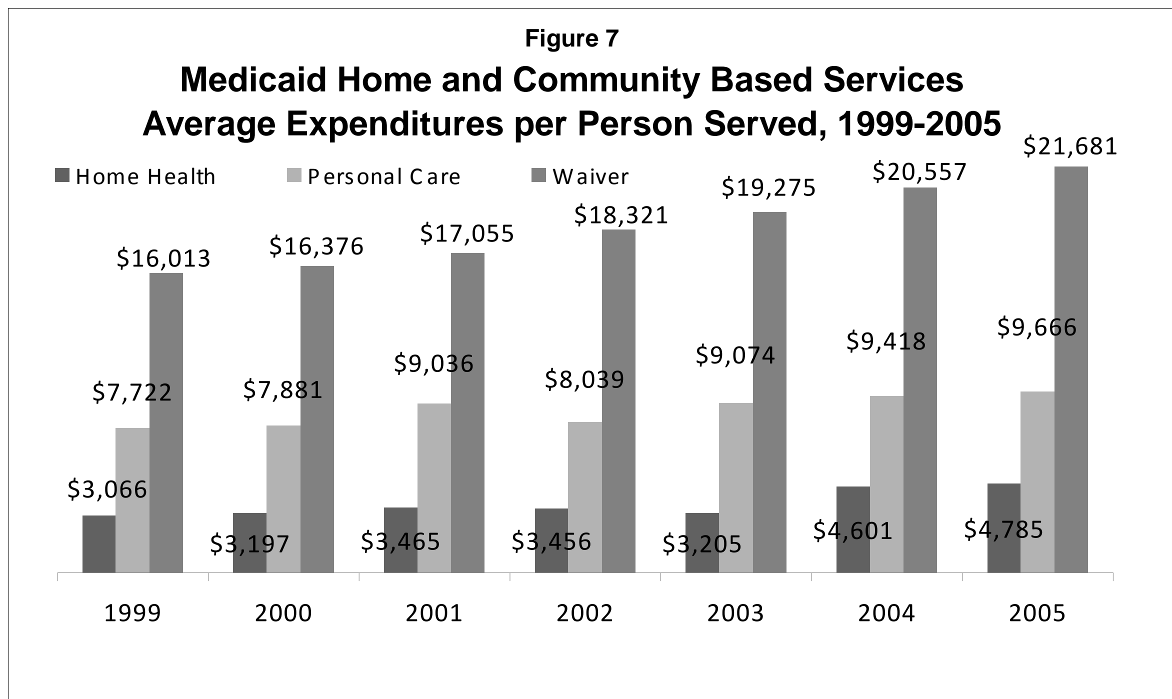
These low expenditure levels per person, particularly for the personal care services programs, are probably too low to provide an adequate level of services for some individuals who need HCBS. Low expenditures levels can result in individuals going to institutional care unnecessarily. States should increase 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).[23] 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.[23] 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.[23] 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.[17]

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.[41] 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.[17] 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.[17] **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.[38] **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).[38] 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.[85] 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.[17] **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.[17] 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.[17] 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.[44] 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.[44] 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.[67]

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

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.[46] 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.[1,46,49,67] 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,[69] but results from wage pass-through evaluations have been mixed.[13,46,48]

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.[13,46, 48,69]

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.[13,48] 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.[46,48,69,70] 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.[71] 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.[1] 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."[1]

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.[72] 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.[72] 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.[73-76] 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.[75,76] 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.[77] 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.[77] **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.[13]

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).[17] 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.[32]

When expenditures for the aged and disabled are examined, Arizona spent 64 percent on HCBS compared with 36 percent for institutional services in 2007.[32] 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.[32] Six states spent more than 50 percent of their dollars on HCBS but none had reached the level of 75 percent in 2007.[32]

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.[32] 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.[32]

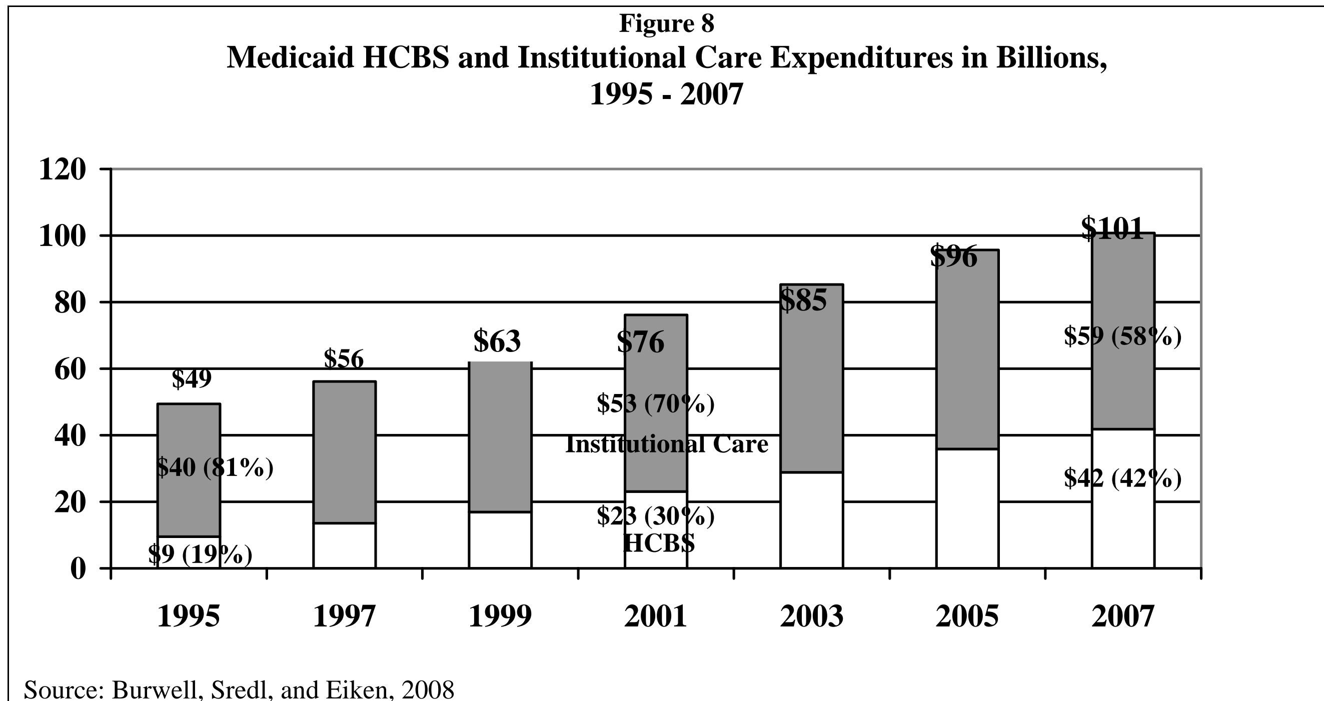


Figure 8
Medicaid HCBS and Institutional Care Expenditures in Billions, 1995 - 2007

Source: Burwell, Sredl, and Eiken, 2008

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 that 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.[38] **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.[78,79] Another found a positive relationship between state HCBS participants and expenditures with greater state incomes per capita.[18] State resources were a robust predictor of use and expenditures for both individuals with DD and for older people and working age individuals.[50] 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.[51] States with low incomes and low HCBS spending often have the highest demand for services (e.g. have higher elderly and disabled populations).[79]

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.[36] 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.[4] 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.[4,80] 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.[81] 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.[18, 51,52,79,82] 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.[51]

Many states use certificate-of-need (CON) or moratorium policies on nursing home beds in order to prevent the unnecessary expansion of beds.[83,84] 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.[4]

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.[50,73,78,79] 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.[78] 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."[35] Another report found that at least 39 states have reported shortfalls in their budgets for Fiscal Year 2009 and/or projected shortfalls for 2010.[86] Half of the states have responded by cutting spending, using reserves, or raising revenues to address the budget problems for fiscal year 2009.[86] At the same time, the economic downturn is increasing Medicaid enrollment and spending.[35] There appears to be a relationship between recent cutbacks in HCBS participants and expenditures in some states[17] and state budget deficits.[87] 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."[88] 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.[89] 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.[90] Other consumers report having had providers who abused drugs or alcohol, have stolen items, or were physically or psychologically abusive and/or sexually violent.[90] 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.[90]

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.[90,91] 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.[88] 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.[88]

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,[92] 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.[13,92,93]

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.[94,95] 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).[1] State requirements vary widely and generally are weak and inconsistent; the state of HCBS worker training *curricula* is often mediocre; and few state have taken steps to create, fund, or otherwise support HCBS training *infrastructure* that supports training for workers.[96] 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.[97] 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.[96]

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.[1,13,46,96]

HCBS workers have very high injury rates in part because workers and users do not receive training in injury prevention,[98] and HCBS workers increasingly tend to provide informal medical tasks and care both inside and outside of the home.[99] 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.[100] Additionally, other states are developing innovative approaches such as establishing career ladders and training opportunities for HCBS workers.[13,46,99] 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.[1]

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.[89] 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.[17] 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.[17] **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.[100,101] 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.[102] 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.[103,104] 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.[105] 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.[105] 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.[37] **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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