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HOME AND COMMUNITY-BASED SERVICES:

PUBLIC POLICIES TO IMPROVE ACCESS, COSTS, AND QUALITY

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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 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.**

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.