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Advancing Access to Medicaid Home and Community-Based Services: Key Issues Based on a Working Group Discussion with Medicaid Experts

Introduction

The purpose of this brief is to frame the current issues and challenges facing Medicaid home and community-based services (HCBS) and to address some practical and potentially cost effective steps the states and the federal government could take to increase access to community-based long-term services and supports.

There is a well known bias in Medicaid policy that steers people with long-term care needs into an institutional setting while most beneficiaries would prefer to remain living in their own homes or community while receiving services. HCBS make staying at home a possibility for many individuals by providing assistance with activities of daily living such as bathing, dressing, eating, help with medications and other kinds of supportive services. States are required to cover nursing home care but have the option to provide personal care and other long-term care services in community-based settings. Over the last 20 years, states have made great progress in shifting the delivery setting for long-term services and supports toward more home-based care but since most HCBS are provided through waivers,[1] wide variation in spending patterns and financial and need eligibility standards exist across the states.

In order to further shift the delivery setting for more costly long-term care services to home and community-based settings, states as well as many consumer and worker advocates are looking to the federal government to provide additional financial support. In this context, the Kaiser Commission on Medicaid and the Uninsured gathered a group of key experts, federal and state officials and advocates to facilitate an open exchange of information and ideas around expanding Medicaid eligibility and access to community-based services, increasing federal financing of long-term services and supports, and addressing community workforce issues. This brief documents some of the highlights from the discussion.[2]

Key Issues

Participants acknowledged the need for additional federal financing in order to increase access to Medicaid home and community-based services. A total of 2.8 million individuals currently receive Medicaid HCBS services and an additional 300,000 individuals are on a waiting list for services, an 18 percent increase over the previous

[1] Medicaid waivers provide a mechanism for states to use federal funds in ways that do not conform to federal standards. Section 1915 waivers permit states to enroll Medicaid beneficiaries in mandatory managed care or to provide HCBS to people who would otherwise need nursing home care.

[2] A companion report citing state examples of expanding access to Medicaid HCBS was prepared following this meeting. See Laura Summer, Efforts in States to Promote Medicaid Community-Based Services and Supports, Kaiser Commission on Medicaid and the Uninsured, September 2009.

1330 G Street NW, Washington, DC 20005
Phone: 202-347-5270, Fax: 202-347-5274
Website: www.kff.org

year.[3] At the same time that demand for HCBS is increasing, states are facing bleak fiscal conditions that are expected to continue into fiscal year 2010 and beyond.[4] The federal government supports efforts to transition people from nursing homes to the community, through nursing home diversion programs and Money Follows the Person grants, but these programs are narrowly targeted and funding is limited. Participants noted that additional federal support in the form of an enhanced federal matching rate for HCBS could provide the necessary incentives for states to expand access to Medicaid HCBS and potentially reduce the cost of providing long term services and supports over time.

Another financing option that could significantly enhance HCBS is increasing the administrative match as a means to improve states' capacity to identify and enroll potentially eligible beneficiaries. Unlike the federal matching rate applied to Medicaid costs that averages 57 percent across the states, the federal matching rate for administrative costs is generally 50 percent. Many of the necessary changes and improvements in HCBS, including uniform assessment tools and the training to use them effectively, require increased administrative effort and states rarely see increased federal support for administrative functions. Participants also noted alternative mechanisms such as grant programs or a model practice center at CMS as a means to provide more resources to states.

Participants agreed that increasing Medicaid income eligibility and resource limits for HCBS could promote individuals' ability to stay in the community. When faced with the need for long-term services and supports, few people have the resources to pay for that care over long periods of time and turn to Medicaid as a last resort once they become impoverished. Medicaid's eligibility criteria is restricted and intended to assist low-income individuals and is not available to everyone who needs long-term services and supports. This creates a problem in particular for individuals to receive HCBS and remain in the community. These individuals need adequate resources to maintain a home and continue living in a community setting.

In order to qualify for Medicaid coverage of long-term services and supports, individuals must first meet financial qualifications in addition to meeting need criteria. For the elderly and people with disabilities with long-term care needs, income limits are often tied to the Supplemental Security Income (SSI) program $674 per month in 2009 – but states can, and often do set higher limits. Thirty-six states, including DC, allow the "medically needy" – those with high medical bills – to spend down to a state-set eligibility standard, and because few people can afford the high cost of nursing home care, 38 states allow individuals needing nursing home care to qualify with income up to 300 percent of SSI ($2,022 per month in 2009).[5] Some states have more restrictive financial eligibility criteria

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[3] Ng, T., Harrington, C., and O'Malley, M., *Medicaid Home and Community-Based Service Programs: Data Update*, Kaiser Commission on Medicaid and the Uninsured, December 2008, http://www.kff.org/medicaid/7720.cfm

[4] NASBO, The Fiscal Survey of States, June 2009, www.nasbo.org/Publications/PDFs/FSSpring2009.pdf

[5] KCMU, Medicaid and Long-Term Care Services and Supports, February 2009, http://www.kff.org/medicaid/2186.cfm

for HCBS than for institutional services.[6] A recent Congressional bill, the Empowered at Home Act (S. 434), would allow states to expand HCBS eligibility criteria up to 300 percent of SSI through a state option.

The elderly and individuals with disabilities who qualify for Medicaid must have very few assets ($2,000 for an individual and $3,000 for a couple, in most states). Restrictions on income and assets for eligibility may inhibit goals to reduce institutional bias. Allowable resources for persons living in the community are very low and insufficient to maintain a home without considerable support from family.[7] Several participants stated that allowing Medicaid beneficiaries who receive long term services in the community to retain more assets could help them pay for home modifications, transportation, or other services that Medicaid may not cover.

Differences in state policies can have serious consequences for people who need long-term services and supports. A person who is financially eligible for Medicaid in one state might not be in another state, or might be eligible for Medicaid but not for Medicaid HCBS. Working group participants indicated a strong interest in raising the income eligibility level to 300% of SSI for the Medicaid HCBS state plan option[8] and extending spousal protections[9] in HCBS to align with spousal impoverishment rules for Medicaid beneficiaries in nursing homes.

In an effort to improve access to HCBS, meeting participants were in favor of expediting program eligibility determinations. A quick eligibility determination process can be especially beneficial for individuals who wish to remain in the community since a delay in access to services could lead to unmet need and entry into a nursing home. Determining financial eligibility is often the most time consuming piece of the Medicaid application process. Individuals must meet both income and resource test limits. Several states operate programs designed to expedite the process. For example, Pennsylvania uses a 24-hour hotline service so that information can be sent and provisional determinations can be made within 24 hours. New Jersey has a pilot program that does not rely on self-reported applicant information but rather uses two databases to determine financial eligibility for Medicaid. Applicants for long-term services whose names appear in the databases may receive conditional financial eligibility for services.[10] Presumptive eligibility is another option that several states are looking into in order to ensure access to community-based

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[6] Ng, T., Harrington, C., and O'Malley, M., Medicaid Home and Community-Based Service Programs: Data Update, Kaiser Commission on Medicaid and the Uninsured, December 2008, http://www.kff.org/medicaid/7720.cfm

[7] Judy Kasper, Barbara Lyons, Molly O'Malley, Long-Term Services and Supports: The Future Role and Challenges for Medicaid, Kaiser Commission on Medicaid and the Uninsured, September 2007.

[8] The DRA of 2005 gave states the authority to offer HCBS as a state plan service rather than through a 1915 waiver.

[9] The Medicaid spousal impoverishment rules are a set of federal standards that states must use to determine eligibility for nursing home residents who are married. States have latitude to set income and asset eligibility levels within federally determined floors and ceilings. States may extend spousal impoverishment protections to people receiving long-term care in the community, but they are not required to do so. For more information see: http://*ltc*.georgetown.edu/pdfs/spousal0207.pdf

[10] Laura Summer, Efforts in States to Promote Medicaid Community-Based Services and Supports, Kaiser Commission on Medicaid and the Uninsured, September 2009.

services. Traditionally, institutional providers have been more willing to provide services before an individual is determined eligible for Medicaid, yet community-based providers have hesitated because of the lack of guarantee of payment. Some states have taken steps to assure community-based providers that they will receive payment for services for those deemed presumptively eligible for Medicaid by asking an individual to sign an agreement indicating responsibility for payment if they are found ineligible.[11]

Building professional consensus on measuring need and development of standardized assessment tools are viewed as important to promote equitable access to long-term services and supports. Approaches to screening and "need" criteria vary across states. Although most states set functional eligibility criteria for HCBS at the same level that is used for care in a nursing facility, 7 waivers used more restrictive functional eligibility criteria for HCBS than for institutional care.[12] The "need for institutional care" is interpreted by each state, using state administered assessment and eligibility systems to determine whether institutional level-of-care criteria are met. In 2001, only 3 states coordinated screening and assessment across long-term care programs by operating a single state administrative agency using uniform need criteria and standard tools and having automated databases.[13] Variability in "need" criteria creates the potential for barriers to access for applicants, who many face difficulties in finding and understanding information on the status of different programs, and in negotiating varying eligibility processes for multiple programs.[14] It has also led to disparities in access across populations. For example, in some states people with developmental disabilities may have more preferential access to HCBS compared to people with physical disabilities.

Over the last decade, the long-term care field has moved toward developing a professional standard for assessing need in the community. The Home and Community Balanced Incentives Act of 2009 (S. 1256) has provisions for creating a standardized, state-wide assessment program to facilitate access to information about home and community-based eligibility and enrollment, as well as other long-term services and supports. It also proposes the use of standardized assessment instruments that could help reduce variation in who receives HCBS within states. Though there is also interest in a national assessment instrument, participants felt that additional evaluation is needed before widespread adoption of a single assessment tool. If a consensus on a standard was reached, an individual's need for assistance could be assessed consistently across populations and states.

Participants also discussed the need for better assessment of unmet need in the community and in particular, better ways to identify individuals in need of HCBS. One example would involve allowing Medicaid HCBS waiver programs to serve people with lower levels of functional disability than those required for people in nursing homes. By allowing states to have different functional criteria for institutional services as compared to

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[11] Ibid.
[12] Charlene Harrington et. al, Medicaid Home and Community-based Services: Data Update, Kaiser Commission on Medicaid and the Uninsured, December 2008, http://www.kff.org/medicaid/7720.cfm
[13] Tonner MC, AJ LeBlanc, C Harrington, State Long-Term Care Screening and Assessment Programs, Home Health Care Serv Q 19(3):57-85.
[14] Judy Kasper, Barbara Lyons, Molly O'Malley, Long-Term Services and Supports: The Future Role and Challenges for Medicaid, Kaiser Commission on Medicaid and the Uninsured, September 2007.

HCBS, and to permit different criteria for individuals with greater HCBS needs than others, states could better target HCBS to people who are at earlier stages of the disabling process as a means to prevent or forestall institutionalization.

Equalizing access to HCBS with nursing home services and ensuring adequate community-based capacity were identified as important goals. While spending on Medicaid HCBS has been growing, more dollars still go towards institutional services. In 2007, spending on Medicaid long-term care services reached $112 billion, with spending on HCBS programs representing 43 percent of total Medicaid long-term care spending.[15] Spending patterns for Medicaid HCBS vary widely among states although demand for services continues to grow. Equalizing access to home and community-based services is one way to reduce the institutional bias in Medicaid and to help reduce state variation in spending for people who use long-term services and supports. Participants noted that in order to expand access to HCBS, states need to ensure community-based capacity and reduce geographical variation in availability of services and providers. In addition, attention by states to issues related to the closing of nursing home beds where there is excess capacity is warranted.

Participants agreed that the waiver process is cumbersome and that using an option could streamline the process and improve access to HCBS across population groups, albeit reduce state flexibility to target services. Historically, the focus of Medicaid long-term care services was on nursing home care but as the emphasis shifted to providing more services in the community, HCBS waivers have become the primary mechanism for expanding access to HCBS. The two other programs states use to provide Medicaid HCBS include the mandatory home health benefit and the optional personal care benefit. HCBS waivers allow states to waive specific requirements of the Medicaid program. For example, states are allowed to target specific population groups, limit the number of waiver slots, limit the program to selected geographical areas, limit services and provide services otherwise not covered by the Medicaid state plan. The 1915c program began with 8 waivers in 6 states in 1982 and by 2005 all states operated at least one bringing the total to 272 HCBS 1915c waivers. [16,17]

HCBS programs are fragmented into many different state programs and inequities in access exist within and across states with different financial eligibility and need determination requirements, assessment procedures, and program administration. As increasing access to Medicaid HCBS has become a priority, participants agreed that the process should be made simpler. Participants cited reduced administrative costs and improved access to services as reasons to pursue consolidation of 1915c waivers. One participant also mentioned that combining 1915c waivers across a state could improve data collection and evaluation of HCBS programs. Other participants noted states' reluctance to adopt a one-size-fits-all approach to waiver authority which is why more states have not

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[15] KCMU and Urban Institute analysis of CMS Form 64 data.
[16] Harrington, et. al., Home and Community-based Services: Public Policies to Improve Access, Costs and Quality, UCSF Center for Personal Assistance Services, January 2009.
[17] Arizona operates its long-term care program under a Section 1115 demonstration waiver.

taken up the HCBS 1915i option.[18] Given experience with waivers over time and the changing views on promoting access to HCBS instead of nursing home care, the 1915i option was developed to allow states to move beyond waiver options. Another reason more states have not taken up the 1915i option is because income eligibility (up to 150% FPL) is too low for most beneficiaries to live in the community. The Empowered at Home Act (S. 434), would allow states to set income eligibility criteria for HCBS up to 300 percent of SSI under the 1915i option. Some stakeholders felt the 1915i option, even in its current form, provides a viable opportunity for certain populations, particularly for adults with mental illness. Policy changes regarding the 1915i option that would benefit people with mental illness transitioning to the community include equalizing the income level for eligibility with 1915c waivers and allowing for coverage of all of the same services as the waivers such as rehabilitation and skills training to assist people with mental illness in the process of securing independent housing.

Meeting participants discussed that case management is an essential component to ensuring successful transition to the community and continued community residence. Medicaid currently covers a broad range of long-term services and supports ranging from mandatory nursing home and home health benefits to optional services and supports needed by people to live independently in the community such as personal care, durable medical equipment, rehab, adult day care, case management, transportation, and respite services for caregivers. In addition, home and community-based waiver services can cover a broader range of non-medical long-term services and supports. As states have taken major steps to shift the delivery of long-term services and supports toward more community-based settings through nursing home diversion and transition programs, the importance of case management services has grown.[19] Medicaid policy allows states to provide case management and targeted case management services to assist in the transition of a Medicaid beneficiary from an institution to the community. Participants noted that the role of a case manager is to assist the beneficiary in gaining access to and coordinating delivery of necessary medical, social and educational care, as well as other services to meet their needs. Maintaining case management services as part of the broader Medicaid benefit package is an essential component to expanding access to HCBS.

Working group participants also stated that difficulty securing community housing was a barrier to serving more Medicaid beneficiaries with long-term care needs in the community. They noted that attention to housing and other supportive services such as home modifications is important to ensure safe, successful transitions from nursing homes and hospitals back to the community.

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[18] The DRA of 2005 gave states a new option (1915i) to provide home-and-community based services rather than through a 1915c waiver. To-date only two states (Colorado and Iowa) have reported taking up this option. The program is only available to those who are already eligible for Medicaid and whose income does not exceed 150% of the federal poverty level (FPL). In contrast, the home and community based 1915c waiver allows states to include individuals with incomes up to 300% of SSI.
[19] Molly O'Malley Watts, Money Follows the Person: An Early Implementation Snapshot, June 2009, http://www.kff.org/medicaid/7928.cfm

Attention should be given to improving access to Medicaid HCBS as part of a strategy to improve care delivery under Medicaid and Medicare for dual eligibles. Nearly 9 million of the poorest, sickest and highest cost people are covered by both Medicaid and Medicare. Today, Medicare pays primarily for acute care services, while Medicaid pays for Medicare premiums and cost sharing and additional services not covered by Medicare, such as long-term care. Although dual eligibles account for only 18 percent of Medicaid enrollment and 20 percent of Medicare enrollment, they account for a disproportionate share of spending in both programs. Nearly half (46%) of all Medicaid expenditures and 28 percent of Medicare spending were made on their behalf in 2005.[20] Dual eligibles rely heavily on Medicaid long-term services and supports and further attention to coordination across the two programs is warranted to ensure greater access to Medicaid HCBS across states, improve quality and contain costs.

A number of integrated models, including PACE programs, state Medicaid waivers and Medicare Special Needs Plans, have developed to bridge the two systems of care in which dual eligibles participate. For example, several states have used Medicaid waivers to provide more integrated and coordinated care for dual eligibles but this approach has been challenging because CMS has not allowed states to count Medicare savings toward "budget neutrality" on waiver reforms. Participants agreed that care delivery could be enhanced by permitting Medicare savings to be shared with Medicaid and/or by improving the coordination of Medicare and Medicaid services.[21] One example would be to expand the medical home model to include a long-term care component as a way to better manage delivery of care for dual eligibles. Recent health reform proposals have emphasized chronic care management and better primary care management. States have tried to better integrate services for duals but further efforts to demonstrate effective ways to serve dual eligibles under Medicaid and Medicare and evaluation of these efforts is needed.

In order for more individuals to be served in home and community-based settings, greater attention to workforce development is necessary. While more than one million formal caregivers provided paid services in the home in 2007, there are continued shortages of HCBS workers, and the demand for formal home care workers is projected to increase in the coming years.[22] Today the shortage of workers varies by geographical regions and types of settings. Efforts to improve the quality of care being delivered in community-based settings and the stability of the workforce could focus on training and recruiting, increasing wages and providing access to benefits such as health insurance and workers compensation. Wages, benefits and training are key issues that influence a worker's decision to continue in a position as a community-based direct care worker.[23]

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[20] KCMU and Urban Institute estimates based on data from MSIS and CMS Form 64. Medicare data from Kaiser Family Foundation analysis of the CMS Medicare Current Beneficiary Survey Cost and Use file, 2005.
[21] Barbara Lyons and Molly O'Malley Watts, Health Reform Opportunities: Improving Policy for Dual Eligibles, KCMU, August 2009.
[22] Harrington, et. al., Home and Community-based Services: Public Policies to Improve Access, Costs and Quality, UCSF Center for Personal Assistance Services, January 2009.
[23] Henry Claypool and Molly O'Malley, Consumer Direction of Personal Assistance in Medicaid: A Review of Four State Programs, Kaiser Commission on Medicaid and the Uninsured, March 2008, http://www.kff.org/medicaid/7757.cfm

Several participants also suggested that CMS could do more to work with and incentivize the states to build their long-term care workforce.

Most people living in the community with long-term services needs rely on help from friends and family. The majority (85%) of total hours of care received by people living at home with long-term care needs are unpaid.[24] Potential investments in workforce development include additional support for caregivers in the form of training or added respite services. The Retooling the Health Care Workforce for an Aging America Act (H.R. 468 and S. 245) introduces several provisions to provide training for direct care workers and family caregivers.

Participants called for greater information sharing and data tracking between CMS and the states. They believed the added value of gathering information on best practices and state innovations would help states learn to manage their long-term care programs more effectively and efficiently. This could also lead to better integration and coordination especially for high needs populations, potentially resulting in cost savings for all payers. Participants discussed the need for more data reporting and evaluation requirements in order to demonstrate cost effective experience in providing HCBS as compared to nursing home care, for example. Greater administrative funds may be required to achieve better data collection and evaluation.

Conclusion

Expanding access to Medicaid HCBS would enable more people to be served in their setting of choice and potentially reduce costs by serving fewer people in institutional settings. In a challenging resource environment, states may look to the federal government to help further shift the balance of Medicaid long-term care delivery systems toward home and community-based settings. Additional federal financial support, coupled with other policy improvements discussed in this report, would give states a strong incentive to further expand HCBS and could lead to reduced state-by-state variation in eligibility and services. Working group participants indicated that despite the array of ongoing challenges facing state Medicaid programs today, there is a commitment to expanding HCBS and to improving the options available for the low-income elderly and individuals with disabilities in need of Medicaid long-term services and supports.

This brief was prepared by Molly O'Malley Watts, Kaiser Commission on Medicaid and the Uninsured, Kaiser Family Foundation.

[24] Mitchell P. LaPlante, Charlene Harrington, and Taewoon Kang, Estimating Paid and Unpaid Hours of Personal Assistance Services in Activities of Daily Living Provided to Adults Living at Home, *Health Services Research* 37, no. 2 (2002):397-415.

1330 G Street NW, Washington, DC 20005
Phone: (202) 347-5270, *Fax:* (202) 347-5274
Website: www.kff.org/KCMU

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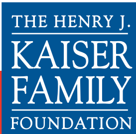

The Kaiser Commission on Medicaid and the Uninsured provides information and analysis on health care coverage and access for the low-income population, with a special focus on Medicaid's role and coverage of the uninsured. Begun in 1991 and based in the Kaiser Family Foundation's Washington, DC office,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