Rebalancing Medicaid Long-Term Services And Supports. Shifting away from primarily financing institutional care, Medicaid is supporting more flexible community-based long-term services and supports.

WHAT’S THE ISSUE?

Twenty-five years after the passage of the Americans with Disabilities Act (ADA), the Medicaid program is also marking an important milestone in system transformation in 2015. The national profile of Medicaid long-term services and supports (LTSS) expenditures has shifted away from primary dependence on institutional care. In 2013 the majority of Medicaid LTSS spending was for the first time focused on home and community-based settings instead of institutional care, and the Centers for Medicare and Medicaid Services (CMS) projects that community-based spending will reach 63 percent of all Medicaid LTSS spending by 2020. However, the fundamental structure of the Medicaid statute continues to promote an “institutional bias” that strongly limits the potential for true balance for beneficiaries.

Since enactment of the ADA on July 26, 1990, there has been a concerted effort at the state, federal, and community levels to transform one of the Medicaid program’s primary roles as an institutional care-focused financing mechanism into a comprehensive and flexible community-based long-term services and supports program. The most obvious testament to this shift is the strong upward trend in Medicaid spending on community-based care options—between 1995 and 2013, Medicaid home and community-based services (HCBS) expenditures increased from 18.0 percent of total Medicaid LTSS spending to 51.3 percent (see Exhibit 1). Medicaid spending on LTSS totaled $146 billion in 2013, representing a 7.6 percent increase in spending on HCBS and a 0.7 percent decrease in spending for institutional services since 2012.

Medicaid’s focus on home and community-based LTSS actually predates the ADA. The movement began with a young girl named Katie Beckett, whose mother successfully advocated that providing the ventilator support and other services that Katie needed at home, instead of in the hospital, would be a more humane and cost-effective approach to caring for her. Medicaid HCBS waivers, giving states the option to provide LTSS in home and community-based settings as an alternative to institutional care, were authorized in 1981 under section 1915(c) of the Social Security Act. Because HCBS waivers can be designed to target specialized services to specific populations, in 2015 there are more than 330 HCBS waivers in operation in forty-seven states and the District of Columbia. While waiver programs today serve a relatively small proportion of Medicaid beneficiaries, they continue...
to represent more than half of HCBS spending, even as new state plan and waiver options have become available.

Congress has provided new options and incentives for states to develop noninstitutional service options for Medicaid beneficiaries, most significantly through the Affordable Care Act (ACA), providing support for the effort to “rebalance” service options in long-term care. However, state progress in providing choice of home and community-based alternatives to institutional care has been uneven, and expenditures for certain population groups continue to be largely institutionally based.

The experience for the elderly is significantly different than for individuals with disabilities younger than age sixty-five. In 2010, 71 percent of national LTSS expenditures for elderly Medicaid beneficiaries was for institutionally based services, compared to only 35 percent of institutional LTSS spending for younger beneficiaries. The prevalence of HCBS also varies by population type: In 2013 HCBS accounted for 72 percent of spending in programs targeting people with developmental disabilities, 40 percent of spending in programs targeting older people or people with physical disabilities, and 36 percent of spending in programs focused on people with serious mental illness or serious emotional disturbance.

In addition, there is substantial variation in how states spend their long-term care dollars—the proportion of HCBS versus institutional care expenditures ranges from 25.5 percent of total LTSS spending in Mississippi to 78.9 percent in Oregon. Twenty-six states report less than 50 percent of spending on HCBS, and twenty-two states and the District of Columbia spend more than 50 percent of LTSS on community-based care (not all states reporting [see Exhibit 2]). While it is worth noting that Mississippi has made significant progress in recent years, the wide state-by-state variation indicates that beneficiaries’ experience with long-term care is strongly influenced by where they live.

There are important structural differences within the Medicaid program that may affect the speed of reform for certain populations. For example, nursing facility services are mandatory under federal Medicaid law, while institutional services for people with intellectual or developmental disabilities, a typically younger population, are an optional service. This may give states more flexibility in system design for younger populations. In addition, the section 1915(c) waivers, used by most states to create Medicaid HCBS, require HCBS to be “cost effective” when compared to the institutional alternative. The relatively higher cost of institutional services for younger populations, especially those with intellectual or developmental disabilities, may result in more options for HCBS being viewed as cost-effective alternatives to institutional care for this population.

A more fundamental challenge to supporting consumer choice of HCBS is that Medicaid reimburses the costs of room and board only for individuals residing in specific institutional settings (that is, hospitals, nursing facilities, and intermediate care facilities...
for people with intellectual or developmental disabilities). Support for room and board is specifically excluded under the section 1915 authorities that provide access to HCBS. States report that securing affordable and accessible housing remains a major barrier to broader use of HCBS.

Finally, the wide variation in the design of HCBS as they have evolved across hundreds of state waivers has raised concern that these alternatives may not always be as effective as they could be in supporting full integration into the broader community for individuals with disabilities. CMS enacted final HCBS regulations in January 2015 that, for the first time, attempt to create a national standard regarding the characteristics of home and community-based care settings and to clarify the components of the person-centered planning that is the hallmark of effective community-based care.

**WHAT’S THE BACKGROUND?**

It is estimated that as many as two-thirds of individuals older than age sixty-five today will need some form of long-term care for up to three years of their lives.

There is national consensus that the vast majority of seniors and people with disabilities would strongly prefer to remain in their homes or in a community-based setting where they can retain their independence and their ability to engage in community life. In addition, research over the years has demonstrated that community-based care can be less costly than institutional care. For example, according to a recent report, in California spending on nursing home care per person was three times higher than for HCBS—$32,406 for nursing facility care versus $9,129 for HCBS in 2008. As a result, many states have shown a strong commitment to developing a robust home and community-based system of LTSS, with states such as Oregon, Minnesota, Alaska, Vermont, and Arizona leading the way in both fee-for-service and managed care delivery systems in which 68–78 percent of all LTSS expenditures are in community settings.

The courts have also played a critical role in accelerating the trend toward self-determination. In 1999 Olmstead v. L.C. was brought to the US Supreme Court in a challenge to Medicaid’s institutional bias. The case was filed by the Atlanta Legal Aid Society on behalf of two developmentally disabled women who had been voluntarily admitted to a locked psychiatric unit at Georgia Regional Hospital, then were required to remain in the unit even after being cleared for community placement by health care professionals after each requested transfer from the hospital to a community-based program.

In what is now the landmark “Olmstead decision,” the Court ruled that unnecessary institutionalization of individuals with disabilities was a violation of Title II of the ADA, and that states are obligated to provide integrated community-based services to people with disabilities to the fullest extent possible. The Court instructed state and local governments to make reasonable modifications to

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**EXHIBIT 2**

States with the Greatest Increase in Medicaid Home and Community-Based Services (HCBS) Expenditures as a Percentage of Total Medicaid Long-Term Services and Supports Expenditures, FY 2011–13

<table>
<thead>
<tr>
<th>State</th>
<th>2011 Increase</th>
<th>2013 Increase</th>
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<tbody>
<tr>
<td>Missouri</td>
<td>11.4%</td>
<td>9.0%</td>
</tr>
<tr>
<td>New Hampshire</td>
<td>6.9%</td>
<td>6.5%</td>
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<tr>
<td>Iowa</td>
<td>6.0%</td>
<td>6.0%</td>
</tr>
<tr>
<td>District of Columbia</td>
<td>5.7%</td>
<td>5.1%</td>
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<tr>
<td>New York</td>
<td>5.0%</td>
<td>4.6%</td>
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<td>Ohio</td>
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<td>Pennsylvania</td>
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<td>New Jersey</td>
<td>4.6%</td>
<td>4.6%</td>
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**Source:** “Medicaid Expenditures for Long-Term Services and Supports in FFY 2013,” Truven Health Analytics, June 30, 2015, page 9.
“In 2013 the majority of Medicaid LTSS spending was for the first time focused on home and community-based settings instead of institutional care.”

current policies, practices, and procedures to accommodate individuals with disabilities. Subsequent federal court rulings have further defined the reach of the Olmstead decision to all disabled populations within the community, not just to people who are currently institutionalized. The Olmstead decision was for many states the beginning of more sweeping efforts to “rebalance” LTSS systems to respond to consumer demand for noninstitutional options. As noted above, states have played a significant leadership role in shifting the balance toward community-based care options.

Congress has also supported further development of HCBS under Medicaid. Most recently, the ACA included a number of provisions designed to strengthen the expansion of community-based care options. Through the extension of the Money Follows the Person initiative and the creation of the Balancing Incentive Program, the federal government is providing resources and financial incentives for states to rebuild their long-term care infrastructures to adequately support access to HCBS. In particular, the Money Follows the Person initiative is designed to support states in transitioning individuals from institutions into community-based programs while building more effective community-based care. It has been a popular initiative, with forty-four states and the District of Columbia participating. The ACA extended the availability of the grants through 2016.

The Balancing Incentive Program (authorized for grant years 2012–15) targets an enhanced federal matching rate across all Medicaid HCBS expenditures for states that are still spending less than 25 percent (5 percent enhanced match) or less than 50 percent (2 percent enhanced match) of all LTSS expenditures in home and community-based care settings, providing additional resources for structural reforms and HCBS expansion. As a requirement for participation, states must commit to creating a “No Wrong Door Single Entry Point” system for individuals seeking LTSS, where individuals can gain access to the information and services they need regardless of how and where they present for care, and regardless of payer source. The goal is for states to provide access to conflict-free case management services and develop a core standardized assessment instrument as components of their plans for system redesign.

The ACA also provided new HCBS design options, permitting states to add HCBS programs to their regular Medicaid state plans, instead of requesting time-limited waiver authority. The Community First Choice state plan option [a new section 1915(k)] includes a 6 percent enhanced federal matching rate for states to provide a community attendant and other support services to individuals who would otherwise require institutional services. The program must be offered statewide with no artificial caps on enrollment. However, it is available only to individuals who meet an institutional level of care need and who are otherwise eligible for Medicaid under a state’s eligibility standards. Service plans are determined based upon a required face-to-face assessment of the individual by a qualified provider using person-centered planning and must involve the beneficiary or his or her authorized representative to the fullest extent possible.

The ACA also improved upon the 1915(i) Medicaid State Plan Option for providing HCBS, which was initially enacted in 2006 and provided an option for states to provide HCBS to individuals not yet at an institutional level of care. The ACA eliminated the use of waiting lists and caps on enrollment, giving states the option to include all services available under 1915(c) waiver authority directly within the state plan and permitting states to target 1915(i) programs to serve specific populations. States also now have the option under 1915(i) to offer HCBS through the Medicaid state plan to individuals with higher incomes (up to 300 percent of the Supplemental Security Income federal benefit rate), even if those individuals are not yet enrolled or currently receiving services. Section 1915(i) has proven especially useful for states seeking options for community-based supports for individuals with serious mental illness, who are difficult to reach under section 1915(c) waivers because of the statutory exclusion of Medicaid payment for individuals who are patients in institutions for mental disease.

The ACA also provided a long-sought opportunity for states to develop a more integrated approach to providing services to individuals who are eligible for both Medicaid and Medicare, a population that represents a major component of all LTSS expenditures for Medicaid. Through the creation of the CMS Center for Medicare and Medicaid Innovation, also known as the Innovation Center, and the Medicare-Medicaid Coordination Office, the law enabled CMS to provide funding and demonstration authority to pilot new models for states to deliver integrated services for dual-
eligible beneficiaries. A dozen demonstration programs have been authorized, with states offering models that integrate services across primary, acute, behavioral health, and LTSS. These models provide the opportunity to enhance access to community-based LTSS, as well as to reduce unnecessary hospitalization and readmissions through improved linkages between (Medicaid-funded) community-based and (Medicare-funded) medical services.

**WHAT’S THE DEBATE?**

While the strong national trend is toward dominance of community-based services, the persistent differences across states and population groups raise important systemic and policy issues. The first is whether there is a “correct” balance between expenditures in home and community versus institutional settings and whether those system expectations should vary by state, by age, or by other population characteristics.

The cause of the differences in the balance between Medicaid institutional and HCBS expenditures for LTSS is not entirely clear. The differences may reflect a less robust demand for HCBS by older adults when compared to the demand from younger populations, or perhaps differences in perception among state policy makers and advocates regarding the value of community integration for younger versus older populations, or for individuals who have intellectual or developmental disabilities versus other forms of disability. State officials often report that the political power of the nursing home industry can slow the development of a more HCBS-focused system for older populations, and states are not required to offer coverage for nursing facility services under Medicaid. In addition, while the Department of Justice reports numerous engagements across the majority of states in recent years, investigating, issuing findings, and even engaging in litigation and settlement negotiations regarding violations of the ADA, its work has largely focused on younger populations (for example, adults with mental illness, individuals with intellectual or developmental disabilities), instead of on older populations, where institutional services remain the norm. This suggests that the ADA has played a less important role in encouraging system reform for older populations to date.

In addition to the inherent institutional bias in federal Medicaid design discussed above, policies outside of Medicaid also influence how different populations use LTSS. For example, Medicare postacute care coverage and reimbursement policies create a pathway from hospital inpatient stays to nursing facilities for rehabilitation. Historically, short-term, Medicare-financed rehabilitation stays often turn into longer-term, custodial stays, which are not covered by Medicare. As a result, individuals who may not initially be Medicaid eligible often “spend down” to Medicaid eligibility after they have already lost their natural supports and even their housing arrangements in the community. The experience of states engaged in the dual-eligible demonstrations may help to further illuminate the issue of what is driving the different utilization patterns among the elderly.

Another important question is how an individual’s health and welfare can be assured in home and community-based settings. Institutional settings have long been required to meet Medicare conditions of participation and are subject to significant federal and state oversight, including regular inspections and certification, standardized data-reporting requirements, a national quality rating system, and a federally proscribed compliance process. This layer of regulation and oversight, created to assure the well-being of vulnerable populations, is often also cited by advocates as perpetuating an institutional atmosphere and threatening beneficiaries’ autonomy, self-direction, and community integration. In contrast, most oversight of HCBS is left to the discretion of individual states, with a level of federal oversight from CMS that focuses primarily on a state reporting on efforts to assure health and welfare.

With HCBS becoming the dominant approach to service delivery, the debate may grow over whether a more standardized, national framework for quality oversight is needed. While some stakeholders might welcome increased standardization, others will fear loss of independence and self-direction. Many advocates argue that quality of life should be a key consideration in assessing the quality of LTSS, regardless of setting.

CMS appears to be endorsing this approach, proposing in the recently published [Medicaid and CHIP Managed Care Notice of Proposed Rule Making](https://www.cms.gov/Regulations-and-Guidance/Guidance/Notice-and-Guidance/Pages/ProposedRule.aspx?content=Medicaid CHIP%20Managed%20Care%20Notice%20of%20Proposed%20Rule%20Making.aspx) that states be required to include quality of life and progress toward community integration as part of performance standards used in managed LTSS arrangements. Under the National Quality Framework, CMS has initiated efforts to develop core measures of quality of care in home and community-based
LTSS, including development and testing of a consumer experience of care instrument, and the Department of Health and Human Services (HHS) has contracted with the National Quality Forum to develop consensus measures of quality for community LTSS.

Most significantly, with the enactment of the new final regulations and the creation of a HCBS toolkit regarding the characteristics of home and community-based settings and the use of person-centered planning in HCBS, CMS has called out the critical role that state Medicaid programs must play in actively promoting community integration for individuals with chronic and disabling conditions. This is causing debate and a reassessment of current services and settings nationwide, as CMS, states, providers, advocates, and consumers engage in negotiating and implementing transition plans designed to assure that state programs will achieve full compliance with the new national standards.

WHAT’S NEXT?

Passing the 50 percent mark for home and community-based services expenditures in Medicaid LTSS represents a level of success in achieving system rebalancing. However, it is clear that the current reform efforts in the nation’s system of LTSS are focused on a level of transformation that goes beyond the simple balancing of expenditures. CMS has raised the bar in terms of system performance by establishing national standards for the characteristics of home and community-based settings of care, emphasizing expectations for person-centered service planning and an obligation to support community integration, in addition to assuring safety, quality, and supervision.

States are also looking for increased accountability, “whole person” service integration, and improved cost controls through new service delivery arrangements that include health homes for individuals with multiple chronic conditions, value-based purchasing arrangements with providers, and capitated managed LTSS. This includes the critical engagement by both federal and state policy makers and stakeholders to improve service delivery and integration of physical, behavioral, and LTSS for dual eligibles in particular. By 2014 the number of states that had implemented some form of managed LTSS arrangements had grown to twenty-three, with additional states moving in this direction in 2015.

The percentage of LTSS provided through managed care organizations increased from 4 percent in FY 2008 to 10 percent in FY 2013, with significant additional growth expected in 2014. Many states adopting capitated managed care arrangements for LTSS expect to see further rebalancing as a result of improved integration of services and enhanced person-centered care management. The success of these efforts is likely to depend on states’ ability to effectively identify and monitor performance goals and to align financial incentives with those desired outcomes.

The role of Medicaid HCBS is increasingly being recognized as an important resource for achieving broader national goals. For example, efforts to end chronic homelessness and to improve treatment and recovery for individuals with mental illness or substance use disorders are focused on strategies to better link Medicaid-funded HCBS with affordable housing. The Department of Housing and Urban Development and HHS have partnered in recent years to improve cross-system collaborations, including redesign of the Section 811 housing program to require closer cooperation between state housing agencies and state Medicaid programs to serve disability populations.

CMS has issued Center for Medicaid and CHIP Services informational bulletins and other guidance to clarify for states how Medicaid services can be used to offer supported housing and supported employment to achieve more effective integration into a community for people living with chronic and disabling conditions. The dual-eligible demonstration initiatives offer an opportunity to better leverage Medicaid LTSS to improve the effectiveness of care across settings and achieve Medicare goals such as reducing preventable hospital readmissions.

This collective movement beyond a narrow focus on “rebalancing” expenditures is critical. The shift to community living must continue to move toward a refinement of expectations for transformation that will ultimately achieve the vision of consumer choice, person-centered services, and individuals able to live in the most integrated community setting.


MaryBeth Musumeci and Henry Claypool, *Olmstead’s Role in Community Integration for People with Disabilities under Medicaid: 15 Years after the Supreme Court’s Olmstead Decision* (Washington, DC: Kaiser Commission on Medicaid and the Uninsured, June 2014).
