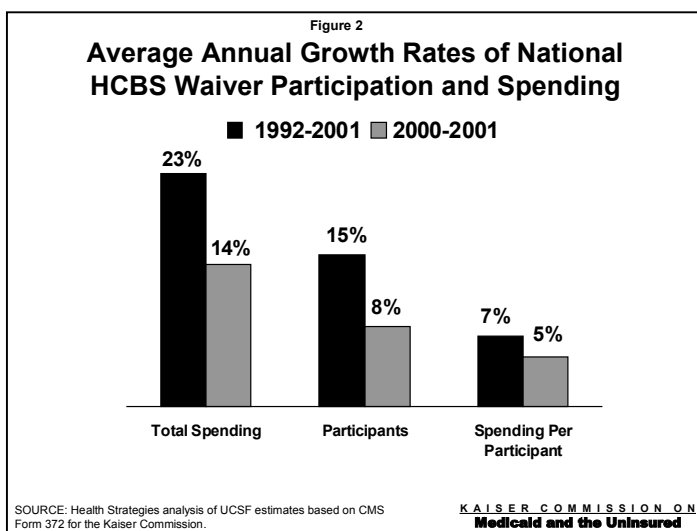
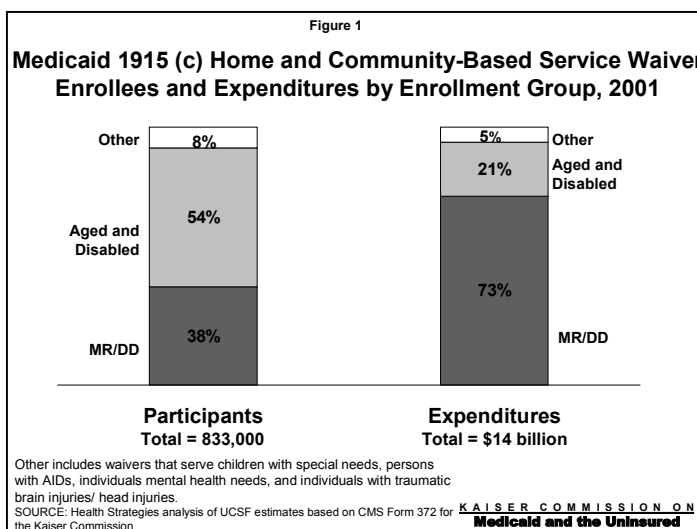
Executive Summary

Medicaid expenditures on home and community-based service (HCBS) waivers dominates spending on community-based long-term care services offered through the Medicaid program. The emergence of this waiver program as the major financing mechanism for Medicaid community-based long-term care services has been swift, shifting from a small to large portion of Medicaid's community-based service benefits over the last decade (from 37% in 1992 to 66% in 2001). As spending on the HCBS waiver program has been growing rapidly, so has the portion of overall Medicaid long-term care spending dedicated towards community-based services rather than institutional care. While Medicaid spending on institutional care remains high, the rapid growth of the waiver program is increasing the percentage of total Medicaid long-term care spending that goes towards community-based long-term care services from 15% in 1992 to 30% in 2002.

Because of its emergence as an increasingly significant source of financing for community-based care within Medicaid, the HCBS waiver program deserves close attention. The unique authority for HCBS waivers permits states to provide a wide variety of unique services not otherwise covered under Medicaid, such as assistance with household tasks, assisted living, supported employment services, accessibility adaptations, and respite care. At the same time, states employ a variety of cost-containment mechanisms to meet federal cost neutrality requirements and to meet state budgetary restrictions. This paper examines trends in HCBS waiver enrollment and spending based primarily on CMS 372 data compiled by the University of California, San Francisco (UCSF) and a survey of state waiver program administrators on cost-containment policies conducted by the UCSF, supplemented with data from the National Health Accounts and CMS 64 data compiled by Medstat.

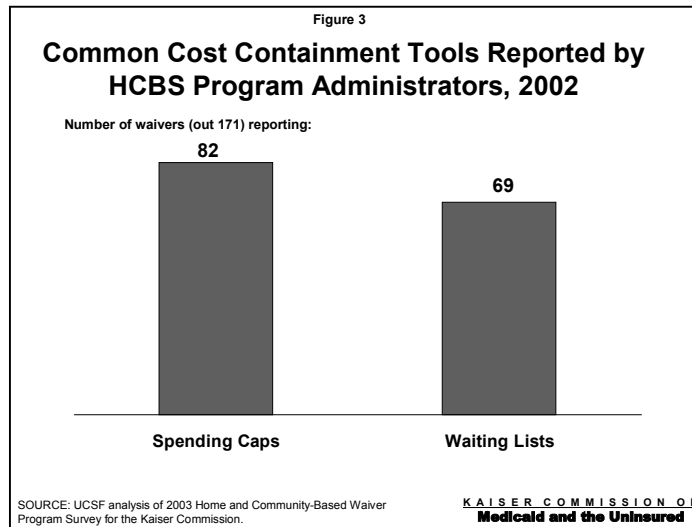
In 2001, 229 waiver programs served 833,000 Medicaid beneficiaries. States typically design their waiver services for a specific target population such as people with developmental disabilities, people with physical disabilities, elderly persons, or persons living with HIV or AIDS. HCBS waiver programs for persons with mental retardation or developmental disabilities (MR/DD) accounted for 38 percent of total waiver program participants, but almost three quarters of total waiver program spending in 2001. Waiver programs for the aged and disabled accounted for over half of the participants, but for only 21 percent of waiver spending (Figure 1).

With revisions in the federal review process in the early 1990s, HCBS waiver program spending took off with a 36 percent growth rate from 1992 to 1993. The movement of MR/DD populations to HCBS waiver programs drove much of the large growth rates of the early 1990s. The average annual growth rate over the past ten years has been high (23%) but this rate masks a moderation in spending growth to 14 percent from 2000 to 2001 (Figure 2). While much lower than the early 1990s, the 2001 waiver spending growth is still higher than institutional spending growth and overall Medicaid spending growth.



States use some form of cost containment for almost every waiver (Figure 3). These often include enrollment limits and per person spending limits. These types of controls are not available for other Medicaid long-term care services. Given the significant authority states have under the waiver program to impose these limitations, Medicaid beneficiaries participating in these programs may be subject to cuts or reductions in needed services. Of the 171 waiver programs responding (out of 221 total), 82 waiver programs reported using spending caps to manage the cost of their programs. These spending caps range across waiver programs from absolute maximum dollar levels on services per participant (hard caps) to targets for average spending per participant (soft caps). Because states often have more potential waiver program participants than available slots, some states establish waiting lists. 69 waiver programs (out of 171)

reported having waiting lists in 2002. The number of people on waiting lists and the length of time spent on waiting lists varied considerably by waiver program.



The unique array of services that can be offered to beneficiaries through HCBS waiver programs make them popular with states and beneficiaries. Programs present an opportunity for beneficiaries to get needed services in the community and out of institutions. At the same time, state budget constraints may threaten the extent to which states are able to address the needs of low-income seniors and persons with disabilities through HCBS waiver programs. In the face of funding pressures, states may place additional limits on the number of beneficiaries served and/or the dollar value of services provided under home and community-based service waivers. The HCBS waiver program remains the most significant avenue through which Medicaid beneficiaries can receive the community-based long-term care services they need and merits continued careful monitoring of enrollment and spending trends.

Introduction

The Medicaid program was created in 1965 to provide federal financing to states offering health care services to low-income people. The original program offered primary and acute care services. In 1968, institutional long-term care, such as nursing facility care, was added to the program. Since that time, the program has grown to cover a wide array of other health care services including some long-term care services provided in a person's home or other community settings. The program provides health care services to three basic groups of low-income Americans: children and their parents, the elderly, and persons with disabilities. Today, states administer the program to over 52 million beneficiaries and together with funding from the federal government, spend \$235 billion annually to provide medical assistance.¹

One of the most unique features of the Medicaid program is its coverage of long-term care services. Aside from a small private long-term care insurance market, Medicaid is virtually the only program that pays for long-term care services. These services include long-standing benefits such as nursing home care and institutional care for people with mental retardation, and a variety of newer community-based long-term care services and supports. These services are provided to people with disabilities under age 65 (including children with disabilities) and the elderly. For many people, their need for long-term care and the significant expense of caring for these needs impoverishes them to the point of qualifying—often for the first time in their lives—for Medicaid payment of these services.

Although almost an equal number of beneficiaries receive Medicaid institutional services and home and community-based services, spending on long-term care services is weighted toward institutional care. In fact, in 2001, 70 percent of Medicaid long-term care spending was for institutional care. This slant toward institutional care has persisted since the inception of the Medicaid program when long-term care was only available in institutions. However, the program is changing and spending on Medicaid home and community-based care is growing. In 1992, only 15 percent or \$6 billion of Medicaid long-term care spending was for home and community-based care. In 2002, this care accounted for \$25 billion or 30 percent of total long-term care spending.

States are required to cover just one non-institutional long-term care benefit: home health services. Beyond this minimum, states have the option of providing personal care services and/or home and community-based services through waivers. There are many similarities and differences between these services. Home health and personal care services are Medicaid state plan benefits, which allow beneficiaries to receive services in their home from home health aides and personal care attendants. Services can include adult day care services, nursing services and medical equipment and supplies. HCBS waiver programs offer similar and at times more expansive services, however, states can use enrollment limits, as well as other tools to limit financial risk.

For the past decade, nowhere has Medicaid home and community-based spending and participation growth been stronger than for Medicaid HCBS waiver programs.

Beneficiaries enrolled in waiver programs receive a wide array of services and supports. The waiver program permits states to design unique benefits with the objective of allowing beneficiaries to remain in the community. The waiver program also permits states to limit services, eligibility and spending in ways that depart significantly from policies traditionally available within the Medicaid program, including in Medicaid state plan home health and personal care services.

This policy brief explains how the HCBS waiver program works including the beneficiaries it serves and the services it offers. The brief also describes the most recent trends in waiver program spending and participation growth over the last decade at a national level, within different HCBS waiver types, and across states. It also examines how states use the waiver authority to control costs in their programs and the potential effect these controls have on beneficiaries.

Methodology

A variety of data sources were used to assess the changes in national and Medicaid long-term care spending and the specific spending and participation trends for Medicaid home and community-based services.

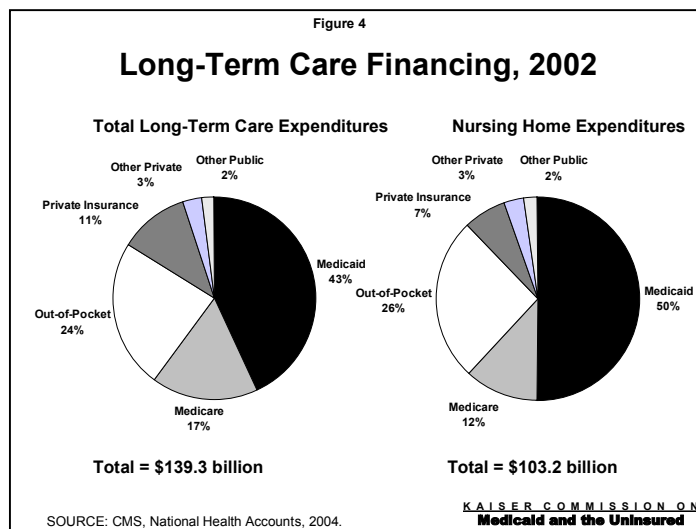
- *CMS 372 Data.* The CMS 372 data used in this study was collected and compiled for the Kaiser Commission on Medicaid and the Uninsured (KCMU) by Charlene Harrington and colleagues at the University of California, San Francisco (UCSF) over the last year. We used CMS 372 data in our analysis to examine the home and community-based waiver program spending and participation at the national and state levels, as well as for different waiver population groups. This data source was necessary to provide detail about Medicaid participation not available on the CMS 64. We focused our analysis on data from 1992 to 2001 because it is the most recent 10-year period for which we had data available. CMS 372 data is reported to CMS annually and provides data on HCBS waiver participants and expenditures by date of service. UCSF collected the 372 data directly from states. In instances where states had outstanding 372 data, state officials were asked to estimate data or provide interim reports. The 372 we present has not been audited federally in the same manner as CMS 64 data. As a result, the 372 spending data is not directly comparable to the CMS 64 data.
- *UCSF Home and Community-Based Service Waiver Program Survey.* University of California, San Francisco conducted a survey of HCBS waiver program administrators for the Kaiser Commission. This survey captured information about waiver program enrollment slots, waiver program spending caps, cost containment tools, and waiting lists for 171 of 229 (75 percent) HCBS waiver programs operating in 2002. The survey is a useful tool, however the data reflects a point-in-time in 2002, and therefore, may not represent program changes since that time.
- *National Health Accounts.* We used 2000, 2001, and 2002 National Health Accounts data to place Medicaid long-term care spending in the context of national spending.

This data set is produced annually by the Centers for Medicare and Medicaid Services (CMS) and provides information about total national health care expenditures for different categories of spending including payer categories. One limitation of this data is that it does not reflect home and community-based waiver program spending as a single category of spending. However, this data is valuable in its tracking of national out-of-pocket spending for health care services and long-term care.

- *CMS 64 Data.* We used CMS 64 data from 1992 to 2001 to look at the change in Medicaid long-term care spending over the last decade. CMS requires states to report their medical assistance expenditures by service category (i.e. nursing homes, HCBS waiver programs) on the CMS 64 reporting form each quarter as well as annually. These reports are audited and used by CMS to calculate the amount of federal Medicaid matching payments each state receives. The CMS 64 data used in this study was compiled by Brian Burwell and colleagues at Medstat.² One of the limitations of this data is that although audited, it does not track the number of people receiving Medicaid services. Therefore, it does not allow us to analyze participation trends under the waiver program.

Overview

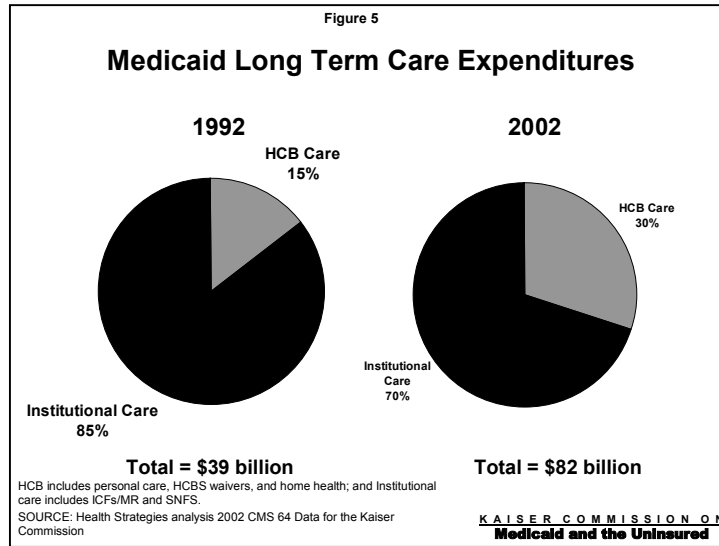
In 2002, national spending on long-term care services was \$139 billion. Medicaid accounted for over 43 percent of long-term care services (\$60 billion) (Figure 4). In contrast, the next largest payer category was out-of-pocket spending, accounting for almost one-quarter, or \$33 billion, in spending.



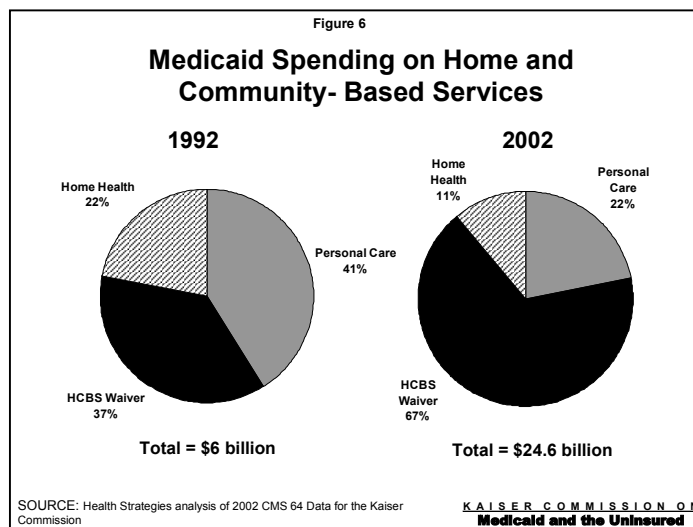
The payer mix changes slightly when total long-term care is broken down by nursing facility and home health care (Figure 4). Medicaid continues to be the major payer for nursing facility care in 2002—contributing \$52 billion—half of the dollars. The next largest payer category was out-of-pocket spending with 26 percent of expenditures. In contrast, according to National Health Accounts data, Medicaid has taken on a much smaller role in home health spending, which is largely financed by Medicare. The Medicare home health benefit accounted for the majority of expenditures (32%) with Medicaid spending accounting for 23 percent, and out-of-pocket expenditures accounting for almost 20 percent of spending. It is important to note that Medicaid home health spending in the National Health Accounts data home health category does not include Medicaid spending on the HCBS waiver program and personal care services.

Medicaid Long-Term Care Services. Total Medicaid long-term care spending grew from \$39 billion in 1992 to \$82 billion in 2002 (Figure 5). The overall increase in spending masks an important shift in the type of services offered by state Medicaid programs. States provide long-term care in both institutional and community settings.³ Between 1992 and 2002, institutional services delivered in nursing facilities and intermediate care facilities for the mentally retarded (ICF/MRs) dropped from 85 percent of total Medicaid long-term care spending to 70 percent. During the same period, home and community-based services, including home health, personal care, and the HCBS waiver program, rose from 15 percent of total Medicaid long-term care spending in 1992 to 30 percent of spending in 2002. These shifts are due to a 16 percent average annual growth rate in home and community-based services spending, pushing Medicaid community-based

long-term care spending from almost \$6 billion in 1992 to \$24.6 billion in 2002. Over this same time period, institutional spending grew relatively slowly at a 5 percent average annual growth rate and total spending of \$33 billion in 1992 and \$53 billion in 2001.



Medicaid Home and Community-Based Services. As community-based care has expanded over the last decade, HCBS waiver programs have become the primary vehicle through which the Medicaid program finances care in the community (Figure 6). As a percentage of total Medicaid home and community-based services spending, HCBS waiver program spending increased from 37 percent in 1992 to 67 percent in 2002. Spending in the other Medicaid home and community-based services areas, specifically personal care and home health services, dropped from 22 percent of total home and community-based spending to 11 percent and from 41 percent to 22 percent, respectively.



Medicaid Home and Community-Based Services: Home Health, Personal Care, and the Waiver Program

There are three main ways a state can provide Medicaid home and community-based services: (1) through the home health benefit; (2) through one of several optional state plan services (personal care services); and (3) through 1915(c) home and community-based service waivers. Each varies in the services that are offered, how they are offered, and to whom they are offered. Figure 7 summarizes the similarities and differences of these three components. The following describes each benefit.

Figure 7
Medicaid Home and Community-Based Programs, 2001

	Mandatory or State Option	Eligibility	Benefits	Statewide Coverage	Enrollment
Home Health Care	Mandatory for individuals 21 and over	No requirement that individual be at risk of institutional care	Must include nursing, home health aides, medical supplies and equipment. May include PT, OT, speech pathology, and audiology services. Limits on services allowed.	Required	50 states + District of Columbia. 728,000 participants
Personal Care	State Option	No requirement that individual be at risk of institutional care	Personal care services, including attendants. Limits on services allowed.	Required	27 states 557,000 participants
HCBS Waivers	State may seek a waiver from the Secretary of HHS. Waivers must meet a cost neutrality test.	Individual must be at risk of institutional care and meet state established targeted criteria	Case management, homemaker/home health aide, adult day health, personal care, habilitation, respite care, and other services requested by state. Limits on services allowed.	Not required. Can limit to certain geographical areas and specific population groups.	229 waivers 833,000 participants

SOURCE: State Reports on CMS Form 372. University of California, San Francisco, 2003; Department of Health and Human Services, Office of the Assistant Secretary for Planning and Evaluation, *Understanding Medicaid Home and Community Services: A Primer*, Washington D.C., October 2000.

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- Home Health.** In 2001, 728,000 Medicaid beneficiaries received home health services home health services, accounting for 11 percent of Medicaid home and community based spending. As a mandatory Medicaid state plan service, all 50 states must provide home health services for individuals 21 and older who are entitled to nursing facility services. A person who is financially eligible for Medicaid and who would otherwise be eligible for nursing facility care is entitled to home health services. Medicaid home health includes the following mandatory services: point-in-time or intermittent nursing, home health aides, medical supplies, and medical equipment. Optional home health services under the Medicaid state plan are physical therapy, occupational therapy, speech pathology, or audiology services.⁴ A state can also elect to provide home health services to additional Medicaid eligible individuals.

Medicaid home health services are different from other Medicaid home and community-based services because federal statute requires all states to offer the benefit to all Medicaid beneficiaries who are over the age of 21 and entitled to nursing facility care. While federal law permits states to apply medical necessity criteria and utilization controls (e.g., one home health visit per day) to the home

health benefit, it also stipulates that the program must provide a sufficient benefit to all users and provide the same service across all the eligibility groups it covers.⁵

- *Personal Care.* Personal care accounted for 23 percent of Medicaid home and community-based spending in 2001. During this time, personal care services were provided to 557,000 Medicaid beneficiaries in 27 states. States offering the personal care benefit have considerable discretion in defining what services are provided. Services can include assistance with Activities of Daily Living (ADLs) and Instrumental Activities of Daily Living (IADLs) such as personal hygiene, light housework, meal preparation, transportation, and medication management. These services can be offered in and outside a beneficiary's home. To qualify for personal care, a person must be categorically eligible or qualify as "medically needy" for Medicaid, and meet state-defined needs criteria, such as being unable to perform a minimum number of Activities of Daily Living (ADLs).

States can elect to provide personal care services to qualifying Medicaid beneficiaries under their state Medicaid plans. As an optional state plan benefit, a state can elect to offer or not offer the personal care benefit at any time, however, similar to home health and other state plan services, once a state elects to provide these services it must provide them to all eligible beneficiaries statewide.

- *1915(c) Home and Community-Based Service Waivers.* HCBS waiver program spending accounted for 66 percent of Medicaid community-based spending in 2001. There are over 229 waiver programs in operation today serving over 833,000 HCBS waiver beneficiaries. Every state, except Arizona, has at least one home and community-based waiver program in operation.⁶ Waiver programs provide a variety of services tailored to meet the unique needs of individual Medicaid beneficiaries. To qualify for a waiver program, Medicaid beneficiaries must meet financial and functional eligibility criteria that are at least as strict as those for a comparable institutional setting.

Medicaid HCBS waiver programs are a departure from state plan home health and personal care service benefits and the Medicaid program as a whole. These waiver programs allow states to cap enrollment, and to limit spending and services for each waiver program participant. Moreover, unlike other Medicaid services, the HCBS waiver programs do not have to provide the same services to similar beneficiaries across the states. These limits within HCBS waivers are a departure from the traditional Medicaid program, in which all individuals who qualify are eligible for services covered under a full benefit package that the state defines within federal guidelines. The HCBS waiver authority permits states to offer a broad array of flexible community services, but it also allows the state to limit the amount of services, spending on these services, and most importantly to limit enrollment in the program in many ways. The waiver program is described in more detail in the following section.

Description of the HCBS Waiver Program. The Medicaid program provides explicit authority for the executive branch to waive or set aside federal Medicaid requirements so that states can more easily administer components of their Medicaid programs. Over time, at least two of these waiver authorities—established under 1915(b) and 1915(c) of the Social Security Act (SSA)—have become a standard part of every state’s Medicaid program. Section 1915(b) allows states to operate Medicaid mandatory managed care programs. Section 1915(c), which was authorized by Congress in 1981, establishes federal requirements for states choosing to provide HCBS waiver programs for individuals who would otherwise qualify for care in institutions. Section 1915(c) allows states to provide home and community-based services to these Medicaid beneficiaries as long as the average per participant Medicaid expenditures for the population in the HCBS program does not exceed 100 percent of the average per participant Medicaid expenditures that are estimated to have occurred for this population if the HCBS program was not implemented.⁷

Under the 1915(c) statute, states can waive provisions of Medicaid law related to comparability and statewide availability of services. Waiving these provisions allow states to create programs that:

- Provide services not otherwise covered under the Medicaid program;
- Target specific geographic areas, populations, or conditions; and
- Cap enrollment in the waiver program by creating waiver enrollment slots.⁸

States use this authority, in combination with the limit on per participant spending, to provide services to discrete and limited groups of beneficiaries and protect themselves from open-ended financial obligations under the Medicaid program. At the same time, the authority allows states to provide beneficiaries with the services they need to stay or move into their own home, the home of a family member, or other community setting, including new and innovative supports that would not be available under Medicaid statute. Often this is accomplished at a lower overall cost than institutional care and with a higher level of beneficiary satisfaction.

- *Services.* Services covered under HCBS waiver programs can include, but are not limited to: case management, care coordination, personal care services, assistance with household tasks, home health, habilitation, adult foster care, assisted living, supported employment services, mental health clinic services, skilled nursing, accessibility adaptations, medical equipment and supplies, respite care, and transportation.⁹ The Centers for Medicare and Medicaid Services must approve any services offered by states under waiver programs. With CMS’ consent, states can provide a wide variety of services to beneficiaries as long as these services are specified in an individualized, written plan of care and are required to keep a person from being institutionalized.¹⁰

With over 229 active HCBS waiver programs, there is considerable variation in the services offered through the programs. Much of this variation is the result of differences in the state Medicaid programs and other state and local programs that

may provide services to the waiver program participants. Waiver programs are structured to use existing local services and delivery structures whenever possible. They are also built around Medicaid state plan services that are already in place and operating within communities, such as home health or personal care services.

- Populations Served.* HCBS waiver programs are typically organized around specific target population groups such as people with developmental disabilities, people with physical disabilities, persons living with HIV or AIDS, children with special needs, mentally ill beneficiaries, and people with traumatic brain injuries. These types of waiver programs offer services specifically geared toward the health care needs and supports necessary for these individuals to live safely in the community. Waiver programs can also serve broader groups of beneficiaries. For instance, a common waiver type—aged/disabled waiver programs—provides services to aged and disabled Medicaid beneficiaries (Exhibit 1). The services provided under this type of waiver program must be sufficient in variety and scope to meet the many different care needs of the frail elderly and people with disabilities who may or may not be elderly.

HCBS waiver programs for persons with mental retardation or developmental disabilities (MR/DD waiver programs) accounted for 38 percent of total waiver program participants, but almost three-quarters of total waiver program spending in 2001. Waiver programs for the aged and disabled accounted for over half of the participants in 2001, but for only 21 percent of waiver program spending (Figure 8).

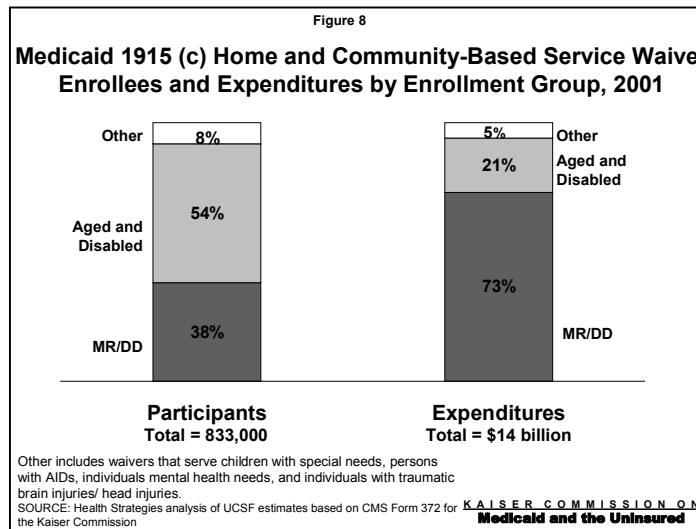


EXHIBIT 1
Maryland Waiver for Older Adults

- *Administration.* The Maryland Department of Aging, Area Agencies on Aging, and Maryland Department of Health and Mental Hygiene.
- *Target Population.* Persons age 50 years and older
- *Financial Eligibility.* Monthly income of \$1590 (300% of the SSI level) and assets of less than \$2500
- *Functional Eligibility.* State-established Medicaid nursing facility level of care
- *Services.* Personal care, respite care, extended home health care, environmental modifications, case management, home-delivered meals, assisted living services, Senior Center Plus, family/consumer training, personal emergency response systems, assistive devices, behavioral consultation services, and nutritional services
- *Service Delivery.* License assisted living facilities and in enrollees' homes
- *Waiver Participants.* Subject to state budget appropriations, 3,235 slots in state fiscal year 2002
- *Waiting List.* Began May 1, 2003, approximately 1,600 participants on waiting list.
- *Actual Spending.* \$13 million in federal fiscal year 2002.

SOURCE: Maryland Waiver For Older Adults Fact Sheet; State reports on CMS form 372, UCSF, 2003; and Maryland Department of Health and Mental Hygiene.

- *Eligibility Requirements.* An individual must be eligible for Medicaid to participate in a HCBS waiver program. This means a person must qualify for Medicaid based on their income, assets, and other criteria, such as state residency requirements. States' eligibility requirements for Medicaid and HCBS waiver programs vary widely from state to state. States can elect to set requirements anywhere within certain broad federal Medicaid eligibility guidelines.¹¹ Generally, a potential HCBS waiver program participant must meet similar Medicaid income and asset level thresholds as Medicaid participants eligible to receive care in an institution.¹²

A waiver program participant must also meet the state's institutional level of care criteria to participate in program. Level of care criteria means participants would require care in an institution without waiver services. Each state defines the particular level of care required for a person to be placed in an institution in accordance with its own policies and guidelines. The level of care criteria can be based on the diagnosis of a certain medical condition, the number of ADLs or IADLs a person is unable to perform, daily hours of nursing services needed, or some other condition-related criteria.¹³ In addition, the level of care criteria is not uniform across institutional settings. Criteria applied to waiver programs must be at least as stringent as criteria applied to the comparable institutional setting. A beneficiary applying to enroll in MR/DD waiver programs must meet the state's ICF/MR level of care, while a person applying for services under an aged/disabled waiver program must meet the state's nursing facility level of care criteria.

Once a person meets general Medicaid eligibility qualifications for income, assets, and residency and is determined to meet the institutional level of care criteria, they may be eligible for a HCBS waiver program. However, states can elect to further

limit waiver participation to specific conditions or age groups, such as persons living with HIV or AIDS or disabled people over the age of 50. Potential waiver participants must fall within these targeted waiver categories to ultimately be eligible for HCBS waiver programs.

- *Federal Approval Process and Cost Neutrality Requirements.* Home and community based service waiver programs are approved initially for three years and can be renewed for up to five years at a time. CMS reviews all waiver program applications to ensure they meet federal statute and regulations including an overall cost-neutrality test. Under federal statute, the average cost of providing care to a waiver program enrollee must not exceed the average cost of providing care to a similar person in an institution.¹⁴ Spending for additional community supports provided to beneficiaries outside of the Medicaid program is not incorporated into the cost-neutrality test. A waiver program has exceeded its overall cost neutrality if the average Medicaid spending per waiver program participant in a year exceeds the comparable average institutional Medicaid spending per person in a year. Within the cost-neutrality rules, a state can elect to provide services in whatever amount and scope is most appropriate for each waiver program participant.

Trends in Home and Community-Based Service Waiver Program Spending

Over the past ten years, states have used the HCBS waiver authority to create hundreds of new waiver programs. As a result, there has been a dramatic increase in home and community-based service waiver program spending from \$2.2 billion in 1992 to \$14.2 billion with an average annual growth rate of 23 percent (Table 1) by 2001.

Several changes to the HCBS waiver program have spurred program growth. First, the Health Care Financing Administration (now called CMS) made significant administrative changes to the program in the early 1990s to ease the HCBS waiver program application and implementation process for states.¹⁵ These changes included the release of a streamlined application process in 1991, which was followed by a surge in the number of applications for waivers.

Another important development was the repeal of the “cold bed rule” in 1994.¹⁶ This rule required states applying for waiver programs to prove to the federal government they would have the institutional bed capacity to serve each waiver program participant if the waiver program did not exist or was shut down. The rule was created to prevent a sudden onslaught of persons with significant health care needs who were living in the community from enrolling in the waiver program.¹⁷ States viewed the cold bed rule as difficult to prove in practice and, as a result, found the waiver application process burdensome. The repeal of this requirement markedly reduced the difficulty of obtaining HCBS waiver program approvals.

An important factor in HCBS waiver program growth and expansion during the 1990s was the shift of entire community MR/DD service systems to HCBS waiver programs. Because Medicaid HCBS waivers are partially financed with federal dollars, states were

inclined to move their community-based service programs for the developmentally disabled, which were traditionally funded at the state and local level, to Medicaid HCBS waiver programs. This process accelerated with the repeal of the cold bed rule, easier application requirements, and the continued efforts of states to move people with developmental disabilities from ICF/MRs to community-based programs. The movement of MR/DD populations to HCBS waiver programs drove the large overall growth rates of the early 1990s, but as more and more states have made this change, there are fewer MR/DD programs and participants to shift over to the Medicaid waiver programs and consequently growth in this category and overall HCBS waiver program spending has slowed significantly.

Throughout the 1990s and today, advocacy groups for people with disabilities have also been working steadily to encourage states to transition people with disabilities from institutions to community settings using HCBS waiver programs as well as home health and personal care state plan benefits. In concert with the advocacy community's efforts, the 1999 *Olmstead* decision (Exhibit 2) has also led many states to create comprehensive long-term care plans that include efforts to transition people or maintain people in community-based settings.¹⁸ The pressure from advocacy groups and *Olmstead* has pushed states to consider community-based care as a viable alternative to institutional care and move to provide services to increasingly more Medicaid beneficiaries in community settings, however, many states face fiscal constraints and are currently unable to implement new initiatives.¹⁹

Exhibit 2 Olmstead Decision

In June 1999, the Supreme Court ruled in *Olmstead v L.C.* it is a violation of the Americans with Disabilities Act (ADA) for states to discriminate against people with disabilities by providing services in institutions when the individual could be served more appropriately in a community-based setting. The decision affirmed that states are required to provide community-based services for people with disabilities if treatment professionals determine that it is appropriate, the affected individuals do not object to such placement, and the state has the available resources to provide community-based services.

The Court suggested that states could establish compliance with the ADA by having: (1) a comprehensive, effective working plan for placing qualified people in less restrictive settings, and (2) a waiting list for community-based services that ensures people can receive services and be moved off the list at a reasonable pace.

Source: Rosenbaum Sara, *The Olmstead Decision: Implications for Medicaid*, for the Kaiser Commission on Medicaid and the Uninsured: Washington, DC, March 2000.

Total Waiver Spending and Participation. Today, HCBS waiver program spending is rising and the average annual growth rate over the past decade has been very high (23 percent). However, the rate of growth has declined since the early 1990s, when spending and participation data for HCBS waiver programs first became available. Figure 9 shows how waiver program growth rates for spending, participation, and spending per participant have changed over the last decade. While the average annual

growth rate over the last decade for total waiver program spending was 23 percent, the growth rate in 2001 slowed to 14 percent compared to 36 percent in 1993.

The two components of total spending growth are growth in participation and growth in spending per waiver participant. Growth in participation has largely driven changes in overall waiver program spending. There were 235,580 HCBS waiver program participants in 1992 and 832,915 participants in 2001 (Table 1). Figure 9 shows how growth in participation has largely mirrored the growth in overall spending, declining from a 26 percent growth rate in 1993 to an 8 percent growth rate in 2001. In contrast, changes in the spending per waiver participant growth rate have remained *relatively* stable over the last decade with an average annual growth rate of 7 percent. Spending per participant increased 8 percent from 1992 to 1993 compared to 5 percent from 2000 to 2001. In 2001, average waiver spending per participant across all types of waiver programs was \$17,070 compared to \$9,187 in 1992.²⁰ While this figure almost doubled over the ten-year period, it is a minor increase relative to overall HCBS waiver program spending which was seven times higher in 2001 than it was in 1992.

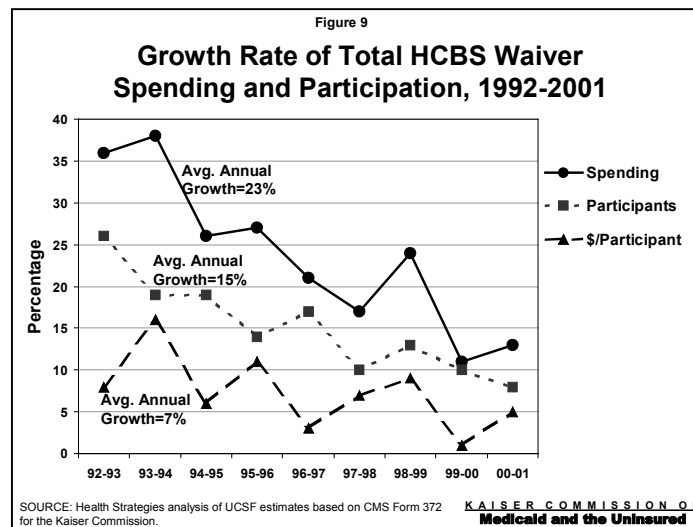


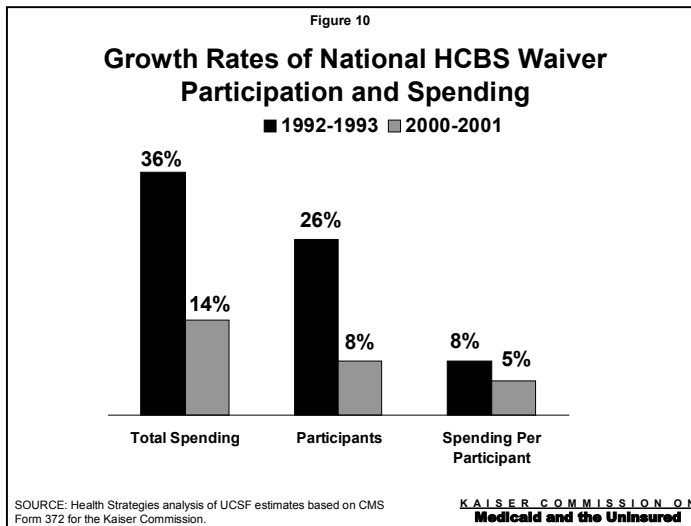
Table 1: Spending and Participation for All Waiver Programs

	1992	2001	Average Annual Growth Rate, 1992-2001
Total Spending	\$2.2 billion	\$14.2 billion	23%
Total Participants	235,580	832,915	15%
Spending Per Participant	\$9,187	\$17,070	7%

SOURCE: Health Strategies analysis of UCSF estimates based on CMS Form 372 for the Kaiser Commission.

Figure 10 provides another illustration of the trends we describe above. The total spending growth rate from 1992 to 1993 was 36 percent compared to 14 percent from

2000 to 2001. The growth rate in waiver participation was 26 percent from 1992 to 1993 compared to eight percent from 2000 to 2001. The growth in spending per participant was eight percent from 1992 to 1993 and five percent from 2000 to 2001.



Spending and Participation for Specific Waiver Populations. We examined spending and participation growth rates for two types of HCBS waiver programs—MR/DD and aged/disabled—to determine how growth in their spending and participation compared to overall spending and participation growth. As the dominant waiver programs, significant change to these waiver programs can influence overall rates of waiver program growth and participation.

MR/DD waiver program spending grew from \$1.4 billion in 1992 to \$10.4 billion in 2001 with the average annual growth rate being 25 percent (Table 2). Participation in MR/DD waiver programs grew almost as quickly over the same time period at an average annual rate of 21 percent with the number of participants growing from 57,627 to 319,946. However, similar to trends in the overall HCBS waiver program spending per participant was *relatively* stable growing only 4 percent per year on average from \$20,431 to \$29,245 during this time.²¹

Table 2: Spending and Participation for MR/DD Waiver Programs

	1992	2001	Average Annual Growth Rate, 1992-2001
Total Spending	\$1.4 billion	\$10.4 billion	25%
Total Participants	57,627	319,946	21%
Spending Per Participant	\$20,431	\$29,245	4%

SOURCE: Health Strategies analysis of UCSF estimates based on CMS Form 372 for the Kaiser Commission.

Spending for the aged/disabled waiver program category grew from \$573 million in 1992 to \$3 billion in 2001, reflecting an average annual growth rate of 20 percent. Participation in these waiver programs also grew at an average annual rate of 12 percent from 155,836 to 446,463 participants over the same time period (Table 3). Like MR/DD waiver programs, spending per participant remained relatively low from 1992-2001, growing only 5 percent on average each year from \$4,852 to \$7,734.²²

Table 3: Spending and Participation for Aged/Disabled Waiver Programs

	1992	2001	Average Annual Growth Rate, 1992-2001
Total Spending	\$573 million	\$3 billion	20%
Total Participants	155,836	446,463	12%
Spending Per Participant	\$4,852	\$7,734	5%

SOURCE: Health Strategies analysis of UCSF estimates based on CMS Form 372 for the Kaiser Commission.

The growth rates for expenditures and participation in the MR/DD population group and the aged/disabled waiver programs are similar to the growth rates in total waiver program spending and participation. Representing over 90 percent of waiver spending and participation, these two types of waiver programs have a heavy influence on overall spending.

Summary of Spending Trends. The HCBS waiver program spending and participation data illustrate a decrease in overall spending and participation growth among and within all waiver population groups. The slowing growth rate reflects the near completion of the shift of MR/DD populations from state and local programs to Medicaid HCBS waiver programs and the natural difficulty of maintaining the high growth rates of the early 1990s as the base of spending gets larger. That is, a growth rate of 36 percent above \$1.4 billion is easier to achieve (requiring an increase in spending of \$500 million) than the same rate above an annual spending amount of \$10.4 billion (requiring an increase in spending of \$3.7 billion). Despite this decline in growth, waiver program expenditures continue to increase from year to year at a rate higher than institutional spending (8.8 percent in 2001) and overall Medicaid spending (10.8 percent in 2001) as states begin to offer waiver programs for aged and disabled populations as well other target groups such as persons living with HIV/AIDs and the mentally ill.²³

However, the slowing growth rate also likely reflects the degree to which states can use the HCBS waiver authority to carefully control the number of Medicaid beneficiaries who enroll in waivers and the amount of spending per waiver participant. The following section describes the cost control mechanisms available to states through the waiver authority, how states use these mechanisms and the possible implications for Medicaid beneficiaries participating in waivers or in need of home and community-based services.

States' Use of Waiver Flexibility and Cost-Containment Tools

Using the statutory waiver authority, states employ a variety of cost-containment strategies to meet federal waiver cost neutrality requirements and to limit waiver program spending so that costs do not exceed state budgetary restrictions.²⁴ These strategies allow states to use HCBS waiver programs to limit long-term care spending and participation in the Medicaid program and to tailor the number of services they offer to waiver program participants. The availability of these tools has made the HCBS waiver program popular with state Medicaid officials. In contrast, the Medicaid home health and personal care state plan benefit permit no such explicit mechanisms to contain spending. Once these state plan benefits are offered, states must provide Medicaid services to all those who qualify regardless of cost.

The cost-containment tools used by states to limit Medicaid home and community-based waiver program spending and participation can have a direct impact on the Medicaid beneficiaries enrolled or those who would like to enroll in HCBS waiver programs. A state can elect to employ most of these cost-containment tools without stringent federal oversight, but each tool discussed below can have an immediate impact on beneficiary access to services and participation in waiver programs. For example, a state can elect to cut a waiver program service to meet budgetary constraints; this has a direct impact on beneficiaries who rely heavily on that service.

In order to understand how states control spending in home and community-based waiver programs, the University of California, San Francisco conducted a survey of 229 waiver programs in 2002, for the Kaiser Commission on Medicaid and the Uninsured. The surveyors requested information from state officials regarding waiver cost-containment tools. They received responses for 171 of the 229 waiver programs. In general, the survey data and discussions with federal and state policy officials indicate the following two main conclusions²⁵:

- Enrollment limits and spending caps are the most commonly used tools used by states to control waiver program expenditures.
- Despite having the flexibility to do so, states are not making dramatic reductions in financial or functional eligibility limits for HCBS waiver programs, or cutting back on regions where services are offered.

Enrollment Limits and Waiting Lists. Setting enrollment limits is a powerful cost-containment tool. Federal 1915(c) waiver statute requires states to limit the number of people it will serve in a waiver program by capping enrollment. This federal enrollment limit can be reduced further by states once they receive federal approval for their HCBS waiver program. This allows states to protect themselves financially against the possibility that demand for HCBS waiver program services may be higher than anticipated. This protection for states, however, may prevent Medicaid beneficiaries who need HCBS waiver program services from receiving them. Often, state enrollment limits lead to waiting lists for those who qualify for HCBS waiver program services.

Table 4 shows a summary of waiver program enrollment slots reported by state officials for each waiver type. This data is limited because it shows only the waiver enrollment slots reported in the survey (171 out of 229 programs). Program administrators reported the data during the survey collection period in 2002; therefore, the data may not reflect the most current enrollment slot numbers. The data is useful, however, because it demonstrates the explicit limits on HCBS waiver enrollment by waiver type. For example, the smallest aged and disabled waiver permits an enrollment of 100 Medicaid beneficiaries while the largest permits 44,680. Across waiver types, almost twice the enrollment slots were available for aged/disabled waivers than for MR/DD (406,141 vs. 222,386). The average number of slots per waiver was 3,556.

Perhaps more importantly, just less than half a million slots were available for aged and disabled waivers, which is consistent with the participation data we received from the CMS 372 data. With only a half a million waiver slots, some seniors or persons with disabilities who are eligible for Medicaid, and have significant care needs, are not receiving waiver services. Without waiver services, people with significant care needs may eventually need to rely on more expensive institutional services.

Table 4: Summary of State Enrollment Limits, 2002

Waivers in Survey*	Minimum Slots	Maximum Slots	Average Slots	Total Slots
MR/DD	97	32,000	3,587	222,386
Aged/Disabled	100	44,680	9,692	406,141
Physically Disabled	32	20,350	2,250	47,247
Children	40	1,071	398	4,781
AIDS/ARC	100	1,650	726	4,358
Mental Health	2,040	2,040	2,040	2,040
TBI/Head Injury	25	1,564	430	6,879
Average			3,556	
Total Slots				693,832

*171 waiver programs (out of 229) responded to the survey.

SOURCE: UCSF analysis of 2003 Home and Community-Based Waiver Program Survey for the Kaiser Commission.

Because states often have more potential waiver program participants than available slots, some states establish waiting lists for waiver program applicants when all the program slots are filled. Those beneficiaries who are placed on waiting lists do not receive any Medicaid HCBS waiver program services. They may continue to receive Medicaid services in an institution or state plan benefits such as home health or personal care. However, unlike the waiver program, these services may not be tailored to the beneficiary's unique needs.

As Table 5 shows, of the 171 waiver programs that responded to the survey, 69 had waiting lists in 2002.²⁶ There were 157,640 people on the waiting lists for these waiver programs in that year. The average number of people on these waiver program waiting lists across all populations was 1,367 people. MR/DD waiver programs in the survey had the largest number of people on waiting lists across the country, with 76,162 people waiting for HCBS waiver program services. Fifty-six percent of MR/DD waiver programs

in the survey had waiting lists and there was an average of 2,270 people on these lists. While only 19 percent, or just three, traumatic brain injury waiver programs had waiting lists, there were a high number of people awaiting waiver services, with 3,907 people on waiting lists.

Table 5: Summary of Waiting Lists By Waiver Program Type, 2002

Types of Waiver*	Number of Waivers Reporting Waiting Lists	Number of People Reported on Waiting Lists	Average Number of People on Waiting Lists
MR/DD	35	72,647	2,270
Aged/Disabled	16	76,162	818
Physically Disabled	8	4,551	569
Children	7	373	75
AIDS/ARC	0	0	0
Mental Health	0	0	0
TBI/Head Injury	3	3,907	1,469
Total (All Waiver Programs)	69	157,640	1,367

*171 waiver programs (out of 229) responded to the survey.

SOURCE: UCSF analysis of 2003 Home and Community-Based Waiver Program Survey for the Kaiser Commission.

Of the 69 waiver programs reporting waiting lists, states provided information about time spent on waiting lists for 41 waiver programs. Of these 41 waiver programs, which represent 18 percent of total HCBS waiver programs, the average waiting time for persons on waiting lists was 10.6 months. Waiver programs for children with special needs and traumatic brain injury had the longest waiting lists with average waits over 20 months. MR/DD waiver programs averaged a 19-month wait for services and waiver programs for the physically disabled and aged/disabled had average wait times between 9 and 10 months.

Per Participant Spending Caps. Federal statute requires service that the average per person Medicaid spending under a home and community-based waiver program not exceed the average per person spending if the person were in a comparable institutional setting. However, some states in the survey report that they limit spending per participant to an amount below the institutional equivalent amount or cost neutrality amount (Table 6). For example, if the average nursing home spending were \$50,000 per person per year, a state would limit per person waiver spending to \$20,000 per year. Per participant spending caps together with enrollment limits ensure that spending on the waiver program will not exceed an appropriated or pre-determined state budget amount.²⁷ Table 6 shows that 82 waiver programs in the survey reported using spending caps that limit spending per participant to an amount below the federally required institutional equivalent spending per person.

Forty of these 82 waiver programs limit the waiver program spending by imposing a “hard cap.” A hard cap is an absolute limit on the maximum dollar value of waiver

program services a participant may receive. For example, one HCBS waiver program reported using a hard cap of \$4,067 per year per waiver participant.

The ability of states to cap spending in Medicaid HCBS waiver programs makes these programs unusual. Medicaid generally permits states to control spending on services through limits on the extent of services available to beneficiaries, particularly by limiting the amount duration and scope of these services. This means that a state may, for example, establish limits on the number of a certain service, like physician visits, that a beneficiary may receive. However, states may not establish predetermined dollar limits on the value of services beneficiaries receive. HCBS waivers provide an exception to this policy.²⁸ Moreover, one of the problems with hard caps is that they can unnecessarily exclude some potential waiver participants who have community care costs over the cap, but under the institutional level. In some HCBS waiver programs with hard caps, this problem is ameliorated by allowing exceptions for a limited number of care plans that may exceed the hard cap.²⁹ Another way to avoid this problem is to exclude certain services from the spending cap calculation. These services may be very expensive or unpredictable for waiver program beneficiaries and therefore could push beneficiaries over the cap. Excluding these types of services from the calculation gives case managers and administering agencies more flexibility to cover higher cost beneficiaries. Another potential problem with a hard cap is that an individual may receive fewer services than what is needed to ensure their health and welfare in an effort to keep them under the cap.

Table 6: Summary of Per Participant Spending Caps

Types of Spending Caps*	Distribution of Waiver Program by Type of Spending Cap	
	(#)	(%)
Waivers with maximum dollar per participant spending caps (hard caps)	40	23.4
Waivers with average cost per participant caps (soft caps)	15	8.8
Other	27	15.8
Total Waivers Reporting Caps	82	48.0
Unknown	15	8.8
No additional expenditure caps reported	74	43.3

*171 waiver programs responded to the survey.

SOURCE: UCSF analysis of 2003 Home and Community-Based Waiver Program Survey for the Kaiser Commission.

Fifteen of the 82 waiver programs in the survey reported that the programs used a “soft cap” to manage costs below the federal cost neutrality limit (Table 6). A soft cap allows states to manage per person spending by establishing a targeted average cost per participant. For example, one waiver program manages around a \$1,200 average spending cap per participant. Although somewhat more challenging to manage, the average cost per participant framework allows states more flexibility in providing services and almost always ensures that participants receive the services they need to remain in the community and avoid institutionalization. This type of cap allows beneficiaries to remain in HCBS waiver programs despite unexpected high cost service

needs, while this is not necessarily the case for waiver program beneficiaries who are subject to hard caps.

States also reported “other” types of caps for 27 waiver programs. Like hard and soft caps, spending caps in the other category are generally below the federal cost-neutrality limit and may therefore limit the amount of services a beneficiary would receive. These caps are generally alternate forms of hard and soft caps with many similar characteristics. The effect of these per participant spending caps on beneficiaries is likely similar to those under hard or soft spending caps.

Services. Another way states can control expenditures is through limits on the amount of services provided to individual HCBS waiver program participants. States may limit hours of service per day or the number of visits, as long as services are provided in sufficient scope to meet the needs of most beneficiaries. The result of these limits is to contain per person spending without setting explicit spending caps on waiver programs.

Survey results indicate that only 9 waiver programs were reported to explicitly limit the hours of service per day for certain services. For example, Virginia limits care for persons in its physically disabled waiver program to 16 hours per day per person, and the District of Columbia limits personal care aide services for MR/DD waiver program participants to the same amount of time. However, federal officials believe that state waiver program administrators are looking to eliminate or cap services in their waiver programs in an effort to curb costs.³⁰ In particular, where they perceive excess capacity (i.e., the majority of participants use less than current service maximums), they are further reducing service limits. While their actions may have little impact on the majority of participants, the few beneficiaries who rely on an underutilized service will notice a reduction in care.

Eligibility Limits. As mentioned previously, states have a great deal of flexibility to set eligibility requirements for their waiver programs as long as the financial and level of care criteria used are at least as stringent as those for nursing home eligibility or ICF/MR eligibility in the state. These financial eligibility limits and level of care criteria, as well as targeting criteria, are unique to each state and each HCBS waiver program. For example, a state can limit waiver program participation, and consequently spending, by requiring potential participants to have lower income and resources than Medicaid nursing facility residents. The state could also set the level of criteria at stricter levels than those required to receive care in a nursing facility. For instance, it could require waiver participants to exhibit difficulty in performing 4 ADLs instead of only 3 ADLs required for nursing facility admission. Finally, as discussed earlier, a state can limit waivers to very specific populations such as persons with disabilities over age 50.

All states limit their HCBS waiver programs to narrow populations or conditions through targeting criteria. However, few states apply eligibility limits that are narrower than the state institutional eligibility limits.³¹ The survey data confirms this observation. In 2002, 9 percent of the HCBS waiver programs in the survey had stricter financial eligibility criteria than the criteria used for institutional care in their respective states. These

numbers have declined since 2000 when 13 percent of programs had more stringent financial eligibility criteria. The same holds true for level of care criteria; fewer than 10 percent of the 171 waiver programs that responded to the survey had more stringent level of care criteria than for institutional care in 2000 and 2002.

Geography. As part of the section 1915(c) waiver statute, states can limit waiver program participation to specific geographic areas such as counties or metropolitan areas. Some states elect to start waivers in one or two geographic areas and then expand waiver services across the state as the program grows. Despite this ability, only 11 waiver programs at the time of the survey were not offered statewide. Based on interviews with federal officials, this appears to be consistent with previous years. Geographic restrictions appear to play a small part in restricting spending for home and community-based waiver programs.³²

Other. As with other Medicaid services, states use several other approaches to limit their spending on waiver programs. A few states have contracted with managed care organizations to provide home and community-based services to find savings in their programs.³³ Some states have elected not to conduct outreach or marketing activities for a program. This can limit enrollment by failing to reduce administrative barriers to enrollment, such as difficult waiver applications or onerous eligibility certification processes. In addition, waiver services that are too limited can make a program unappealing and reduce demand. Therefore, a short waiting list or empty waiver slots may indicate a problem in one of these areas instead of a program that is meeting community demand.

Summary

The HCBS waiver program has evolved over the past decade from a very small part of Medicaid long-term care spending in 1992 to the program most likely to equalize Medicaid spending on institutional and community-based services in the next decade. As it has grown over the past ten years, states have increasingly used the HCBS waiver authority to offer specially tailored home and community-based services exclusively to specific populations in ways they cannot through Medicaid state plan community-based long-term care services (i.e., personal care and home health). After the loosening of federal requirements in the early 1990s, the spending growth rate has averaged 23 percent annually over the past 10 years. The number of Medicaid beneficiaries enrolled in waivers has grown from less than a quarter of a million to over 800,000. While spending continues to grow quickly, it has slowed from the extremely high growth rates of the early 1990s (i.e., 36 percent from 1992 to 1993).

As participation and spending on the waiver program have grown, many Medicaid beneficiaries have received specialized community-based services that have met their long-term care needs. However, the waiver program, which allows for community-based long-term care service innovation at the local level, also allows states to apply cost control mechanisms. The UCSF survey data shows that states widely use these mechanisms, such as enrollment caps, service limits, and limits on spending per waiver.

Policy Implications

Three major factors: (1) the importance of the waiver program in meeting unique long-term care needs of Medicaid beneficiaries in the community, (2) the significant control states exert over cost containment mechanisms, and (3) the rapid HCBS waiver spending growth have significant policy implications for the HCBS waiver program in the future. The unique array of services that can be offered to beneficiaries through HCBS waiver programs make them popular not only with states, but beneficiaries. These programs present an opportunity for beneficiaries to get the right amount of services they need, when they need them and they allow beneficiaries to remain in the community and out of institutions.

Although the waiver program has helped provide important community-based alternatives to institutional care, states' ability to limit the scope of services and the population that receives services changes the face of the Medicaid program. These types of state constraints represent a departure from the traditional Medicaid program in which beneficiaries are largely entitled to program services. Enrollment limits prevent many Medicaid beneficiaries from getting the services they need and Medicaid beneficiaries who are able to enroll in waivers may experience limits on the services they can obtain or how many dollars can be spent for their care. As state spending on Medicaid HCBS waiver programs continues to grow, even at the more recent moderate rates, the fundamental differences between HCBS waiver programs and traditional Medicaid may become more critical. The HCBS waiver program is now the dominant program through which Medicaid home and community-based waiver services are delivered, far exceeding delivery through traditional Medicaid state plan services such as home health and personal care.

The number of seniors and persons with disabilities under age 65 who are predicted to need long-term care services over the next three decades will continue to rise. While HCBS waiver programs will begin to address some of the needs of low-income seniors and others in need of community care, they will not address all of these needs. The states' power to limit the scope and duration of services to specific Medicaid beneficiaries may leave Medicaid beneficiaries with two options for their care—limited services in the community, or care in an institution. As the HCBS waiver program grows, a careful balance must be struck between what is an adequate amount of services for each individual in the community and offering community services to as many beneficiaries as possible.

A careful balance must also be struck between offering more and more waiver programs and adequately assessing the quality of care delivered to beneficiaries in these programs. Medicaid HCBS waiver program growth has occurred so quickly, it has outpaced state and federal regulatory activities to ensure that public dollars are spent on high quality care. A recent GAO report identified serious quality oversight concerns across all HCBS waiver programs.³⁴ According to the report, CMS had limited information from states to help determine the quality of care under waivers. Available information reflected the failure of states to provide necessary services, inadequate

plans of care, and insufficient case management. As the home and community-based waiver program continues to grow, quality assurance and oversight of care will become increasingly important for the beneficiaries who use waiver services. It will also require additional resources from CMS and states to oversee properly.

Without broad policy changes, the HCBS waiver program remains the most significant avenue through which Medicaid beneficiaries can receive the community-based long-term care services they need. Because of waiver program's important role in providing community-based long-term care services, careful monitoring of HCBS waiver spending trends and continued examination of the impact of state cost control mechanisms are crucial to ensuring that an institutional alternative is maintained in the future.

ENDNOTES:

¹ Kaiser Commission estimates based on CBO and OMB data, 2004.

² This data was downloaded from www.hcbs.org on May 22, 2002. Although CMS 64 data is the most reliable source of Medicaid data reported by states to the Federal government, there are several caveats related to its integrity. First, data is based on date of payment so states can delay payments to providers in an effort to shorten a fiscal year and consequently reduce total payments in one fiscal year. Second, the CMS 64 is a claim for Federal payment. CMS may disallow some of these claims as not eligible for Federal matching payments. In this instance, adjustments are made to future CMS 64 reports. Third, CMS 64 data only represents fee-for-service spending. However, the majority of long-term care spending by states is fee-for-service.

³ States are mandated to provide long-term care in institutions such as nursing facilities or intermediate care facilities for the mentally retarded (ICF/MRs). Community-based care includes home health, personal care services, and HCBS waiver programs.

⁴ 42 CFR Parts 440.70(b), Federal Register, October 2002.

⁵ Department of Health and Human Services, Office of the Assistant Secretary for Planning and Evaluation, *Understanding Medicaid Home and Community Services: A Primer*, Washington D.C., October 2000; and Kitchener, Ng, and Harrington, *Medicaid Home and Community-Based Services: Program Data, 1992-200*, University of California at San Francisco, June 2003.

⁶ Arizona's entire Medicaid program operates as a Section 1115 demonstration waiver program.

⁷ 42 U.S.C. 1396n, *Section 1915(c) Social Security Act*. Interpretation and implementation of this statutory requirement is discussed later in the paper.

⁸ Centers for Medicare and Medicaid Services, *State Medicaid Manual Part 4, Section 4440-4442.3* accessed July 14, 2003, at http://cms.hhs.gov/manuals/pub45/pub_45.asp; and 42 U.S.C. 1396n, *Section 1915(c) Social Security Act*.

⁹ Centers for Medicare and Medicaid Services, *State Medicaid Manual Part 4, Section 4440-4442.3* accessed July 14, 2003, at http://cms.hhs.gov/manuals/pub45/pub_45.asp

¹⁰ Department of Health and Human Services, Office of the Assistant Secretary for Planning and Evaluation, *Understanding Medicaid Home and Community Services: A Primer*, Washington D.C., October 2000.

¹¹ For a larger and more comprehensive discussion about financial eligibility, see KCMU's *Medicaid Resource Book: Eligibility, Benefits, Financing, and Administration*, July 2002.

¹² HCBS waiver programs allow states to waive provisions of Medicaid statute related to "deeming", or the counting of spouse's or parents' incomes and assets in determining Medicaid eligibility. The income of spouses and parents are not counted when determining financial eligibility for Medicaid institutional care. Under Medicaid statute, the income and assets of parents and spouses of Medicaid participants living in the community must be counted when determining Medicaid eligibility. HCBS waiver programs allow states to waive this provision, so participants can live in the community and qualify for Medicaid. In addition, under the waiver program, states can maintain spousal impoverishment rules for spouses of HCBS waiver program participants.

¹³ Department of Health and Human Services, Office of the Assistant Secretary for Planning and Evaluation, *Understanding Medicaid Home and Community Services: A Primer*, Washington D.C., October 2000.

¹⁴ 42 U.S.C. 1396n, *Section 1915(c) Social Security Act*. 42 CFR Parts 441, Federal Register, July 25, 1994.

¹⁵ Miller, Ramsland, and Harrington, *Trends and Issues in the Medicaid 1915(c) Waiver Program*, Health Care Financing Review, Summer 1999.

¹⁶ Lutzky, Alecxih, Duffy, and Neill, *Review of the Medicaid 1915(c) Home and Community Based Services Waiver Program Literature and Program Data, Final Report*, Washington, D.C.: The Lewin Group, June 2000 and 42 CFR Parts 441, Federal Register, July 25, 1994.

¹⁷ This is often called the "woodwork effect" and refers to individuals who, despite significant chronic health care needs, choose not to receive care in institutions and to remain in the community. However, these same persons would be more likely to enroll in a HCBS waiver program if it was offered.

¹⁸ Fox-Grage, Folkemer, and Lewis, *The States' Response to the Olmstead Decision: How are States Complying?* Forum for State Health Policy Leadership: National Council of State Legislatures, February 2003.

¹⁹ Coleman, Fox-Grage, and Folkemer, *State Long-Term Care: Recent Developments and Policy Directions 2003 Update*: Forum for State Health Policy Leadership: National Council of State Legislatures, July 2003.

²⁰ Spending per participant numbers are not adjusted for inflation.

²¹ These high per participant spending figures reflect the high costs of providing care to developmentally disabled persons. The institutional equivalent spending per resident for ICF-MR care with 16 or fewer residents is approximately \$81,000 per year (AAMR 2004 *State of the States in Developmental Disabilities*), on average, far higher than care provided to aged persons in nursing facilities.

²² Spending and participation for other waiver population groups—physically disabled, HIV/AIDS, children, TBI/head injury—make up a much smaller portion of total waiver spending and participation (Figure 5). Our analysis indicates that these types of waivers influence about 10 percent of year-to-year growth of the waiver spending.

²³ President's Budget 2004 baseline, CMS Office of the Actuary.

²⁴ Department of Health and Human Services, Office of the Assistant Secretary for Planning and Evaluation, *Understanding Medicaid Home and Community Services: A Primer*, Washington D.C., October 2000.

²⁵ In addition to the survey, we interviewed CMS Medicaid Disabled and Elderly Health Program Group staff on August 26, 2003 for this paper.

²⁶ States have several different approaches to setting up waiting lists and this can impact the number of people on the waiting lists. Some states allow people to register for more than one waiver program, register by service instead of waiver program, or place their names on the waiting list in anticipation of requiring an institutional level of care. All of these approaches have an impact on the total number of people on waiting lists, in some cases, individuals may be counted multiple times.

²⁷ Tumlinson, Ramchand, and Mendelson, *The Essential Elements of Cost Estimation*, Center for Health Care Strategies, September 2001.

²⁸ For a fuller discussion of state discretion in designing Medicaid benefits, including amount duration and scope requirements, see Schneider and Garfield, *Medicaid as a Health Insurer: Current Benefits and Flexibility*, Kaiser Commission on Medicaid and the Uninsured, November 2003.

²⁹ Department of Health and Human Services, Office of the Assistant Secretary for Planning and Evaluation, *Understanding Medicaid Home and Community Services: A Primer*, Washington D.C., October 2000.

³⁰ Centers for Medicare and Medicaid Services, Center for Medicaid and State Operations, Disabled and Elderly Health Program (DEHPG) staff, Interview conducted on August 26, 2003.

³¹ Department of Health and Human Services, Office of the Assistant Secretary for Planning and Evaluation, *Understanding Medicaid Home and Community Services: A Primer*, Washington D.C., October 2000; and Weiner, Tilly, and Alecxih, *Home and Community-Based Services in Seven States*, Health Care Financing Review, Spring 2002.

³² Centers for Medicare and Medicaid Services, Center for Medicaid and State Operations, Disabled and Elderly Health Program (DEHPG) staff, Interview conducted on August 26, 2003.

³³ An experienced managed care organization can potentially offer states per capita cost savings through efficient management and delivery of services and sometimes offers care coordination and one-stop-shopping to the waiver enrollee. These managed HCBS waiver programs use 1915(b) freedom of choice waivers in combination with 1915(c) waivers. To date, only Wisconsin Health Partners, Texas Star Plus, and Minnesota Senior Health Options/Disability Health Options have employed this approach.

³⁴ General Accounting Office, Report to Congressional Requesters, *Federal Oversight of Growing Medicaid Home and Community-Based Waivers Should be Strengthened*, Washington D.C., June 2003.

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