



Medicaid-Financed Home and Community-Based Services Research / A Synthesis

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Executive Summary

Medicaid long-term care (LTC) spending is rising rapidly, consuming larger portions of Medicaid program outlays. Due to these cost pressures, policymakers are relying more heavily on home and community-based services (HCBS) over traditional institutional care, such as nursing homes, to reduce spending.

Medicaid LTC spending trends are projected to continue. From 2006 to 2014, the Centers for Medicare and Medicaid Services (CMS) projects total Medicaid spending to increase at an average annual rate of about 8.5 percent. The LTC population is projected to drive most of this growth.¹ To counter the trend, states and the federal government have sought to deliver these services in the most efficient manner, and for the past decade they have looked to HCBS as a strategy to slow Medicaid LTC expenditures.

Purpose

Over the years, it has been difficult to assess peer-reviewed research on HCBS program success in reducing total LTC costs, mainly because cost-effectiveness findings by the states have offered conflicting results. In this context, cost-effectiveness means that HCBS expansion produced no new costs for states. Understanding HCBS outcomes has been made even more difficult by the lack of information on states' HCBS quality assurance and improvement strategies, particularly as HCBS has expanded. These uncertainties are magnified by increasing Medicaid budget pressures. New Medicaid program options to expand HCBS services, authorized by the Deficit Reduction Act (DRA) of 2005 have also heightened state interest in HCBS options.

To inform policy discussions at the federal and state levels, the American Health Care Association (AHCA) commissioned Avalere Health to review and report on the most recent HCBS cost-effectiveness and quality research. The literature review was conducted during September and October 2006. The purpose of this report is to provide a balanced synthesis of what is known and what is not known about HCBS programs in the current body of peer-reviewed literature. The intent is not to present one LTC service option as superior or inferior to another.

Key Findings of the Literature Review

> Cost-Effectiveness Findings

Recent studies and most state-level work confirm older findings that the provision of HCBS does not reduce the overall growth of total LTC spending. Key cost-effectiveness findings include:

- **Spending patterns.** HCBS expansion has not stopped total LTC spending growth. Nursing home cost growth has slowed in some states. However, HCBS has grown significantly in all states. In many instances, HCBS growth has offset reduced spending on nursing homes.
- **Comparison deficiencies.** Many cost-effectiveness studies do not compare like populations and/or do not use a control group. Specifically, two researchers indicate that when study participants are allowed to choose a LTC service setting (i.e., nursing home or HCBS) they select the setting that will best meet their perceived needs and preferences. Such an approach introduces participant bias or preference, skewing findings and reducing the chances that researchers are comparing like populations.

- **Criteria for real LTC cost aversion.** HCBS has slowed total state LTC spending only when states implement: 1) strategies that ensure only populations at risk of nursing home or intermediate care facility for persons with mental retardation (ICF/MR) services receive HCBS (i.e., “substitution”); 2) HCBS expenditure controls (i.e., caps on waiver budgets or number of enrollees, service limits, individualized budgeting, person centered planning); and 3) global LTC budgeting practices. In the latter, states directly couple HCBS expansion with efforts to reduce facility-based spending.
- **Ongoing role for facility-based services.** Nursing homes will remain an important component of the LTC spectrum because some research indicates that certain resident traits and service needs differentiate nursing home populations from HCBS populations. People are more likely to be served in nursing homes if they have a cognitive impairment, Alzheimer’s, low activities of daily living (ADL) scores, low socio-economic status, and/or little or no source of informal care.
- **Small private ICF/MR vs. HCBS.** Recent national ICF/MR research reinforces earlier findings that cost differences between HCBS Medicaid waiver residential services and small private community-based ICFs/MR are difficult to assess. Furthermore, a 2006 report highlights a number of reasons that small private ICFs/MR “in the community costs” might be higher than HCBS waiver costs. However, some recent state research confirms other findings that HCBS is less costly than care in ICFs/MR. The research makes clear that HCBS is less costly than care provided in large publicly operated ICFs/MR.
- **Legislators and cost considerations.** The literature indicates that state and federal decision-makers are primarily focusing on HCBS for reasons other than reducing costs. High profile surveys of the public indicate a strong consumer preference for HCBS, and *Olmstead* litigation has made recognition of such preferences a policy priority. The literature also often references nursing home quality issues and related public concern as reasons policymakers are promoting HCBS.

The DRA provisions to expand HCBS services may render technical discussions of state budgetary cost-effectiveness less relevant than they were in previous policy debates. The new DRA state plan options do not require states to prove to CMS that HCBS waiver services cost the same or less than institutional services. Historically, states primarily have used Section 1915(c) or Section 1115 waivers to deliver HCBS; under these authorities, states must document Medicaid cost savings or budget neutrality to the federal government. However, cost-effectiveness will remain a concern for states and the federal government; virtually all states must balance their budgets on an annual basis and deficit reduction is an increasing imperative for federal policymakers.

> Quality Findings

Nursing homes and HCBS programs, state plan or Medicaid waiver, are governed by separate quality requirements. Nursing homes are responsible for meeting federally mandated quality requirements as well as statewide Medicaid provider participation rules. HCBS program quality approaches vary state-by-state and, within a state, by population (i.e., aged, persons with disabilities) and by HCBS program. Key quality findings from the literature include:

- **HCBS data lacking.** There remains a significant lack of information on HCBS quality, unlike nursing homes, which have many federal and state reporting requirements. Additionally, unlike nursing homes, there is no national HCBS quality dataset or system. Lacking complete information on LTC service options, consumers and

families often base their preference for HCBS over facility-based services because of concerns about the loss of privacy and personal preferences for tailored home-like environments.

- **HCBS and nursing home innovations respond to consumer preferences.** Both HCBS and nursing facility providers have made consumer preferences a priority in improving service delivery, focusing on consumers preferences for when, where, how, and by whom services are delivered. To date, researchers have focused on the impact of HCBS providers' efforts; however, little information is known about the impact of facility-based service approaches that focus on resident preferences, such as culture change initiatives. (Nursing home culture change efforts focus on improving resident experiences by improving workplace conditions and developing resident-driven plans of care.)
- **Comparisons uneven.** Nursing home and HCBS quality measurement systems are inherently different. Nursing homes have national and statewide quality assurance requirements that are outlined in federal and state regulations, whereas HCBS do not. CMS's HCBS Quality Framework provides broad guidance for states but does not mandate a uniform dataset or reporting system. States use a wide variety of quality definitions and measures. Interstate – and even within states – HCBS program comparisons are virtually impossible because of variations in state HCBS quality strategies.
- **CMS changes.** Previous research and CMS evaluations on HCBS waivers for persons with mental retardation and related developmental disabilities (MR/DD) identified serious quality issues including increased mortality. State examples include California, Illinois, and Oregon. However, since these findings in the late 1990s, CMS has initiated three important changes: 1) release of the HCBS Quality Framework; 2) award of a HCBS waiver quality technical assistance contract to the Human Services Research Institute (HSRI); and 3) the addition of a required quality assurance and measurement strategy in Section 1915(c) waiver applications and renewals. While one study documented improvements in HCBS waiver quality efforts on behalf of persons with MR/DD, as with waivers and other HCBS programs targeted to seniors and other types of disabilities, very little peer-reviewed information is available on HCBS program quality.

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Methodology

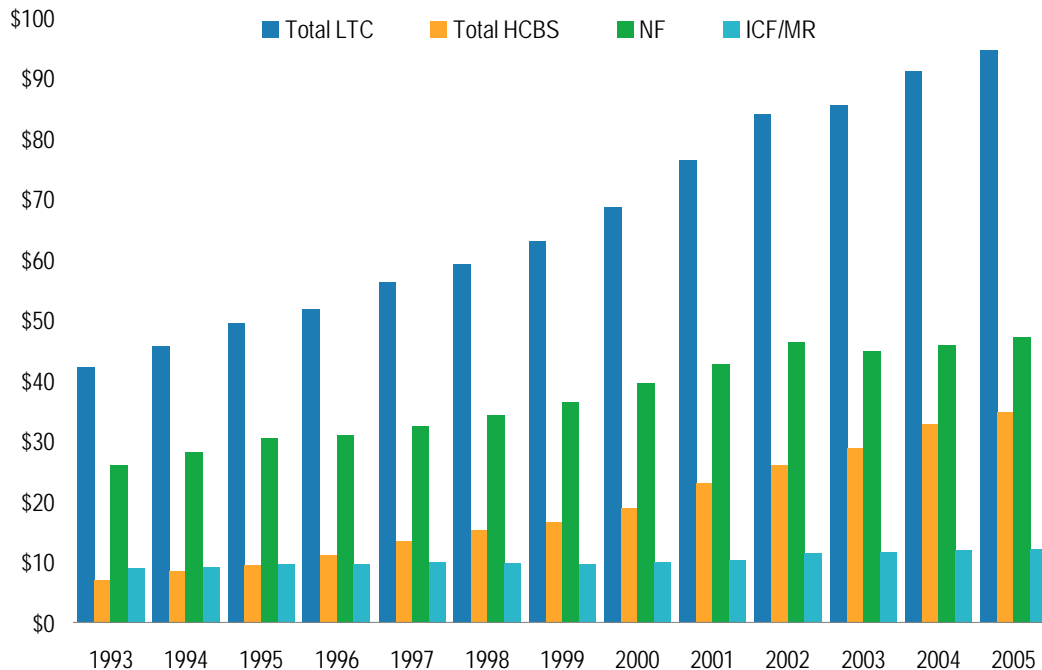
In August 2007, AHCA commissioned Avalere Health to complete a literature review on HCBS cost-effectiveness and quality. The Avalere literature review is intended to build on a similar 2003 review by AHCA. Conducted over September and October 2006, Avalere focused on identifying and reviewing peer-reviewed research released during or after 2003. However, certain seminal works published before 2003 are included as well as other references to provide context. The literature review was primarily limited to peer-reviewed work and Avalere avoided research funded by the LTC industry. Avalere also included some independently conducted state research.

Introduction

Medicaid is a major LTC payment source.² The federal government and the states jointly finance Medicaid while the states administer the program within broad federal guidelines for eligibility and benefits. Medicaid-financed LTC programs vary widely from state-to-state in terms of eligibility and benefit offerings.

Between 1993 and 2005, total Medicaid LTC spending grew by 57 percent.³ Research also shows that aged, blind, and disabled Medicaid beneficiaries using LTC services make up only 7 percent of the total Medicaid population, but consume 52 percent of all Medicaid dollars.⁴ Seventy-five percent of aged, blind, and disabled Medicaid beneficiary expenditures are for LTC services.⁵

Figure 1. Medicaid Long-Term Care Expenditure Growth (in Billions)



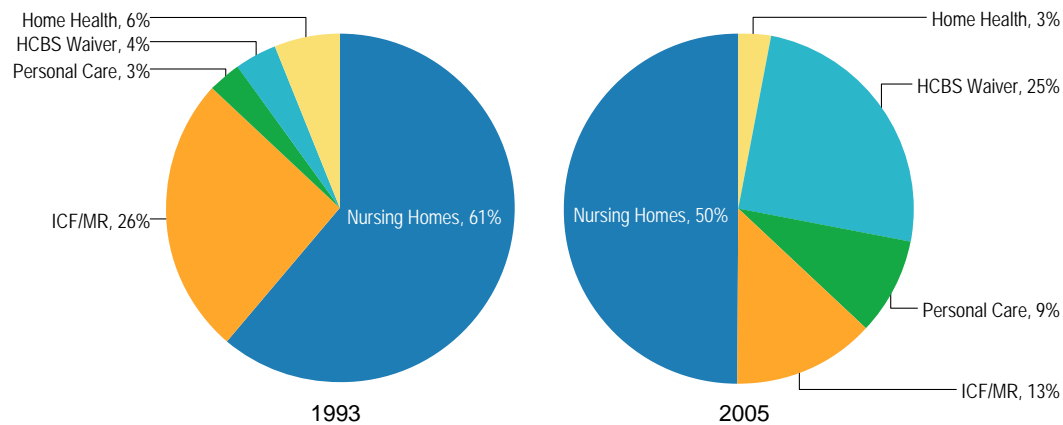
Source: Avalere analysis using MEDSTAT Group data.

Over the period from 2006 to 2014, the CMS Office of the Actuary projects total Medicaid spending to increase at an average annual rate of about 8.5 percent, with the LTC population driving most of this growth.⁶ Because of Medicaid-financed LTC expenditure growth rates, states and the federal government have strong incentives to deliver such services in the most efficient methods possible.

Medicaid Long-Term Care Spending Trends

Medicaid LTC services are provided in facilities, such as nursing homes and intermediate care facilities for persons with mental retardation (ICFs/MR), and in individuals' homes and the community – referred to as HCBS. As Figure 1 illustrates, Medicaid spending on all HCBS (which includes personal care, HCBS waivers, and home health) is increasing faster compared to spending on nursing homes and ICFs/MR. Figure 2 shows that between 1993 and 2005, HCBS spending (e.g., personal care, home health, and HCBS waiver) as a percent of total Medicaid LTC spending increased from 13 percent to almost 37 percent.⁷ As a percent of total Medicaid LTC spending, nursing home expenditures decreased by 11 percentage points (from 61 percent of total to 50 percent) while ICF/MR outlays declined by half (from 26 to 13 percent).

Figure 2. Percent of Total Medicaid LTC Spending: Shift Towards HCBS



Source: Avalere analysis using MEDSTAT Group data.

Today, spending growth on HCBS outpaces institutional spending in some states. In most states, HCBS spending on behalf of persons with MR and related developmental disabilities (MR/DD) outpaces institutional spending. HCBS growth is driven by state policy goals to slow Medicaid LTC rates of spending growth and to meet consumer demand for more LTC service options in the community (see below for discussion of HCBS cost controls). The shift from reliance on facility-based services to HCBS is likely to continue as states and the federal government seek to slow overall program growth.

HCBS Expansion

While states have a variety of options to deliver HCBS, the Section 1915(c) Medicaid waiver program has been their primary approach. By federal law, HCBS programs are intended to serve as an alternative to institutional services. States only may serve populations with HCBS waivers that meet their institutional (e.g., nursing home, ICF/MR,

or hospital) eligibility requirements. HCBS programs must serve as a comparable alternative, or substitute, for facility-based services.

All states have at least one HCBS waiver program, although they target different populations and offer different services under each waiver.⁸ In 2003, approximately 978,155 Medicaid beneficiaries were served in 257 distinct waiver programs.⁹ Under the Section 1915(c) waiver authority, states may provide services not covered by the Medicaid program. States also have considerable flexibility when crafting HCBS waiver benefit packages including development of new types of services, provider participation criteria, and quality assurance strategies.

HCBS and Costs

To implement a Section 1915(c) waiver program, a state must seek approval from CMS. HCBS waivers are initially approved for three years, and may be renewed every three or five years. CMS uses a national standard protocol to assess waivers.¹⁰ One of the key federal assessment requirements for initial waiver applications and renewals is documentation that the waiver is cost-effective. In this context, CMS defines cost-effectiveness as a comparison of the costs of Medicaid HCBS waiver participants, both medical and LTC, to the costs of serving the same population in an institutional setting.

States must prove to CMS that serving institutionally eligible individuals in HCBS waiver programs costs the same or less than when services are provided through institutions. Section 1915(c) waivers must meet CMS's definition of cost-effectiveness; all active waivers meet the CMS definition of cost-effectiveness or must have a corrective plan of action for the waiver to become cost-effective.

States use a variety of tools to meet CMS's requirements. For example, states may limit HCBS enrollment to only those individuals who are eligible for institutional services and by setting income and assets requirements. Additionally, unlike Medicaid state plan services, states may cap waiver enrollment and spending by implementing a global budgetary cap and maintain waiting lists for HCBS program services. In 2005, 30 states reported HCBS waiver waiting lists.¹¹ Some research has found that the removal of waiting lists can increase LTC costs significantly.¹²

States also control spending through benefit package design, including limiting service definitions, number of service hours, and provider payment rates.¹³ Additionally, Medicaid does not reimburse for housing costs and basic living expenses, such as food and utilities. HCBS waiver participants must pay for housing (e.g., room) and personal expenses (e.g., board). Medicaid pays room and board costs for beneficiaries receiving institutional services such as nursing home or ICF/MR.

Implications for Total Long-Term Care Spending

When developing HCBS programs, states must consider the impact on total LTC spending, both existing institutional outlays and potential HCBS expenditures. Ensuring total LTC spending budget neutrality is complex and dependent on estimating how

Other Medicaid HCBS Programs

States also use other Medicaid state plan options to deliver HCBS. These include Medicaid-financed home health and personal assistance services. These services are not subject to cost-effectiveness requirements and states may not limit enrollment. However, as with Section 1915(c) waiver programs, states may limit service hours and beneficiaries must pay for room and board.

many people will need LTC and how many of those are nursing home eligible but would apply for HCBS.

For the remainder of this report, cost-effectiveness is exclusively used in the context of state budgetary cost-effectiveness, or overall budget neutrality. State budgetary cost-effectiveness means that HCBS produced no new Medicaid-financed LTC costs and/or reduced total LTC costs.

HCBS Quality

Nursing facilities and ICFs/MR are heavily regulated, must meet national quality requirements, and must report on an array of federally mandated datasets. Outside of broad guidance documents, CMS has not developed national HCBS quality requirements or related standardized HCBS quality reporting elements. Additionally, HCBS programs are not as consistently structured as facility-based services. HCBS waiver programs serve different populations and provide different benefit packages. For example, the state of Pennsylvania maintains 10 waiver programs, including waivers for persons with MR/DD, seniors, persons with physical disabilities, and persons with head injuries. Each waiver program's benefit package and provider participation criteria are different. Such variation, while meeting consumer preferences for personalization of services, makes quality measurement and programmatic comparisons difficult.

Additionally, because HCBS programs (including waivers, home health, and personal assistance services state plan options) are delivered in homes and communities, service systems are dispersed and include multiple service providers. For example, services for one HCBS program participant can include several case managers, adult day care or employment providers, residential service providers, medical providers, mental or behavioral health providers, and transportation service providers. To address the complex network of HCBS delivery systems and providers, states now are required to submit more comprehensive Section 1915(c) waiver quality assurance strategies than in the past. Home health and personal assistance services are only subject to standard Medicaid program quality requirements. However, the nature of HCBS service delivery makes developing and measuring HCBS quality challenging.¹⁴

HCBS Cost-Effectiveness Findings

States must prove to CMS that serving institutionally eligible individuals in HCBS waiver programs costs the same or less than institutional services. When considering an initial waiver application or renewal, CMS requires documentation that the program will be cost-effective. CMS cost-effectiveness is defined by comparing the costs of Medicaid HCBS waiver participants, both medical and long-term care, to the costs of serving the same population in an institutional setting. All active HCBS waiver programs meet the CMS definition of cost-effectiveness.

The literature discussed below addresses HCBS impacts on total state LTC spending. This report, and the findings presented below, use the term cost-effectiveness to exclusively refer to state budgetary cost-effectiveness. State budgetary cost-effectiveness means that HCBS produced no new Medicaid-financed LTC costs. In the research, HCBS cost-effectiveness is a question of whether the addition of HCBS programs, waiver or Medicaid state plan option, did or did not increase overall state LTC spending.

Theme 1: HCBS expansion has not stopped Medicaid LTC expenditure growth. While nursing home cost growth has slowed, HCBS expenditures have increased significantly. In many instances, HCBS growth appears to have offset total LTC savings produced from reduced nursing home spending.

Recent research appears to confirm earlier work indicating that HCBS is not cost-effective for states. Longstanding research on HCBS programs has revealed that most HCBS programs increase total long-term care spending and are not cost-effective for state LTC budgets.¹⁵ For a number of years, these studies have been cited in federal policy guidance documents on HCBS impacts.^{16 17} The most widely recognized HCBS study, the National Long-Term Care Channeling Demonstration, found little empirical evidence of HCBS cost-effectiveness for states.¹⁸ Recent work on new forms of HCBS, such as cash and counseling programs, reinforces earlier findings of increased LTC costs due to HCBS expansion. A 2006 study of the Arkansas cash and counseling program found that cash and counseling is more cost-effective than traditional HCBS services, but that the program does not reduce overall LTC costs.¹⁹ A 2003 study on home care produced similar findings indicating that HCBS was increasing costs.²⁰

Other research raises questions about the potential for HCBS to meet future demand and continue to slow Medicaid LTC spending rates. There is evidence that HCBS services, even as currently funded, do not meet need the needs of program participants. For example, a 2002 study found that HCBS availability does not decrease informal caregiver efforts. Such findings support other research that informal caregivers are supplementing HCBS-funded care in order to meet the needs of individuals with significant needs in HCBS settings.²¹ Additionally, a 2005 study found that almost 261,000 individuals were on waiting lists for 102 waivers in 30 states, up from approximately 206,000 in 2004.²² And, a 2004 study estimates that approximately 44 million people are providing informal LTC.²³ The study also indicates that – of surveyed households – 67 percent expressed the need for help in providing care. Other research predicts decreases in informal LTC capacity.²⁴

Theme 2: The literature does not appear to adequately control for differences among study participants or study settings (e.g., nursing home and HCBS).

Many cost-effectiveness studies do not compare like populations and/or do not use a control group.

A 2006 HCBS literature review discusses potential flaws in study design and concludes that the body of work prevents any definite conclusion being formed regarding state cost-effectiveness of HCBS waiver services.²⁵ This analysis points out that even in two multi-state evaluations as well as other smaller studies, the evidence on cost implications of existing HCBS policies is, "relatively weak." The author argues that the experimental design "used in most studies of cost impact leaves open the issue of selection bias among the treatment and control groups." The author further notes that the body of state-by-state research is limited and the methodology is not made available for peer-review critique before publication. In an earlier study, researchers indicated that an evaluation of HCBS cost-effectiveness in Arizona was hindered by the lack of a "randomized controlled study design (see text box for an explanation)."²⁶ However, in the same Arizona study, the author concluded that HCBS was cost-effective primarily because the state was successful in identifying and enrolling only people who were at risk for nursing home placement and limiting HCBS access to such individuals (see discussion of "substitution," below). In other work using randomized controlled and comparison group methods, the authors indicate that when HCBS is offered, many people who seek LTC services are at a low risk of entering a nursing home.²⁷

Researchers have studied differing sets of variables that influence the risk of nursing home placement making substitution difficult to define. HCBS is intended to serve as a substitute for facility-based services. State budgetary cost-effectiveness hinges on the concept of substituting less costly HCBS services for facility-based services only to those who are truly at risk of nursing home placement. Substitution's impact on cost-effectiveness is discussed in more detail below. However, studies consider different factors that influence individuals' decisions to seek LTC services and the type of LTC service. Such variation raises questions about how people at risk of nursing home placement are defined. Factors typically assessed include the availability or absence of family caregivers or other informal care, health status, and education level. For example, some research addresses functional capacity and health while other research considers health and socio-economic issues. Still other research considers a mix of the preceding elements and prior experience with LTC. An example of how these factors influence HCBS findings is research examining whether the availability of publicly financed HCBS crowds out informal caregiving. A 2002 study found that the availability of formal in-home care did not impact the use of informal care.²⁸ Rather, the authors note that

Randomized Controlled Study

A "randomized controlled study" is one in which there are two groups, one treatment group and one control group. The treatment group receives the treatment under investigation (e.g., HCBS), and the control group receives either no treatment or some standard default treatment (e.g., facility-based services). Patients are randomly assigned to all groups.

Assigning patients at random reduces the risk of bias and increases the probability that differences between the groups can be attributed to the treatment. It is important to note, however, that gaining federal and/or state approval for randomized controlled studies in publicly financed programs is difficult. Random assignment does not allow for consumer choice among services or service settings.

beneficiary care needs influence the level of use of formal and informal care. However, other research, though older, shows some reduction in informal care due to the introduction of formal care.²⁹ Still other research states that more work should be done to better tie level of care needs and service needs.

Nursing home and HCBS payment systems are markedly different. In most states, nursing home payment rates are related to individual nursing homes' costs of delivering needed services with payments based on residents' needs. Additionally, many states also limit payment for certain types of costs and many provide additional payments for direct resident care. States also regularly adjust rates to reflect changes in homes' costs or in the care needs of the residents that homes serve. Conversely, HCBS rates typically are not adjusted by individual provider or for beneficiary level of need. HCBS programs pay the same rate for everyone using a particular benefit. However, waivers often offer levels of service such as regular case management and high-intensity case management. Additional levels of payment granularity are rare. Researchers – while using valid comparison study methods – point out the limitations of study designs that attempt to crosswalk nursing home reimbursement systems with differing HCBS reimbursement methods.³⁰

Theme 3: HCBS has slowed total state LTC spending only when states implement: 1) strategies that ensure only populations at risk of nursing home services receive HCBS (i.e., controlling for the “woodwork effect”); 2) HCBS expenditure controls; and/or 3) global LTC budgeting practices. In the latter, states couple HCBS expansion with efforts to reduce facility-based spending.

There is some evidence that certain state programs can be cost-effective under very controlled circumstances. The literature indicates that HCBS can increase overall LTC costs if enrollment is only limited to people at risk of nursing home placement.³¹ Effective targeting, or substitution, to only nursing home at-risk populations is limited to a handful of state programs. In a 1993 study, researchers found that control groups that did not have access to home care were only marginally more likely to enter a nursing home than those who did have access to home care.³² A 1995 re-analysis of the LTC channeling demonstration identified instances of HCBS cost-effectiveness but only when services were provided to people with higher institutionalization risk.³³

In an early study that also merits mention, The Lewin Group analyzed work conducted on the woodwork effect (see text box).³⁴ One study reviewed by Lewin shows an inverse relationship between increasing home care use and functional impairment. In response to new HCBS benefits, less impaired individuals were more likely to increase their use of LTC services. Lewin also discusses how program design can determine whether states experience the woodwork effect or not. HCBS programs

Woodwork Effect

Many individuals prefer to remain in their own homes and communities. Such people will forego available institutional services in order to remain at home even though they may have functional limitations just as severe as individuals receiving institutional services.

When HCBS is offered, however, people who would not previously accept institutional services will apply for HCBS. A long-standing concern about HCBS has been that it produces such induced demand and drives up Medicaid LTC costs. Induced LTC demand is also called the “woodwork effect” because previously unassessed people come “out of the woodwork” to apply.

that are not designed to target beneficiaries who would otherwise be institutionalized result in cost growth and new enrollment, as demonstrated by a study of a California waiver program analyzed by Lewin.

Lewin authors are careful not to suggest that this is the only factor determining success, as other studies of very targeted HCBS programs – such as in Georgia – found different design flaws. For example, a recent report commissioned by the state of Indiana indicates that it has not implemented adequate nursing home diversion tools and maintains high bed capacity relative to need. The analysis notes this lack of control has the potential of eliminating any savings from the state's investment in HCBS, and suggests that the state couple its HCBS investments with efforts to decrease reliance on institutional services.³⁵

Over the past 20 years, states have gained considerable experience with HCBS program design and operation to reduce costs.³⁶ Research shows that between 1992 and 2005, the number of HCBS waivers grew from 155 to 257. With such experiences, states have developed more sophisticated HCBS management techniques to reduce costs.³⁷ However, other literature finds that targeting services to only those who need institutional service levels is not sufficient. Complementary steps must be taken to control institutional spending. Without this two-prong approach, even an expansion of targeted HCBS programs is more likely to increase rather than decrease total LTC costs.³⁸

In addition to HCBS waiver management improvements, states also have implemented new managed LTC delivery systems to promote HCBS, including offering services through capitated managed-care plans, which often integrate Medicare-funded acute care and Medicaid-funded LTC benefits. Features of such programs include more data collection and provider performance measurement. They also more consistently assess program participants than do traditional fee-for-service programs; more consistent assessment decreases the chances of woodwork and increases the probability of substitution. A November 2001 preliminary evaluation of Florida's managed LTC diversion program found overall program savings and, more recently, an APS study of Wisconsin's Family Care program – a managed LTC waiver arrangement – also produced savings.^{39, 40} However, considerable literature indicates that integration and managed care, such as the Social Health Maintenance Organization demonstrations (S/HMO), fail to lower costs and had inconsistent effects on health and functional status as well as quality of care.⁴¹ Programs of All-Inclusive Care for the Elderly (PACE) programs are the exception, and they have been found to reduce costs.⁴²

However, since these studies were conducted, states have gained new administrative tools to ensure that Medicare pays first and Medicaid pays only as a last resort for persons who are dually eligible for both programs. Such strategies may increase the chance of HCBS cost-effectiveness for state LTC budgets.⁴³ A 2001 article points out that an alternative payment system that ensures substitution and closely ties participant need with total per person spending could minimize waste and improve outcomes.⁴⁴ Finally, new work is emerging to further inform strategies aimed at identifying populations at risk of facility-based placement.⁴⁵

A 1999 study illustrates the impacts of effective targeting. Researchers compared Michigan Medicaid HCBS service recipients to Ohio nursing home residents and found that HCBS recipients were younger on average than their nursing home cohorts and had very similar levels of impairment. Both groups had similar percentages of reduced

physical function and special services. However, the authors note that more home care clients fell into the clinically complex category than nursing home residents, while nursing home residents had higher levels of impaired cognition. The authors also found that nursing home residents had lower scores on the activities of daily living (ADL) index and were therefore more resource intensive than home care patients. For these reasons, they believe the Michigan Medicaid program was successful in tailoring its eligibility criteria to those most at risk for entering nursing homes.⁴⁶

Finally, an older Lewin Group and AARP Public Policy Institute study examined HCBS and nursing home beneficiaries served and overall expenditures in Colorado, Oregon, and Washington. The authors concluded that these states' HCBS programs were cost-effective alternatives to nursing home care because they targeted seriously impaired populations who were likely to otherwise need facility intensive services. Based on estimated disabled and elderly population growth, the authors found that the three states saved between 9 and 23 percent of projected LTC spending in 1994.⁴⁷

Theme 4: Nursing homes will remain a critical segment of the LTC spectrum because research indicates that certain traits and service needs differentiate nursing home residents from HCBS populations, and that some populations will remain reliant on nursing home services.

Research indicates that nursing home populations have higher levels of need. A January 2006 analysis of three national datasets describing LTC populations in residential settings indicated that people receiving LTC services in residential settings have similar types of needs, primarily ADL support and assistance related to Alzheimer's disease or other dementias. Residential care populations tend to be more dissimilar from home care populations. Additionally, in two of the three national datasets, nursing facility residents were found to have considerably more ADL limitations and much higher prevalence rates of Alzheimer's and related dementias.⁴⁸ Additional work reached similar conclusions. In a 2003 comparison of assisted living providers and nursing homes, researchers concluded that nursing home residents had more intense service needs. Researchers at the Agency for Healthcare Research and Quality (AHRQ) indicate that nursing home residents are older and had a greater degree of dependence in 1996 than they did in 1987.⁴⁹

In 1999, Brandeis University researchers concluded that nursing homes were increasingly serving people with greater needs as well as those in post-acute care stays. The researchers suggest that the acuity increases could be attributed to more seniors and people with disabilities residing in assisted living or other HCBS settings. The authors also note that data issues make such a determination extremely difficult.⁵⁰ At the state level, two studies found nursing home acuity increases. Data on nursing home residents in the state of Ohio indicates that level of care needs have increased over the past decade.⁵¹ Research on LTC utilization in Florida found that nursing home residents have more intense service needs than people in assisted living and HCBS settings.⁵² No research was found that discusses acuity increases over time and changes in consumer service preferences as acuity changes. However, it is important to point out that some research indicates that assisted living residents and nursing home residents are becoming more similar.⁵³ Such findings support the notion that some programs have achieved substitution.

Certain beneficiary characteristics appear to increase the need for nursing home services. In a 2002 study, researchers determined that access to informal support plays an important role in what LTC services people use. Specifically, unmarried individuals with a chronic illness were more likely than married individuals with a chronic illness to be in a residential care facility – such as assisted living – rather than receiving HCBS in their own homes. Furthermore, unmarried individuals with a severe cognitive impairment or ADL deficiencies were more likely to be served in a nursing home than to be in HCBS.⁵⁴ Another study indicates that people with less intense care needs often chose to enter and remain in nursing homes due to the fear of a repeat health crisis.⁵⁵ Such individuals also expressed concern about perceived declines in independence while attempting to live at home.⁵⁶ Other literature reinforces findings that Alzheimer’s, dementia, and other cognitive impairments appear to play a critical role in determining where someone receives services; the portion of the national nursing home population with such a disability has significantly increased.⁵⁷ Nursing home residents also are more likely to be single (e.g., widowed, unmarried, or divorced) and older. However, a recent Lewin Group study points out that the percentage of older LTC users being served in nursing homes has significantly decreased.⁵⁸ However, Lewin researchers also said that current limitations of national LTC datasets make conclusions about where older individuals are being served difficult.

Theme 5: Cost-effectiveness is measurable when comparing large ICFs/MR to HCBS waivers, but becomes less clear when comparing small private ICFs/MR to HCBS.

A 2006 report highlights a number of reasons that small private ICFs/MR “in the community costs” might be higher than HCBS waiver costs. A 2006 University of Minnesota Institution on Community Integration study found that comparing the cost-effectiveness of Medicaid HCBS waiver settings with small private Medicaid-financed ICFs/MR is difficult.⁵⁹ Researchers also indicate that ICFs/MR costs may be inflated by a tendency for Medicaid waivers to serve people with less intense needs despite federal requirements that the populations meet the same level of care.

The literature is consistent in its finding that HCBS is cost-effective when compared to large, public ICFs/MR. Medicaid expenditures are higher for developmentally disabled individuals in large ICF-MR than those that receive care in the community.⁶⁰ The annual Medicaid expenditures per average daily recipient of care provided in large ICFs/MR services was \$117,600 compared to \$39,627 per each HCBS recipient.⁶¹

Other research confirms prior findings that HCBS is less costly than care in private ICFs/MR. A recent study of individuals with MR/DD in Oklahoma found a statistically significant cost difference between the two care settings. The mean adjusted cost for individuals with MR/DD who reside in Oklahoma in the institutional setting was \$138,720 per year compared with \$123,384 in the community setting.⁶² There is little consensus in older literature as to whether one setting is more cost-effective than another for individuals with mental retardation.⁶³

Theme 6: Policymakers appear to be promoting HCBS services for reasons other than cost-effectiveness considerations.

In addition to responding to cost pressures, policymakers must also respond to constituent LTC service preferences while ensuring quality of care through oversight and adequate reimbursement. State policymakers are faced with difficult LTC decisions often with limited access to peer-reviewed research.⁶⁴ In recent years, HCBS expansion has been a key strategy for slowing Medicaid LTC spending. And, the literature highlights three key factors that encourage policymaker interest in HCBS expansion.⁶⁵ First, high profile surveys of the public indicate a preference for HCBS. Second, the literature often references quality nursing home issues and public concern; however, several sources highlight the lack of information on HCBS quality. And, third, the Supreme Court's 1999 *Olmstead* decision has proven an important policy driver.⁶⁶ Additionally, research on state officials – such as governors' health policy analysts and state legislators – indicates that these important decision-makers are often overwhelmed with LTC information, confused by conflicting findings, and not provided with information they consider reliable (i.e., local, state-specific information).⁶⁷

HCBS Quality Findings

Nationwide, there are approximately 257 HCBS waiver programs and 27 states with a related Medicaid personal assistance services (PAS) state plan option. Most states offer a Medicaid home health state plan option. HCBS waiver programs are tailored to a variety of populations, including seniors, people with MR/DD, young adults with physical and other disabilities, children with serious emotional disturbances, persons who have HIV/AIDS, people with a traumatic brain injury, and medically fragile children. In keeping with diverse waiver populations and differing service needs, waiver benefit packages vary considerably. State plan PAS and home health benefit packages tend to be more consistent from state-to-state and are typically not tailored to a specific population.

However, waiver participants, PAS and home health users are served through local/regional service systems and provider networks differ among states and often by target population. Additionally, although HCBS programs operate under the same federal statutory and regulatory framework, service configuration varies considerably by target population and state. Because HCBS are delivered in peoples' homes and communities, they are furnished among widely dispersed sites. Furthermore, HCBS waiver service delivery networks are composed of dispersed and often overlapping sets of providers. For example, they typically include state and local public agencies, large and small private-sector provider organizations, several case managers, individual personal assistants and attendants, clinicians, and, increasingly, neighbors and other community members who support individuals. Gathering data on quality and operating quality improvement strategies in such programs is extremely challenging. In contrast, facility-based services are highly regulated and services are similar among states. Such similarity makes quality measurement less difficult and allows for provider and programmatic comparability.

Theme 1: There remains a significant lack of information on HCBS quality, unlike nursing homes, which have many federal and state reporting requirements. Fundamental differences in service delivery models, and consumer bias, make comparisons of HCBS to nursing home service quality extremely challenging.

Considerable nursing home quality research is available, but little HCBS literature exists to make comprehensive assessments and comparisons of HCBS quality. In 2003, the General Accountability Office (GAO) found some improvements in nursing home quality but also identified serious problems.⁶⁸ A 2005 GAO report said CMS nursing home survey data show a significant decline in the proportion of nursing homes with serious quality problems. However, the study also highlights inconsistencies in how states conduct surveys and points out understatements of serious quality problems.⁶⁹ At the same time, interstate or national research on HCBS quality is extremely limited. The majority of quality research highlights consumer satisfaction with HCBS (i.e., quality of life measurement).⁷⁰ However, considerably less information is available on health care outcomes and level of disability or functionality on a national basis. And, the literature has not addressed how HCBS quality is defined across states, or even within states. Designing HCBS quality strategies has proven extremely difficult.⁷¹ In 2003, GAO highlighted the absence of information on how HCBS waivers are performing and the need for additional state and federal oversight.⁷² A 50-state survey indicated that no state has a consolidated strategy for collecting, comparing, and reporting nursing home and HCBS consumer satisfaction and program outcomes.⁷³

However, some literature shows improved clinical outcomes in HCBS settings. In a 2005 study, researchers followed participants in an “Aging in Place” program and nursing home residents. Researchers suggest that receiving services in the home, when coupled with nurse coordination services, produces clinical outcomes superior to nursing home care. The authors highlight the strength of their findings because – while they used a quasi-experimental design – participants were matched for comparative study.⁷⁴ However other researchers are critical of “quasi-experimental design” and point to the need for the use of control groups.

Quasi-Experimental Design

A quasi-experimental design is a study that shares many features with an experimental design but lacks a key element, like a random assignment and a control group (see page 12). Because such studies lack random assignment, participant bias may influence findings.

Additionally for many years, states were not required to submit detailed quality assurance strategies with Section 1915(c) waiver applications or renewals. Recently, CMS reinstated a requirement that states submit a detailed quality plan and researchers expect more robust data to be available in the future.

Theme 2: Nursing home and HCBS services quality measurement systems are inherently different.

HCBS has no national quality requirements comparable to facility rules. Interstate – or even within state – HCBS program comparisons are virtually impossible because of variations in state HCBS quality strategies. One study assessed HCBS quality strategies on a state-by-state basis.⁷⁵ The study emphasized that there is not a “one-size-fits-all” model for HCBS programs. As noted above, GAO highlighted the absence of information on how HCBS waivers are performing and the need for additional state and federal oversight.⁷⁶ Often, authority for waiver program oversight is split among several agencies making quality, licensing, and coordination of quality assurance data collection challenging.⁷⁷ CMS requires a summary level annual report on waiver performance – focusing exclusively on enrollment and costs. Unless a problem emerges with a waiver, CMS only reviews performance every three to five years for program re-authorization and states have the option of requesting an independent evaluation of the waiver.⁷⁸ In contrast, nursing home quality heavily relies on a federally mandated data system called the Minimum Data Set (MDS) that allows intra- as well as interstate comparability among facilities.⁷⁹ MDS is reported regularly, and nursing homes are subject to both federal and state licensure and survey requirements.

New CMS guidance may not result in more comparable HCBS quality information. Measuring quality in the community has been consistently challenging.^{80, 81} A 2003 study on two computerized HCBS quality improvement tools in Indiana also encountered many difficulties with measurement.⁸² CMS recently developed the HCBS Quality Framework, an attempt to provide a common structure for HCBS quality system development.⁸³ However, the CMS initiative does not allow comparison among HCBS programs or between HCBS and nursing facilities.⁸⁴ Other than a handful of smaller initiatives (such as the state MR/DD directors’ Core Indicators Project), no other HCBS comparative tools exist.

Consumer-directed services in HCBS pose additional quality measurement challenges for states. Consumer-directed services are a key trend in HCBS service delivery. These programs give beneficiaries, or their families, the authority to develop service plans that are primarily driven by their preferences and may counter program quality improvement strategies. Many consumer-directed programs allow beneficiaries to hire or fire, train, schedule, and pay their direct support staff.⁸⁵ Highly individualized service plans and more dispersed service providers make quality measurement and comparisons in consumer-directed programs very challenging. Administering consumer-directed services is not only administratively complex, but Medicaid regulations may present barriers to quality improvement strategies. For example, a HCBS participant with a heart condition might choose to smoke. CMS developed a “risk management” guide to help states design quality assurance strategies that reconcile consumer-directed services principles with Medicaid requirements. The guide is intended to help states balance quality of life measurement with quality of care measures. It addresses health, behavioral, and personal safety risks.⁸⁶ Additionally, states must offer the choice of using consumer direction; some people, seniors in particular, do not find full consumer direction attractive (i.e., financial management and support staff management for care plans). However, as noted above, each state crafts unique quality strategies for these programs.

HCBS is also delivered in managed and integrated care programs; research has not shown significantly improved quality outcomes in such programs. Research on Medicare and Medicaid integration and managed-care projects, such as the S/HMO demonstrations, found that these programs failed to significantly lower costs and had inconsistent effects on health and functional status as well as quality of care.^{87, 88} Although the research addresses total expenditures (not just LTC), PACE programs are considered the primary exception to limited integrated care model outcomes.⁸⁹

Theme 3: As HCBS programs grow, service systems will become more complex (e.g., more participants and more providers); quality and quality measurement may become a more significant challenge.

Research indicates that reimbursement affects facility-based and HCBS quality by impacting the number, adequacy, and quality of providers. Researchers in a 2006 national study of HCBS service variations point to differing levels of reimbursement as a key factor in provider availability.⁹⁰ A lack of qualified providers will impact HCBS participant access to services as well as desired programmatic and participant-level outcomes.

The literature consistently relates quality to adequate LTC provider staffing levels; a shortage of HCBS staff would negatively impact quality. Increasing demand for LTC services due to aging and increased rates of chronic illness likely will result in direct-care worker shortages, especially as the number of seniors in the United States begins to rise rapidly.⁹¹ This demographic change will be compounded by the fact that the vast majority of LTC is informal.⁹² And research predicts a decrease in the availability of informal LTC care.⁹³ These combined changes will magnify current LTC staffing issues and impact HCBS quality.

Researchers indicate that LTC job demand will be greatest in home care settings – 70 percent more will be needed – while nursing home job demand is projected at 26 percent.⁹⁴ Institutes of Medicine (IOM) researchers indicate that the turnover rates of home health care staff are higher than among nursing home staff. High turnover rates

among LTC providers increase costs and negatively impact quality.⁹⁵ A 2006 study on trends in the personal assistance workforce found that while the HCBS workforce has grown substantially, fierce competition for direct support staff will continue due to increasing demand for HCBS services.⁹⁶ Finally, while nursing home staffing levels have been mandated,⁹⁷ HCBS staffing levels are not standardized; HCBS staff-to-participant ratio requirements vary from program-to-program within states.

Some research indicates that HCBS programs provide inadequate case management, which can impact service access and quality outcomes. In particular, HCBS populations (e.g., people who are Medicaid beneficiaries, have disabilities, and are low-income) have difficulty accessing health care and need assistance from case management services. In a 2003 study of federal oversight of HCBS waiver programs, the GAO found that case management was inadequate.⁹⁸

Theme 4: Nursing homes are implementing quality improvement efforts that will improve quality of care.

In keeping with LTC trends toward consumer-driven care, many nursing homes are now using resident-centered models to improve quality of care. Quality of care is closely associated with quality-of-life.⁹⁹ Researchers indicate that nursing home culture change offers a way direction for nursing homes to improve resident satisfaction.¹⁰⁰

Other work indicates that facilities are integrating more patient centered service delivery models (i.e., culture change) and implementing related quality measures.¹⁰¹ Studies of culture change initiatives highlight positive outcomes for residents as well as for facilities via improved employee job satisfaction and higher employee retention rates.¹⁰²

Culture Change

Nursing home culture change focuses on improving resident experiences by improving workplace conditions and improving facilities' workforces. Culture change initiatives often provide training grant money, job advancement training, resident respect and dignity training, and more direct care training. Culture change also attempts to create a more personalized home-like environment.

Theme 5: Previous research and CMS evaluations on HCBS waivers for persons with MR/DD identified serious quality issues including increased mortality. However, CMS and states have made improvements in quality in HCBS targeted to persons with MR/DD.

In the mid-1990s, researchers at the University of California Riverside found evidence of increased mortality among persons with MR/DD participating in HCBS waiver programs over persons with MR/DD in ICFs/MR. Other serious quality problems were identified in the MR/DD waivers in Oregon and Illinois. Since that time, however, states and CMS have made improvements. CMS's recently developed HCBS Quality Framework attempts to provide a common structure for HCBS quality system development. However, the framework does not allow comparison among HCBS programs or between HCBS and ICF/MR.¹⁰³ Research also shows an improvement in state oversight of MR/DD waivers.¹⁰⁴ However, as noted above, aside from the CMS HCBS Quality Framework there is no standard HCBS quality strategy that would facilitate comparison among HCBS programs.

Conclusion

To date, the literature finds limited evidence of overall HCBS cost-effectiveness for state LTC budgets and only under very specific circumstances. Programs are found to be cost-effective when states ensure that only people who are truly at risk of nursing home placement enter the waiver. Additionally, reduced Medicaid spending growth is generally possible when states place controls on both HCBS expenditures and nursing home utilization.

DRA provisions to promote HCBS services may significantly alter past HCBS cost-effectiveness debates, specifically debates of whether HCBS promotes substitution of nursing facility care and leads to the woodwork effect. First, substitution is a key concept in ensuring that an HCBS program does not increase total LTC spending. It hinges on the provision of HCBS in place of facility-based services to only people who meet and need the nursing home level of care. To achieve state budgetary cost-effectiveness, substituted HCBS services also must cost the same or less than facility-based services.

However, under the DRA HCBS state plan option, HCBS may not serve as a nursing home alternative. States must design HCBS state plan option programs that have a different level of care than nursing homes. Differing levels of care for HCBS and nursing homes make substitution impossible. Second, states may cap enrollment or spending under the HCBS state plan option and may make changes in the program when costs become a concern. Such a policy option also may reduce the incidence of woodwork (e.g., induced demand for services).

The DRA also contains a state plan option that allows states to deliver Medicaid coverage that would have required a Section 1115 Research and Demonstration waiver in the past. Benchmark benefit plans allow states to craft new benefit packages and new eligibility requirements for services. This state plan option and the DRA Self-Determined Services state plan option, similar to cash and counseling, may reshape the cost-effectiveness debate and raise questions about the applicability of earlier research conducted on the Section 1915(c) HCBS waiver program and other HCBS programs. Specifically, benchmark benefit plans and Self-Determined Service state plan options will include new types of services, new and unstudied assessment tools, and new levels of care that will determine functional eligibility for facility-based and HCBS. These new programmatic elements may impact substitution and woodwork in different ways that have not yet been addressed in the literature.

Based on this literature review, whether using waivers or state plan options, cost-conscious states seeking budgetary savings must effectively target HCBS to only at-risk populations. Additionally, the LTC landscape appears to be fundamentally changed due to new federal policy options and state innovations. These changes raise important research questions:

- **People in nursing homes are older and have more intense service needs than in the past.** Have the needs of people receiving HCBS also changed?
- **HCBS expansion could lead to woodwork effect spending increases.** What are the states' beneficiary quality of life and budgeting considerations as HCBS populations' needs place pressure on HCBS program capacity?

- **Because of the DRA, states have more HCBS expansion options that are not subject to cost-effectiveness requirements.** Furthermore, these options offer states spending controls that previously only were available when using a waiver. Will HCBS waivers still dominate HCBS programming?
- **HCBS expansion will lead to less demand for facility-based care.** How will states ensure access to an array of LTC services as beneficiaries' LTC needs change?

In light of future population growth demand for LTC services, further research on these questions will help inform states and the federal government as they continue to explore new approaches to financing and delivering care while ensuring beneficiary access to LTC in the most appropriate setting, be it HCBS or facility-based.

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