Trends

Medicaid Home And Community-Based Services: National Program Trends

Some states may lack the capacity to respond effectively to the rising demand for home and community-based services.

by Martin Kitchener, Terence Ng, Nancy Miller, and Charlene Harrington

ABSTRACT: Long-term care (LTC) policymakers face mounting pressures to expand Medicaid home and community-based services while the cost of institutional provision continues to rise and consume the bulk of Medicaid LTC spending. This paper presents the latest program trends in the three Medicaid home and community-based services programs (waivers, home health, and state-plan personal care) and reports a national survey of cost control policies used on waiver programs in 2002. The findings show slowing annual rates of participation growth on individual programs, widespread use of cost controls on waivers including waiting lists, and the persistence of large interstate variations in Medicaid’s provision of these services.

IN 2001 Medicaid was the second-largest budget item for most states and paid for 44 percent of the nation’s estimated $132 billion in long-term care (LTC) spending. While institutional care consumes 70 percent of Medicaid LTC spending, public demand and the 1999 Olmstead Supreme Court decision require that states expand alternative home and community-based service programs.

With forty-three states reporting budget deficits in 2003, the current National Governors’ Association (NGA) LTC initiative reflects growing concern about Medicaid LTC and the need for information on trends in home and community-based service programs.

In this paper we extend existing knowledge of Medicaid home and community-based program spending and participation in two ways. First, we draw from the most recent and comprehensive available data set (2001) to present national program trends for the three Medicaid home and community-based programs (waivers, state-plan personal care, and home health) and for total Medicaid home and community-based services. Second, we report findings from a national survey of cost control policies used on waiver programs in 2002.

The Programs

The only two mandated Medicaid LTC benefits are institutional care and home health services for participants eligible for institutional care. However, Medicaid regulations allow states to use combinations of three programs to provide home and community-based services either directly or through a variety of contractual arrangements: Section 1915(c) waivers, state-plan personal care services

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Waivers. Since 1981, states have used authority under Section 1915(c) of the Social Security Act to request a waiver of certain federal Medicaid requirements (including statewide program coverage) to establish home and community-based waiver programs. These programs attract federal-match funds and allow states to provide a wide range of services to participants who would otherwise be in an institution, including optional Medicaid benefits (such as personal assistance) and services not otherwise authorized by federal Medicaid statute (such as home modifications).6

In addition to the federal-match funding and service flexibility that these waivers provide to states, the program also allows states to control costs in four ways.7 First, states must demonstrate, for each waiver, that Medicaid per participant costs are no greater than per participant costs for institutional care at the comparable level of care (such as in a nursing home). Second, states are required to limit the number of available “slots” on each waiver. Third, states have discretion to set medical and financial eligibility criteria for waivers and to cap spending on the services provided. Fourth, states may limit waiver programs to certain geographical areas (for example, a county) and population groups (for example, those who are mentally retarded and developmentally disabled [MR/DD] and those with traumatic brain injury/spinal cord injury [TBI/SCI]). Although few studies have examined waiver programs by target group, MR/DD waivers are known to be the most numerous and among the most costly (in part because of high levels of need for care).8

Personal care services. Since 1975, states have had the option of offering personal care services as a Medicaid benefit.9 States have considerable discretion in defining these services, but programs typically involve non-medical assistance with activities of daily living (ADLs) for participants with disabilities and chronic conditions. Unlike waivers, the PCS benefit must be available to all categorically eligible groups, but states can opt to include the medically needy (those who spend down to the state standard for medical care).10 Although few studies have examined PCS programs, states are known to vary in the amount and scope of services provided (for example, only some states provide these services outside the participant’s residence).11

Home health. For Medicaid participants other than those eligible for institutional care, Medicaid home health nursing services are optional. States can vary the amount, scope, and duration of benefits offered, as long as they remain sufficient to reasonably achieve their purpose and remain the same for all eligible groups.12 Although studies have reported falling use of Medicare home health services since the Balanced Budget Act (BBA) was passed in 1997, less is known about Medicaid home health nursing services or program trends.13

Study Design And Methods
This study conducted descriptive analyses of a data set compiled from four main sources: (1) the Centers for Medicaid and Medicare Services (CMS) Form 372 waiver reports, (2) the authors’ national surveys of PCS and home health programs, (3) CMS Form 64 spending data for Medicaid home health and personal care services, and (4) the authors’ national survey of waiver policies.14

CMS Form 372. Since 1994 the authors have collected annually from state officials the CMS Form 372 that reports unduplicated participant and spending data for each waiver program. Data requests through April 2004 (using e-mail, fax, telephone, or some combination) produced all but one of the 218 reports for 1999, all but one of the 227 reports for 2000, and all but six of the 231 reports for 2001. For missing reports, figures were estimated using linear interpolation from previous years’ data.

Annual surveys of PCS and home health programs. Since 2000 the authors have surveyed state officials annually to collect unduplicated participant and spending data for all Medicaid PCS and home health programs. Data requests through April 2004 (using e-mail, fax, or telephone) produced Medicaid home health program data from fifty states.
for 1999, forty-seven states for 2000, and forty-six states for 2001 ($N = 51$, including the District of Columbia), and PCS program data from all twenty-eight participating states for 1999, all but one of the twenty-nine states for 2000, and all but two of the twenty-nine states for 2001. Because state officials were unable to report home health and PCS program data for earlier years, we use CMS Form 64 spending figures reported by Medstat (no accurate prior-year data exist for PCS and home health program participants).15

Waiver policy survey. In the spring of 2003 the authors surveyed state officials responsible for each waiver to examine policies, including cost controls such as waiting lists, in 2002. Through April 2004, requests (using e-mail, fax, or telephone) produced responses from 224 of the 231 waivers reported in 2001.

Study Results

Growth in Medicaid home and community-based programs, 1992–2001. The number of Medicaid home and community-based programs and most of their participants, spending, and inflation-adjusted spending grew during this period (Exhibit 1). The addition of seventy-six waivers over the decade ensured that the program became the largest in terms of both spending (nearly 60 percent of total Medicaid home and community-based services) and participants (40 percent). In contrast, between 1999 and 2001 the number of states offering personal care services as a Medicaid state-plan-optional benefit increased by only one (New Mexico). Although Delaware and Rhode Island offered the PCS benefit in 2001, both states reported zero spending and recipients.

Growth in Medicaid home and community-based service participation during the 1990s was driven by the 258 percent increase in waiver participants, a trend that continued in 2001 with a 10 percent increase. Although participation in the home health program witnessed near-flat annual growth over much of 1999–2001, national participation in the PCS program fell by 0.4 percent in 2001.

Despite the fact that the annual growth rate in total Medicaid home and community-based service participants fell from 6 percent in 2000 to 4 percent in 2001, annual spending on each program continued to increase, typically above the general rate of inflation. Moreover, the 12.5 percent growth in waiver spending fueled 13 percent growth in total Medicaid home and community-based services spending in 2001.

Standardized program participation and spending trends, 1999–2001. Controlling for population dynamics, participation growth in the largest program (waivers) ensured that the rate of total Medicaid home and community-based program participation continued to rise steadily through 2001 (Exhibit 2). Within this broader trend, in 2001 annual home health participation rose slightly, but national PCS participation fell.

Between 1999 and 2001, inflation-adjusted spending per participant grew for home health, state-plan personal care, and total Medicaid home and community-based services. However, it did not keep pace with rapid expansion in the program (Exhibit 2).

Waiver program data by target group, 2001. Reflecting the discretion allowed to states under Medicaid regulations, the national total of 231 waivers reported in 2001 was targeted toward population groups as follows: aged and disabled, 94; MR/DD, 76; others (including children), 41; and TBI/SCI, 20. While MR/DD participants (39 percent of the total) consumed nearly 75 percent of total waiver spending, aged and disabled participants (58 percent of the total) received only 24 percent of total expenditures (Exhibit 3).16

Interstate variation. In 2001 there remained dramatic state-to-state variations in standardized measures of total Medicaid home and community-based program participation and spending. The national average was 7.47 participants per 1,000 state residents; Minnesota’s rate (19.91) was almost twenty times higher than Tennessee’s (0.96).17 In terms of spending per participant, the national average was $10,333; Tennessee’s spending ($37,668) was almost twelve times higher than that of neighboring Mississippi ($3,283).

Waiver cost control policies. Ninety-
seven of the 224 waiver programs responding to our policy survey (43 percent) reported the use of discretionary financial caps in 2002. Fifty programs specified a maximum annual dollar amount per participant ($7,451–$108,000), twenty-eight used a cap on average annual participant costs across the program ($5,340–$217,000), and nineteen reported a variety of other methods. Among the 224 responding waivers, 87 (across 36 states) reported total waiting lists of 157,312 people in 2002: 76,804 people were waiting for elderly services; 67,683 were waiting for MR/DD services; and the length of reported lists ranged

<table>
<thead>
<tr>
<th>EXHIBIT 1</th>
<th>National Medicaid Home And Community-Based Services Summary Program Trends, 1992–2001</th>
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</thead>
<tbody>
<tr>
<td>Waivers</td>
<td></td>
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<tr>
<td>Programs</td>
<td>155</td>
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<tr>
<td>Participants</td>
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<td>Home health</td>
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<td>State-plan PCS</td>
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<td>CPI-adjusted spending (millions of dollars)</td>
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</tbody>
</table>

**SOURCES:** See below.

**NOTES:** All states except AZ operate 1915(c) waivers. AZ operates an 1115 waiver and reports Medicaid home health program data. Consumer Price Index (CPI)-adjusted spending reported in constant 2001 dollars.

2 Estimated data, 1 PA waiver.
3 Estimated data, 1 AR waiver.
4 Estimated data, waivers by state: CA 2, NH 1, NY 1, PA 1, SC 1.
6 Data not available.
7 Estimated data, TN.
8 Estimated data, AL, MT, TN, TX.
9 Estimated data, ND, NH, OR, TN, TX.
10 Estimated data, MT.
11 Estimated data, ID, NH.
from 2 people to 47,014. The national average time spent on waiting lists was four months, with the longest reported time being sixty months.

Discussion And Conclusions

With LTC policymakers facing the challenges of budget deficits, Medicaid institutional LTC spending growth of 9 percent in 2001 to $49.5 billion, and pressures to expand Medicaid home and community-based programs, it is increasingly important to track program and policy trends. This study drew from the most recent and comprehensive available data set to report four main findings.

First, the 21 percent increase in national waiver participation during 1999–2001 fueled continued growth in total Medicaid home and community-based service spending and participants. Perhaps not surprisingly, however, inflation-adjusted average national waiver spending per participant did not keep pace; it fell 3 percent between 1999 and 2001.

Second, this study indicates that some states may be restricting access to waivers through the use of policies such as spending caps and waiting lists. Given the budget deficits reported by forty-three states in 2003, the extension of such cost control policies can reasonably be anticipated. Taken together, these first two findings suggest that it was likely that the twin appeals of federal-match funding and the cost control features of the waiver program underpinned its relative appeal to states, as evidenced by much faster growth of waiver participation compared with Medicaid home service spending.
health and PCS programs.

Third, and in contrast to the waiver program, inflation-adjusted spending per participant continued to grow through 2001 for the home health and PCS programs. That said, in 2001 national PCS participation fell despite the development of a new PCS program in New Mexico. Targeted research is required to determine whether or not the “lost” PCS participants are now being served in other programs.

Fourth, our analysis highlights the persistence of large interstate variations in participation and spending in the individual home and community-based programs and in total Medicaid home and community-based services. Because variations in participation may reflect access issues, this theme warrants focused attention to complement analyses of home and community-based service spending and service quality.20 These pressures are likely to increase with developments including litigation against states following the Olmstead decision and the president’s New Freedom Initiative, which includes the goal of moving institutionalized people into home and community-based settings.21 Findings from this study indicate that in the current climate of state budget deficits and rising Medicaid institutional LTC spending, some states may lack the capacity to respond effectively to these pressures.

CONTINUED MONITORING of the trends reported in this paper is needed, to assist policymakers as they seek to address unmet need and rising consumer demand for home and community-based services.20 This research was funded in part by the Kaiser Commission on Medicaid and the Uninsured (Grant no. 00-1355C) and the National Institute on Disability and Rehabilitation Research (Grant nos. H133B031102 and CG0207A). The views expressed in the paper are those of the authors and do not necessarily reflect those of the sponsors.
NOTES


11. LeBlanc et al., “State Medicaid Programs.”


14. Each survey uses a separate, standard instrument; copies are available from Martin Kitchener, martink@itsa.ucsf.edu. All data are coded using standard protocols and entered into an SPSS data set for analysis. Although most programs and states report data by federal fiscal year, some report by calendar or state fiscal year. For simplicity in this analysis of national trends, all data are reported by “year.”

15. Eiken and Burwell, Medicaid HCBS Waiver Expenditures.

16. A single target-group code is assigned to each waiver with reference to information sources, including CMS waiver application documents, waiver titles, and state officials. The aged and disabled target group includes 448,916 aged/disabled participants (spending of $2.8 billion) plus 98,854 disabled/physically disabled participants ($520 million).

17. Complete findings by state are available as Supplemental Exhibit 1 on the Health Affairs Web site, content.healthaffairs.org/cgi/content/full/hlthaff/24/1/206/DC1.

18. Eiken and Burwell, Medicaid HCBS Waiver Expenditures.

19. Institute of Medicine, Improving the Quality of Care of Long-Term Care (Washington: National Academies Press, 2001).
