



# Effective Health Care Program

## Long-Term Care for Older Adults: A Review of Home and Community-Based Services Versus Institutional Care

### Executive Summary

#### Introduction

Long-term care (LTC) refers to a broad range of services designed to provide assistance over prolonged periods to compensate for loss of function due to chronic illness or physical or mental disability.<sup>1</sup> LTC includes hands-on, direct care as well as general supervisory assistance. The type, frequency, and intensity of services vary; some people need assistance for a few hours each week, whereas others need full-time support. LTC differs from acute or episodic medical interventions because it is integrated into an individual's daily life over an extended time.<sup>2</sup> LTC spans three realms: (1) assistance with essential, routine activities such as eating, bathing, dressing, and tasks required to maintain independence, such as preparing meals, managing medications, shopping for groceries, and using transportation; (2) housing; and (3) medical care. Often, LTC is associated with institutional settings such as nursing homes (NHs). However, LTC is also provided in a variety of noninstitutional settings collectively referred to as Home and Community-Based Services (HCBS).

For this report, we compared LTC for older adults delivered through HCBS with care delivered in NHs.

#### Effective Health Care Program

The Effective Health Care Program was initiated in 2005 to provide valid evidence about the comparative effectiveness of different medical interventions. The object is to help consumers, health care providers, and others in making informed choices among treatment alternatives. Through its Comparative Effectiveness Reviews, the program supports systematic appraisals of existing scientific evidence regarding treatments for high-priority health conditions. It also promotes and generates new scientific evidence by identifying gaps in existing scientific evidence and supporting new research. The program puts special emphasis on translating findings into a variety of useful formats for different stakeholders, including consumers.

The full report and this summary are available at [www.effectivehealthcare.ahrq.gov/reports/final.cfm](http://www.effectivehealthcare.ahrq.gov/reports/final.cfm).

Care through HCBS may be provided in a variety of settings, including recipients' homes; group living arrangements such as congregate housing, adult foster care,



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residential care (RC) and assisted living (AL) facilities (the last two terms are often used interchangeably although they are not always synonymous—we use the term AL throughout this report); and community settings such as adult daycare and adult day health. Services provided via HCBS may include care coordination or case management, personal care assistant service, personal attendant service, homemaker and personal care agency services, home hospice, home-delivered meals, home reconfiguration or renovation, medication management, skilled nursing, escort service, telephone reassurance service, emergency helplines, equipment rental and exchange, and transportation. HCBS also include educational and supportive group services for consumers or their families. Some services provided through HCBS are construed as respite care meant to relieve family caregivers. Services may need to be pieced together from multiple agencies and independent providers, with or without overall coordination or management.

NHs are State-licensed institutional facilities offering 24-hour room and board, supervision, and nursing care. NH services may include personal care, activities of daily living (ADL) support, medical management, nursing management, medication management, restorative nursing, palliative care, physical rehabilitation (either as a short-term service associated with postacute care or as maintenance rehabilitation), social activities, and transportation. NH care may also include family councils and support groups for informal caregivers.

AL appeared as a care modality in the 1980s and is now offered and licensed under a variety of names. AL presents a taxonomic problem because it varies so widely in the degree of privacy and space of the living arrangements offered and in the extent and range of services provided. The variation stems both from State licensure policies (that either require or prohibit specified services or living characteristics) and from the business models of the providers.<sup>3</sup> AL rarely offers the intensity of care, especially nursing care, found in NHs. Nonetheless, AL is an institution, albeit often a more livable one. Further complicating this picture is the emergence of so-called comprehensive care retirement communities in which a single campus offers services ranging from unassisted housing to AL to NHs. For this review, we examined the services individually. We categorized care provided in AL facilities as a subset of HCBS. However, we also examined AL separately, because in many ways, it represents a midway position between NH care and care in a recipient's home.<sup>4</sup>

Currently, more than 11 million individuals need LTC to assist them with life's daily activities.<sup>5</sup> The majority of these individuals (55%) are 65 years or older.<sup>5</sup> About two-thirds of Americans age 65 and older will eventually need some type of LTC for an average of 2 years.<sup>6,7</sup>

LTC needs are met through a combination of unpaid services provided by family members and paid assistance. More than three-quarters of community-dwelling adults rely exclusively on unpaid LTC assistance from family members.<sup>5,8</sup> Paid LTC services are financed through both public and private means. Medicaid, the public program jointly funded by Federal and State governments and administered by the States, is the largest source of public funding for LTC. Medicaid finances 40 percent of total national LTC spending.<sup>9</sup>

Almost 1.4 million individuals currently live in NHs.<sup>10</sup> NH care is a mandatory benefit under Medicaid for individuals who meet the eligibility criteria. In 2009, NH expenditures accounted for about 64 percent of Medicaid LTC expenditures for older adults and people with physical disabilities.<sup>11</sup>

Costs per individual for NH care generally exceed those for HCBS. Therefore, State governments (the major decisionmakers for LTC policies and care), have increasingly prioritized HCBS as a method to restrain LTC costs. The increased focus on HCBS has also been fueled by other factors. For example, consumers have expressed a preference for more LTC in the community, and the Supreme Court *Olmstead* decision stated that LTC services should be provided in the most integrated setting appropriate to the needs of qualified individuals with disabilities.<sup>12</sup>

Medicaid spending is rising faster for HCBS than for NHs. The national percentage of Medicaid spending on HCBS more than doubled from 1995 to 2009, from 19 percent to 43 percent.<sup>13</sup> Within Medicaid, spending for HCBS varies among different populations. In 2009, HCBS expenditures made up about 36 percent of LTC expenditures for older adults and people with physical disabilities.<sup>11</sup>

States have options for financing HCBS through Medicaid, including HCBS waivers, mandatory home health State plan services, and optional personal care State plan services. For individuals who meet the eligibility requirements, these services are provided in lieu of NH services.<sup>14</sup> States may also use funds from the Older Americans Act (OAA) and from general revenue to provide HCBS.<sup>15</sup>

Out-of-pocket expenditures make up about 22 percent of LTC spending, and private LTC insurance makes up about 9 percent.<sup>9</sup>

Both NHs and HCBS may offer equivalent services, but they differ in philosophy and emphasis. Meaningful comparisons require that the nuanced strengths and weaknesses of each setting be given careful attention. Outcomes in LTC result from a complex interplay among the characteristics of older adults, the environment, and the services delivered.

A successful mode of care meets the need for assistance, moderates the rate of functional decline, and improves quality of life. For older adults who need LTC, the choice of one form of care over the other requires a careful evaluation of the tradeoffs between competing priorities—for example, between safety and independence. The process of choosing a mode and setting of care may be influenced by multiple factors such as access, affordability, availability of informal support, and individual preferences. In addition, State regulatory frameworks and reimbursement policies profoundly affect the type of services offered and their availability across settings.

Initially, HCBS was considered an alternative to NH care. Early demonstration projects (from the mid-1970s through the late 1980s) on the effectiveness and costs of expanding LTC to include HCBS generated a large body of empirical literature as well as literature reviews.<sup>2,16,17</sup> By the mid-1990s, newer models of organizing, financing, and delivering care were used. These advances have not been adequately synthesized in the literature.<sup>18</sup> Additionally, thinking has shifted regarding the role of HCBS. The value of HCBS is no longer judged solely by its potential as a lower cost substitute for NH care. Instead, HCBS is now viewed as an LTC modality that is preferred by many older adults and that may enhance their quality of life. A synthesis of the latest evidence and an assessment of the state of the literature may help inform the policy debate as well as highlight areas for future research.

## Scope and Key Questions

This comparative effectiveness review targets direct comparisons of LTC provided through HCBS and in NHs. Substantial differences in case mixes between older adults served through HCBS and in NHs made indirect comparisons impossible. That is, heterogeneity in case mix precluded our ability to compare the findings of the

two bodies of literature that focused either on older adults served by HCBS or on adults in NHs. We examined studies with both cross-sectional and longitudinal designs. Cross-sectional studies compared outcomes across settings at a specific time. Longitudinal studies compared change in outcomes over a defined time period ranging from 6 months to 5 years. We examined published and grey literature from the United States and published literature from economically developed countries with well-established health and LTC systems.

We defined population, intervention, comparator, outcomes, setting, and timing as follows:

### Population

The population for this study included older adults (age  $\geq 60$ ) receiving LTC either through HCBS or in NHs. We adjusted the age ceiling for the Program of All-Inclusive Care for the Elderly (PACE), which begins eligibility at age 55. Patient characteristics that could modify outcomes include age, race/ethnicity, sex, socioeconomic status, functional status, clinical status, cognition, rural or urban settings, morbidities, mental illness, payer, prior service use, and disability history. Studies focusing on postacute care, such as Medicare home health services, were not included. Postacute care is care provided to individuals discharged from a hospital; it aids in their recuperation and rehabilitation and typically lasts less than 30 days.

### Intervention

HCBS refers to services provided in an array of noninstitutional settings. These include recipients' homes; community-based group-living arrangements such as congregate housing, adult foster care, and RC and AL facilities (the last two terms are sometimes used interchangeably, but we refer to AL exclusively); and community settings such as adult daycare and adult day health. Services provided via HCBS include care coordination or case management, personal care assistant service, personal attendant service, homemaker and personal care agency services, home hospice, home-delivered meals, home reconfiguration or renovation, medication management, skilled nursing, escort services, telephone reassurance services, emergency help lines, equipment rental and exchange, and transportation. Care through HCBS also includes educational and supportive group services for consumers or their families. Some aspects of HCBS are construed as respite care meant to relieve family caregivers.

For this review, we examined AL as a separate subset of HCBS, because it encompasses aspects of both community-based and institutional care.

### **Comparator**

NHs are State-licensed institutional facilities offering 24-hour room and board, supervision, and nursing care. Their services may include personal care, support for ADL, medical management, nursing management, medication management, restorative nursing, palliative care, physical rehabilitation (either as a short-term service associated with postacute care or as maintenance rehabilitation), social activities, and transportation.

### **Outcomes**

We separately examined resident outcomes and costs. We used data from cross-sectional studies to compare the characteristics of HCBS recipients and NH residents. We used longitudinal data to assess change in outcomes over time between HCBS recipients and NH residents. Outcomes of interest included physical function, mental health outcomes (e.g., depression and anxiety), quality of life, social function, satisfaction, outcomes related to family caregivers, death, place of death, use of acute care services (e.g., hospitals, emergency departments), and harms (e.g., accidents, injuries, pain, abuse, and neglect).

To examine costs, we considered all relevant costs to programs such as Medicaid and other public programs and costs to individuals and their families. These costs included spending on LTC services, acute care services, transfer programs, and opportunity costs to family caregivers.

### **Setting**

This review includes studies from the United States and international studies from these economically developed countries with well-established health and LTC systems: Canada, United Kingdom, Australia, and New Zealand, as well as Norway, Sweden, and other European countries. We analyzed international studies separately.

### **Timing**

The outcomes were assessed at periods of 6 months to many years.

### **Key Questions (KQs)**

**KQ 1. What are the benefits and harms of long-term care (LTC) provided through home and community-based services (HCBS) compared with institutions such as nursing homes (NHs) for adults age 60 and older who need LTC?**

- a. To what extent do HCBS and NHs serve similar populations?**
- b. How do the outcomes of the services differ when tested on similar populations?**
- c. What are the harms to older adults as a result of care at HCBS and NHs?**

**KQ 2. What are the costs (at the societal and personal levels) of HCBS and NHs (per recipient and in the aggregate) for adults age 60 and older? Costs may include direct costs of care as well as resource use and family burden.**

Direct costs of care refer to program and individual spending on LTC services for HCBS recipients and NH residents. Resource use includes program and individual spending on acute care services such as physician and hospital care as well as spending by other subsidy or transfer programs. Family burden includes the opportunity costs of care.

## **Methods**

### **Topic Refinement and Review Protocol**

The topic for this comparative effectiveness review was publicly nominated through the Agency for Healthcare Research and Quality's (AHRQ's) Effective Healthcare Web site <http://effectivehealthcare.ahrq.gov/index.cfm/submit-a-suggestion-for-research/>. We developed the KQs after a topic refinement process. The topic refinement process included a preliminary review of the literature and consultation with a Key Informant panel of LTC experts and stakeholders representing policy, consumer, and research perspectives. The draft KQs were posted for public comment on the Web site from October 10, 2011, to November 3, 2011. Public comments did not result in changes to the KQs.

A Technical Expert Panel (TEP) was convened to provide methodological and content expertise. Panel members provided input on the KQs, which they deemed to be appropriate, but they recommended lowering the age limit for inclusion from 65 to 60 years. We revised the age limit and added specific subquestions (1a and 1b; the text currently labeled 1c was present) to address the issue of differences in a case mix across settings.

The review protocol was posted for public comment on the AHRQ Effective Healthcare Program Web site on December 20, 2011. The protocol was sent to Panel members.

## Literature Search Strategy

We used several strategies to identify potential relevant studies from published and grey literature sources. We searched the bibliographic databases MEDLINE (via OVID) and AGELINE for randomized controlled trials (RCTs) and observational studies of LTC published from 1995 to March 2012. We supplemented bibliographic database searches with backward and forward citation searches of relevant articles and by hand searching. To ensure the completeness of the review and to identify missing publications, we compiled a list of prominent authors in the field and searched specifically for their work. Finally, we asked TEP members to review the included set and provide missing literature (if any) from their personal files.

To identify additional reports, we searched grey literature sources including Web sites of relevant Federal and State agencies (such as the Centers for Medicare & Medicaid Services and the Administration on Aging), research organizations (such as the Lewin Group, Abt Associates, and Mathematica Policy Research), foundations (such as the Robert Wood Johnson Foundation), and advocacy groups.

## Eligibility Criteria

The target population was older adults (age  $\geq 60$ ) who needed LTC. RCTs and quasi-experimental observational study designs were eligible for inclusion. Studies needed to include some comparison of HCBS and NHs. Studies could compare the populations across HCBS and NHs at a specific time (cross-sectional design) or evaluate changes in outcomes over time (longitudinal design). To capture studies most relevant to the current delivery of LTC in the United States, we limited studies by date (1995 to March 2012), language (English), and geographical location (United States and these economically developed countries with well-established health and LTC systems: Canada, United Kingdom, Australia, and New Zealand, as well as, Norway, Sweden, and other European countries). Grey literature studies that satisfied the above criteria were also eligible.

## Study Selection

Bibliographic database search results were downloaded to an Endnote reference management system. Eligible studies were identified in two stages. In the first stage, two investigators independently reviewed titles and abstracts of all references; studies deemed eligible for inclusion by either investigator were further evaluated. In the second stage, two investigators independently reviewed full

text to determine whether studies met inclusion criteria. Differences in full-text screening decisions were resolved by discussion or, when necessary, by consultation with a third investigator. For all studies excluded at the full-text screening stage, eligibility status and one exclusion reason were documented. Reasons for exclusion were coded as non-English language study; pre-1995 study; not a geographical setting of interest (countries other than the ones listed above); postacute care population (short-stay NH residents or Medicare home health recipients); no relevant comparison; no relevant settings or sample; and no relevant characteristics or outcomes.

## Data Extraction

One reviewer extracted data from included studies directly into evidence tables, and a second reviewer validated the data. Disagreements were resolved by consensus or, when needed, by consultation with a third reviewer. We abstracted data based on study design; location (the United States or international); sample populations; type of intervention and comparison (setting, services provided); length of followup for longitudinal studies; characteristics of study participants; and outcomes.

## Risk of Bias Assessment of Individual Studies

We assessed methodological risk of bias of longitudinal peer-reviewed studies from the United States using criteria specific to study design according to current AHRQ guidance.<sup>19</sup> Two reviewers independently assessed risk of bias for each study, and the full team of investigators validated the assessments.

We assessed risk of bias using questions adapted from the RTI International item bank for risk of bias.<sup>20</sup> Evaluation of selection bias was a key component of risk of bias assessment; studies that accounted for differences in case mix across setting using techniques such as multivariate analysis, propensity score matching, or instrumental variables were given a higher rating. In addition to selection bias, we evaluated completeness of intervention specification, use of equivalent outcome measures across experimental and control groups, and differential loss to followup. We assessed summary risk of bias as high, moderate, low, or unclear based on the overall risk of bias created by the individual components assessed.

## Data Synthesis

Heterogeneity in populations, interventions, and settings across studies precluded quantitative synthesis of results. Instead, we analyzed results qualitatively to arrive at conclusions regarding the extent of similarity between

populations served by HCBS and NHs and to assess the differences in outcomes of the services when tested on similar populations. Throughout the analysis, we considered AL as a separate category within HCBS because it encompasses elements of both institutional and community-based care. We separately analyzed international studies to account for contextual differences. We also separately analyzed results from grey literature.

We compared characteristics of HCBS recipients with those of NH residents using data from cross-sectional and longitudinal studies that reported case mix. We compared HCBS (including AL) recipients with NH residents across the domains of physical function, cognition, mental health, and comorbidities. We used data from longitudinal studies to compare changes in outcome trajectories over time between HCBS recipients or AL residents and NH residents for a range of outcome domains: physical function, cognitive function, mental health, mortality, use of acute care services, harms, and costs.

### **Strength of the Body of Evidence**

We evaluated the overall strength of evidence using methods developed by the AHRQ Evidence-based Practice Center Program<sup>21</sup> for the same outcome domains as above. We aggregated all relevant outcome measures within a particular outcome domain and evaluated strength of evidence based on the aggregated set. Because many possible outcome measures may be used within one domain, and because all included studies used an observational design, consistency in the direction of effect was of interest. We evaluated strength of evidence on four required domains:

- Risk of bias (whether the studies for a given outcome or comparison had good internal validity). We rated overall risk of bias as low, moderate, or high based on individual study designs and conduct. For each outcome (such as cognitive function) and each comparison (such as a broad definition of HCBS versus NH, or AL as a subset of HCBS versus NH) we assigned an overall risk of bias based on the average of the individual study risk of bias scores. We assigned a moderate risk of bias rating if the preponderance of studies were of moderate risk of bias, or if one study involved a study population several times larger than the other contributing studies combined. We assigned a high risk of bias rating if the preponderance of individual studies were high risk of bias, or if a moderate risk of bias study did not have a large enough study population to justify dominating the rating.

- Consistency (whether the included studies had the same direction of effect). We rated consistency as consistent, inconsistent, or unknown (e.g., a single study was evaluated).
- Directness (reflecting a single, direct link between the intervention of interest and the outcome, or the direct comparison of the interventions of interest). Directness was assigned as either direct or indirect.
- Precision (degree of certainty surrounding an effect estimate of a given outcome). Precision was assigned as either precise or imprecise. Since we did not conduct a quantitative meta-analysis of the findings, we based precision on the individual study measures. Since the outcome domains were assessed as aggregates of relevant outcome measures, the precision score also reflected how fully the set of outcome measures described the outcome domain.

The full team of investigators, using consensus, rated the individual domains qualitatively and assigned an overall strength of evidence summary rating of high, moderate, or low strength of evidence for domains in KQ 1b, KQ 1c, and KQ 2. We did not rate strength of evidence for KQ 1a. We based strength of evidence on the longitudinal peer-reviewed studies from the United States. Although relevant international and grey literature studies supplemented our analysis, we did not include them in the strength of evidence ratings.

Given the absence of RCTs, we graded no outcome as having high-strength evidence. We graded an outcome as insufficient when evidence did not permit a conclusion. Thus, a single small observational study for a given outcome and comparison was always rated as insufficient. For all other bodies of evidence, we took the perspective of policymakers facing decisions within a political environment and process: even when evidence is lacking, decisions are required. Therefore, we took a liberal stance on grading evidence as low-strength rather than insufficient. We graded evidence as low if the studies within a set were high risk of bias but consistent in their finding of benefit or no difference (and directness was automatic because we reviewed only studies of direct comparisons of HCBS with NH using patient-centered outcomes).

### **Applicability**

We assessed applicability<sup>22</sup> separately from strength of evidence based on the following criteria: eligibility requirements for enrollment; case mix; type, frequency,

and intensity of services delivered; outcomes measured; and setting (country/geographical region; rural/urban).

## Results

Results are presented by KQ. Detailed evidence tables are available in the full report.

### Results of Literature Searches

Of 2,043 references, 73 were identified as potentially relevant to the comparison, based on a review of titles and abstracts. Full-text screening resulted in a final list of 36 eligible articles. Hand searching produced an additional six articles, five of which were grey literature reports, resulting in a final tally of 42 articles addressing 32 different studies.

We identified no eligible RCTs. Of the 42 observational articles included, 37 were peer-reviewed journal articles, and five were from grey literature reports. The peer-reviewed journal articles included 22 cross-sectional studies and 15 longitudinal studies (of which 14 were used in the analytic set). Eight international studies were among the 42.

### KQ 1: Benefits and Harms of HCBS Compared With NHs for Older Adults Using LTC

#### KQ 1a: Similarity of Populations Served by HCBS and NH

On average, NH residents were more physically and cognitively impaired than HCBS recipients and AL residents. Mental health and clinical status outcomes were mixed. Parallel data from grey literature studies reflected the same pattern.

#### KQ 1b: Outcomes in Populations Served by HCBS Versus NHs

The 14 studies comparing the trajectories of HCBS recipients or AL residents with NH residents over time had high risk of bias, resulting in low-strength or insufficient evidence for all outcomes examined. Overall, the studies provided low-strength evidence that the rate of change in physical function, cognition, and mental health did not differ significantly between AL and NH residents. Evidence was insufficient for the outcomes of interest for the HCBS versus NH comparison. Two studies provided low-strength evidence that mortality did not differ between AL and NH residents, but evidence was insufficient for the HCBS versus NH comparison. Evidence was also insufficient for comparing acute care use between both AL versus NH and HCBS versus NH.

### KQ 1c: Harms in HCBS and NHs

Two studies provided low-strength evidence that harms differed between HCBS recipients and NH residents. Recipients of HCBS experienced higher rates of some harms, and NH residents experienced higher rates of other harms. Evidence was insufficient for comparing harms of AL versus NH.

### KQ 2: Costs of HCBS and NHs

One study provided insufficient evidence that Medicaid expenditures were higher for HCBS recipients than for NH residents. Other program and individual expenditures were not analyzed. No studies analyzed expenditures for AL versus NH residents.

## Discussion

We found very few studies from which to draw conclusions for any given outcome of interest. Sparse literature and design problems resulted in low-strength or insufficient evidence for the seven outcomes we examined in detail. Table A provides a summary of the key findings and strength of evidence for the KQs addressed in this review. Several factors, discussed in detail below, must be considered in interpreting this body of evidence.

Most studies did not provide detailed descriptions of settings and services received; few studies specified the type, frequency, or intensity of services. Analyses of the effectiveness of these modalities must describe both the clientele and the services in enough detail to provide needed context and to allow for judging applicability. Additionally, most studies did not report whether participants received any informal care.

Most studies did not adequately address the problems of selection bias or attrition. Further, the settings where individuals receive LTC may not reflect personal choice or fit, but instead be largely a function of payment systems and policy environments. Attempts to make indirect comparisons are complicated by issues of selection, case mix, and attrition. If not adequately dealt with by study design, these issues also impede direct comparisons.

Distinguishing between longstanding and new LTC users is difficult. Few studies used an admission cohort. Outcomes may differ between newcomers to the LTC system and those who have lived with limitations or received services for a long time, yet studies infrequently distinguished between the two. Additionally, followup times for tracing outcomes of interest were often short. Longer followups are needed because outcomes may not continue on the same trajectory over longer periods.

**Table A. Summary of key findings and strength of evidence for outcome domains**

Domain/Outcome	Key Findings/Strength of Evidence
<b>KQ 1b</b>	
Changes in physical function	<ul style="list-style-type: none"> <li>• Three studies provided low-strength evidence (high risk of bias) that the rate of change in physical function did not differ between AL and NH residents over time.</li> <li>• One study provided insufficient evidence for the HCBS versus NH comparison; this study found that HCBS recipients had better physical functioning compared with NH residents at most points in time, but it did not test the change over time between the groups.</li> </ul>
Changes in cognitive function	<ul style="list-style-type: none"> <li>• Two studies provided low-strength evidence (high risk of bias) that the rate of change in cognitive function did not differ between AL and NH residents over time.</li> <li>• One study provided insufficient evidence for the HCBS versus NH comparison; this study found that HCBS recipients had higher cognitive functioning compared with NH residents at most points in time, but it did not test the change over time between the groups.</li> </ul>
Changes in mental health	<ul style="list-style-type: none"> <li>• Three studies provided low-strength evidence (high risk of bias) that the rate of change in mental health did not differ between AL and NH residents over time.</li> <li>• One study provided insufficient evidence for the HCBS versus NH comparison; this study found that HCBS recipients had less depression compared with NH residents at several points in time, but it did not test the change over time between the groups.</li> </ul>
Mortality	<ul style="list-style-type: none"> <li>• Two studies provided low-strength evidence (high risk of bias) that mortality did not differ between AL and NH residents.</li> <li>• One study provided insufficient evidence for the HCBS versus NH comparison; this study found that HCBS and PACE recipients had higher median survival compared with NH residents.</li> </ul>
Acute care utilization	<ul style="list-style-type: none"> <li>• One study provided insufficient evidence for acute care use for the AL versus NH comparison; this study found higher rates of hospitalization for AL versus NH residents for the mild dementia group, but no difference for the moderate/severe dementia group.</li> <li>• One study provided insufficient evidence for acute care use for the HCBS versus NH comparison; this study found no difference in the odds of hospitalization between HCBS recipients and NH residents, and lower odds of hospice referral for NH residents.</li> </ul>
<b>KQ 1c</b>	
Harms	<ul style="list-style-type: none"> <li>• Two studies provided low-strength evidence (high risk of bias) that harms differed. HCBS recipients experienced higher rates of some harms, and NH residents experienced higher rates of other harms.</li> <li>• One study provided insufficient evidence for harms for the AL versus NH comparison; this study found no difference in pain and discomfort between AL and NH residents.</li> </ul>
<b>KQ 2</b>	
Costs	<ul style="list-style-type: none"> <li>• One study provided insufficient evidence for Medicaid expenditures for the HCBS versus NH comparison. This study found that HCBS recipients had lower Medicaid expenditures, but other relevant program and individual expenditures were not analyzed.</li> <li>• Evidence was insufficient for comparing expenditures between AL and NH due to no studies examining this outcome.</li> </ul>

AL = assisted living; HCBS = home and community-based services; KQ = Key Question; NH = nursing home; PACE = Program of All-Inclusive Care for the Elderly

Most studies were not explicit about who was included in each examined group. For instance, most studies did not specify whether individuals receiving postacute care (short stay) were included or excluded from the study populations. Postacute care is provided to individuals upon discharge from a hospital; it is intended to aid their recuperation and rehabilitation. Postacute care typically lasts less than 30 days. In contrast, LTC is integrated into a person's life over an extended time. These groups may experience different outcomes and have different characteristics and preferences. Thus, investigators must be explicit about who is included or excluded.

Outcome measures and data collection varied across studies. This made it difficult to compare results. Comparisons of outcome trajectories must take into account differences in care environments, including which measurements are used and who collects the data. NH policies and environments restrict residents' activities. For example, few, if any, NH residents are allowed to bathe by themselves. Thus, NH residents' ADL measures reflect less ability for self-care.

Another concern related to ceiling or floor effects is that HCBS recipients and NH residents may have different starting points for their respective trajectories. Given their greater level of disability at the outset, NH residents may have less opportunity to decline and may show little change in the typical measures used. We must also acknowledge the potential for right censoring, whereby the higher mortality rate in NHs may remove the most disabled residents. We could not determine whether these important issues affected the results of any studies in this review.

The review of costs was limited given the insufficient evidence from published studies. The supporting evidence from grey literature sources suggests that cost comparisons are typically incomplete and do not include many relevant sources, including other public program expenditures, individual expenditures, and family burden.

Applicability is limited; many of the samples are not generalizable (often small, limited by geography, or specific programs that do not apply to populations outside the study). Most of the studies were conducted on samples of Medicaid patients.

### **Implications for Policy Decisionmaking**

Given the generally weak literature to assess the relative effectiveness of HCBS and NHs, policy decisions will likely continue to be made on the basis of preferences and beliefs (largely the preferences and beliefs of

policymakers but perhaps those of consumers, as well). The paradigm for comparing HCBS and NHs has shifted over time. Initially, HCBS was seen as a potentially less expensive alternative to NHs. Now, HCBS is increasingly viewed as a preferable care modality that enhances clients' quality of life. NH environments and living settings are frequently very restrictive, and few would now be surprised that quality of life was higher for those in HCBS.

### **Research Gaps**

The weakness of the literature stands in sharp contrast to the importance of the topic. Many stakeholders want to know about the relative effectiveness of alternative modes of LTC. As budgets tighten and as demographically driven demand increases, states and other entities are seeking more efficient ways to deliver LTC. Better research is needed to address questions related to LTC delivered through HCBS versus NH, including the changes in outcome trajectories over time, harms, and costs.

Existing literature is difficult to review due to heterogeneity of services, settings, populations, and measures. Randomization to HCBS or NHs could ensure that the respective populations are comparable on measured as well as unmeasured factors. However, practical and ethical issues make the use of randomized designs highly unlikely. In the absence of RCTs, well-designed prospective studies could contribute valuable information. Prospective studies should pay careful attention to selection bias, preferably with direct and comparable measurement and assessment in both settings.

Future research needs are extensive. Studies should be designed to address both methodological issues and fundamental questions such as the tradeoffs residents face when choosing between settings. Table B summarizes the research gaps. Addressing these issues will enable better analyses and help consumers and policymakers make informed, evidence-based choices. Areas of future research, organized by KQ, are provided in the main body of the report.

### **Conclusions**

The question of how LTC delivered through HCBS and in NHs affects outcome trajectories of older adults is difficult to resolve due to limited evidence and the methodological limitations of studies reviewed. More and better research is needed to draw robust conclusions about how setting influences outcomes and costs of older adults using LTC.

**Table B. Summary of research gaps to address**

<b>Methodological Issues</b>	<b>Findings</b>	<b>Research Needs</b>
Define interventions	<ul style="list-style-type: none"> <li>• Descriptions of interventions were vague</li> </ul>	<ul style="list-style-type: none"> <li>• Careful descriptions of the nature of the settings and services and the extent of the services received</li> <li>• Report whether individuals receive informal care</li> </ul>
Composition of persons served	<ul style="list-style-type: none"> <li>• NH residents were generally more impaired than HCBS recipients in terms of physical and cognitive function, but composition was mixed for mental health and clinical status; the distributions overlapped for HCBS and NH groups</li> <li>• Domains were difficult to compare across studies because of the differences in measures and scales</li> <li>• Method of ascertainment and timing often varied for measures across settings</li> <li>• Details about the study populations were not always specified</li> </ul>	<ul style="list-style-type: none"> <li>• Systematic data collection using standardized measures at meaningful time intervals</li> <li>• Specify populations included in study (i.e., whether individuals receiving postacute care were included or excluded and whether individuals are new or long-standing LTC users)</li> </ul>
Selection bias	<ul style="list-style-type: none"> <li>• Efforts to account for case mix differences were often weak</li> </ul>	<ul style="list-style-type: none"> <li>• More and better efforts to adjust for selection bias, including:               <ul style="list-style-type: none"> <li>– Propensity scores</li> <li>– Instrumental variables</li> <li>– Ideal types</li> <li>– Multivariate analysis</li> <li>– Measures of social support and attitudes</li> </ul> </li> </ul>
Attrition bias	<ul style="list-style-type: none"> <li>• Attrition bias was often ignored</li> </ul>	<ul style="list-style-type: none"> <li>• Methods to deal with attrition, especially death:               <ul style="list-style-type: none"> <li>– Use death as worst functional case</li> <li>– Use two-stage models</li> </ul> </li> </ul>
Dealing with change in care setting/services received	<ul style="list-style-type: none"> <li>• No detail was generally provided about whether individuals moved between settings</li> </ul>	<ul style="list-style-type: none"> <li>• Describe and account for persons moving from one type of care to another</li> </ul>
Outcome measures	<ul style="list-style-type: none"> <li>• Outcome measures were not always similar across settings or studies</li> </ul>	<ul style="list-style-type: none"> <li>• Use standardized measures. Choose those most capable of showing meaningful change and measure at appropriate intervals</li> </ul>
Rates of change in physical function, cognition, and mental health	<ul style="list-style-type: none"> <li>• Similar rates of change for AL and NH residents but indeterminate for HCBS recipients versus NH residents</li> <li>• Possible ceiling and/or floor effects</li> </ul>	<ul style="list-style-type: none"> <li>• Better adjustment for case mix differences</li> <li>• Better analyses to examine floor and ceiling effects</li> </ul>
Utilization of acute care	<ul style="list-style-type: none"> <li>• Insufficient evidence</li> </ul>	<ul style="list-style-type: none"> <li>• Examine various types of acute care use</li> <li>• More efforts to adjust for selection bias</li> <li>• Better adjustment for case mix</li> </ul>
Harms	<ul style="list-style-type: none"> <li>• Results on harms were mixed</li> </ul>	<ul style="list-style-type: none"> <li>• Consistent and comprehensive measures of harms, including psychological and social harms</li> </ul>

**Table B. Summary of research gaps to address (continued)**

<b>Methodological Issues</b>	<b>Findings</b>	<b>Research Needs</b>
Other outcomes	<ul style="list-style-type: none"> <li>Studies did not measure many other relevant domains</li> </ul>	<ul style="list-style-type: none"> <li>Other important outcomes include quality of life, social functioning, community integration, experience of care, and satisfaction</li> <li>Use standardized measures of functioning applicable to both settings</li> </ul>
Costs	<ul style="list-style-type: none"> <li>Results were insufficient</li> <li>Cost comparisons appear to be incomplete since they do not include all relevant expenditures (expenditures by public programs and individual expenditures)</li> <li>No consideration of family burden</li> </ul>	<ul style="list-style-type: none"> <li>Cost comparisons should account for all relevant public and individual spending on either side of the HCBS and NH ledger:                             <ul style="list-style-type: none"> <li>Spending by Medicaid, Medicare, and public subsidy programs (room and board, rent, transportation, and food stamps)</li> <li>Spending by individuals and their families (direct out-of-pocket and insurance spending and costs of informal care provided by family members)</li> </ul> </li> </ul>
<b>Topical Issues</b>	<b>Findings</b>	<b>Research Needs</b>
Longitudinal studies	<ul style="list-style-type: none"> <li>The number of longitudinal studies was limited</li> </ul>	<ul style="list-style-type: none"> <li>More studies that trace change in status over time</li> </ul>
Applicability/generalizable populations	<ul style="list-style-type: none"> <li>Samples were often drawn from unique settings</li> </ul>	<ul style="list-style-type: none"> <li>More generalizable samples</li> </ul>
Differences within subgroups	<ul style="list-style-type: none"> <li>No studies performed subgroup analysis</li> </ul>	<ul style="list-style-type: none"> <li>More attention to samples that capture various subgroups by major problem (e.g., diagnosis, functional level) or socioeconomic status</li> <li>More attention to characterizing dementia</li> </ul>
Defining and weighting outcomes	<ul style="list-style-type: none"> <li>Most studies looked at discrete outcomes</li> </ul>	<ul style="list-style-type: none"> <li>Outcomes are multidimensional; determining what kind of care is best requires weighting the multiple possible outcomes:                             <ul style="list-style-type: none"> <li>Some form of utility weighting exercise with relevant respondents may be useful</li> </ul> </li> </ul>
Private market	<ul style="list-style-type: none"> <li>Most studies focused on Medicaid populations</li> </ul>	<ul style="list-style-type: none"> <li>Studies on private pay clients</li> </ul>

AL = assisted living; HCBS = home and community-based services; LTC = long-term care

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## Full Report

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