

**HOME AND COMMUNITY-BASED SERVICES:  
PUBLIC POLICIES TO IMPROVE ACCESS, COSTS, AND QUALITY**

**By**

**Charlene Harrington**

**Terence Ng**

**Stephen H. Kaye**

**Robert Newcomer**

**University of California, San Francisco**

**Center for Personal Assistance Services**

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The report presents the views of the authors and not those of our funding agencies.



## TABLE OF CONTENTS

Executive Summary	iii
Introduction	1
Access to Medicaid HCBS Services	2
Medicaid HCBS Programs	2
Trends in Home Health, Personal Care, and 1915(c) Waiver Participants	2
Inequities in Access to Services Across States	3
Inequities in Access for Target Groups	5
Federal HCBS Initiatives	6
Fragmentation of HCBS Programs	7
Lack of Public Data on HCBS	8
Workforce Problems and Shortages	9
Informal Caregivers	9
Formal Direct Care Workforce	10
Workforce Data	11
Registry and Intermediary Information	11
Lack of Consumer Choice	11
Unmet Need for Services	12
Cost Issues	14
Trends in Home Health, Personal Care, and 1915(c) Waiver Expenditures	14
Inequities in the Cost of HCBS Services Per Person	15
Reduced Costs of HCBS Services Compared to Institutional Care	15
State HCBS Cost Containment Policies	16
Inadequate Wages and Benefits and Reimbursement Policies	18
Limited Woodwork Effect	20
Need to Coordinate Medicare and Medicaid Funding	20
Imbalance in HCBS Spending	20
Regulation of Nursing Home Beds.	22
Challenging Resource Environment	23
Quality Issues	23
Federal and State Oversight	24
Training Requirements and Procedures	25
Consumer Directed Services	26
Medicaid Restructuring	27
Summary	27
References	28

# **HOME AND COMMUNITY-BASED SERVICES: PUBLIC POLICIES TO IMPROVE ACCESS, COSTS, AND QUALITY**

## **EXECUTIVE SUMMARY**

The population of the US is aging with the number of adults aged 65 and older almost doubling from 12 percent in 2005 to almost 20 percent of the population by 2030. With the population aging, the demand for long term care (LTC), particularly services at home, is increasing. Of those individuals receiving LTC services in the US, most paid services were funded by the government. In 2006, of the total \$177.6 billion in estimated spending for LTC nationally, \$124.9 billion was for nursing homes (excluding hospital-based LTC) and \$52.7 billion was spent on home care.

Medicaid is the primary payer for LTC services for individuals with low incomes, paying for 45.8 percent of nursing home care and 37.6 percent of home health in the US in 2006. Medicaid is a joint federal and state program, which covers individuals who are on Supplemental Security Income and those who meet each state's income and asset requirements (the categorically needy). In some states, it also pays for individuals who spend down their incomes to each state Medicaid level because of medical costs (the medically needy).

Medicaid home and community based services (HCBS) has been the focus of widespread efforts by the federal and state government to expand access for several reasons. First, there is a growing demand by individuals to remain in their homes for as long as possible rather than to live in institutions. Second, the Supreme Court ruled in the Olmstead case in 1999 that individuals have the right to live at home or in the community if they are able to and choose to do so, rather than to be placed in institutional settings by the government. Third, a number of subsequent lawsuits against states have encouraged states to expand access to HCBS. Finally, in the past decade, the federal government has provided a number of initiatives and resources to assist states in complying with the Olmstead decision and in rebalancing their services from institutional to HCBS. In spite of these efforts, there are inequities in access to services and many individuals have unmet needs for HCBS.

The focus of this report is to examine issues of access, cost, and quality for Medicaid HCBS programs. The trends in state Medicaid HCBS programs, target groups, participants, and expenditures are summarized. The paper shows the progress in providing Medicaid HCBS but also identifies many current problems and policies. Inequities in access to services and limited funds result in unmet needs for HCBS. HCBS cost issues have been a primary focus of policy makers and quality problems are largely not addressed. Policy recommendations are made to improve access, costs and quality at the federal and state levels in the future.

## **ACCESS TO MEDICAID HCBS SERVICES**

There are three main programs that states use to provide Medicaid HCBS: (1) optional 1915(c) HCBS waivers, (2) the mandatory home health benefit, and (3) the optional state plan personal care services benefit. Other federal and state programs and initiatives also provide HCBS. In 2005, almost 2.8 million individuals received Medicaid HCBS through the waiver, home health care, and personal care service programs. HCBS participants have been growing at a rate of 7 percent per year since 1999.

**Widespread inequities in access to Medicaid HCBS exist across states.** The average number of Medicaid HCBS participants was 9.4 per 1,000 population, but ranged from 3 to 15 per 1,000 population in states in 2005 (a five fold difference across states). Annual HCBS expenditures per capita averaged \$118 in 2005, but varied from \$30 to \$363 in states in 2005 (a 12 fold difference). The limited access to services and spending in some states creates hardships for individuals who need services in those states and may lead to unnecessary institutionalization. **Federal policies should increase access to HCBS and ensure equity in access to Medicaid HCBS across states, which would require additional federal and state funding and setting uniform eligibility and need standards for HCBS.**

**Inequities in the access to HCBS occur by target group across states, where some groups receive more services and expenditures than others and other groups have no access to HCBS in some states.** Individuals with developmental disabilities were 41 percent of HCBS waiver participants but accounted for 74 percent of spending. The aged and disabled were 49 percent of participants but accounted for 20 percent of spending, while all other groups were only 10 percent of participants and 6 percent of spending. Some groups such as children, individuals with traumatic brain injury, mental illness, HIV/AIDS, and other conditions have limited or no access to HCBS in some states. This imbalance is related in part to the optional nature of the Medicaid HCBS program, limited federal and state Medicaid funding for HCBS, and the federal cost neutrality formula requirement for waivers. **The Medicaid HCBS program should be a mandatory program for all individuals based on consumer needs and not target groups. Federal and state HCBS funding levels need to be increased to ensure equity in funding for all Medicaid participants who need HCBS.**

**CMS has developed a number of new HCBS initiatives in states but states vary in their willingness and ability to implement these initiatives.** This has created more inequities in access to HCBS across states and many of these programs have not been evaluated. **The federal government should determine which Medicaid HCBS programs are useful and effective and should implement the most promising programs in all states.**

**HCBS are fragmented into many different state programs.** The many federal HCBS programs and policies have led states to offer these different HCBS programs in many departments within each state, with different financial eligibility and need determination requirements, assessment procedures, and program administration. Combining and consolidating HCBS programs would reduce administrative costs, improve access to services, and allow for uniform financial eligibility and need determination, assessment procedures, and program administration. **Major federal legislative reform is needed to combine and consolidate federal HCBS programs and initiatives for all target groups and eligibility categories.**

**Aggregate data on state Medicaid HCBS are not uniformly available to the public and HCBS consumer information and claims data are not generally accessible to researchers.** Although some HCBS expenditure data are available, federal and state aggregate data on HCBS programs, participants, policies, and outcomes are not generally available to the public and CMS has no uniform reporting requirements for 1915(b) waivers, 1115 waivers, and other new initiatives. Moreover, researchers generally do not have access to Medicaid and Medicare LTC client claims data. **The federal government should establish uniform aggregate reporting on participants, services, expenditures, policies, and outcomes across all Medicaid HCBS programs. The federal government should ensure that researchers and public officials have access to state**

**Medicaid and Medicare data on individuals (without the disclosure of names) to study the access, costs, and quality of HCBS programs.**

**Nationally, the majority of care in the home is provided by informal (unpaid) caregivers.** The burdens of care giving by informal caregivers are high and little support is available. **Public programs should offer greater support and respite to informal caregivers to help them continue to provide care and to improve the quality of care provided.**

**More than one million formal caregivers provided paid services in the home in 2007, but there are continued shortages of HCBS workers.** The demand for formal home care workers are projected to increase in the coming years. Studies have shown that the supply of home health agencies in states has a positive effect on HCBS waiver participants and/or expenditures. The use of independent providers and paid family caregivers can add to the supply of home care workers by allowing consumers to recruit helpers who might not otherwise consider care giving work. **Federal and state governments need to adopt policies that plan for and support the expansion of the HCBS workforce to meet the growing demand.**

**Planning and evaluation of the HCBS workforce is limited by the lack of ongoing, reliable data about the workforce.** The shortages of workers vary by geographical regions and types of settings and the workforce is highly unstable with rapid turnover of HCBS workers. Workforce data are needed on: (1) the number of direct services HCBS workers (full and part time) who work for organizations or as independent providers including their characteristics and work settings; (2) the stability of the workforce (turnover and vacancies); (3) compensation of workers (wages and benefits including health insurance, workers compensation, and other benefits); and (4) worker and consumer injury rates. **The federal and state workforce surveys need to be improved to better capture needed HCBS workforce data.**

**Access to HCBS workers can be improved by the establishment of HCBS registries and intermediaries.** These registries and intermediaries are entities used by both consumers and providers to interface with each other. Information about registries and intermediaries, however, is often difficult to find and not available in some areas. **The government should establish a national on-line listing of all HCBS registries and intermediaries to provide basic information for job matching, screening services, training, and health benefits for workers.**

**Because HCBS access problems in many states, Medicaid consumers are often not given a choice of the types of services and the setting in which to receive the services, especially those individuals discharged from hospitals.** Many individuals enter LTC after hospitalization and are given little choice about the services they receive and are often sent to nursing homes because of inadequate planning for and access to HCBS. Studies show wide variations in Medicaid preadmission screening programs and most states have very limited controls on admissions to nursing homes. State provisions to ensure consumers a choice of providers and living arrangements are limited. Some states have developed models for streamlined screening programs, presumptive Medicaid financial eligibility, fast-track assessment, and assistance with the selection of living arrangements. **The federal government should establish clear minimum standards for states to ensure that consumers have a choice of living arrangements and to provide assistance to those individuals who want and are able to use HCBS programs rather than institutional care. All states should be required to have streamlined screening programs to ensure presumptive**

**financial eligibility, fast-track assessment, and assistance with the selection of living arrangements.**

**A large unmet need for HCBS has been documented from data from national surveys, state officials, large and long waiting lists for waiver services, and multiple lawsuits and complaints against states for failure to provide HCBS services.** Additional HCBS services are needed for almost all groups in most states, including states that have expanded HCBS programs. States with low rates of HCBS participation and spending need the most immediate help to expand their HCBS programs. **The federal government urgently needs to expand Medicaid HCBS funds to states to improve access to HCBS.**

## **COSTS ISSUES**

In 2005, total Medicaid spending on home and community-based services was \$35.1 billion (\$23 billion for waivers, \$7.7 billion on state plan personal care services, and \$4.4 billion on home health services). Between 1999 and 2005, total Medicaid HCBS spending increased by 13 percent annually, which was higher than the average annual increase in the Medicaid program (10.5 percent).

**Spending levels for the average participant in HCBS programs vary widely across states.** Annual spending on Medicaid home and community-based services averaged \$12,627 per person in 2005, but this ranged from \$5,822 to \$37,052 in states and varied across the different programs. **The federal government should establish per participant spending guidelines for HCBS to increase spending, taking into account state cost of living differences to bring greater uniformity to HCBS spending across states.**

**Federal cost neutrality requirements for HCBS are so stringent that state HCBS spending is dramatically lower than institutional spending.** The per-person spending on Medicaid HCBS services is substantially lower than Medicaid institutional services, even when adjusted to account for room and board costs (HCBS waiver expenditures were \$44,000 per person lower than Medicaid institutional spending in 2002) for a national savings of \$2.6 billion in 2002. **Federal cost neutrality requirements for HCBS should be eliminated to allow states to base HCBS spending on consumer needs without arbitrary cost ceilings.**

**States use a range of restrictive HCBS cost-containment strategies to meet federal waiver cost neutrality requirements and to limit spending.** Fifteen states do not cover the medically needy and Texas does not cover the medically needy aged and disabled. Some states restrict financial eligibility for HCBS waivers (to 100 percent of Supplemental Security Income)(SSI) compared to the restrictions for institutional care of 300 percent of SSI. **States should be required to cover all medically needy who need LTC and they should be required to use a financial eligibility standard of at least 300 percent of SSI for all HCBS programs.**

**Low Medicaid asset levels in states restrict access to LTC for many who are poor and near poor.** Low asset levels for Medicaid are used by most states to allow Medicaid beneficiaries to retain no more than \$2,000. States are allowed to increase the Medicaid asset levels to a maximum of \$6,000. **States should be required to expand the asset level to the federal allowable limit for HCBS.**

**Some states do not use spousal impoverishment rules to protect the assets of a community spouse for HCBS.** In contrast, all states are required to have spousal impoverishment rules for the Medicaid nursing home program. Moreover, state spousal impoverishment rules apply only to the categorically needy. **States should be required to use the same spousal impoverishment rules for HCBS as for nursing homes for both the categorically and the medically needy groups.**

**Federal HCBS waiver policies require HCBS programs to use institutional need criteria for eligibility.** This results in limited access to HCBS compared to access to nursing homes and removes the flexibility of using HCBS to prevent institutionalization. **The federal government should remove the link between HCBS and institutional need criteria for all HCBS programs.**

**Most states use HCBS cost controls including fixed expenditure ceilings, service limits, hourly limits, and geographic limits within the states.** These policies constrict access to HCBS and may have a negative impact on individuals who need services. **Federal policies should require states to adopt more generous HCBS spending policies based on consumer need.**

**Medicaid wages and benefits for HCBS workers are low and contribute to an unstable workforce and workforce shortages.** Low wages and benefits are among the most important factors resulting in an undersupply of workers and higher turnover rates. Many workers have less than fulltime employment, incomes at near poverty levels, and no health benefits. CMS quality improvement projects should be expanded to help state Medicaid programs address the recruitment and retention of HCBS workers. **State Medicaid programs should increase pay and fringe benefits for direct care workers through such measures as wage pass-throughs, setting wage floors, establishing minimum percentages of service rates directed to direct-care labor costs, and other means.**

**Medicaid reimbursement policies for HCBS providers vary widely by provider types, by consumer target groups, and by location within states as well as across states, creating inequities for consumers and providers.** HCBS reimbursement policies should take into account actual provider costs, inflation adjustments, regulatory requirements, and other factors to stabilize provider payments, improve quality, and ensure access to HCBS. **Federal guidelines should be established in order to reduce the variation and inequities in HCBS provider reimbursement within and across state programs.**

**Policy makers and state officials have been concerned about the potential for a “woodwork effect” for HCBS, which has limited the expansion of HCBS.** The woodwork effect is one where individuals may take advantage of new HCBS programs even though they would not be willing to use institutional services, which would result in high costs to states. New research shows that states that expanded their HCBS programs, however, have not had increased costs or have had a reduction in their total LTC costs over time. **Educational efforts are needed to reassure federal and state policy officials that expanding HCBS may result in some initial costs but HCBS programs should have a positive effect on spending over time.**

**The Medicare and Medicaid LTC and HCBS programs are generally not coordinated or integrated.** With the exception of the PACE managed care program, the lack of coordination results in cost shifting between the programs and can increase the consumer’s risk for hospitalization, emergency room use, and nursing home use and poor quality of care. More demonstrations could be undertaken to combine Medicaid and Medicare funding and administration

within states. **There is a need to combine Medicare and Medicaid programs and funding to improve the access to appropriate HCBS, reduce costs, and improve the quality of care.**

**The disproportional amount of Medicaid spending on institutional care compared to HCBS is a major concern.** In spite of the steady growth in HCBS spending, the Medicaid program reported spending 58.5 percent of total LTC on institutional services and 41.5 percent on HCBS services in 2007. Expenditures ratios vary widely across states. One question is what should be the proportion of spending on HCBS. It seems likely that 75 to 100 percent of total spending for DD services could be on HCBS and perhaps HCBS spending for the aged and disabled could reach 75 to 90 percent of total LTC spending. **The federal government should set target levels to increase HCBS spending as a percent of total state LTC spending for individuals with DD and people with other disabilities and support states to meet these targets over time. The growth in state HCBS spending needs to be accelerated in order to rebalance the total expenditures for HCBS, by increasing new federal spending for HCBS. One approach is to raise the federal medical assistance percentage (FMAP) for all HCBS services.**

**Research studies have shown that state policies that lower the institutional bed supply can result in expanded access to HCBS and reductions in the use of institutional care.** Six studies have shown that lower nursing home bed supply in states increases state Medicaid HCBS participants, HCBS expenditures, or increasing the share of HCBS spending to total LTC spending. Many states use certificate-of-need (CON) or moratorium policies on nursing home beds in order to prevent the unnecessary expansion of beds, which have been shown to be related to increasing the per capita spending on HCBS and on the share of state spending on HCBS. **Educational efforts are needed to inform federal and state policy makers about the importance of keeping LTC bed supply low, by using state certificate of need and moratorium programs, with possible federal financial support for such regulatory programs.**

**On-going financial crises at the national and state levels threaten the continued access to and spending on Medicaid HCBS.** Special efforts are needed to encourage states to maintain the progress that has been made in expanding HCBS participants and expenditures. **The federal government needs to assume greater responsibility for paying for Medicaid LTC services, either by expanding the role of Medicare for LTC and/or increasing the funds to states for LTC and HCBS.**

## **QUALITY ISSUES**

The goal of HCBS programs is to maximize the quality of life, functional independence, health, and well being of the population. In spite of the importance of quality, the quality of HCBS is largely unknown and there are many complaints about poor HCBS quality.

**Federal and state government has responsibility to ensure the quality of HCBS.** CMS has undertaken quality initiatives to improve the overall quality of HCBS, but there are few oversight requirements and no outcome measures for HCBS (except for home health agencies). An independent assessment of these federal and state quality efforts and monitoring is needed to suggest improvements. **The federal government should develop guidelines or regulations for quality in HCBS care programs. Regular federal and state inspections of HCBS programs should be undertaken to improve consumer protections. The federal government should**

**develop outcome measures appropriate for HCBS that can be used by providers, regulators, and consumers in monitoring the quality of care.**

**There are no federal training requirements to become a direct care worker in HCBS, except for home health agencies.** State HCBS program training requirements vary widely and generally are weak and inconsistent and training program availability varies across states and local areas. Having more training of both formal and informal caregivers as well as consumers should improve the quality of services and reduce injuries. This will also help ensure more appropriate services and improve access. **States should make joint training programs available for (both paid and unpaid) caregivers and consumers to improve quality and provide support and resources to caregivers and consumers.**

**Consumer-directed services are important to assure the quality of HCBS for many consumers.** Many consumers want to select, hire, fire, and train their own caregivers, and manage the services they receive. Even though consumer directed services and choice have been strongly promoted by CMS, many state HCBS programs do **not** allow consumer direction in 2007. **The federal government should require states to make available the option for consumer-directed services in all Medicaid HCBS programs.**

**The Cash & Counseling demonstration programs have been useful in expanding access to HCBS at home and satisfaction with services.** A few states participated in a demonstration project that is now available to states under the new 1915(j) waiver programs, which encourages states to expand the cash and counseling option. **Cash and Counseling programs should be expanded to all states.**

## **MEDICAID RESTRUCTURING**

**Ultimately, many of the problems of inequities in access to HCBS, inequities in expenditures, and quality problems are related to limited funding for HCBS and the decentralized state administration of the Medicaid program.** LTC has become an increasing financial burden on the states (almost 33 percent of total Medicaid spending in 2007). As the demand for HCBS and institutional services increases, more financial pressures are placed on the Medicaid program. The inequities in access to HCBS are a function of the limited Medicaid funding for the HCBS program and the decentralized nature of the program. The administrative fragmentation of the state HCBS programs has grown worse as the federal government started more HCBS initiatives.

Federal Medicaid policies could consolidate Medicaid programs and institute more uniform requirements for providing HCBS including: need criteria, financial eligibility, assessment procedures, screening, choice requirements, payment policies, spending policies and other policies. In order to accomplish this change politically, perhaps the federal government would have to pay most or all of the costs for Medicaid LTC.

One option would be to fully federalize all those individuals who are dually eligible for Medicare and Medicaid services. This would facilitate the joint operation and administration of these two programs and allow the Medicaid LTC program to be operated as a part of the larger Medicare program. This would allow the development of uniform access to services, funding for the program, and quality oversight administered by the federal government.

Perhaps a more attractive financial option for states is to have Medicaid LTC folded into the federal Medicare program as a Medicare Part E program, which has been proposed by some policy makers. This would facilitate LTC reform and relieve the burden of LTC from the states. It would facilitate coordination between Medicare and Medicaid LTC benefits and allow for greater uniformity in LTC access, expenditures, and quality. It would protect the gains that states have made in HCBS access and protect spending from the current and frequently recurring state budget problems.

**Legislation could be undertaken to merge the Medicaid LTC program into the Medicare program to create a combined Medicare and Medicaid LTC program.**

## **SUMMARY**

This report examined issues of access, cost, and quality for Medicaid HCBS programs. State Medicaid programs are addressing growing enrollments and an increasing demand for LTC at a time of serious federal and state financial crises. Medicaid has made rapid progress over the last decade in expending HCBS programs to a growing number of target groups and participants. Medicaid HCBS expenditures have increased rapidly but are still below spending for institutional services. In spite of the progress in providing Medicaid HCBS, there are many current problems, including inequities in access to services and limited funds for HCBS that can cause serious problems for individuals and can force individuals into institutions unnecessarily. There are widespread unmet needs for HCBS in the Medicaid and general population. HCBS cost issues have been a primary focus of policy makers and quality problems have largely not been addressed with regulatory oversight and training programs. Policy changes can be made to improve access, costs and quality at the federal and state levels in the future.

## **HOME AND COMMUNITY-BASED SERVICES: PUBLIC POLICIES TO IMPROVE ACCESS, COSTS, AND QUALITY**

The population of the US is aging with the number of adults aged 65 and older almost doubling (from 37 million to over 70 million between 2005 and 2030) from 12 percent to almost 20 percent of the population by 2030.<sup>1</sup> With the population aging, the demand for long term care (LTC), particularly services at home, is increasing. Over 13.2 million individuals living at home and the community received 21.5 billion hours of help per year from either informal or formal paid help in the US.<sup>2,3</sup> Of those individuals who need help, over half were reported to be under age 65 and 24 percent were living alone.<sup>3</sup>

In addition to those individuals who were living at home, 1.44 million individuals were living in 16,145 nursing homes<sup>4</sup> and 96,600 individuals with developmental disabilities were living in 6,440 intermediate care facilities for the developmentally disabled (ICF-DD).<sup>5</sup> In addition, there were 131,407 licensed residential care facilities with 1,483,691 beds in the US in 2007.<sup>4</sup>

Of those individuals receiving LTC services in the US, most paid services were funded by the government. In 2006, of the total \$177.6 billion in estimated spending for LTC nationally, \$124.9 billion was for nursing homes (excluding hospital-based LTC) and \$52.7 billion was spent on home care.<sup>6</sup> Of the total, Medicare paid for 23 percent, Medicaid and other public funds paid for 43 percent, out-of-pocket funds paid for 22 percent, and private insurance and other sources paid for 12 percent.<sup>6</sup>

The Medicare program provides short-term LTC services to individuals who are aged and disabled.<sup>7</sup> Medicare services are provided by nursing homes and home health agencies to individuals who need skilled nursing or therapy services on a short term basis. After Medicare services are completed, some individuals may need continued LTC services and they will need to pay for these services directly out-of-pocket or use private LTC insurance to cover the care.

Medicaid is the primary payer for LTC services for individuals with low incomes, paying for 45.8 percent of nursing home care and 37.6 percent of home health in the US in 2006.<sup>6</sup> Medicaid is a joint federal and state program that covers individuals who are on Supplemental Security Income and those who meet each state's income and asset requirements (i.e. categorically needy). The Medicaid program also allows state to pay for individuals with low incomes who spend down their incomes to the Medicaid level because of medical costs (i.e. medically needy program).<sup>8,9</sup> Institutional care (i.e. nursing homes, intermediate care for the mentally retarded, institutions for mental disease) is a mandated Medicaid program, while home and community based services (HCBS) are generally optional state programs. Home health care, however, is mandatory for individuals who meet the requirements for institutional care.<sup>10-12</sup>

Medicaid HCBS has been the focus of widespread efforts by the federal and state government to expand access for several reasons. First, there is a growing demand by individuals to remain in their homes for as long as possible rather than to live in institutions.<sup>13</sup> Second, the Supreme Court ruled in the Olmstead case in 1999 that individuals have the right to live at home or in the community if they are able to and choose to do so, rather than to be placed in institutional settings by the government.<sup>14</sup> Third, a number of lawsuits against states have encouraged states to expand access to HCBS.<sup>15</sup> Finally, in the past decade, the federal government has provided a number of initiatives and resources to assist states in complying with the Olmstead decision and in rebalancing

their services from institutional to HCBS. In spite of these efforts, there are inequities in access to services and many individuals have unmet needs for HCBS.

The focus of this paper is to examine issues of access, cost, and quality for Medicaid HCBS. The paper summarizes the trends in state Medicaid HCBS programs, target groups, participants, and expenditures. The purpose is to assess progress in providing Medicaid HCBS services and to identify current problems and policies that need to be addressed at the federal and state levels in the future. The paper documents the unmet need and lack of access to services for many individuals, the cost issues in providing HCBS services, and the quality problems.

## **ACCESS TO MEDICAID HCBS SERVICES**

### **Medicaid HCBS Programs**

There are three main programs that states use to provide Medicaid HCBS: (1) optional 1915(c) HCBS waivers, (2) the mandatory home health benefit, and (3) the optional state plan personal care services benefit. The HCBS waiver program was established under 1915(c) of Title XIX of the Social Security Act in 1981.<sup>10-12</sup> The waivers allow states to waive specific requirements of the Medicaid program for: comparability (not targeting to groups), statewide eligibility for all who need services, and income and resources for the medically needy. In these waivers, states are allowed to target specific population groups, limit the number of waiver slots, limit the program to selected geographical areas, limit the services provided, and provide services otherwise not covered by the Medicaid state plan. Waivers are limited to individuals who meet the state eligibility requirements for institutional care and states must ensure that the program costs will not be more expensive than institutional services. The 1915(c) waiver program began with 8 waivers in 6 states in 1982<sup>16</sup> and grew steadily to 214 waivers in 1999 in 29 states.<sup>10-12</sup> By 2005, all states operated the Medicaid home health benefit and 272 HCBS 1915(c) waivers (Arizona operated its long-term care program under a Section 1115 demonstration waiver).<sup>17</sup>

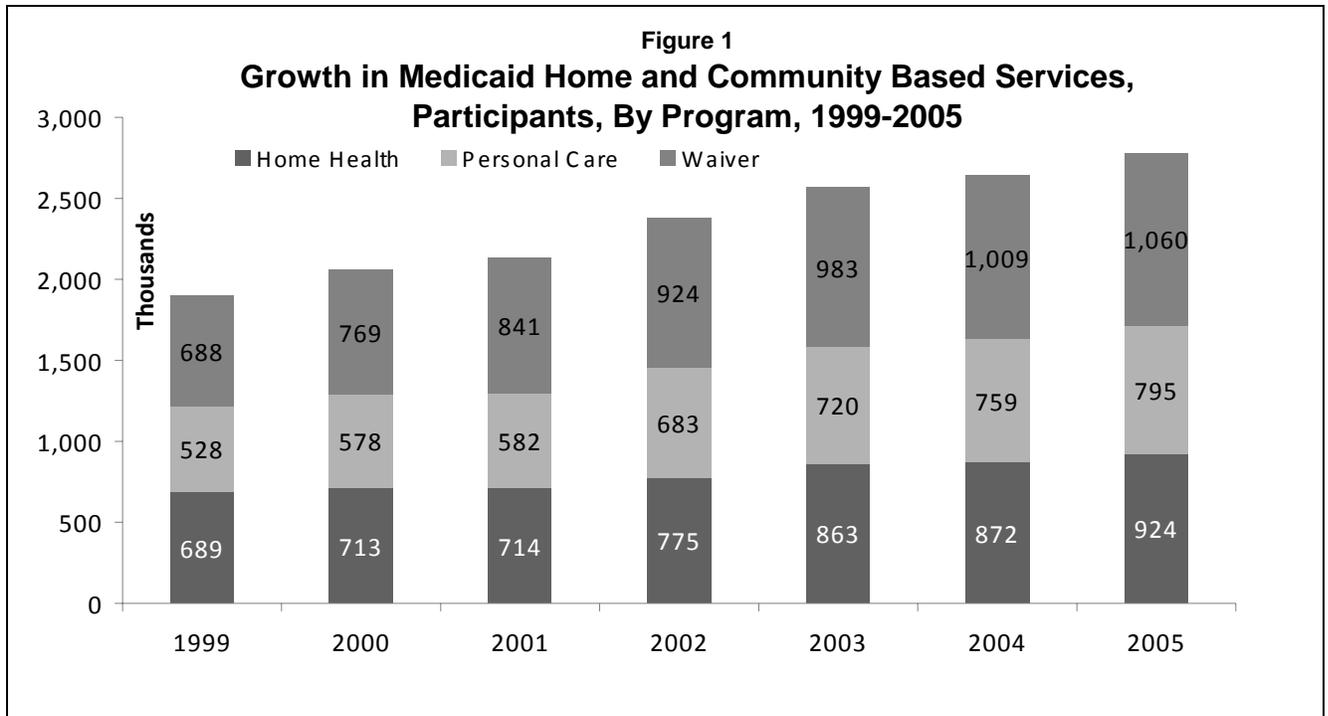
The personal care services (PCS) program was established in 1975 to allow for a Medicaid state plan optional benefit to provide assistance with activities of daily living (ADL)(e.g. bathing and dressing) and instrumental activities of daily living (IADL) (e.g. preparing meals and shopping). The program must be offered on a statewide basis to all age and population groups who meet the need criteria established by states. The personal care program was offered in 26 states in 1999 and grew to 30 programs in 2007.<sup>17-20</sup>

The Medicaid home health program is a mandatory state plan benefit for individuals who are entitled to nursing home care. States may also offer home health services to optional eligibility groups and can determine the amount, scope and duration of benefits. Home health is offered by all states and serves all Medicaid age groups and population groups.<sup>11-12</sup> Although most home health is for post-hospital skilled nursing, 10 percent of individuals received homemaker services and 21 percent received personal care services.<sup>21</sup>

### **Trends in Home Health, Personal Care, and 1915(c) Waiver Participants**

In 2005, almost 2.8 million individuals received Medicaid HCBS. Of those recipients, 1,060,356 individuals were served through HCBS 1915(c) waivers, 924,259 individuals received care through the home health benefit, and 794,642 individuals received personal care services through the

optional state plan benefit in 2005 (Figure 1).<sup>17</sup> Between 1999 and 2005, the national number of individuals receiving Medicaid home and community-based services grew steadily by an average of 7 percent annually, which was more than the 5.6 percent average annual increase in total Medicaid enrollment in the same period.<sup>17</sup>



Sources: UCSF analysis of CMS Form 372 data and UCSF program surveys.

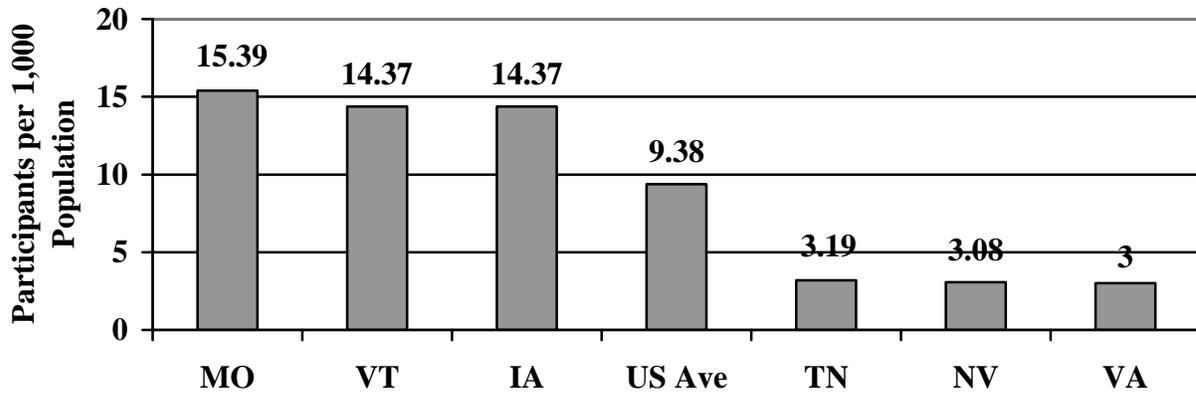
States may have other HCBS demonstrations initiatives (e.g. 1915b and 1115 waivers) which are not included here but are discussed later and some states have state funded HCBS programs that are included. Also some participants receive services from more than one HCBS program but these unduplicated counts are unavailable.

### **Inequities in Access to Services Across States**

**Widespread inequities in access to Medicaid HCBS exist across states.** Rates of Medicaid HCBS participation vary widely across states. The average number of HCBS participants in the US was 9.38 per 1,000 US population, having increased from 6.83 per 1,000 population in 1999 (a 5 percent annual increase).<sup>17</sup> The states with the highest participation rates in 2005 were Missouri (15.4 per 1,000 population), Vermont and Iowa (14.4), and New York (14.1). The states with the lowest total participation rates were Virginia (3.0), Nevada (3.1), and Tennessee (3.2). This shows a five fold difference across states in access to HCBS (Figure 2).<sup>17</sup>

Over the 1999 to 2005 period, there were wide inter-state variations in the changes in Medicaid HCBS participants. The annual changes ranged from increases in North Carolina (23 percent), Hawaii and Mississippi (22 percent respectively), to reductions in New Hampshire (-6 percent) and Rhode Island (-4 percent).<sup>17</sup> Four states showed a reduction in participants per 1,000 between 1999 and 2005, which may have been related to fiscal deficits or cost control efforts.<sup>17</sup>

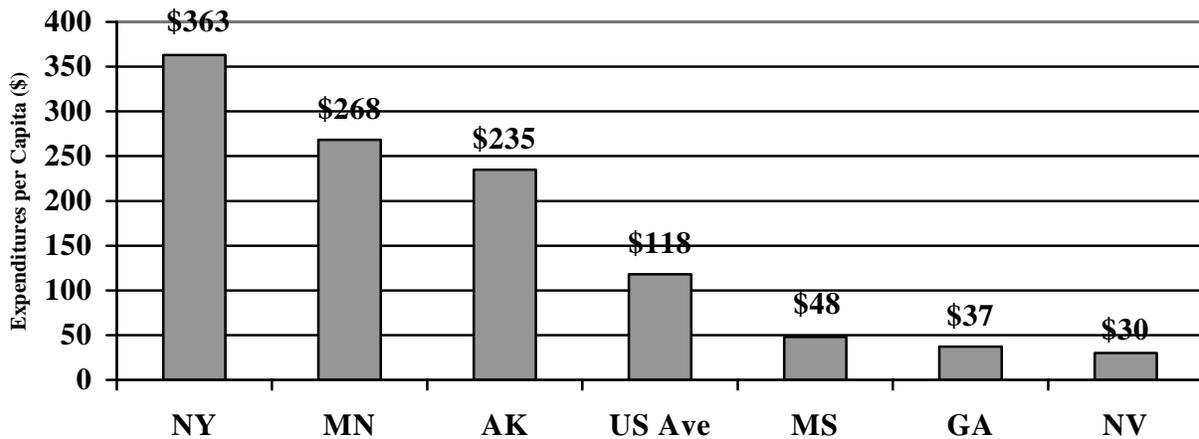
**Figure 2:  
Inter-State Variation in HCBS: 3 Highest & 3 Lowest  
Participants per 1,000 Population, 2005**



Sources: UCSF analysis of CMS Form 372 data and UCSF program surveys.

The inequities in access are also reflected in the variation in total HCBS expenditures per capita across states. (Figure 3).

**Figure 3  
Inter-State Variation in HCBS: 3 Highest and 3 Lowest  
Expenditures per Capita, 2005**



Sources: UCSF analysis of CMS Form 372 data and UCSF program surveys.

While the national average HCBS expenditures per capita was \$118 in 2005, having increased by 11 percent annually since 1999, states with the highest expenditures per capita were New York (\$363), Minnesota (\$268), and Alaska (\$235).<sup>17</sup> States with the lowest expenditures per capita were Nevada (\$30), Georgia (\$37), and Mississippi (\$48) in 2005.<sup>17</sup> This shows a 12 fold difference in expenditures per capita across states

These wide variations in access across states create hardships for individuals who need services. The variations are allowed because HCBS are optional Medicaid program without federal guidelines on financial eligibility or need criteria. More important, some states do not have the state matching funds and/or the public support for expanding the HCBS programs. **Federal policies should increase access to HCBS and ensure equity in access to Medicaid HCBS across states, which would require additional federal and state funding and setting uniform eligibility and need standards for HCBS.**

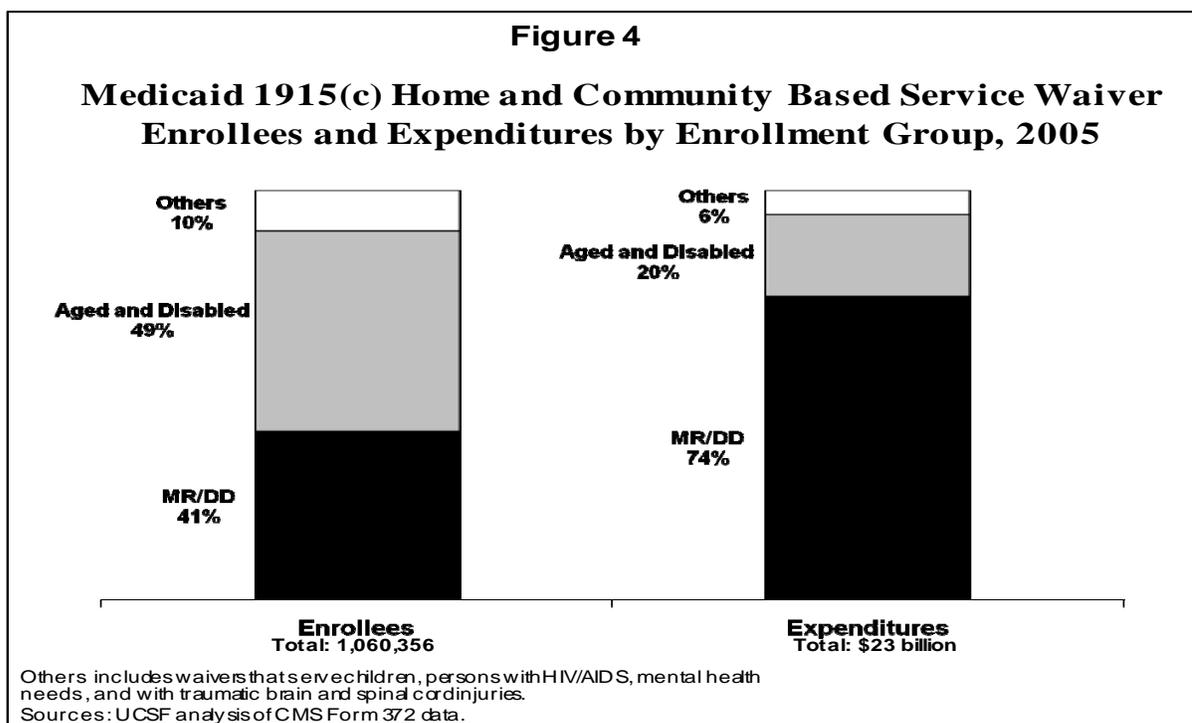
### **Inequities in Access for Target Groups**

**Inequities in the access to HCBS occur by target group across states, where some groups receive more services and expenditures than others and other groups have no access to HCBS in some states. Federal policies should ensure equity in access to HCBS across states.** The Medicaid personal care programs and home health programs are required by Medicaid rules to cover all age groups and population groups, but data are not available on the characteristics of individuals served in the programs.

In the 1915(c) waiver program, the majority of participants (524,628) received services through waivers targeted to the aged and aged/disabled, making up 49 percent of total waiver participants in 2005.<sup>17</sup> The next largest group (433,955) was enrolled in waivers for persons with mental retardation/ developmental disabilities (MR/DD) with 41 percent of waiver participants. Those with physical disabilities accounted for only 5 percent (57,714) of total waiver participants. The smallest waivers were for children with special needs (17,354), individuals with HIV/AIDS (14,258), individuals with traumatic brain and spinal cord injuries (TBI/SCI) (10,580), and individuals with mental health needs (1,867).<sup>17</sup>

In 2005, of the overall \$23 billion in expenditures for HCBS waivers, the vast majority of spending on HCBS waivers was targeted to individuals with DD.<sup>17</sup> Although individuals in DD waivers accounted for just 41 percent of total waiver participants, expenditures on the DD waivers accounted for 74 percent of all spending (Figure 4). The aged and disabled were 49 percent of participants but accounted for 20 percent of spending while all other groups were only 10 percent of participants and 6 percent of spending.

The imbalance in spending across target groups has been the situation since the programs began.<sup>22</sup> Under the cost neutrality requirements, expenditures for programs for the DD are compared to the costs of the ICF-DD facilities, which have historically had higher payment rates than nursing homes, allowing higher HCBS expenditures for DD.<sup>23</sup> The effectiveness of DD advocacy organizations has also been an important factor in increased spending on DD.<sup>24</sup>



There is no evidence that the differences in spending are based on consumer needs. This imbalance in access to HCBS waiver funding may have negative consequences for the aged and disabled and other target groups in terms of financial burden, unmet needs, and potential unnecessary institutionalization. **The Medicaid HCBS program should be a mandatory program for all individuals based on consumer needs and not target groups. Federal and state HCBS funding levels need to be increased to ensure equity in funding for all Medicaid participants who need HCBS.**

### Federal HCBS Initiatives

**CMS has developed a number of new HCBS initiatives in states but states vary in their willingness and ability to implement these initiatives.** In the past decade, there have been many federal initiatives to expand HCBS in the states.<sup>25</sup> In 2001, President Bush announced the New Freedom Initiative (NFI) (using an executive order), a cross-governmental policy and funding program that aimed to remove barriers to community living for people with disabilities and provide additional momentum to efforts to comply with the Olmstead court ruling and the Americans with Disabilities Act, 1990.<sup>26-29</sup> Real Choice Systems Change Grants (RCSCG) were awarded primarily to develop service infrastructure, and not to provide direct services. Over \$2.2 million in grants were awarded to states by CMS between 2001 and 2005, along with technical assistance grants.<sup>30,31</sup>

Section 1115 Research and Demonstration Projects are allowed by the Social Security Act to test policy innovations in the Medicaid program. Under Section 1915(b) Managed Care/Freedom of Choice Waivers, states can implement managed care delivery systems and limit individuals' choice of providers, expand eligibility to individuals not otherwise eligible under the Medicaid program, provide services not typically covered, or use innovative service delivery systems. CMS had 80 approved 1915(b) waivers, but only 10 were for HCBS in 2007.<sup>32</sup> These include the Texas

STAR+PLUS program that serves disabled and elderly beneficiaries through a managed care delivery system with an enhanced drug benefit (\$345 million in 2007)<sup>32</sup> and the Michigan prepaid specialty mental health and substance abuse services for developmental disability. Vermont developed a 1115 waiver program in 2005 with a global cost cap for 5 years to increase access to HCBS and reduce the use of institutional care, and was able to increase the proportion of HCBS from 34 percent of enrollees to 48 percent and spending from 19 percent to 34 percent by 2008.<sup>33</sup>

Money Follows the Person (MFP) is another program designed to assist in transitioning individuals from institutional care back to living at home or in the community. There were 31 MFP grants awarded to states, with \$1.4 billion in funds to transition 37,731 individuals out of institutional settings over a five-year demonstration period.<sup>33-35</sup>

The Program of All-Inclusive care for the Elderly (PACE) is a capitated managed care program for the frail elderly who are dually eligible for Medicaid and Medicare services, using an adult day health center and multidisciplinary teams to provide in-home medical and social services. There were PACE programs in 20 states with \$492 million in Medicaid expenditures in 2007.<sup>32</sup> In addition, 21 states reported offering LTC partnership programs for asset protection.<sup>35</sup> A new psychiatric residential treatment facility demonstration grant was started to allow states to provide HCBS to children with serious emotional problems and 10 states were given awards in 2006 for the program.<sup>35</sup> Another program which is an optional Medicaid state plan benefit is the targeted case management program which may include the aged and disabled. In 2007, 45 states reported having targeted case management and spent \$2.7 billion on these services.<sup>32</sup>

Another new initiative was established by the Deficit Reduction Act (DRA) of 2005 that gives states increased flexibility in delivering LTC services in community-based settings.<sup>36</sup> This act allowed CMS to establish the 1915(i) program in January 2007 for states to offer HCBS as a state plan benefit. States can offer HCBS to those who are **not** eligible for institutional services, which CMS calls breaking the “eligibility links”. Individuals must meet specific needs-based criteria established by states which can be based on need or functional criteria such as ADLs, or state risk factors.<sup>37</sup> States can limit eligibility to specific geographic areas, to the categorically needy, and to specific services without the renewals required every 3-5 years for waivers. States do not have to demonstrate that services cost the same or less than institutional services (as in the 1915(c) program). The problematic part of the legislation is the limit on Medicaid eligibles to those with incomes that do not exceed 150 percent of poverty (which is lower than the 300 percent of poverty allowed in the 1915(c) waiver and for institutional care).<sup>37</sup> Iowa was the first state to receive approval to add 1915(i) services to its state plan to offer statewide case management services and habilitation services to individuals needing psychiatric treatment.<sup>37</sup>

In summary, CMS has developed a number of new initiatives to stimulate the development of HCBS in states and states have responded by undertaking a number of demonstration projects to prevent institutionalization and/or to transition individuals out of institutions. While some of these programs have been evaluated, others have not. These new innovative programs have contributed to the fragmentation in access to services. **The federal government should determine which Medicaid HCBS programs are useful and effective and should implement the most promising programs in all states.**

## **Fragmentation of HCBS Programs**

**HCBS are fragmented into many different state programs.** The many federal HCBS programs and initiatives have led states to have a variety of different HCBS programs which are often located in many departments. One problem with the current 1915(c) waiver requirements is that states are only allowed to specify one target population for each waiver, which encourages separate waivers for different groups. For example, Colorado reported 13 and Florida reported 14 1915(c) waivers in 2007.<sup>32</sup> CMS reported that California had 24 and Florida had 27 total waivers (1915 b, c or 1115) in 2008. Every program and initiative generally has a different administrative structure and policies. In addition, HCBS programs are frequently located in multiple departments within states. Many Medicaid HCBS programs are closely related to other state programs in aging, mental health, developmental disabilities, housing, vocational rehabilitation, and many other programs with separate federal and state funding systems and administrative structures.

The fragmentation creates separate administrative costs for each program, because they often have different administrative structures, financial eligibility criteria, need criteria, screening and assessment procedures, provider recruitment and management, reimbursement structures, and quality oversight procedures. Although the new federal initiatives have created innovations, they appear to have further fragmented the HCBS programs, including the new 1915(i) waivers. This many programs within states adds to the confusion for consumers and the public, who often do not know what programs are available and how to access programs. State Medicaid officials have reported frustrations with the administrative burdens of the Medicaid program.<sup>35</sup>

Some states have tried to create single entry points to obtain services at a state or local level, but this becomes increasingly difficult with the many available programs. Other successful state efforts that have been identified include appointing a single state agency to administer the LTC system or to coordinate funding efforts. Some states have developed uniform assessment instruments for both institutional and HCBS care, coordinated financial eligibility and fast track need determination programs.<sup>38, 39</sup> While some states have tried to address these problems of fragmentation, other states have not.<sup>39</sup>

Efforts are clearly needed to consolidate HCBS programs across Medicaid and other programs. CMS recently suggested changing the 1915(c) HCBS waiver requirements to allow waivers to serve more than one target population to allow a consolidation of waiver programs.<sup>40</sup> This effort would not be sufficient to address the size and complexity of state HCBS programs that need restructuring.

Combining and consolidating HCBS programs would reduce administrative costs, improve access to services, and allow for uniform financial eligibility and need determination, assessment procedures, and program administration. **Major federal legislative reform is needed to combine and consolidate federal HCBS programs and initiatives for all target groups and eligibility categories.**

## **Lack of Public Information about HCBS Programs**

**Aggregate data on state Medicaid HCBS are not uniformly available to the public and HCBS consumer information and claims data are not generally accessible to researchers.** One major problem is the lack of access to aggregate data on ongoing HCBS programs including the 1915(b) and 1915(c) waivers, the 1115 waivers, and the demonstrations. CMS has a uniform reporting form

(form 372) for the 1915(c) waiver program (although the reports are due two years after implementation) and public data are not available from CMS. Moreover, there are no uniform aggregate reporting requirements for 1915(b) and the 1115 waiver programs so the number of participants, expenditures, and service in these programs are largely unavailable. Public data are also generally not available on many of the new CMS HCBS initiatives including the outcomes and the number of individuals enrolled.

Another problem is the lack of access to individual Medicaid and Medicare LTC consumer claims data. Of the total eligible for Medicaid, 14 percent are dually eligible for Medicare.<sup>41</sup> States generally have not collected and analyzed individual consumer data to study LTC utilization and expenditures patterns for types of services over time and comparative data across states are not available. States spending on Medicaid HCBS services may be reducing spending on Medicaid institutional services and Medicare spending but without individual data, it is difficult to evaluate LTC utilization and expenditures.

**The federal government should establish uniform aggregate reporting on participants, services, expenditures, policies, and outcomes across all Medicaid HCBS programs. The federal government should ensure that researchers and public officials have access to state Medicaid and Medicare data on individuals (without the disclosure of names) to study the access, costs, and quality of HCBS programs.**

### **Workforce Problems and Shortages**

One major barrier to access to HCBS is the shortages of HCBS workers, including both informal caregivers and formal care providers, who are paid for services.

**Informal Caregivers. Nationally, the majority of home care is provided by informal (unpaid) caregivers.** Estimates are that 84 percent of caregiving hours are provided by family members and friends. Moreover only 3.2 million (25 percent) out of 13.2 million individuals who received care, received any paid help.<sup>3</sup> In 2007, there was an estimated 34 million caregivers who provided informal care to individuals, estimated to have an economic value of \$375 billion.<sup>42</sup>

Many studies report on the burdens of caregiving by informal caregivers and the negative effects that LTC giving has on the health and mortality of caregivers. Caring for a family member may contribute to psychiatric and physical illness, including increased levels of depression, anxiety disorders, and the risk of mortality.<sup>13,42</sup>

On a federal level, the National Family Caregiver Support Program was established (in the Older Americans Act in 2000) for Area Agencies on Aging (AAAs) to develop and provide caregiver services, but funding has been modest and there is wide interstate variation.<sup>13,42</sup> Additional funding for these programs could be valuable along with funding for the Lifespan Respite Care Act which was passed, and providing tax credits to offset some of the direct caregiver expenses.<sup>42</sup>

The Institute of Medicine (IOM) pointed out the important benefits of providing informal caregivers with “better training and improving their integration with the formal health care team” because they are often inadequately prepared to provide care and use home-based technologies.<sup>1</sup> As a result, the IOM recommended that “public, private, and community organizations should provide funding and ensure that adequate training opportunities are available in the community for informal caregivers.”<sup>1</sup>

**Public programs should offer greater support and respite to informal caregivers to help them continue to provide care and to improve the quality of care provided.**

**Formal Direct Care Workforce. More than one million formal caregivers provided paid services in the home in 2007, but there are continued shortages of HCBS workers.** Overall, more than 3 million individuals were employed in LTC in 2006 including direct care workers (e.g., nurses aides, home health aides, personal care aides) who work in nursing homes, personal care facilities, home care agencies, residential care, or other organizations (e.g., hospitals, rehabilitation centers).<sup>13,43</sup>

According to data from the Current Population Survey, there were almost 900,000 personal care workers providing care in the home or community in 2004, which probably underestimates the “self-employed” caregivers directly hired by families or individuals to provide home care.<sup>44</sup> As the demand for assistance with activities of daily living increased from 2.6 million individuals in 1989 to 4.1 million in 2004, the personal assistance workforce increased from 110.2 PAS workers per 1,000 needing ADL help to 214 workers per 1,000 during that period (94.2 percent increase).<sup>44</sup> By 2007, the number of PAS workers grew to more than a million, but the number of workers vary widely across states (from 49 workers per 1,000 people in Mississippi to 269 in New York).<sup>45</sup>

Using American Community Survey data in 2005, about 90% of direct care workers are women and approximately 53 percent are Black, Hispanic, or Native American, with this proportion varying widely within and between communities.<sup>46</sup> The median age of personal care workers and home care aides was 45 and about 25 percent were reported to be immigrants in 2005.<sup>45</sup>

Although the recent and rapid growth in the HCBS workforce has paralleled increased Medicaid HCBS spending, the demand for HCBS workers is continuing to increase as the number of individuals needing HCBS is predicted to increase in the coming years.<sup>13,46-48</sup> The Bureau of Labor Statistics projected that between 2006 and 2016 the US will need nearly 1 million new direct care workers to meet the demand from the growth in the population needing PAS.<sup>43</sup> The projected need for new direct-care workers is projected to exceed the number of women aged 25-54 entering the labor force by 28 percent.<sup>49</sup> The IOM estimated that states will need an additional 3.5 million direct care providers (a 35 percent increase from current levels) just to maintain the current ratio of providers to the total population by 2030.<sup>1</sup>

The supply of providers is important in ensuring access to services. Four studies have shown that the supply of home health agencies in states has a positive effect on HCBS waiver participants and/or expenditures.<sup>18,50-52</sup> One study showed that states with increased community-based care (e.g., home health agencies) were positively associated with state per capita rates of use, expenditures, and the share of Medicaid LTC dollars supporting 1915(c) waivers.<sup>51</sup> The use of independent providers and paid family caregivers can also add to the supply of home care workers by allowing consumers to recruit caregivers who might not otherwise consider care giving work.

**Federal and state governments need to adopt policies that plan for and support the expansion of the HCBS direct care workforce to meet the growing demand.**

**Workforce Data. Planning and evaluation of the HCBS workforce is limited by the lack of ongoing, reliable data about the workforce.** In order to plan and evaluate the progress in improving access to workers, policy makers are limited by the lack of ongoing, reliable data about the direct-care workforce. There are shortages of workers that vary by geographical regions and

types of settings. In addition, the workforce is highly unstable with rapid turnover of HCBS workers, estimated to be more than 50 percent annually.

Although some states have management information on the number of services, consumers served, and expenditures, they rarely have information about the workforce. Although there is some information available about workers in nursing homes and home health agencies, little information is available about workers in residential care, group homes, supportive living, home health, personal care, and home care settings. The Department of Labor and the American Community Survey from the US Census Bureau obtain some information on HCBS workers but information about independent workers (those who do not work for agencies) and small non-institutional providers are not included in the former and the information about the types and locations of work are limited.<sup>44,53</sup>

Workforce data are needed on: (1) the number of direct services HCBS workers (full and part time) who work for organizations and independent providers including their characteristics and work settings; (2) the stability of the workforce (turnover and vacancies); (3) compensation of workers (wages and benefits including health insurance, workers compensation, and other benefits); and (4) worker and consumer injury rates. **The federal and state workforce surveys need to be improved to better capture needed HCBS workforce data.**

**Registry and Intermediary Information. Access to HCBS workers can be improved by the establishment of HCBS registries and intermediaries.** Registries and intermediaries are entities used by both consumers and providers to interface with each other.<sup>54</sup> They can assist in: empowering consumers and workers with information, tools and services; promoting the quality of care and the quality of jobs through training and other supports; supporting good matches of workers and consumers; creating access to reliable backup services; and providing “one-stop” type administration and operational efficiencies and functions that support service fulfillment. Currently, information about registries and intermediaries are available only at local and/or state levels and are often difficult to find and not available in some areas. **The government should establish a national on-line listing of all HCBS registries and intermediaries to provide basic information for job matching, screening services, training, and health benefits for workers.**

### **Lack of Consumer Choice**

**Because HCBS access problems in many states, Medicaid consumers are often not given a choice of the types of services and the setting in which to receive the services, especially those individuals discharged from hospitals.** Of all nursing home residents, 36 percent are admitted from hospitals and 29 percent are admitted from home, and the remainder from other institutions.<sup>55</sup> Hospitals patients are often discharged with little time for planning and setting up appropriate HCBS, which often results in unnecessary institutionalization.

Studies show wide variations in Medicaid preadmission screening programs and most states have very limited controls on admissions to nursing homes.<sup>56,57</sup> States often allow nursing homes to screen patients after admission and provide little help in obtaining HCBS as an alternative to institutional services. In contrast, the state of Washington has developed an effective preadmission screening program using both presumptive financial eligibility (assume that individuals with low incomes will meet Medicaid eligibility) and fast track assessment procedures (rapid assessment within 48 hours including weekends to determine need and assist in planning for post hospital care).

These procedures increase consumer choice, increase access to HCBS, and prevent unnecessary nursing home admissions.<sup>58</sup>

**The federal government should establish clear minimum standards for states to ensure that consumers have a choice of living arrangements and to provide assistance to those individuals who want and are able to use HCBS programs rather than institutional care. All states should be required to have streamlined screening programs to ensure presumptive financial eligibility, fast-track assessment, and assistance with the selection of living arrangements.**

## **Unmet Need for HCBS**

**A large unmet need for HCBS has been documented from data from national surveys, state officials, large and long waiting lists for waiver services, and multiple lawsuits and complaints against states for failure to provide HCBS services.** In spite of the growth in HCBS and the new initiatives, there is unmet need for HCBS across the country even in states that have expanded HCBS programs.

**National Survey Data.** National surveys have reported unmet need for HCBS across the nation. Of those individuals living in the community who need or receive help, 2.7 million individuals had an institutional level of care need and had low incomes in 2003.<sup>59</sup> Of these individuals, 607,000 at the basic financial level (i.e. 100 percent of the SSI level or the federal poverty level) and 886,000 at the expanded level (300 percent of the SSI level or the federal poverty level) do **not** receive paid services and may have unmet needs for help.<sup>59</sup>

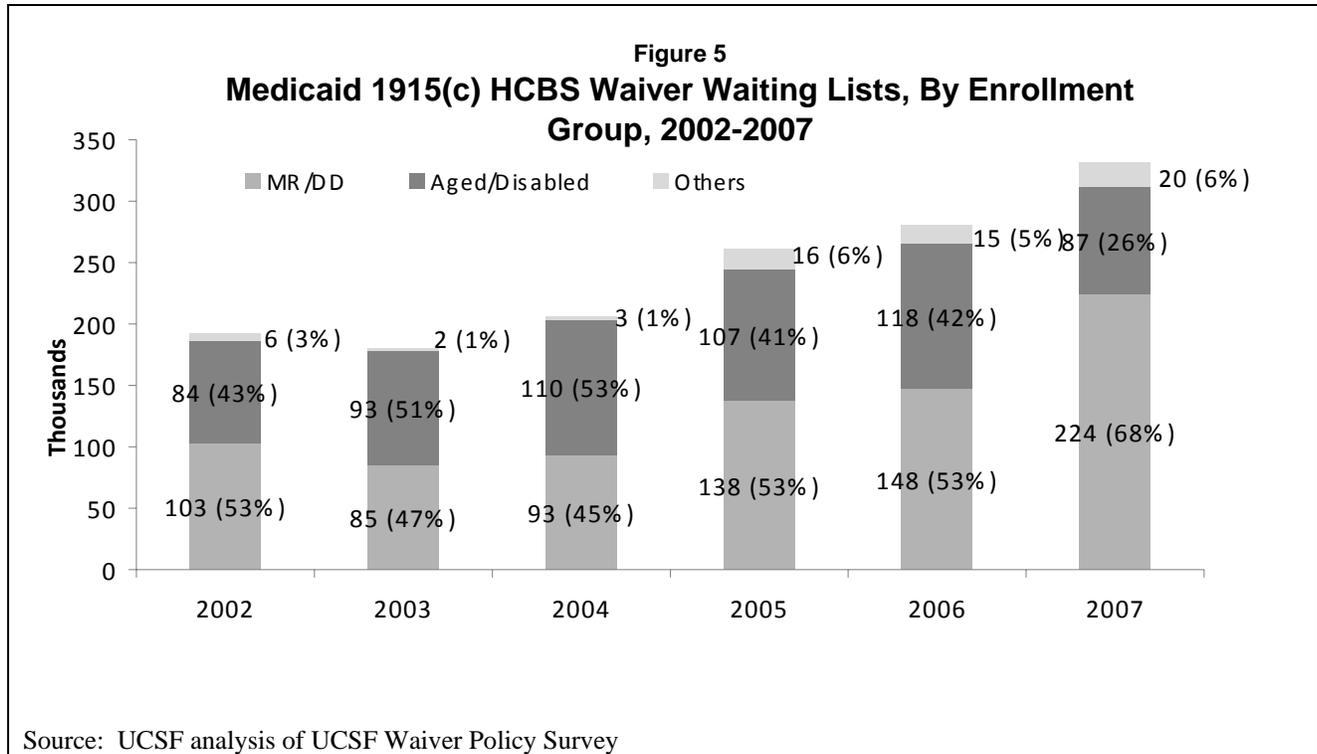
Another study showed that 21.4 percent of 15.1 million individuals who needed help have unmet needs, and generally, these individuals had a shortfall of 16.6 hours of help per week and those living alone had even greater shortfalls in help.<sup>3</sup> Individuals who had unmet needs for help reported many negative consequence of unmet need and dissatisfaction including discomfort, distress, mobility restriction, going hungry, weight loss, dehydration, and many other serious problems.<sup>3</sup> Another study of Medicare and Medicaid eligible individuals in six states showed that 58 percent of those needing help with activities of daily living reported unmet needs that could result in serious consequences, such as falls. Individuals in states with greater use of paid home care had a lower likelihood of unmet needs.<sup>60</sup>

**State Officials.** States often have more individuals in need of waiver services than the number of available spaces, called program “slots.” State officials have reported a variety of program needs for special target groups that are not met by existing programs, especially programs for children, the mentally ill, and those with traumatic brain injuries.<sup>61,62</sup>

**Waiting Lists.** Another indication of unmet need can be identified from state waiting lists for Medicaid HCBS 1915(c) waiver services. In 2007, 37 states reported waiting lists (primarily among those living in the community) and 10 states said they did not have waiting lists.<sup>17</sup> In 2007, there were 106 waivers with waiting lists with 331,689 individuals on waiver waiting lists (Figure 5).

Waivers for the MR/DD population had the greatest number of individuals on waiting lists (224,147) followed by waivers serving the aged and aged/disabled (87,338). The waiting lists have increased from 192,447 reported in 2002 to 331,689 in 2007 and by more than 18 percent between 2006 and 2007.<sup>17</sup>

In 2007, the average length of time an individual spends on a waiting list varied by type from 9 months for aged waivers to 26 months for children’s waivers and 25 months for MR/DD waivers.<sup>17</sup> Most state waiver waiting lists (72 percent) were screened for Medicaid eligibility before or after being placed on the waiting list and most states prioritize individuals on waiting lists (63%) in 2007.<sup>17</sup> Those individuals who are unable to have their needs met may go into institutional care unnecessarily.



**Olmstead Supreme Court Ruling and Litigation.** Another indication of the unmet need for HCBS services is the continued litigation related to the 1999 US Supreme Court ruling in the case of *Olmstead v. L.C.*<sup>14</sup> This ruling, under Title II of the Americans with Disabilities Act (ADA, 1990), found that the plaintiffs had the right to receive care in the most integrated setting appropriate and that their unnecessary institutionalization was discriminatory and violated the ADA.<sup>15</sup>

The *Olmstead* ruling has led to complaints against states being filed with the Department of Justice (627 complaints by 2004).<sup>63,64</sup> The Office of Civil Rights reported resolving 250 complaints about community integration (OCR, 2005).<sup>65,66</sup> At least 148 *Olmstead* or related lawsuits have been reported that have raised issues on behalf of people who are institutionalized or at risk of institutionalization because of a lack of HCBS.<sup>15,63,64</sup>

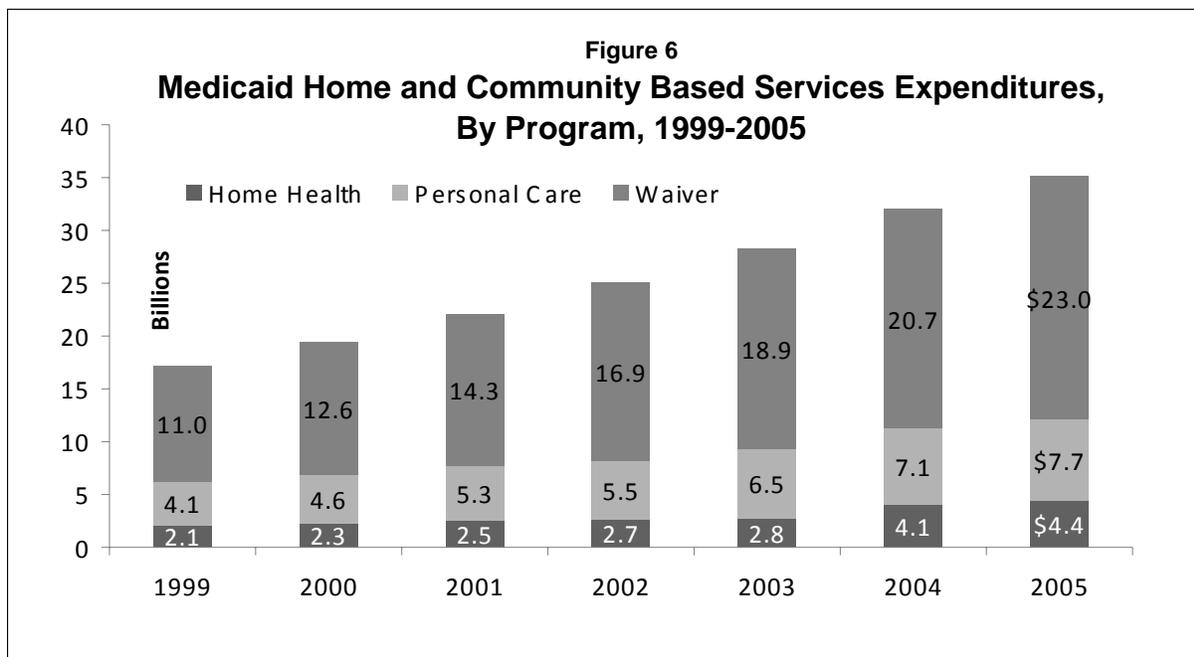
In view of the unmet need for HCBS services, the most pressing need is for the expansion of access to services. Additional HCBS services are needed for almost all groups in most states, including states that have expanded HCBS programs. States with low rates of HCBS participants and

spending need the most urgent help in expanding their HCBS programs. **The federal government urgently needs to expand Medicaid HCBS funds to states to improve access to HCBS.**

## COST ISSUES

### Trends in Home Health, Personal Care, and 1915(c) Waiver Expenditures

In 2005, total Medicaid spending on HCBS was \$35.1 billion (Figure 6). In 2005, Medicaid spending on HCBS waivers was \$23 billion, compared to \$7.7 billion on state plan personal care services, and \$4.4 billion on home health services.<sup>17</sup> Between 1999 and 2005, total Medicaid spending on HCBS increased by almost \$18 billion (104 percent) or an average annual increase of 13 percent.<sup>17</sup> This compares to an average annual increase of 10.5 percent for total Medicaid expenditures in the same period.



Sources: UCSF analysis of CMS Form 372 data and UCSF program surveys.

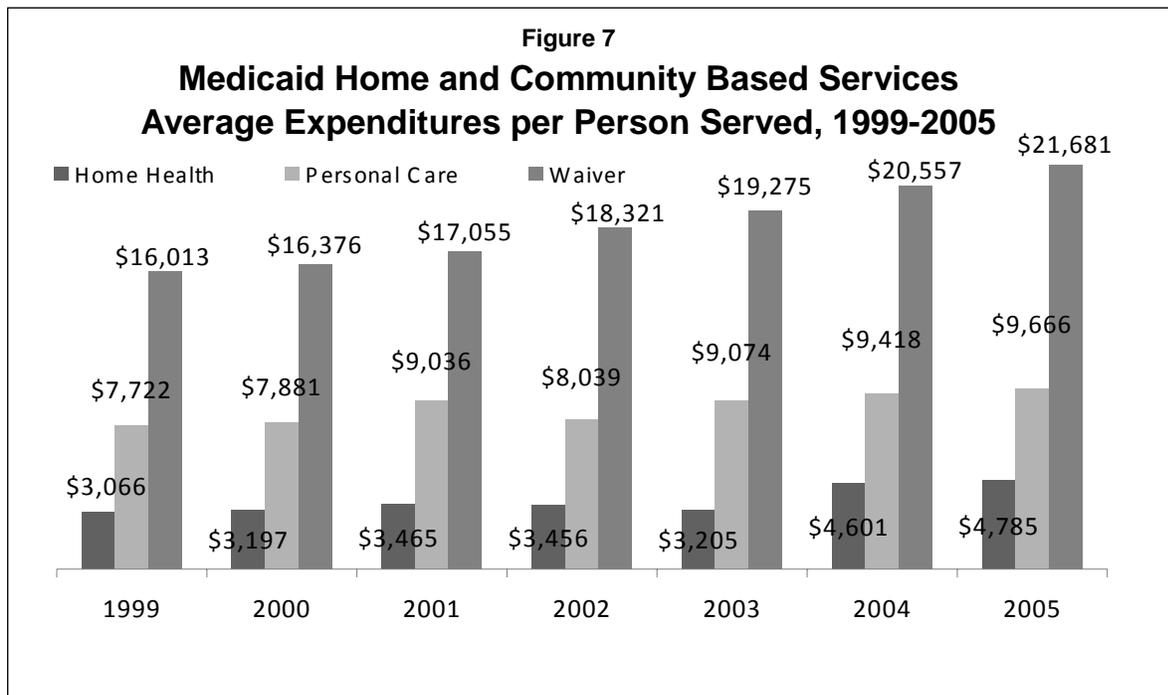
### Inequities in the Cost of HCBS Services Per Person

#### Spending levels for the average participant in HCBS programs vary widely across states.

National per person spending on Medicaid HCBS averaged \$12,627 in 2005, although there was great variation among the states, ranging from \$5,822 in Arkansas to \$37,052 in Rhode Island.<sup>17</sup> The spending varies across the different programs from \$4,795 for home health participants, to \$9,666 for personal care to \$21,681 for waiver participants in 2005 (Figure 7). This difference is in part related to differences in the types of HCBS provided through the different home and community-based service options because the waiver program is directed to individuals who would qualify for institutional services while the personal care program may be used for prevention, support, or at-risk groups.

These low expenditure levels per person, particularly for the personal care services programs, are probably too low to provide an adequate level of services for some individuals who need HCBS. Low expenditures levels can result in individuals going to institutional care unnecessarily. States should increase HCBS per person spending to make spending more comparable to Medicaid spending for institutional services.

**The federal government should establish per participant spending guidelines for HCBS to increase spending, taking into account state cost of living differences to bring greater uniformity to HCBS spending across states.**



### Reduced Costs of HCBS Services Compared to Institutional Care

**Federal cost neutrality requirements for HCBS are so stringent that state HCBS spending is dramatically lower than institutional spending.** The per-person spending on Medicaid HCBS services is substantially lower than Medicaid institutional services. HCBS waiver programs by law are required to set eligibility criteria to the level for each state's institutional services. In order to control costs, states must demonstrate **cost neutrality** so that the average expenditures for each 1915(c) waiver do not exceed the state estimated Medicaid expenditures for a comparable level of care (i.e. hospital, nursing facility (NF), or intermediate care for the mentally retarded/developmentally disabled (ICF-MR/DD) levels).<sup>23</sup> HCBS services do not include room and board costs whereas institutional services cover such costs.

A study, using state waiver cost estimate data and taking into account room and board costs, showed that Medicaid annual per-participant HCBS waiver expenditures was about \$44,000 lower per person than Medicaid institutional spending in 2002.<sup>23</sup> These savings varied across target populations from 63 percent lower than nursing facilities, 70 percent lower than ICF-MR/DD, and

84 percent lower than hospital expenditures. The savings were greatest for children (about \$143,000). The overall national savings from HCBS waivers was \$2.6 billion in 2002.<sup>23</sup> In conclusion, HCBS cost less on average than institutional care in states and savings can be accrued to the states by using HCBS for individuals who need care. Additional HCBS spending may be able to further reduce institutional costs.

On the other hand, the cost neutrality formulas are arbitrarily limiting the amount of funds that can be allocated to HCBS programs and are overly stringent and burdensome. When spending so restricted, individuals with disabilities may be forced into institutions unnecessarily. The CMS Money Follows The Person demonstration program was designed to allow states to take funds allocated for individuals living in institutions to provide care at home. This approach is appealing because it allows the shifting of institutional funds to the Medicaid HCBS programs. **Federal cost neutrality requirements for HCBS should be eliminated to allow states to base HCBS spending on consumer needs without arbitrary cost ceilings.**

### State HCBS Cost Containment Policies

**States use a range of restrictive HCBS cost-containment strategies to meet federal waiver cost neutrality requirements and to limit spending.** The Medicaid 1915(c) waiver program allows states to use a broad range of cost-containment strategies to meet federal waiver cost neutrality requirements and to limit waiver spending so that costs do not exceed state budgetary restrictions. A recent survey of states showed that every state used some type of cost-containment for HCBS programs.<sup>17</sup>

**Financial Eligibility. Medicaid eligibility must cover the categorically eligible but they do not have to provide coverage for the medically needy (those who spend down their income because of medical bills).** Fifteen states do not cover the medically needy and Texas does not cover the medically needy aged and disabled.<sup>41</sup> This limitation in eligibility has a negative effect on the aged and disabled who need HCBS.

Most states set financial eligibility for HCBS waiver programs at 300 percent of Supplemental Security Income (SSI) (\$1,869/month in 2007), which is the same level as for nursing homes. Of the waiver programs, however, 24 percent used more restrictive financial eligibility standards for HCBS than for nursing facilities.<sup>17</sup> In 2007, 18 percent of state home health program and 44 percent of states with personal care programs did **not** allow the medically needy and/or those in the EPSDT program to participate in the programs.<sup>17</sup> **States should be required to cover all medically needy who need LTC and they should be required to use a financial eligibility standard of at least 300 percent of SSI for all HCBS programs.**

**Low Medicaid asset levels in states restrict access to LTC for many who are poor and near poor.** Low asset levels for Medicaid are used by most states to allow Medicaid beneficiaries to retain no more than \$2,000. States are allowed to increase the Medicaid asset levels to a maximum of \$6,000.<sup>38</sup> **States should be required to expand the asset level to the federal allowable limit for HCBS.**

**Some states do not use spousal impoverishment rules to protect the assets of a community spouse for HCBS.** The HCBS program allows but not require states to use spousal impoverishment rules to protect the assets of a community spouse, as they are required to have for

nursing homes (allows up a maximum of \$104,400 and between \$1,711 and \$2,610 per month in income).<sup>38</sup> Also CMS has interpreted the HCBS spousal improvement rules to only apply to the categorically needy and not to the medically needy. **States should be required to use the same spousal impoverishment rules for HCBS as for nursing homes for both the categorically and the medically needy groups.**

**Functional Eligibility. Federal HCBS waiver policies require HCBS programs to use institutional need criteria for eligibility.**<sup>85</sup> This can limit access to HCBS and this may result in greater use of institutional care. With the new provisions under the 1915(i) waivers discussed earlier, states have the option of increasing nursing home criteria while reducing HCBS need criteria for the 1915(j), although it is not clear how many states will use this waiver. By increasing the stringency of nursing home need criteria and lowering the HCBS criteria, states may be able to reduce institutional care use.

In contrast, some states have limited access to HCBS, beyond what is currently required by the federal regulations, by setting functional eligibility criteria that are stricter than those used for nursing homes. Although most states used the same criteria for both HCBS and institutional services, 7 waivers (out of 277) used more restrictive functional eligibility criteria for waivers in 2007.<sup>17</sup> **The federal government should remove the link between HCBS and institutional need criteria for all HCBS programs.**

**Cost Controls. Most states use HCBS cost controls including fixed expenditure ceilings, service limits, hourly limits, and geographic limits within the states.** More than two-thirds of all waiver states (69%) utilized some form of cost controls in 2007. Many states used a mixture of fixed expenditure ceilings, service limits, hourly limits, and geographic limits within the states.<sup>17</sup> More than one-third of all states (35%) utilized either expenditure or service limits or both in their home health programs in 2007 while 47 percent of all states with optional state plan personal care programs used cost control limits.<sup>17</sup> Although such strategies may control program costs, they constrict access to services and may have a negative impact on individuals being able to remain at home or the adequacy of services, especially in states with service limitations. Beneficiaries in states with service limitations may also have inadequate services and unmet needs. **Federal policies should require states to adopt more generous HCBS spending policies based on consumer need.**

### **Inadequate Provider Wages and Benefits and Reimbursement Rates**

**Medicaid wages and benefits for HCBS workers are low and contribute to an unstable workforce and workforce shortages.** A number of factors contribute to the under supply of direct care workforce, particularly low wages and benefits. A recent study using Current Population Survey data showed that the earnings of personal and home care workers in the home increased from \$5.41 in 1989 to \$8.40 in 2004, but the increase was less than those for nursing home aides and food counter workers during the period.<sup>44</sup> Only 29.4 percent of personal care and home care workers received health benefits under employer coverage in 2004. Many workers reported (44.5 percent) variable work hours or fewer than 35 hours of work per week in 2004.<sup>44</sup> Data from the Bureau of Labor Statistics, showed that between 1999 and 2006, the national median wages for personal care and home care workers increased from \$7.50 to \$8.54 per hour or an average of 2 percent per year. When adjusted for inflation, real wages declined by 4 percent during the period.<sup>67</sup>

Nearly 60 percent of states reported that hourly wages for personal and home care workers were below 200 percent of the federal poverty level.<sup>67</sup> Because many workers have less than fulltime employment, their wages are extremely low.<sup>68</sup>

Not surprisingly, almost 30 percent of direct care workers (includes personal and home care and institutional care workers) live at near poverty income levels and are more likely than other workers to rely on public benefits to supplement their wages. Forty percent of direct-care workers live in households that rely on one or more public benefits, such as Medicaid or food stamps, reflecting the heavy public subsidies required to compensate for the low wages and inadequate benefits received by most of these workers.<sup>46</sup> Even those working for provider organizations (as opposed to those who are self-employed) have access to limited benefits.

Studies suggest that increasing wages and benefits can help to retain direct care workers, which can improve the continuity and quality of care.<sup>1,46,49,67</sup> To increase wages for direct care workers, states have implemented wage pass-through policies. As of 2003, 26 states reported increasing compensation for both paid and unpaid direct care workers via such policies,<sup>69</sup> but results from wage pass-through evaluations have been mixed.<sup>13,46,48</sup>

Additional strategies to increase direct care worker compensation and benefits include: establishment of wage floors, reimbursement rate enhancement methods tied to workforce outcomes, specification of minimum allocation of rate to direct care labor costs, reform of procurement and contracting standards, minimum wage improvements, living wage ordinances health insurance initiatives, transportation subsidies for home care workers, collective bargaining and the development of career ladders.<sup>13,46, 48,69</sup>

Further complicating matters is that direct care worker positions are physically and emotionally demanding, and with few opportunities for advancement in the same work role. Moreover, direct care workers perceive that their jobs lack respect both from supervisors and care recipients within the LTC sector and from the public.<sup>13,48</sup> In combination, the working situation, high injury rates, low wages and benefits, perceptions of lack of respect, and inadequate training contribute to a high rate of annual staff turnover. This rate is 40-60% among direct service workers generally. The high rate of turnover of staff on the job is problematic for quality and continuity of care as well.<sup>46,48,69,70</sup> Among other things turnover is a burden for consumers and for organizations and payers who must continually provide training.

CMS has funded a number of quality improvement projects, a large direct service worker demonstration project designed to improve methods of recruiting and retaining direct service workers, and a National Direct Service Worker Resource Center.<sup>71</sup> These projects should be expanded to help state Medicaid programs address the recruitment and retention problems of the HCBS direct care workforce. Projects to improve worker retention include: career ladders, changes in supervision practices (including those associated with direct hire practices for PAS recipients) to recognize and involve the direct care worker in decision-making about care.

The IOM recommended an increase in the quality of direct care jobs through improvements in the job environment and adequate financial compensation for their current and expanding roles.<sup>1</sup> Specifically the IOM recommended that **“State Medicaid programs should increase pay and fringe benefits for direct-care workers through such measures as wage pass-throughs, setting**

wage floors, establishing minimum percentages of service rates directed to direct-care labor costs, and other means.”<sup>71</sup>

**Medicaid reimbursement policies for HCBS providers vary widely by provider types, by consumer target groups, and by location within states as well as across states creating inequities for consumers and providers.** Although most states have standard Medicaid reimbursement policies for nursing homes (which vary widely across states), the reimbursement policies for HCBS providers within states (as well as across states) vary widely by provider types (home care agencies, residential care, group homes), by consumer groups (DD versus aged and disabled clients), and by location. State Medicaid HCBS payment policies have been described as primitive at best, and are often not based on the actual cost of providing services.<sup>72</sup> The local and state HCBS payment policies generally do not include inflation adjustments. The wide variations in payment rates are often associated with decentralized rate setting policies (by counties or other entities) and are often subjected to annual political processes rather than based on the costs of providing services with adjustments for inflation. Often there are no standard procurement policies or regular reviews or audits of providers. Payment policies often do not take into account quality and the need to access to services and may not be rational, defensible, verifiable, systematic, or equitable.<sup>72</sup> Policies also need to take into account the need to expand the availability of HCBS providers and to improve the stability and quality of the workforce.

HCBS reimbursement policies should take into account actual provider costs, inflation adjustments, regulatory requirements, and other factors to stabilize provider payments, improve quality, and ensure access to HCBS. **Federal guidelines should be established in order to reduce the variation and inequities in HCBS provider reimbursement within and across state programs.**

Medicaid rate-setting controls on nursing homes have been in widespread use by states. Prospective payment systems for nursing homes have been found to be related to lower expenditures on nursing homes.<sup>73-76</sup> Medicaid reimbursement rates are generally well below the Medicare rates. Controlling Medicaid institutional rates has been criticized because it tends to result in nursing home reductions in staffing levels and poor quality of care.<sup>75,76</sup> Rather than reducing Medicaid reimbursement rates, one approach is for Medicare and Medicaid programs to develop more stringent financial accountability requirements. This approach could direct funds for care into specific cost centers to ensure that funds are used for direct and indirect care rather than for profits and administrative costs. **Federal guidelines should be set for Medicaid institutional reimbursement methods and rates that ensure financial accountability and quality.**

### **Limited Woodwork Effect**

**Policy makers and state officials have been concerned about the potential for a “woodwork effect” for HCBS, which has limited the expansion of HCBS.** This concern is that if HCBS are expanded, individuals who previously received only informal care might take advantage of new HCBS program even though they would not be willing to use institutional services.

A recent study examined this issue by studying Medicaid HCBS and institutional spending trends in the states between 1995 and 2005.<sup>77</sup> This study compared states with low HCBS expenditures (spending below the national median) with states with high spending divided into those that had (1) expanding HCBS and (2) established HCBS spending. State offering extensive HCBS had spending growth comparable to those states with low HCBS spending. States that had well-

established HCBS programs had much less overall LTC spending growth compared to those with low HCBS spending because these states were able to reduce institutional spending. There appeared to be a lag of several years before institutional spending appeared to decline. In contrast, states with low levels of HCBS expenditures had an increase in overall costs, as their institutional costs increased. Thus, states that expanded their HCBS programs have not had increased costs or have had a reduction in their total LTC costs over time.<sup>77</sup> **Educational efforts are needed to reassure federal and state policy officials that expanding HCBS may result in some initial costs but HCBS programs should have a positive effect on spending over time.**

### **Need to Coordinate Medicare and Medicaid Funding for LTC**

**The Medicare and Medicaid LTC and HCBS programs are generally not coordinated or integrated.** In addition to the fragmentation of HCBS programs at the state level, the Medicare and Medicaid LTC and HCBS programs are not coordinated or integrated. (The PACE program described above is an exception because it operates with joint Medicare and Medicaid funding under a managed care program.) In general, there are no fee-for-service programs that allow for the coordination of Medicare and Medicaid LTC benefits. This results in cost shifting between the programs and can increase the risk for hospitalization, emergency room use, and nursing home use.<sup>13</sup>

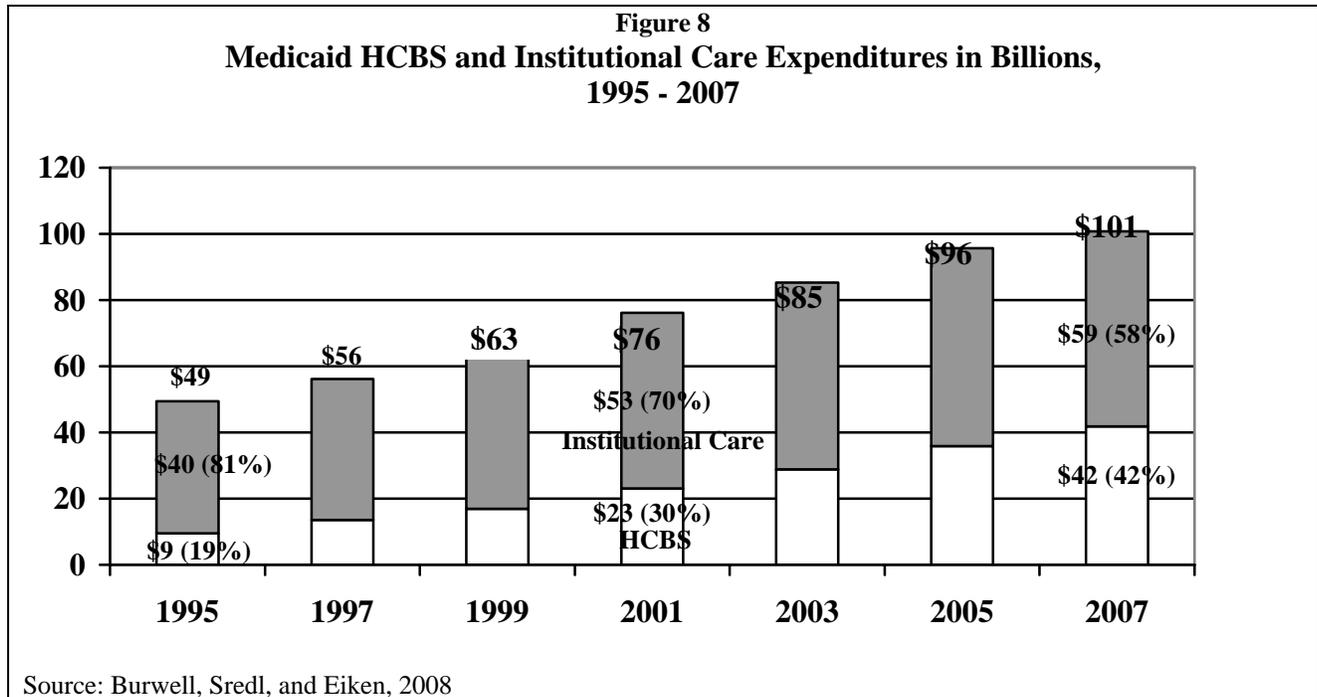
The Medicare hospital program has an incentive to discharge patients as soon as possible to reduce costs. Discharges often occur before appropriate post-discharge services can be arranged and early discharge may lead to unnecessary nursing home placement because HCBS are not available at home. This can result in poor quality of care or lack of care after discharge. State HCBS programs may benefit Medicare by reducing hospitalization and nursing home placement but there is no mechanism by which state Medicaid programs can recoup the savings to Medicare. More demonstrations could be undertaken to combine Medicaid and Medicaid funding and administration within states. **There is a need to combine Medicare and Medicaid programs and funding to improve the access to appropriate HCBS, reduce costs, and improve the quality of care.**

### **Imbalance in HCBS Spending**

**The disproportional amount of Medicaid spending on institutional care compared to HCBS is a major concern.** In spite of the steady growth in HCBS spending, the Medicaid program reported spending \$58.99 billion (58.5 percent of total LTC) on institutional LTC services and \$41.8 billion (41.5 percent of total LTC) on HCBS services in 2007 (Figure 8).<sup>17</sup> Expenditures on HCBS grew by 341 percent between 1995 and 2007 while institutional care grew by 48 percent as total Medicaid LTC expenditures grew by 105 percent. Variations in state spending ranged from New Mexico and Oregon which spent only 27 percent on institutional LTC and 73 percent on HCBS to Mississippi, which spent 87 percent on institutional LTC and only 13 percent on HCBS.<sup>32</sup>

When expenditures for the aged and disabled are examined, Arizona spent 64 percent on HCBS compared with 36 percent for institutional services in 2007.<sup>32</sup> Tennessee spent 99 percent and Mississippi spent 98 percent on institutional services for the aged and disabled. The national average was 69 percent for institutional care and 31 percent of HCBS for the elderly.<sup>32</sup> Six states spent more than 50 percent of their dollars on HCBS but none had reached the level of 75 percent in 2007.<sup>32</sup>

In contrast, Oregon spent 100 percent on HCBS for the developmentally disabled and Mississippi spent 100 percent on institutional care for the developmentally disabled in 2007.<sup>32</sup> Overall, 8 states spent 90 percent or more of total LTC spending on HCBS services and 21 states spent 75 percent or more of their Medicaid LTC dollars on HCBS for the DD population. The national average was 63 percent for HCBS and 37 percent for institutional care for DD in 2007.<sup>32</sup>



One question is what should be the proportion of spending on HCBS. If spending for the DD population is already 63 percent on HCBS and 10 states spend more than 90 percent and 21 states spend 75 percent or more on HCBS for DD, it seems likely that 75 to 100 percent of total spending for DD services could be on HCBS.

Although the aged and disabled are far behind the DD population in the proportion spent on HCBS, perhaps the proportion of HCBS spending for the aged and disabled could also reach 75 to 90 percent of total LTC spending, although this will take a longer time period at the current growth rate. **The federal government should set target levels to increase HCBS spending as a percent of total state LTC spending for individuals with DD and other disabilities and to support states to meet these targets over time.**

Even though HCBS expenditures are increasing as a proportion of the total, the growth in HCBS has primarily been for the DD population rather than for the aged and physically disabled. AARP estimated that it would be 2020 before HCBS spending on the aged and disabled is equal to the proportion of total spending on institutional care for the aged and disabled.<sup>38</sup> **The growth in state HCBS spending needs to be accelerated in order to rebalance the total expenditures for HCBS, by increasing new federal spending for HCBS. One approach is to raise the federal medical assistance percentage (FMAP) for all HCBS services.**

Five studies have shown the importance of state resources in expanding HCBS. Two studies showed that state economic environment was an important influence on total, as well as HCBS waiver expenditures.<sup>78,79</sup> Another found a positive relationship between state HCBS participants and expenditures with greater state incomes per capita.<sup>18</sup> State resources were a robust predictor of use and expenditures for both individuals with DD and for older people and working age individuals.<sup>50</sup> Another study reported that federal policies that address state resource issues may spur growth in community-based LTC, which, in most states, continues to be limited.<sup>51</sup> States with low incomes and low HCBS spending often have the highest demand for services (e.g. have higher elderly and disabled populations).<sup>79</sup>

There are many policy approaches to increasing revenues to states for HCBS. The many new federal grants give additional funds to states for targeted programs. This approach has its limitations because those states with low incomes and low HCBS spending may also be the least able or willing to apply for federal grants so that using grants to give funds to states may increase disparities in spending across states.

Another approach is to increase the federal matching funds for HCBS. The federal medical assistance percentage (FMAP) is the rate at which states are reimbursed for most Medicaid service expenditures based on a formula that provides higher reimbursement to states with lower per capita incomes relative to the national average (and vice versa); it has a statutory minimum of 50 percent and maximum of 83 percent.<sup>36</sup> The current FMAP for LTC or HCBS makes no provision for states that have higher disability rates and higher demand for LTC, so his policy could be changed. The FMAP could be raised to 85 percent such is used for the Money Follows The Person demonstration program or to higher levels. **One approach is to raise the federal medical assistance percentage (FMAP) for all HCBS services.**

### **The Regulation of Nursing Home Beds**

**Research studies have shown that state policies that lower the institutional bed supply can result in expanded access to HCBS and reductions in the use of institutional care.** In the US, the number of skilled nursing facilities declined by 2 percent and beds declined by 3 percent (to 1.7 million) between 2004 and 2007.<sup>4</sup> There were 46 nursing facility beds per 1,000 aged 65 and over population in the US in 2007 but the bed supply varies widely across states.<sup>4,80</sup> Although the aged population has grown across the country, nursing home occupancy rates have steadily declined to 85 percent, indicating excess capacity in most areas in 2007.<sup>81</sup> Some of this decline appears to be related to the growth in HCBS alternative services.

Six studies have shown that lower nursing home bed supply in states increases state Medicaid HCBS participants, HCBS expenditures, or increasing the share of HCBS spending to total LTC spending.<sup>18, 51, 52, 79, 82</sup> A recent study showed that states with decreased nursing home bed capacity were positively associated with state per capita rates of HCBS use, expenditures, and the share of Medicaid LTC dollars supporting 1915(c) waivers.<sup>51</sup>

Many states use certificate-of-need (CON) or moratorium policies on nursing home beds in order to prevent the unnecessary expansion of beds.<sup>83,84</sup> By 2007, 43 states (including the District of Columbia) regulated the growth of new nursing home beds and/or facilities through either a CON and/or a moratorium, 26 states regulated ICF-DD facilities, and 12 states included residential care/assisted living facilities.<sup>4</sup>

Four studies showed that the regulation of nursing home beds has a strong effect on increasing the per capita spending on HCBS and on the share of state spending on HCBS.<sup>50,73,78,79</sup> One study showed that state regulation of LTC bed supply had the most substantive effect on increasing the share of dollars supporting 1915(c) waivers from 11.6 to 20 percent over the study period.<sup>78</sup> State regulations on supply of institutional providers are important policies to expand access to HCBS and control the costs of institutional care. **Educational efforts are needed to inform federal and state policy makers about the importance of keeping LTC bed supply low, by using state certificate of need and moratorium programs, with possible federal financial support for such regulatory programs.**

### **Challenging Resource Environment**

**On-going financial crises at the national and state levels threaten the continued access to and spending on Medicaid HCBS.** The downturn in the economy has resulted in lower revenues for the federal and state governments and growing unemployment that has created budget crises at the state level. In fiscal year 2009, “over half of the states faced significant budget shortfalls and slower than anticipated state revenue growth.”<sup>35</sup> Another report found that at least 39 states have reported shortfalls in their budgets for Fiscal Year 2009 and/or projected shortfalls for 2010.<sup>86</sup> Half of the states have responded by cutting spending, using reserves, or raising revenues to address the budget problems for fiscal year 2009.<sup>86</sup> At the same time, the economic downturn is increasing Medicaid enrollment and spending.<sup>35</sup> There appears to be a relationship between recent cutbacks in HCBS participants and expenditures in some states<sup>17</sup> and state budget deficits.<sup>87</sup> With the current financial crises at the federal and state levels, the potential for cutbacks in HCBS funding is high.

Special efforts are needed to encourage states to maintain the progress that has been made in expanding HCBS participants and expenditures. **The federal government needs to assume greater responsibility for paying for Medicaid LTC services, either by expanding the role of Medicare for LTC and/or increasing the funds to states for LTC and HCBS.**

### **QUALITY ISSUES**

CMS defines quality as “the degree to which services and supports for individuals and populations increase the likelihood for desired health and quality of life outcomes and are consistent with current professional knowledge.”<sup>88</sup> For HCBS, the goal is to maximize the quality of life, functional independence, health, and well being of the population.

In spite of the importance of quality, the quality of HCBS is largely unknown (except that home health agencies and hospice programs must meet federal certified standards to receive Medicare and Medicaid funding). Although many consumers of HCBS in the home report satisfaction with their care and services, other users have identified common problems.<sup>89</sup> These include: poor reliability of workers coming to work on time, last minute cancellations of work, problems with carrying out the work assignments, low quality of services received, communication problems between the users and providers, negative provider attitudes, and poor skills of providers.<sup>90</sup> Other consumers report having had providers who abused drugs or alcohol, have stolen items, or were physically or psychologically abusive and/or sexually violent.<sup>90</sup> Consumers have reported having to fire

providers, which has caused stress. Other consumers report negative consequences from receiving poor care such as pressure ulcers or being soiled for long periods.<sup>90</sup>

Consumers of home care and personal care are particularly vulnerable because their care is largely provided in the home and hidden from other individuals. Consumers are sometimes afraid to complain because of the short supply of available attendants for replacements and the lack of emergency back-up services or fear of retaliation.<sup>90,91</sup> The vulnerability of individuals being cared for at home is much greater than that for individuals living in institutions.

## **Federal and State Oversight**

**Federal and state government has responsibility to ensure the quality of HCBS.** CMS has undertaken quality initiatives to improve the overall quality of HCBS. CMS developed a quality tool kit for states about quality assurance and quality improvement and disseminated information to states and it employed contractors to assist with the development and deployment of quality initiatives.<sup>88</sup> In addition, CMS also developed protocols for states to address in designing their HCBS quality oversight and CMS monitors and oversees the design, implementation and operation of HCBS waiver programs.<sup>88</sup>

The federal government requires inspections and certification for institutions, home health agencies, and hospice programs. Federal inspections for nursing homes are every 9-15 months, but home health agency inspections have been reduced to every 3 years and hospice program to every 6 years. Residential care facilities are entirely regulated by state programs and vary widely across states. Because HCBS waiver programs now pay for residential care,<sup>92</sup> the oversight of residential care quality becomes a federal issue. Several studies have raised serious questions about the quality of care in residential care and assisted living programs where state requirements and monitoring has been notoriously weak.<sup>13,92,93</sup>

Waiver programs, personal care, and home care providers do not have any federal or state inspection and certification requirements and most states have limited oversight of these programs. The federal oversight of the waiver programs is primarily based on paper reviews and responding to problem areas.

The current federal and state quality oversight efforts are extremely limited. An independent assessment of these federal and state quality efforts and monitoring is needed to evaluate the efforts and suggest improvements. **The federal government should develop guidelines or regulations for quality in HCBS. Regular federal and state inspections of HCBS programs should be undertaken to improve consumer protections.**

CMS has developed extensive outcome measures for nursing homes and home health agencies based on uniform assessments and quarterly reporting about consumers of services.<sup>94,95</sup> In contrast, CMS has not developed any outcome measures for residential care, waivers, personal care, or home care programs for individual consumers. **The federal government should develop outcome measures appropriate for HCBS programs that can be used by providers, regulators, and consumers in monitoring the quality of care.**

## Training Requirements

**There are no federal training requirements to become a direct care worker in HCBS, except for home health agencies.** Being a direct care worker does not require high-school education or English proficiency. Formal training for home health agencies is minimal (e.g., up to 75 hours if working in a Medicare or Medicaid certified organization).<sup>1</sup> State requirements vary widely and generally are weak and inconsistent; the state of HCBS worker training *curricula* is often mediocre; and few states have taken steps to create, fund, or otherwise support HCBS training *infrastructure* that supports training for workers.<sup>96</sup> A report that examined state requirements for Medicaid-funded personal care services found 301 sets of requirements for HCBS across Medicaid programs in all 50 states and the District of Columbia.<sup>97</sup> The median number of required training hours was only 28, but nearly half of the requirements did not specify the required training hours. Furthermore, 26 percent of training requirements allowed attendants to begin work before completing the required training.<sup>96</sup>

These limited requirements place HCBS in competition with entry level jobs in other service industry sectors of the economy (e.g., fast food) that pay comparable or higher hourly wages, and that offer more certainty with respect to work schedules and full time salaries, and even such minimal benefits as sick days and holidays, and health insurance.<sup>1,13,46,96</sup>

HCBS workers have very high injury rates in part because workers and users do not receive training in injury prevention,<sup>98</sup> and HCBS workers increasingly tend to provide informal medical tasks and care both inside and outside of the home.<sup>99</sup> HCBS workforce interventions, initiatives, and training programs are geared towards increasing workforce recruitment and retention. Centers for Independent Living (CILs), AAAs, and many state Medicaid programs have recently been implementing training programs for community-based caregivers and the consumer-directed HCBS workforce. Washington and Maine offer trainings for HCBS workers and consumers in consumer-directed environments.<sup>100</sup> Additionally, other states are developing innovative approaches such as establishing career ladders and training opportunities for HCBS workers.<sup>13,46,99</sup> State interest in improving training requirements and training systems for HCBS workers is strong and growing.

The IOM recommended that states and the federal government should increase minimum training standards for all direct-care workers including personal care assistants. In addition, the federal requirements for certified home health aides should be increased to at least 120 hours with a demonstration of competence in the care of older adults as a criterion for certification.<sup>1</sup>

Disability advocacy organizations, however, disagree with mandatory training requirements because of their concern that such training programs will reduce consumer-directed services. These advocacy organizations do support voluntary training programs for both paid and unpaid caregivers and that such programs should be provided by states. Newer model training programs are now providing joint training for care providers and consumers, which can improve quality while reinforcing the importance of consumer-directed services.

State HCBS program training requirements vary widely and generally are weak and inconsistent and training program availability varies across states and local areas. Having more training of both formal and informal caregivers as well as consumers should improve the quality of services and reduce injuries. This will also help ensure more appropriate services and improve access. **States should make joint training programs available for (both paid and unpaid) caregivers and**

**consumers to improve quality and provide support and resources to caregivers and consumers.**

### **Consumer Directed Services**

**Consumer-directed services are important to assure the quality of HCBS for many consumers.** Studies have shown a strong consumer preference for consumer directed services and independent providers as well as high satisfaction levels with such services.<sup>89</sup> Many consumers want to select, hire, fire, and train their own caregivers and manage the services they receive.

Even though consumer directed services and choice have been strongly promoted by disability community advocates and by CMS through its regulations, less than a quarter (24%) of home health programs allowed consumer direction in services in 2007.<sup>17</sup> There was an increase in the number of state personal care programs that allowed consumer direction (from 31 percent of states in 2006 to 47 percent of states in 2007) although about 80 percent of states with waiver programs reported some consumer directed options.<sup>17</sup> **The federal government should require states to make available the option for consumer-directed services in all Medicaid HCBS programs.**

**Cash & Counseling Demonstrations.** The Cash & Counseling demonstration programs have been useful in expanding access to HCBS at home and satisfaction with services. A cash and counseling demonstration project was sponsored by the Robert Wood Johnson Foundation (RWJF), the US Assistant Secretary for Planning and Evaluation (ASPE), and the Administration on Aging (AoA) under an 1115 research and demonstration waiver.<sup>100,101</sup> Established in 1998 in three states (Arkansas, New Jersey, and Florida), it gave Medicaid consumers needing personal assistance services a choice between receiving the traditional agency-delivered services authorized by the state or managing cash allowances to obtain these services themselves. Consumers were given a flexible budget to manage and decide for themselves what mix of goods and services will best meet their personal care needs, including home modifications that help them live independently.<sup>102</sup> The evaluation results from the Arkansas demonstration found that Cash & Counseling participants were more satisfied with the quality of their services, had increased access to paid care, had fewer unmet service needs, and experienced an improved quality of life.<sup>103,104</sup> After the initial demonstration, 11 additional states were awarded Cash & Counseling grants in October 2004. These programs have been useful in expanding access to HCBS at home.

**1915(j) Waivers.** The Deficit Reduction Act (DRA) of 2005 gave states the authority to establish the 1915(j) waiver to expand the Cash and Counseling option. CMS issued a final rule in January 2007 to allow more Medicaid beneficiaries to be in charge of their own personal assistance services, instead of having those services directed by an agency.<sup>105</sup> Medicaid beneficiaries who need help with the activities of daily living may hire, direct, train and fire their own personal care workers. Beneficiaries may hire qualified family members who may already be familiar with the individual's needs to perform personal assistance (not medical) services.<sup>105</sup> The state may target populations, limit the number of individuals eligible for the program, limit the geographical areas for the program, and employ a financial management entity to make payments to providers, track costs and manage the program. Five states have been approved for the 1915 (j) Cash and Counseling program: Alabama, Oregon, Arkansas, Florida, and New Jersey.<sup>37</sup> **Cash and Counseling programs should be expanded to all states.**

## MEDICAID RESTRUCTURING

**Ultimately, many of the problems of inequities in access to HCBS, inequities in expenditures, and quality problems are related to limited funding for HCBS and the decentralized state administration of the Medicaid program.** LTC has become an increasing financial burden on the states (almost 33 percent of total Medicaid spending in 2007). As the demand for HCBS and institutional services increases, more financial pressures are placed on the Medicaid program. The inequities in access to HCBS are a function of the limited Medicaid funding for the HCBS program and the decentralized nature of the program. As shown above, the administrative fragmentation of the state HCBS programs has grown worse as the federal government has started more HCBS initiatives.

Federal Medicaid policies could consolidate Medicaid programs and institute more uniform requirements for providing HCBS including: need criteria, financial eligibility, assessment procedures, screening, choice requirements, payment policies, spending policies and other policies. In order to accomplish this change politically, perhaps the federal government would have to pay most or all of the costs for Medicaid LTC.

One option would be to fully federalize all those individuals who are dually eligible for Medicare and Medicaid services. This would facilitate the joint operation and administration of these two programs and allow for Medicaid LTC program to be operated as a part of the larger Medicare program. This would allow the development of uniform access to services, funding for the program, and quality oversight administered by the federal government.

Perhaps a more attractive financial option for states would be to have Medicaid LTC folded into the federal Medicare program as a Medicare Part E program, which has been proposed by some policy makers. This would facilitate LTC reform and relieve the burden of LTC from the states. It would facilitate coordination between Medicare and Medicaid LTC benefits and allow for greater uniformity in LTC access, expenditures, and quality. It would protect the gains that states have made in HCBS access and protect spending from the current and frequently recurring state budget problems. **Legislation could be undertaken to merge the Medicaid LTC program into the Medicare program to create a combined Medicare and Medicaid LTC program.**

## SUMMARY

This report examined issues of access, cost, and quality for Medicaid HCBS programs. State Medicaid programs are addressing growing enrollments and an increasing demand for LTC at a time of serious federal and state financial crises. Medicaid has made rapid progress over the last decade in expending HCBS programs to a growing number of target groups and participants. Medicaid HCBS expenditures have increased rapidly but are still below spending for institutional services. In spite of the progress in providing Medicaid HCBS, there are many current problems, including inequities in access to services and limited funds for HCBS that can cause serious problems for individuals and can force individuals into institutions unnecessarily. There are widespread unmet needs for HCBS in the Medicaid and general population. HCBS cost issues have been a primary focus of policy makers, and quality problems have largely not been addressed with regulatory oversight and training programs. Policy changes can be made to improve access, costs and quality at the federal and state levels in the future.

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