

Medicaid Home and Community Based Services: Proposed Policies to Improve Access, Costs, and Quality

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The U.S. population is aging, with the number of adults aged 65 and older expected to almost double from 37 million in 2005 to over 70 million in 2030, or from 12 to almost 20 percent of the population (Institute of Medicine, 2008). Because the population is aging, the demand for long term care (LTC), particularly services at home, is increasing. In the U.S., over 13.2 million individuals living at home and in the community receive 21.5 billion hours of help per year from either informal or formal paid help (LaPlante, Harrington, and Kang, 2002).

Medicaid is the most critical public program for individuals who are aged and disabled because, according to 2006 data, it pays for almost 46 percent of all nursing home care and 38 percent of home health in the U.S. (Catlin, Cowen, Hartman, Heffler, and the National Health Expenditure Accounts Team, 2008). Medicaid home and community based services (HCBS) have been the focus of widespread efforts by the federal and state governments 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 Olmstead-related lawsuits against states have required 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 LTC services from institutional to HCBS (Kitchener, Ng, and Harrington, 2007).

Inequities in access to Medicaid HCBS services are widespread, and limited funds have resulted in many unmet needs for HCBS. As HCBS cost issues have been a primary focus of policy makers, access and quality problems have not been sufficiently addressed. As 2009 marks the beginning of a new presidency and Congress, it is important to examine the progress that has been made in providing Medicaid HCBS along with the many current problems. The focus of this article is to examine

issues of access, cost, and quality for Medicaid HCBS programs and to suggest policy changes.

Access to Medicaid HCBS

Medicaid HCBS are provided through three main programs: (1) optional 1915(c) HCBS waivers, (2) the mandatory home health benefit, and (3) the optional state plan personal care services benefit. Many 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. Participants in these programs have grown at an average rate of 7 percent per year since 1999 (Ng, Harrington, and O'Malley, 2008).

Unmet Need for HCBS. In spite of the steady growth in participants over the past ten years, a large unmet need for HCBS has been expressed in national survey data, by state officials, through large and long waiting lists for waiver services, and in multiple lawsuits and complaints against states for failure to provide HCBS (LaPlante, Kaye, Kang, and Harrington, 2004; Kitchener, et al., 2007; Ng, et al., 2008). Additional HCBS 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 for states to improve access to HCBS.

Program Inequities. There are widespread inequities in access to Medicaid HCBS across states. In 2005, the national average number of Medicaid HCBS participants was 9.4 per 1,000 people, but

ranged from 3 to 15 per 1,000 people in different states. Also in 2005, annual HCBS expenditures per capita averaged \$118, but varied from \$30 to \$363 in states (Ng et al., 2008). The limited access to services and spending in some states creates hardships for individuals who need services and may even lead to unnecessary institutionalization.

Inequities in the access to HCBS occur by target group across states. Individuals with developmental disabilities made up 41 percent of HCBS waiver participants but accounted for 74 percent of spending in 2005. In contrast, 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 (Ng et al., 2008). 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. These inequities are likely to continue unless Medicaid HCBS becomes a mandatory program for all individuals based on consumer needs rather than based on state options to fund certain target groups.

Fragmentation. The many federal HCBS programs and policies have led states to offer a range of different HCBS programs in many departments within each state, with different financial eligibility and need determination requirements, assessment procedures, and program administration (Burwell, Sredl, and Eiken, 2008). In the past ten years, the Centers for Medicare and Medicaid Services (CMS) has developed a number of new HCBS initiatives in states but states vary in their willingness and ability to implement these initiatives. Combining and consolidating HCBS programs could 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.

Consumer Choice Limited. Because of HCBS access problems in many states, Medicaid consumers have limited options for the types of services and the setting in which to receive the services, especially those individuals discharged from hospitals. Many individuals require LTC after hospitalization but are given little choice about the services they receive, so are often sent to nursing homes because of inadequate planning for and access to HCBS. Medicaid preadmission screening programs vary across states and most states exercise limited controls

on nursing home admissions (Tonner, Harrington, and LeBlanc, 2001). Some states have developed models for streamlined screening programs, presumptive Medicaid financial eligibility, fast-track assessment, and assistance with the selection of living arrangements (Kitchener, Ng, Willmott, and Harrington, 2005). The federal government needs to

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.

Cost 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) (Ng et al., 2008). Between 1999 and 2005, total Medicaid HCBS spending increased by an average of 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 (Ng et al., 2008).

In spite of the HCBS spending growth, Medicaid continues to spend a disproportional amount on institutional care compared to HCBS. Medicaid reported spending 58.5 percent of total LTC on institutional services and 41.5 percent on HCBS

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services in 2007 (Burwell, et al., 2008). 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) matching rate to states for all Medicaid HCBS services.

Policymakers and state officials have been concerned about the potential for a “woodwork effect” to have 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 (Kaye, LaPlante, and Harrington, 2008). 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.

Restrictive Cost Containment. The statutory federal cost neutrality requirements for Medicaid HCBS are so stringent that state Medicaid HCBS spending is dramatically lower than institutional spending. The per-person spending on Medicaid HCBS 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 \$40 billion in 2002 (Kitchener, Ng, Miller, and Harrington, 2006). 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. Some states

restrict financial eligibility for HCBS waivers to 100 percent of Supplemental Security Income (SSI) compared to 300 percent of SSI for nursing homes (Ng, et al., 2008). States should be required to cover all medically needy who need LTC and to use a financial eligibility standard of at least 300 percent of SSI 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. Some states do not use spousal impoverishment rules to protect the assets of a community spouse for HCBS in contrast to the federal requirement for spousal impoverishment rules for nursing home programs. Federal HCBS waiver policies require HCBS programs to use institutional need criteria for eligibility but this limits access to HCBS compared 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 and expand spousal impoverishment rules.

Provider Wages/Benefits. Medicaid wages and benefits for HCBS workers are low and contribute to an unstable workforce and worker shortages. Low wages and benefits are among the most important factors resulting in an undersupply of workers and high turnover rates. Many workers have less than fulltime employment, incomes at near poverty levels, and no health benefits (Kaye, Chapman, Newcomer, and Harrington, 2006). 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 (Seavey and Salter, 2006).

Medicaid reimbursement policies for HCBS providers vary widely by provider types, by consumer target groups, and by location within states as well

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as across states, creating inequities for consumers and providers (Seavey and Salter, 2006). 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.

Poor Medicare Program Coordination. 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, nursing home use and poor quality of care. There is a need to coordinate or combine Medicare and Medicaid programs and funding to improve the access to appropriate HCBS, reduce costs, and improve the quality of care.

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 (Grossman, Kitchener, Mullan, and Harrington, 2007).

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). The federal government should develop guidelines or regulations for quality in HCBS care programs, and 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 (U.S. Department of Health and Human Services, 2006). Providing more training to both formal and informal caregivers as well as consumers should improve the quality of services and reduce injuries and could ensure more appropriate services (Paraprofessional Healthcare Institute, 2005). States could 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 did 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 and Counseling demonstration programs have been useful in expanding access to HCBS, and consumers have expressed satisfaction with services (Mahoney, Simone, and Simon-Rusinowitz, 2000). A few states had participated in a demonstration project that is now available to all states under the new 1915(j) waiver programs, which encourage 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 states, making up almost 33 percent of total Medicaid spending in 2007 (Burwell et al., 2008). As the demand for HCBS and institutional

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services increases, more financial pressures will be placed on the Medicaid program.

Federal Medicaid policies could consolidate Medicaid programs and institute more uniform requirements for providing HCBS. In order to accomplish this change politically, the federal government may have to pay most or all of the costs for Medicaid LTC. Another option is to fully federalize Medicare and Medicaid services for all those individuals who are dually eligible. 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, with 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 fold Medicaid LTC 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 promote 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.

Conclusions

State Medicaid programs are addressing growing enrollments and increasing demand for LTC at a time of serious federal and state financial crises. Medicaid has made rapid progress over the last decade in expanding 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 populations. HCBS cost issues have been a primary focus of policy makers, and quality problems largely have not been addressed with regulatory oversight and training programs. Policy changes should be made to improve future access,

costs, and quality at the federal and state levels.

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