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



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

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Preface

The Agency for Healthcare Research and Quality (AHRQ) conducts the Effective Health Care Program as part of its mission to organize knowledge and make it available to inform decisions about health care. As part of the Medicare Prescription Drug, Improvement, and Modernization Act of 2003, Congress directed AHRQ to conduct and support research on the comparative outcomes, clinical effectiveness, and appropriateness of pharmaceuticals, devices, and health care services to meet the needs of Medicare, Medicaid, and the Children's Health Insurance Program (CHIP).

AHRQ has an established network of Evidence-based Practice Centers (EPCs) that produce Evidence Reports/Technology Assessments to assist public- and private-sector organizations in their efforts to improve the quality of health care. The EPCs now lend their expertise to the Effective Health Care Program by conducting comparative effectiveness reviews (CERs) of medications, devices, and other relevant interventions, including strategies for how these items and services can best be organized, managed, and delivered.

Systematic reviews are the building blocks underlying evidence-based practice; they focus attention on the strength and limits of evidence from research studies about the effectiveness and safety of a clinical intervention. In the context of developing recommendations for practice, systematic reviews are useful because they define the strengths and limits of the evidence, clarifying whether assertions about the value of the intervention are based on strong evidence from clinical studies. For more information about systematic reviews, see www.effectivehealthcare.ahrq.gov/reference/purpose.cfm.

AHRQ expects that CERs will be helpful to health plans, providers, purchasers, government programs, and the health care system as a whole. In addition, AHRQ is committed to presenting information in different formats so that consumers who make decisions about their own and their family's health can benefit from the evidence.

Transparency and stakeholder input are essential to the Effective Health Care Program. Please visit the Web site (www.effectivehealthcare.ahrq.gov) to see draft research questions and reports or to join an email list to learn about new program products and opportunities for input. Comparative Effectiveness Reviews will be updated regularly.

We welcome comments on this CER. They may be sent by mail to the Task Order Officer named below at: Agency for Healthcare Research and Quality, 540 Gaither Road, Rockville, MD 20850, or by email to epc@ahrq.hhs.gov.

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Structured Abstract

Objectives. To compare long-term care (LTC) for older adults delivered through Home and Community-Based Services (HCBS) with care provided in nursing homes (NHs) by evaluating (1) the characteristics of older adults served through HCBS and in NHs; (2) the impact of HCBS and NH care on outcome trajectories of older adults; and (3) the per person costs of HCBS and NH care, costs for other services such as acute care, and family burden.

Data sources. Bibliographic databases MEDLINE[®] and AGELINE[®]; grey literature in the form of program evaluation reports and reports and analyses from Web sites of relevant State and Federal agencies and research organizations; citation searches of articles; and hand searches.

Review methods. We included randomized controlled trials (RCTs) and observational studies that directly compared LTC for older adults (age ≥ 60) served through HCBS and in NHs. Studies were limited by date (1995–March 2012), language (English), and geographical location (United States and other economically developed countries with well-established health and LTC systems). Because assisted living (AL) encompasses elements of institutions, we treated it as a separate category within HCBS. We compared the characteristics of LTC recipients and the impact of the setting on outcome trajectories for physical function, cognition, mental health, mortality, use of acute care services, harms, and costs. We qualitatively synthesized results. We assessed the risk of bias and applicability of individual studies and graded the overall strength of evidence for each examined outcome.

Results. We identified 42 relevant studies (37 peer reviewed, 5 grey literature). We identified no RCTs. Of the 37 peer-reviewed articles, 22 evaluated recipient characteristics at a specific time, and 15 analyzed outcome trajectories over time (of which 14 were used in the longitudinal analytic set). On average, NH residents had more limitations in physical and cognitive function than both HCBS recipients and AL residents, but mental health and clinical status were mixed. The 14 studies that compared the outcome trajectories of HCBS recipients or AL residents with NH residents over time had a high risk of bias, resulting in low or insufficient evidence for all outcomes examined. In comparing AL with NH, low-strength evidence suggested no differences in outcomes for physical function, cognition, mental health, and mortality. In comparing HCBS with NHs, low-strength evidence suggested that HCBS recipients experienced higher rates of some harms while NH residents experienced higher rates of other harms. Evidence was insufficient for other outcome domains and comparisons. Evidence was also insufficient for cost comparisons.

Conclusions. Determining whether and how the delivery of LTC through HCBS versus NHs affects outcome trajectories of older adults is difficult due to scant evidence and the methodological limitations of studies reviewed. More and better research is needed to draw robust conclusions about how the setting of care delivery influences the outcomes and costs of LTC for older adults.

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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.¹ 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.² 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.

Care through HCBS may be provided in a variety of settings, including recipients' homes; group living arrangements such as congregate housing, adult foster care, 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.³ 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.⁴

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

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.^{5,8} 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.⁹

Almost 1.4 million individuals currently live in NHs.¹⁰ 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.¹¹

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.¹²

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.¹³ 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.¹¹

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.¹⁴ States may also use funds from the Older Americans Act (OAA) and from general revenue to provide HCBS.¹⁵

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

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.^{2,16,17} By the mid-1990s, newer models of organizing, financing, and delivering care were used. These advances have not been adequately synthesized in the literature.¹⁸ 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 ≥ 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 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 ≥ 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.¹⁹ 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.²⁰ 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 Program²¹ 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 applicability²² 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.

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.

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

Domain/Outcome	Key Findings/Strength of Evidence
<i>KQ 1b</i>	
Changes in physical function	<ul style="list-style-type: none"> • 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. • 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.
Changes in cognitive function	<ul style="list-style-type: none"> • 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. • 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.

Table A. Summary of key findings and strength of evidence for outcome domains (continued)

Domain/Outcome	Key Findings/Strength of Evidence
<i>KQ 1b (continued)</i>	
Changes in mental health	<ul style="list-style-type: none"> • 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. • 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.
Mortality	<ul style="list-style-type: none"> • Two studies provided low-strength evidence (high risk of bias) that mortality did not differ between AL and NH residents. • 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.
Acute care utilization	<ul style="list-style-type: none"> • 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. • 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.
<i>KQ 1c</i>	
Harms	<ul style="list-style-type: none"> • 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. • 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.
<i>KQ 2</i>	
Costs	<ul style="list-style-type: none"> • 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. • Evidence was insufficient for comparing expenditures between AL and NH due to no studies examining this outcome.

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

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.

Table B. Summary of research gaps to address

Methodological Issues	Findings	Research Needs
Define interventions	<ul style="list-style-type: none"> • Descriptions of interventions were vague 	<ul style="list-style-type: none"> • Careful descriptions of the nature of the settings and services and the extent of the services received • Report whether individuals receive informal care
Composition of persons served	<ul style="list-style-type: none"> • 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 • Domains were difficult to compare across studies because of the differences in measures and scales • Method of ascertainment and timing often varied for measures across settings • Details about the study populations were not always specified 	<ul style="list-style-type: none"> • Systematic data collection using standardized measures at meaningful time intervals • 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)
Selection bias	<ul style="list-style-type: none"> • Efforts to account for case mix differences were often weak 	<ul style="list-style-type: none"> • More and better efforts to adjust for selection bias, including: <ul style="list-style-type: none"> – Propensity scores – Instrumental variables – Ideal types – Multivariate analysis – Measures of social support and attitudes

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

Methodological Issues	Findings	Research Needs
Attrition bias	<ul style="list-style-type: none"> Attrition bias was often ignored 	<ul style="list-style-type: none"> Methods to deal with attrition, especially death: <ul style="list-style-type: none"> Use death as worst functional case Use two-stage models
Dealing with change in care setting/services received	<ul style="list-style-type: none"> No detail was generally provided about whether individuals moved between settings 	<ul style="list-style-type: none"> Describe and account for persons moving from one type of care to another
Outcome measures	<ul style="list-style-type: none"> Outcome measures were not always similar across settings or studies 	<ul style="list-style-type: none"> Use standardized measures. Choose those most capable of showing meaningful change and measure at appropriate intervals
Rates of change in physical function, cognition, and mental health	<ul style="list-style-type: none"> Similar rates of change for AL and NH residents but indeterminate for HCBS recipients versus NH residents Possible ceiling and/or floor effects 	<ul style="list-style-type: none"> Better adjustment for case mix differences Better analyses to examine floor and ceiling effects
Utilization of acute care	<ul style="list-style-type: none"> Insufficient evidence 	<ul style="list-style-type: none"> Examine various types of acute care use More efforts to adjust for selection bias Better adjustment for case mix
Harms	<ul style="list-style-type: none"> Results on harms were mixed 	<ul style="list-style-type: none"> Consistent and comprehensive measures of harms, including psychological and social harms
Other outcomes	<ul style="list-style-type: none"> Studies did not measure many other relevant domains 	<ul style="list-style-type: none"> Other important outcomes include quality of life, social functioning, community integration, experience of care, and satisfaction Use standardized measures of functioning applicable to both settings
Costs	<ul style="list-style-type: none"> Results were insufficient Cost comparisons appear to be incomplete since they do not include all relevant expenditures (expenditures by public programs and individual expenditures) No consideration of family burden 	<ul style="list-style-type: none"> 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"> Spending by Medicaid, Medicare, and public subsidy programs (room and board, rent, transportation, and food stamps) Spending by individuals and their families (direct out-of-pocket and insurance spending and costs of informal care provided by family members)
Topical Issues	Findings	Research Needs
Longitudinal studies	<ul style="list-style-type: none"> The number of longitudinal studies was limited 	<ul style="list-style-type: none"> More studies that trace change in status over time
Applicability/generalizable populations	<ul style="list-style-type: none"> Samples were often drawn from unique settings 	<ul style="list-style-type: none"> More generalizable samples
Differences within subgroups	<ul style="list-style-type: none"> No studies performed subgroup analysis 	<ul style="list-style-type: none"> More attention to samples that capture various subgroups by major problem (e.g., diagnosis, functional level) or socioeconomic status More attention to characterizing dementia
Defining and weighting outcomes	<ul style="list-style-type: none"> Most studies looked at discrete outcomes 	<ul style="list-style-type: none"> Outcomes are multidimensional; determining what kind of care is best requires weighting the multiple possible outcomes: <ul style="list-style-type: none"> Some form of utility weighting exercise with relevant respondents may be useful
Private market	<ul style="list-style-type: none"> Most studies focused on Medicaid populations 	<ul style="list-style-type: none"> Studies on private pay clients

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

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.

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Introduction

Definition

Long-term care (LTC) refers to a broad range of services designed to provide assistance over prolonged periods. LTC services attempt to compensate for loss of function due to chronic illness or physical or mental disability.¹ LTC represents the intersection of personal services, housing, and medical care (especially chronic disease management). LTC varies in frequency and intensity according to the needs of the recipients. It includes hands-on, direct care as well as general supervisory assistance. LTC includes support for activities of daily living (ADLs), instrumental activities of daily living (IADLs), and routine nursing services such as administration of medications.² LTC may affect older people's quality of life. Its impact also extends to family members, who are often the primary source of support for older adults with functional limitations.² LTC may include services and supports for family members and other unpaid caregivers.

This review compares LTC for older adults delivered through Home and Community-Based Services (HCBS) with care delivered in nursing homes (NHs).

HCBS refers to services provided in an array of noninstitutional settings, including recipients' homes; community group living arrangements such as congregate housing, adult foster care, 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 day care and adult day health.

NHs are state-licensed institutional facilities offering 24-hour room and board, supervision, and nursing care. NH services may include personal care, 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 AL settings vary so widely in the degree of privacy and space of the living arrangements 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.³ AL rarely offers the intensity of care, especially nursing care, found in nursing homes. 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 care in NHs care and care in recipients' own homes.⁴

The services provided through HCBS resemble those provided in NHs. However, HCBS services may need to be pieced together from multiple agencies and independent providers, with or without overall coordination or management. Care through HCBS includes 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 help lines, equipment rental and exchange, and transportation. HCBS also includes 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. Formal rehabilitation may also be provided at home, usually as a short-term postacute service associated with Medicare.

Background

Currently, more than 10 million community residents and 1 million nursing home residents need LTC to assist them with life's daily activities.⁵ The majority of these individuals (55 percent) are 65 years and older.⁵ About two-thirds of Americans age 65 and older will eventually need some type of LTC for an average of 2 years.^{6,7}

LTC needs are met through a combination of paid assistance and unpaid services provided by family members. More than three-quarters of community-dwelling adults rely exclusively on unpaid LTC assistance from family members.^{2,5} 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, financing 40 percent of total national LTC spending.⁸

At present, almost 1.4 million individuals reside in the 15,690 nursing homes in the United States.⁹ Approximately 4 percent of the population age 65 and older live in nursing homes.¹⁰ NH care is a mandatory benefit under Medicaid for individuals that meet the eligibility criteria. In 2009, NH expenditures accounted for about 64 percent of the \$80 billion in Medicaid LTC expenditures for older adults and people with physical disabilities.¹¹

Costs per individual for NH care generally exceed those for HCBS. For this reason, states (the major decisionmakers for LTC policies and care) have increasingly prioritized HCBS as a method to restrain LTC costs. Other reasons for increased focus on HCBS include consumer preferences for more LTC in the community and the Supreme Court Olmstead decision stating that LTC services should be provided in the most integrated setting appropriate to the needs of qualified individuals with disabilities.¹²

About 43 percent of total Medicaid LTC dollars are dedicated to HCBS programs for all recipient groups. Medicaid spending is rising faster for HCBS than for NH. The national percentage of Medicaid spending on HCBS more than doubled from 1995 to 2009, from 19 percent to 43 percent.¹³ Within Medicaid, spending for HCBS varies among different populations. In 2009 HCBS expenditures accounted for about 36 percent of the \$80 billion in Medicaid LTC expenditures for older adults and people with physical disabilities.¹¹ The use and economic consequences of LTC services are expected to increase in the next few decades as the population ages.

States have various options for delivering HCBS, of which the Medicaid Section 1915(c) HCBS waivers are the most common. States can apply for HCBS waivers to the Centers for Medicare & Medicaid Services (CMS) to provide LTC through HCBS as opposed to NHs (www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Waivers/Waivers.html).

The HCBS waivers allow states to offer services not typically covered under Medicaid to subsets of Medicaid beneficiaries (e.g., aged and physically disabled, intellectually and developmentally disabled) rather than as a universal benefit to all Medicaid beneficiaries within the state. Thus, individuals who meet certain minimum state-determined eligibility criteria (e.g., income and need requirements at a minimum of NH eligibility) are able to receive HCBS under Medicaid in lieu of NH services. Medicaid HCBS waivers allow states to limit the number of

individuals who can receive services during a year and to use waiting lists if all approved slots are filled. Services that can be provided through waivers vary and include homemaker services, home health aide services, personal care services, adult day services, and case management.¹⁴ Waivers are subject to cost-neutrality requirements. This means that states must demonstrate to CMS that using HCBS waivers to serve institutionally eligible individuals costs the same or less than providing services to these individuals in NHs. States can initially receive approval for the HCBS waivers for 3 years, with potential for renewal every 3 or 5 years.¹⁵

States can also offer HCBS through state plan benefits. The most common state plan benefits are the mandatory home health state plan service and the optional personal care state plan service. Generally the state plan benefits must be available to all individuals who meet the eligibility requirements. Thus, these services cannot be limited as they can under the HCBS waivers.¹⁶ Services through the home health state plan include part-time nursing services, home health aide services, medical supplies and home equipment, and other services at state discretion. Personal care services include services that provide assistance with ADLs and IADLs. New options under the Deficit Reduction Act (DRA) of 2005 and the Patient Protection and Affordable Care Act of 2010 give states more flexibility with these programs.¹⁴

HCBS Medicaid dollars for community residential care are restricted to the service component and exclude room and board costs. Consumers are expected to cover room and board through their own income. NH care also requires most of the income of residents who are financed in full or part by Medicaid. NH payment, however, includes room and board, leaving the resident with only the state-permitted small personal needs allowance.

In addition to Medicaid, states use other mechanisms to fund LTC services. Older Americans Act (OAA) funding is appropriated to states to provide LTC services such as home-delivered meals, in-home assistance, and adult day services for individuals 60 and older. Many states also use general revenue funds to provide LTC services.¹⁷

About 22 percent of LTC services are financed by out-of-pocket payments. In the United States, Medicaid and out-of-pocket payments make up the majority of LTC spending. Only 9 percent is supported by private LTC insurance.⁸ About one in six individuals age 65 and older with an annual income greater than \$20,000 have private LTC insurance coverage. Many such policies now include coverage for both HCBS and NH care, paying similar daily benefits for both.¹⁸

Initially, HCBS was considered an alternative to NH care. Early demonstration projects (from the mid 1970s through late 1980s) addressed the effectiveness and costs of expanding LTC to include HCBS. These projects generated some empirical literature as well as literature reviews.¹⁹⁻²¹ By the mid 1990s, newer models of organizing, financing, and delivering care were implemented. Medicaid-funded HCBS expanded substantially through the aforementioned waivers that allowed states to implement such care on a limited basis with funds that would have traditionally gone to NH care.

Many studies, including the National Long-Term Care Channeling Demonstration, found that HCBS did not reduce LTC spending.^{22,23} Some studies found that HCBS actually increased expenditures.²⁴ Other studies found that after the initial increase needed to start an HCBS program, spending decreased in states with well-established noninstitutional programs compared with states with minimal noninstitutional services.²⁵ Findings across states have been inconsistent due to the difficulty of assessing the cost and effectiveness of HCBS.¹⁵ Also, many studies have compared dissimilar populations or failed to use a control group.¹⁵

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.

Some programs that aim to keep people in home and community-based settings rather than in NHs loom in the background of this analysis. For example, PACE (Program of All-Inclusive Care of the Elderly) is a program designed to use capitated payment to better integrate services for older persons who are eligible for both Medicare and Medicaid and for NH care. PACE attempts, whenever possible, to substitute HCBS for NH care. Various types of residential housing for older people have begun to offer ascending levels of support in order to allow individuals to remain in residence even as their care needs increase.

Comparing NHs and HCBS

Apples-to-apples comparisons and meaningful evaluations of outcomes between HCBS and NHs are challenging. Heterogeneity is significant among LTC recipients, both within and across settings. Delivered services vary by type, frequency, and intensity. Comparisons of HCBS and NHs require an understanding of the actual comparisons that investigators made—i.e., the characteristics of those served, the service mix, and the methods used to assess the populations served by HCBS and NHs.

LTC effectiveness is measured by the extent to which HCBS and NHs moderate the rate of functional decline or other well-being measures. Multiple measures across a range of domains (physical function, cognition, mental health, and quality of life) are used to assess outcome trajectories of HCBS recipients and NH residents over time.

Assessments of NH residents tend to rely on a standardized approach to data collection called the Minimum Data Set (MDS). Since 1999, all Medicare- and Medicaid-certified nursing homes have used the MDS (see <https://www.cms.gov/site-search/search-results.html?q=minimum%20data%20set>). The MDS relies primarily on data derived from staff observations and interpretations of behavior over a period of time. The latest version of the MDS (MDS 3.0), implemented in 2010, incorporates some resident interview items. As a tool designed to assess function in an institutional setting, the MDS emphasizes elements and domains relevant to the institutional experience. Full re-assessments are performed annually; specific parameters are re-assessed quarterly or if significant change has occurred. The MDS plays a crucial role for Medicare and Medicaid reimbursement.

The MDS has been adapted for use in the home-care setting. The home-care version (called the interRAI HC or MDS-HC) relies on the observations of those providing the home care. The items of the home version are not completely consistent with items of the MDS (see <http://www.interrai.org>).²⁶ Unlike the MDS, which is almost universally used in U.S. NHs, the home version of this tool has not been widely adopted for individuals receiving HCBS.

Moreover, eligibility and plans for LTC services delivered through Medicaid waivers are most often based on direct assessments of clientele by case managers. Such assessments are not aligned with the MDS. To effectively compare and interpret outcome trajectories of HCBS recipients and NH residents over time, careful attention must be given to the domains addressed by the tools used for each group, the measures of disability used, the methods of ascertainment, and the appropriateness of the followup periods.

Comparisons of costs between the two settings are difficult. Cost comparisons must account for both costs to various public programs (i.e., spending by Medicaid and other public programs) and costs to individuals (i.e., spending by individuals and their families). This includes spending on LTC services and on other services. People receiving HCBS through Medicaid continue to be eligible for a variety of transfer programs not available to NH residents, including food stamps and housing subsidies. These expenditures must be counted. Other relevant costs include spending for acute care services such as physician and hospital care and medications. Because most acute care for older adults is paid for by Medicare, Medicare spending should be included. For those who are financially eligible, Medicaid pays premiums, deductibles, and co-pays for Medicare-covered services, so this Medicaid spending must be counted. Finally, the out-of-pocket and opportunity costs to individuals and families providing LTC assistance are relevant. The out-of-pocket costs include spending on LTC services and acute care services (including insurance premiums, deductibles, and co-pays). Opportunity costs include burden to family and other unpaid caregivers. Informal or unpaid caregiving occurs for both HCBS recipients and NH residents. In both cases, the time commitment is challenging to measure and itemize, because of the difficulty of distinguishing between the burden of additional care and ordinary family activity.

Reason for the Review

The purpose of this review is to support policy and research decisionmaking. This review is timely, as policymakers try to determine the effectiveness and costs associated with different types of LTC. Current financial retrenchment and budgetary pressures intensify the need to identify effective means of delivering LTC services while minimizing costs. For the growing number of older adults who need LTC, identifying the setting or program that comports with their preferences while best serving their needs is a critical priority. This work complements an ongoing review on outcomes for cognitively impaired AL residents, conducted by the RTI-UNC Evidence-based Practice Center.

Scope and Key Questions

Scope of the Review

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 separate 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 compare outcomes across settings at a specific point in time; whereas longitudinal studies compare changes in outcomes over a defined time period 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, timing, and setting as follows:

Population

The population for this study included older adults (age ≥ 60) receiving LTC either through HCBS or in NHs, with adjustment for the age ceiling for PACE, where eligibility begins at 55.

Patient characteristics that could modify outcomes include age, race/ethnicity, sex, socioeconomic status, functional status, clinical status, cognition, rural/urban, morbidities, mental illness, payer, prior service use, and disability history. We excluded studies that focused on postacute care, such as Medicare home health services. Postacute care is care provided to individuals discharged from a hospital; it is intended to aid 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 day care and adult day health. Services provided through 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 examine 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. NH services may include personal care, support for ADLs, 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 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 such as accidents, injuries, pain, abuse, and neglect.

To examine costs, we considered all relevant costs to public 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, and transfer programs, and opportunity costs to family caregivers.

Timing

The outcomes were assessed at 6 months to many years.

Setting

This review includes studies from the United States and international studies from 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.

Key Questions

We developed the Key Questions (KQs) after a topic refinement process. Topic refinement included a preliminary review of the literature and consultation with a Key Informant panel of LTC experts and stakeholders. Key Informants affirmed the importance of the issue of differences in case mix across settings in evaluating studies on LTC. Discussions with Key Informants also helped us define the settings and services covered under HCBS. Based on Key Informant input, we (1) identified HCBS settings to include recipients' own homes, group living arrangements such as room and board, adult foster care and assisted living, and nonresidential settings such as adult day care; and (2) excluded studies focusing on short-stay NH residents and recipients of Medicare home health services in order to confine the review to the LTC population.

The draft KQs were posted for public comment on the Agency for Healthcare Research and Quality (AHRQ) Effective Health Care Program Web site from October 10, 2011, to November 3, 2011. The comments received in response to the posting related to three themes: (1) whether individuals with specific diagnoses fare better as recipients of HCBS than as NH residents, (2) the impact of caregivers and caregiver-related outcomes across settings, and (3) the availability of HCBS and its effect on use of NHs. Public comments did not result in changes to the KQs because the questions already addressed the themes expressed.

We also received input from the Technical Expert Panel, who deemed the KQs to be appropriate. The panel did, however, recommend lowering the age limit for inclusion from 65 to 60 years to accommodate Medicaid waiver and other programs that set eligibility at age 60. We revised the age limit and added specific sub-questions (1a and 1b) to address the issue of differences in case mix across settings. The final KQs are below.

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 older adults, aged 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? (Reported harms include accidents, injuries, inadequate preventive care, unnecessary hospitalizations, and concerns about abuse or neglect.)

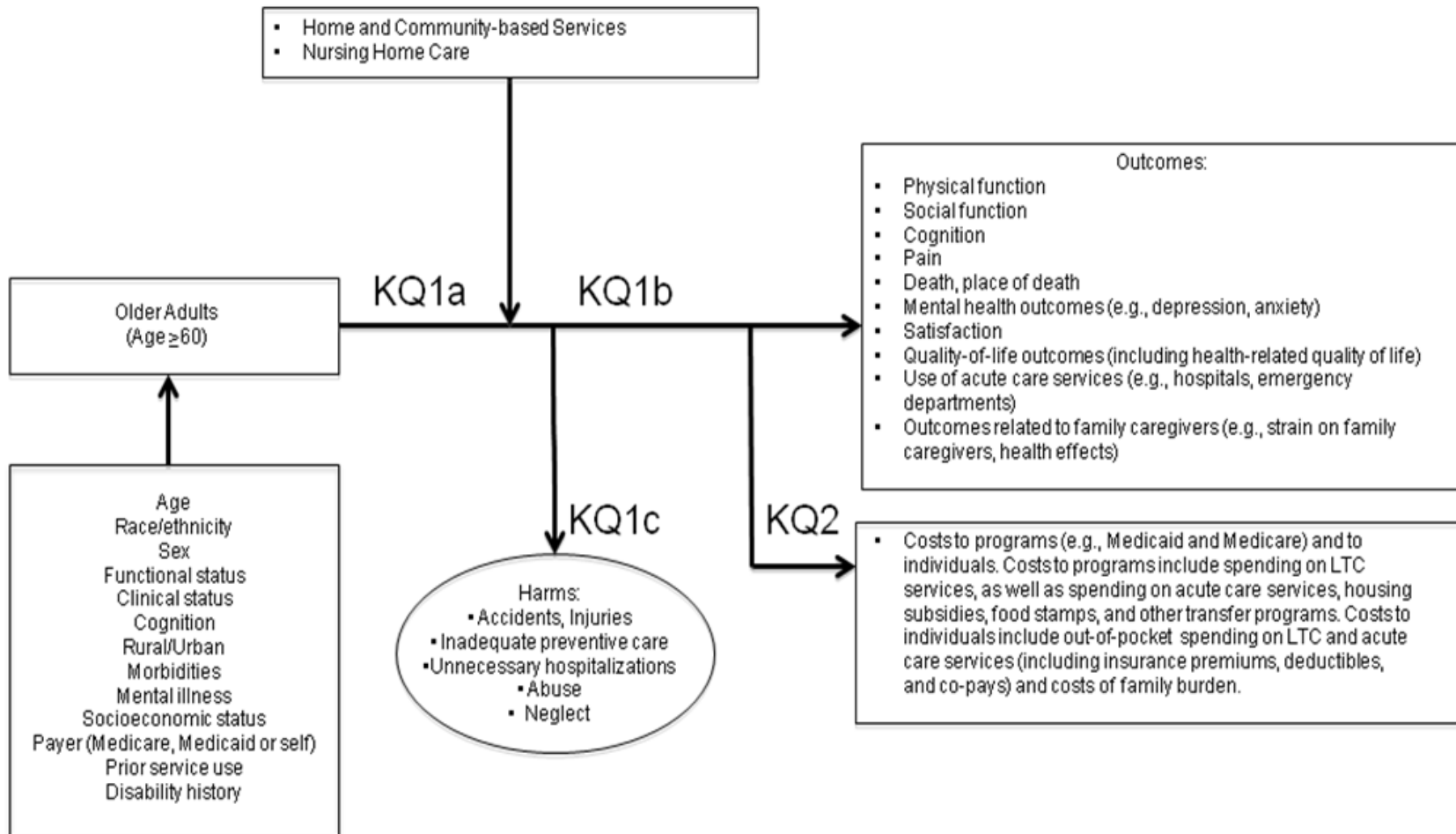
KQ 2. What are the costs (at the societal and personal levels) of HCBS and NHs (per recipient and in the aggregate) for adults age 60 and older? Costs may include direct costs of care as well as resource use and family burden.

Direct costs of care refer to public 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.

We anticipated that outcomes could be modified by patient characteristics. These include socio-demographic characteristics (age, sex, race/ethnicity); health status (functional, clinical status, morbidities, mental illness, disability); cognition; and other characteristics such as rural/urban location, socioeconomic status, payer status, and prior service use.

Figure 1 shows the analytical framework for our KQs.

Figure 1. Analytical framework for review of home and community-based services versus institutional care for older adults



KQ = Key Question; LTC = long-term care

Methods

We conducted the comparative effectiveness review of long-term care (LTC) for older adults following the methods suggested in the Agency for Health Care Research and Quality (AHRQ) Methods Guide for Effectiveness and Comparative Effectiveness Reviews (<http://www.effectivehealthcare.ahrq.gov/methodsguide.cfm>). The main sections in this chapter reflect the elements of the protocol publicly posted on the AHRQ Effective Healthcare program Web site, and they correspond to the PRISMA checklist.²⁷

Topic Refinement and Review Protocol

The topic for this comparative effectiveness review was publically nominated through the Effective Healthcare Web site. Investigators developed preliminary Key Questions (KQs) with input from various stakeholder groups (Table 1). The KQs were posted on AHRQ’s Web site for public comment for 4 weeks. Public comments and input from the Technical Expert Panel (TEP), convened to provide methodological and content expertise, were used to develop the final KQs and protocol.

Table 1. Perspectives and organizations represented by Key Informants

Perspective	Organization
Policy	<ul style="list-style-type: none"> Centers for Medicare & Medicaid Services Office of Disability, Aging and Long-term Care Policy, Assistant Secretary for Planning and Evaluation, Department of Health and Human Services
Provider	<ul style="list-style-type: none"> American Health Care Association Leading Age
Consumer	<ul style="list-style-type: none"> National Center for Assisted Living AARP
Research	<ul style="list-style-type: none"> Scripps Gerontology Center, Ohio

Literature Search Strategy

An exploratory search indicated that relevant literature would be scarce and difficult to locate. Therefore, we used several strategies to identify potential relevant studies. 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. The search algorithm, developed with input from content experts and a biomedical librarian and independently reviewed by another librarian, consisted of a combination of text words and subject index terms in the following categories: intervention (long-term care); services (nursing home [NH] and various types of Home and Community-Based Services [HCBS]); and study design (RCTs and observational studies). We collected search terms related to NHs and HCBS, and combined them using the Boolean AND operator to retrieve articles that compared NHs and HCBS. We retrieved relevant RCTs and observational trials using search filters specific to study design. The search algorithm with the specific strings and index terms is listed in Appendix A. We used an equivalent search strategy for AGELINE database by adapting the search terms to meet database specific syntax requirements.

Bibliographic database searches were supplemented with backward and forward citation searches of relevant articles and by hand searching. We compiled a list of prominent authors in the field and searched specifically for their work to identify missing publications. Finally, we asked the TEP to review the included set and provide missing literature (if any) from their

personal files. We searched the grey literature in the form of program evaluation reports, reports to government, and analyses from research organizations and foundations. We developed a comprehensive list of grey literature sources with input from the TEP. Grey literature sources (Appendix B) included Web sites of relevant federal and state agencies (such as the Centers for Medicare & Medicaid Services [CMS] 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.

Inclusion and Exclusion Criteria

The target population was older adults (age ≥ 60) using 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 particular time point (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 economically developed countries with well-established health and LTC systems, including Canada, United Kingdom, Australia, and New Zealand, as well as Norway, Sweden, and other European countries). Specific eligibility criteria organized by PICOTS (Population, Intervention, Comparator, Outcomes, Timing, Setting) framework are listed in Table 2. Grey literature studies that satisfied the above criteria were also eligible for inclusion.

Table 2. Inclusion criteria

Domain	Criteria for Inclusion
Population	<ul style="list-style-type: none"> Older adults (age ≥ 60) using LTC (with exception for recipients of PACE where eligibility begins at 55)
Intervention	<ul style="list-style-type: none"> LTC through HCBS
Comparator	<ul style="list-style-type: none"> LTC in NHs
Outcomes	<ul style="list-style-type: none"> Physical function, cognition, 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) Harms, including accidents, injuries, inadequate preventive care, unnecessary hospitalizations, abuse, or neglect Costs to programs (i.e., Medicaid and other public programs) and to individuals. Costs to programs include spending on LTC services, as well as spending on acute care services, housing subsidies, food stamps, and other transfer programs. Costs to individuals include out-of-pocket spending on LTC and acute care services (including insurance premiums, deductibles, and co-pays) and costs of family burden
Timing	<ul style="list-style-type: none"> Longitudinal studies: varying periods ranging from 6 months to many years
Setting	<ul style="list-style-type: none"> U.S.; economically developed countries with well-established health and LTC systems (Canada, Australia, United Kingdom, New Zealand, Norway, Sweden, and other European countries)
Study Design	<ul style="list-style-type: none"> Cross-sectional studies and longitudinal studies that directly compare populations and outcomes of care between HCBS recipients and NH residents
Publication dates	<ul style="list-style-type: none"> 1995 to March 2012
Language	<ul style="list-style-type: none"> English

HCBS = Home and Community-Based Services; LTC = Long-Term Care; NH = Nursing Home; PACE = Program of All-Inclusive Care for the Elderly

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 if 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 was documented. Reasons for exclusion were coded as: non-English language study; pre-1995 study; not a geographical setting of interest (countries other than those listed above); postacute care population (short-stay NH residents or Medicare home health recipients); no relevant comparison; no relevant settings or sample; no relevant characteristics or outcomes. The excluded studies and the reason for exclusion are listed in Appendix C.

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 on study design; location (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. Appendix D is an evidence table, organized alphabetically by author name.

Risk of Bias 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.²⁸ Two investigators independently assessed the risk of bias of each study. The full team of investigators validated the assessments.

We found no RCTs that met inclusion criteria. We assessed risk of bias using questions adapted from the RTI item bank for risk of bias.²⁹ Evaluation of selection bias was a key component of risk of bias assessment. We gave a higher rating to studies that accounted for differences in case mix across setting using techniques such as multivariate analysis, propensity score matching, or instrumental variables. 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 assigned summary risk of bias ratings (high, moderate, low, or unclear) based on the overall risk of bias created by the individual components assessed.

Data Synthesis

Heterogeneity in populations and interventions/settings across studies precluded quantitative synthesis of results. Instead, we analyzed results qualitatively to arrive at conclusions regarding (1) the extent to which HCBS and NHs serve similar populations and (2) the differences in outcomes of the services when tested on similar populations. We separately analyzed the results from the grey literature and international studies.

We compared characteristics of HCBS recipients with those of NH residents using data from cross-sectional and longitudinal studies that reported case mix. We evaluated differences in populations across settings in the domains of physical function, cognition, mental health, and comorbidities. We qualitatively synthesized results from individual studies to evaluate the extent to which HCBS and NHs serve similar populations.

To compare outcomes of care for HCBS versus NHs, we first categorized longitudinal studies by the outcome domain investigated. We compared results across settings for specific outcome domains such as physical function, cognitive function, mental health, use of acute care services, harms, and costs. We qualitatively synthesized result to evaluate the differences in trajectories of older adults as a result of care provided through HCBS or in NHs. Throughout the analysis, we treated assisted living (AL) as a separate subset within HCBS, because AL encompasses elements of both community-based and institutional care. We analyzed international studies separately to account for differences in context. We also analyzed grey literature studies separately.

Strength of the Body of Evidence

We evaluated the overall strength of evidence using methods developed by the AHRQ Evidence-based Practice Center Program³⁰ for the following outcomes: physical function, cognitive function, mental health, mortality, use of acute care services, harms, and costs. We aggregated all relevant outcome measures within a particular outcome domain and evaluated strength of evidence based on the aggregated set. Because many possible outcomes measures may be used within one domain, and because all included studies used an observational design, we were interested in consistency in the direction of effect. We evaluated strength of the 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 showed 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 can be either direct or indirect.
- Precision (degree of certainty surrounding an effect estimate of a given outcome). Precision is either precise or imprecise. Since we did not conduct 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 reflects how fully the set of outcome measures describes the outcome domain.

The full team of investigators worked through consensus to rate the individual domains qualitatively. The team assigned an overall strength of evidence summary rating of high, moderate, or low strength of evidence for domains in KQ1b, KQ1c, and KQ2. We did not rate strength of evidence for KQ1a. We based strength of evidence on the longitudinal peer-reviewed studies from the United States; relevant international and grey literature studies supplemented our analysis but were not included 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. Thus, we took a liberal stance for assigning a low rating. We graded evidence as low-strength 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 only reviewed studies of direct comparisons of HCBS with NH using patient centered outcomes).

Applicability

According to AHRQ guidance,³¹ we assessed applicability defined as the extent to which effects observed in published studies are likely to reflect the expected results when the specific intervention is applied to the population of interest in “real world” contexts. We assessed applicability 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 the timing of measurement; and sources of financing (Table 3).

Table 3. Criteria for assessing applicability

Domain	Criteria Used To Assess Applicability
Population	<ul style="list-style-type: none"> • Criteria for enrollment into the program • Characteristics of population enrolled: demographics; clinical status; functional status; morbidities; cognition; mental illness; and source of finance (Medicaid or self)
Intervention	<ul style="list-style-type: none"> • LTC through HCBS <ul style="list-style-type: none"> – Type, frequency, and intensity of services – Availability and access to programs
Comparator	<ul style="list-style-type: none"> • LTC in NHs
Outcomes	<ul style="list-style-type: none"> • Outcomes assessed (or not assessed) and the time period over which they were assessed
Setting	<ul style="list-style-type: none"> • Country/geographical region; rural/urban

HCBS = Home and Community-Based Services; LTC = Long-Term Care; NH = Nursing Home

Peer Review and Public Commentary

Experts in LTC from research and consumer organizations were invited to provide external peer review of this systematic report; AHRQ and an associate editor also provided comments. See the Acknowledgments section for a full listing of peer reviewers. The draft report was posted on the AHRQ Web site for 4 weeks to elicit public comment. Public comments were received from the American Health Care Association, as well as three individuals. We addressed all reviewer comments, revising the text as appropriate, and documented everything in a disposition of comments report that will be made available 3 months after the Agency posts the final systematic review on the AHRQ Web site.

Results

Introduction

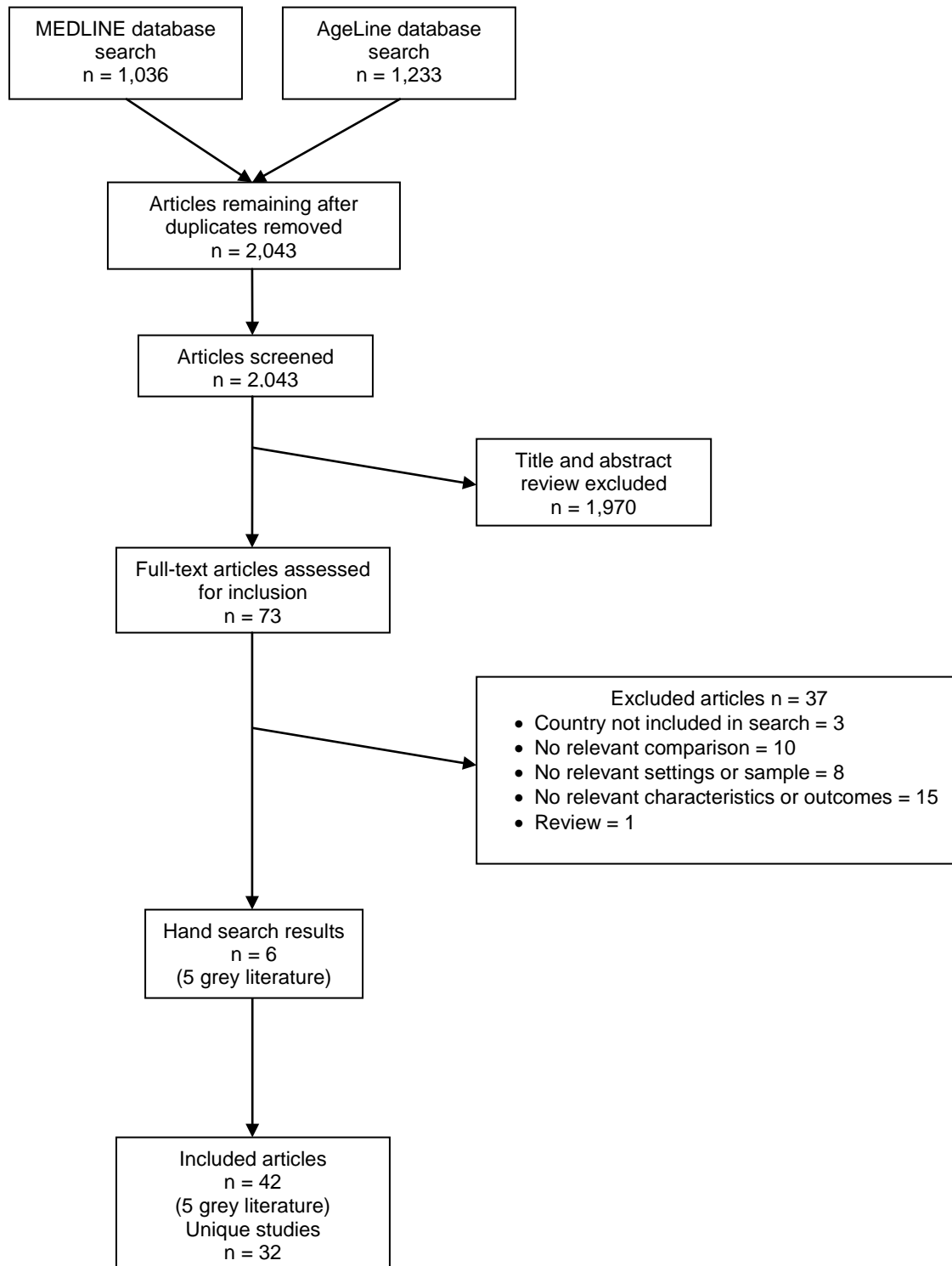
Our findings are organized by Key Question (KQ), following an overview of the literature search results and a description of the included studies. The section includes tables with characteristics and outcomes for each KQ. Articles that used the same population sample are grouped together within these tables.

Due to heterogeneity in study populations, settings, and measurement of outcomes, we could not synthesize results quantitatively. Therefore, we based all conclusions on qualitative analysis. We used cross-sectional studies only to examine case mix addressed in KQ 1a. We assessed risk of bias only for the longitudinal peer-reviewed studies from the United States for KQs 1b, 1c, and 2. The risk of bias assessments and overall strength of evidence ratings appear in Appendix E and Appendix F. Only outcomes that were assessed for strength of evidence are reported in the strength of evidence table in Appendix F. We excluded no studies from analysis based on risk of bias.

Results of Literature Searches

Our search yielded 2,043 unique references. Figure 2 describes the results of the literature search and screening process. A total of 73 full-text articles were screened for final inclusion. Of the 37 articles excluded at the full-text screening stage, 3 were nonapplicable countries, 10 had no relevant comparison, 8 had no relevant settings or sample, 15 had no relevant characteristics or outcomes, and 1 was a review. Excluded references and reasons for exclusion are listed in Appendix C. This step in database searching produced a total of 36 articles for final inclusion. Hand searching produced an additional 6 articles, 5 of which were grey literature reports, for a total of 42 articles that addressed 32 unique studies.

Figure 2. Literature flow diagram for review of long-term care for older adults



Description of Included Studies

No randomized controlled trials (RCTs) were identified. Of the 42 observational studies included in the review, 37 were peer-reviewed journal articles,³²⁻⁶⁸ and five were grey literature reports.⁶⁹⁻⁷³ The peer-reviewed journal articles included 22 cross-sectional studies^{33-38,40,41,43,45-47,49,53,55,57,59,61,63,65-67} and 15 longitudinal studies.^{32,39,42,44,48,50-52,54,56,58,60,62,64,68} Of the 15 peer-reviewed longitudinal studies, 14 were used as the analytic set for outcomes for KQs 1b, 1c, and 2.^{32,39,42,44,48,50,52,54,56,58,60,62,64,68} Three grey literature reports that provided longitudinal data are also included as part of the analytic set for outcomes for KQs 1b, 1c, and 2, but we did not assess risk of bias for these reports. Eight studies included in the review are international.^{32,35,37,38,49,57,58,66} Twelve studies focused on populations with dementia.^{34,35,40,45,47,49,52,53,62,65,68} One study⁶⁴ focused on PACE (Program for All-Inclusive Care for the Elderly) enrollees. Although there have been numerous studies on PACE, no others met the inclusion criteria for this review by explicitly comparing Home and Community-Based Services (HCBS) recipients and nursing home (NH) residents. Most PACE studies compared PACE enrollees to non-PACE enrollees but did not specify the residence of the individuals (i.e., in home and community settings or in NHs). Thus these studies were not eligible for inclusion in this review.

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

KQ 1a: Similarity of Populations Served by HCBS and NHs

Key Points

- NH samples were consistently more impaired than HCBS (including assisted living [AL]) samples in terms of both physical function and cognition.
- The picture with mental health and clinical status was mixed.

Detailed Synthesis

Tables 4–15 present cross-sectional data that compare samples of individuals receiving care in NHs, through HCBS, and/or in AL settings at baseline. Tables 4 and 5 contrast the physical function (measured in various ways) in peer-reviewed studies for those receiving HCBS and/or in AL settings with those in NHs. In all cases, NH residents were more disabled than their counterparts.

Tables 6 and 7 contrast levels of cognitive functioning of study participants from the peer-reviewed studies. Once again, NH samples were consistently more impaired than HCBS and AL samples.

The picture with mental health is more mixed. As shown in Tables 8 and 9, three studies^{35,48,60} found more depression in NH residents than in those receiving HCBS, while one study found more depression in HCBS recipients⁶⁴ and another study found no difference between the groups.⁵⁷ Compared with AL residents, more NH residents were depressed in two studies^{45,54} and fewer in two.^{40,62} Comparisons of other measures of mental health are also mixed. Three studies^{38,43,59} found no difference in psychological well-being or life satisfaction between

HCBS or AL recipients and NH residents, while two studies^{42,66} found HCBS or AL recipients to have better psychological well-being.

Tables 10 and 11 summarize mixed information on clinical status. In one study,³⁶ the number of conditions was lower for NH residents than for HCBS recipients, while another study found that NH residents had higher case-mix scores than HCBS recipients.⁶¹ One study⁵² found that NH residents had more of three specific conditions than did HCBS recipients, but the differences were not significant. The comparison is likewise mixed with AL. The rate of conditions among NH residents was higher in two studies,^{36,62} but lower in a third.⁴⁰

Parallel information from the grey literature reflects a similar pattern. As shown in Table 12, physical function was more impaired in NH residents than in HCBS recipients or AL residents. Likewise, cognitive function was more impaired in NH residents than in those receiving HCBS or in AL (Table 13), although one study showed a similar rate of cognitive impairment between residents in AL and NH.⁶⁹ The prevalence of depression (Table 14) was higher for NH residents than for HCBS recipients.⁷² Rates of mental disorders were similar for those receiving care in NHs and HCBS settings.⁷³ As shown in Table 15, the rates of comorbidities were similar for HCBS recipients and NH residents.⁷² NH residents generally had more comorbidities than those in AL.⁷³

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

Key Points

- Evidence was low strength or insufficient for all of the outcomes examined.
- Low-strength evidence suggested that the rate of change in physical function did not differ between AL and NH residents over time. Evidence was insufficient for the HCBS versus NH comparison.
- Low-strength evidence suggested that the rate of change in cognitive function did not differ between AL and NH residents over time. Evidence was insufficient for the HCBS versus NH comparison.
- Low-strength evidence suggested that the rate of change in mental health did not differ between AL and NH residents over time. Evidence was insufficient for the HCBS versus NH comparison.
- Low-strength evidence suggested that mortality did not differ between AL and NH residents. Evidence insufficient for the HCBS versus NH comparison.
- Evidence was insufficient for acute care utilization for the AL versus NH comparison and for the HCBS versus NH comparison.
- Other outcomes were rarely examined.
- No studies conducted subgroup analysis.

Detailed Synthesis

Tables 16–18 describe the analyses performed and list the outcome domains addressed in the modest collection of longitudinal studies. Outcomes were measured in terms of functional change (physical or cognitive), mental health, mortality, and use of acute care services. Evidence was low strength or insufficient for the outcomes examined in detail.

Table 19 summarizes the results for physical function over time for HCBS recipients or AL residents with NH residents for peer-reviewed studies from the United States. Frytak et al. 2001⁴² found that although AL residents were more functional at the outset of the study, their rate of

decline in physical function was the same as that of NH residents. In the study by Pruchno and Rose 2000,⁵⁴ AL residents maintained better function throughout, but the rate of change in functional ability did not differ between AL and NH residents over time. Sloane et al. 2005⁶² found no significant differences in the mean rate of decline in function between AL and NH residents for the cohort with mild dementia or for the cohort with moderate or severe dementia. These three studies provided low-strength evidence (due to high risk of bias of the studies) that the rate of change in physical function did not differ between AL and NH residents over time. Marek et al. 2005⁴⁸ found that NH residents remained more disabled than HCBS clients over 24 months, but they did not evaluate rate of change in function between NH and HCBS recipients. This study provided insufficient evidence for the HCBS versus NH comparison of change in physical function.

Table 20 summarizes the U.S. longitudinal peer-reviewed studies that examined changes in cognitive function. Two studies^{54,62} showed no significant differences in trends in cognition between AL and NH residents. Due to high risk of bias, these two studies provided low-strength evidence that the rate of change in cognitive function did not differ between AL and NH residents over time. Marek et al. 2005⁴⁸ showed that NH residents remained more impaired than HCBS recipients at most time points, but they did not evaluate rate of change in cognition between the two groups. This high-risk-of-bias study provided insufficient evidence for the HCBS versus NH comparison of change in cognitive function.

Table 21 summarizes the results from the U.S. peer-reviewed studies in terms of mental health outcomes. Two studies^{54,62} found that changes in depression scores did not differ significantly between AL and NH residents. Frytak et al. 2001⁴² found no difference in psychological well-being scores from the SF-36 between AL and NH residents and no change over time for either group. The three studies provided low-strength evidence that the rate of change in mental health did not differ between AL and NH residents over time. Marek et al. 2005⁴⁸ found that depression was higher for NH residents than for HCBS clients at 6 and 12 months, but not at baseline. The difference disappeared for the 18- and 24-month followup times. However, this study did not analyze the rate of change in depression between HCBS recipients and NH residents. This high-risk-of-bias study provided insufficient evidence for the HCBS versus NH comparison for change in mental health.

Two U.S. peer-reviewed studies that compared mortality in residents of AL versus NH (Table 22)^{54,62} found no differences. Another study found that median survival was lowest for NH residents and highest for PACE enrollees, with HCBS recipients falling between the two.⁶⁴ Two peer-reviewed international studies (Table 23) showed that individuals in nursing homes had a higher risk of mortality.^{50,58} A study from the grey literature (Table 24) showed the highest odds of mortality for NH residents, followed by those in HCBS and AL, compared with individuals not yet receiving long-term care (LTC).⁷¹ The two published studies from the United States provided low-strength evidence (due to high risk of bias of the studies) that mortality did not differ between AL and NH residents; evidence was insufficient for mortality for the HCBS versus NH comparison.

As shown in Table 25, two peer-reviewed studies from the United States examined the use of acute care services. Mitchell et al. found no significant difference in the odds of hospitalization for HCBS recipients compared with NH residents.⁵² NH residents, however, had lower odds of using hospice services. Sloane et al. found that among persons with mild dementia, those in AL used hospitals more than those in NHs,⁶² but they found no difference for those with moderate or severe dementia. Due to the high risk of bias of both studies, evidence was insufficient for the

use of acute care services for AL versus NH residents and for HCBS recipients versus NH residents.

Other outcomes are presented in Appendix G, Tables G1 and G2.

No studies conducted subgroup analysis to determine whether outcomes differed between subgroups of HCBS recipients and NH residents for characteristics such as socioeconomic status.

KQ 1c: Harms in Populations Served by HCBS Versus NHs

Key Points

- The strength of evidence for harms was low for the HCBS versus NH comparison, and it was insufficient for AL versus NH.
- Harms differed between HCBS recipients and NH residents. HCBS recipients experienced higher rates of some harms and NH residents experienced higher rates of other harms. Evidence was insufficient for harms for the AL versus NH comparison.

Detailed Synthesis

Three U.S. peer-reviewed studies measured harms (Table 26). The strength of evidence for harms was low for the HCBS versus NH comparison and insufficient for AL versus NH. Rigler et al. examined inappropriate medication use;⁵⁶ the overall unadjusted rate was higher for HCBS recipients than for NH residents. Mitchell et al. compared end-of-life care for older individuals with advanced dementia.⁵² Compared with HCBS recipients, NH residents had lower odds of pain, shortness of breath, and use of anti-anxiety medication, but higher odds of having a feeding tube, experiencing pneumonia, having a pressure ulcer, or using oxygen therapy. These two studies provided low-strength evidence that harms differed between HCBS recipients and NH residents, since HCBS recipients experienced higher rates of some harms and NH residents experienced higher rates of other harms. Another study found that neither pain nor discomfort differed at baseline or over time between individuals in AL and NHs.⁴² This high-risk-of-bias study offered insufficient evidence for the AL versus NH comparison.

KQ 2: Costs for Populations Served by HCBS Versus NHs

Key Points

- The strength of evidence for costs (or expenditures) for HCBS versus NHs was insufficient.
- Although Medicaid expenditures for HCBS recipients and NH residents were analyzed, other program and individual expenditures were not examined. Costs related to family burden were not addressed.

Detailed Synthesis

Table 27 compares data on expenditures from one U.S. peer-reviewed study.⁶⁰ This study analyzed individuals' Medicaid expenditures and found that HCBS was less expensive. However, the study did not analyze other program and individual expenditures. This high-risk-of-bias study provided insufficient evidence on costs for HCBS recipients compared with NH residents. No studies analyzed costs for AL versus NH residents.

Table 28 presents expenditure data from grey literature studies. One study on private LTC insurance users compared monthly expenditures on LTC for HCBS recipients and residents of

AL and NHs. It found that expenditures were highest for NH residents.⁷¹ Three studies measured annual per-client Medicaid expenditures and found that total Medicaid expenditures were higher for NH residents compared with HCBS recipients or AL residents.^{69,70} These studies did not include other program or individual expenditures, nor did they address costs related to family burden.

Table 4. Description of participant physical function: U.S. cross-sectional and longitudinal peer-reviewed studies

Study	Measure of Physical Function	HCBS/AL	NH	Significance	Summary
Ohio HCBS Waiver Applebaum et al., 2004 ³³	Mean number of ADL impairments; range 0-6	HCBS: 3.0	3.9	NR	On average, HCBS recipients had fewer ADL impairments
Borrayo et al., 2002 ³⁶	Mean number of ADL impairments; range 0-5	HCBS: 2.24 (SD 1.81) AL: 2.21 (SD 1.82)	3.98 (SD 1.32)	NR	On average, HCBS recipients and AL residents had fewer ADL impairments
^a Dementia Care Project Port et al., 2005 ³³	Mean number of ADLs in which resident was independent; range 0-7	AL: 3.4 (SD 2.4)	2.4 (SD 1.8)	p=0.001	On average, AL residents were more independent in ADLs
^a Edelman et al., 2005 ⁴⁰	Mean number of ADL dependencies; range 0-6	AL: 2.5 (SD 2.0)	3.8 (SD 2.2)	p<0.01	On average, AL residents had fewer ADL dependencies
Gaugler, 2006 ⁴³	Mean number of ADL dependencies; range not specified	HCBS: 2.04 (SD 3.01) AL: 1.75 (SD 1.86)	5.59 (SD 3.57)	p<0.05 for NH vs. HCBS and for NH vs. AL	On average, HCBS recipients and AL residents had fewer ADL dependencies
Lee et al., 2001 ⁴⁶	Mean number of ADL dependencies; range 0-14, with higher scores indicating more dependency	HCBS: 5.07 (SD 2.13)	7.67 (SD 3.72)	p<0.001	On average, HCBS recipients had fewer ADL dependencies
Mehdizadeh, 2002 ⁵¹	Mean number of ADL impairments; range 0-6	HCBS: 2.6	3.2	p≤0.05	On average, HCBS recipients had fewer ADL impairments
Oregon Assisted Living Frytak et al., 2001 ⁴²	Mean ADL score; range 0-100, with higher scores indicating more dependence	AL: 16.88	57.09	NR	On average, AL residents had fewer ADL dependencies
Collaborative Studies of Long-Term Care subsample Sloane et al., 2005 ⁶²	Mean ADL impairment score from MDS ADL; range 0-28, with higher scores indicating more impairment	AL: 7.6 (SD 7.9)	11.9 (SD 8.2)	p=0.001	On average, AL residents had fewer ADL impairments

Table 4. Description of participant physical function: U.S. cross-sectional and longitudinal peer-reviewed studies (continued)

Study	Measure of Physical Function	HCBS/AL	NH	Significance	Summary
Wieland et al., 2010 ⁶⁴	Mean number of ADL dependencies; range 0-6	HCBS: 0.45 PACE: 1.05	2.25	NR	On average, HCBS and PACE recipients had fewer ADL dependencies
Shugarman, et al., 1999 ⁶¹	Mean ADL Index score; range 4–18, with higher scores indicating more dependence	HCBS: 6.99	9.74	p<0.001	On average, HCBS recipients had fewer ADL dependencies
ASPE private LTC insurance cohort Doty et al., 2010 ³⁹	ADL impairments (percentage)	HCBS: 18% with <2, 52% with 2-4, 30% with 5+ AL: 36% with <2, 44% with 2-4, 20% with 5+	12% with <2, 31% with 2-4, 57% with 5+	NR	HCBS and AL groups had fewer individuals with higher numbers of ADL impairments
^a Mitchell et al., 2004 ⁵²	MDS ADL score, with higher scores indicating more dependence (percentage)	HCBS: 70.2% score 0-20, 23.1% score 21-27, 6.7% score 28	24.3% score 0-20, 36.2% score 21-27, 39.3% score 28	p<0.001, p<0.001, p<0.001	HCBS group had fewer individuals with higher ADL dependency
Reinardy and Kane, 1999 ⁵⁵	Number of ADLs requiring some help (percentage)	HCBS: 85% with 0-1, 9% with 2-3, 6% with 4+	54% with 0-1, 14% with 2-3, 32% with 4+	NR	HCBS group had fewer individuals that required some help with several ADLs
Collaborative Studies of Long-Term Care subsample Zimmerman et al., 2003 ⁶⁷	Impairment in at least one of six ADLs (percentage)	AL(a): 37% AL(b): 25% AL(c): 15%	83%	NR	AL groups had fewer individuals requiring help in an ADL
^a Beattie et al., 2005 ³⁴	Mean motor ability item average; range 0-4 for six items, with higher scores indicating poorer motor ability	AL: 0.35 (SD 0.48)	0.76 (SD 0.71)	p<0.01	On average, AL residents had better motor ability
Franks, 2004 ⁴¹	Mean SIP-NH score; higher scores indicate more disability	AL: 22.8	41.7	NR	On average, AL residents had less disability

Table 4. Description of participant physical function: U.S. cross-sectional and longitudinal peer-reviewed studies (continued)

Study	Measure of Physical Function	HCBS/AL	NH	Significance	Summary
^a Leon and Moyer, 1999 ⁴⁷	Mean SF-36 Physical Functioning Subscale score; range 0-100, with higher values indicating higher functioning	AL: 46.7 (SD 32.04)	20.15 (SD 23.30)	p<0.001	On average, AL residents had higher functioning
Pruchno and Rose, 2000 ⁵⁴	Mean MAI functional ability; range 15-45, with higher scores indicating better function	AL: 40.03	34.89	p<0.001	On average, AL group had better functioning
Schroeder et al., 1998 ⁵⁹	Mean Physical Activity Questionnaire for the Elderly score; higher score indicates greater physical activity levels	AL: 6.8 (SD 1.4)	1.2 (SD 0.3)	p≤0.05	On average, AL residents had greater physical activity levels
Collaborative Studies of Long-Term Care subsample Sloane et al., 2003 ⁶³	Required partial or complete assistance with locomotion at study enrollment (percentage)	AL: 20.0%	38.1%	p=0.021	AL group had fewer individuals requiring partial or complete assistance with locomotion at enrollment

ADL = Activities of Daily Living; AL = Assisted Living; ASPE = Assistant Secretary for Planning and Evaluation; HCBS = Home and Community-Based Services; LTC = Long term care; MAI = Multilevel Assessment Instrument; NH = Nursing Home; NR = Not reported; PACE = Program of All-Inclusive Care; SD = Standard Deviation; SF-36 = Short-Form Health Survey; SIP-NH = Sickness Impact Profile for Nursing Homes

Note: Table rows ordered by similar measures of physical function.

^aStudy focused on samples with dementia.

Table 5. Description of participant physical function: international cross-sectional and longitudinal peer-reviewed studies

Study	Measure of Physical Function	HCBS/AL	NH	Significance	Summary
^a Boersma et al., 1997 ³⁵ The Netherlands	Mean ADL score; range 0-10, with higher scores indicating more ADL dependency	HCBS(a): 4.2 HCBS(b): 4.9	8.4	NR	On average, HCBS recipients had fewer ADL dependencies
Challis et al., 2000 ³⁷ England	Median Barthel score; range 0-20, with lower scores indicating more dependency	HCBS: 14.3	8.7	p<0.001	On average, HCBS recipients had less dependency
^a Margallo-Lana et al., 2001 ⁴⁹ United Kingdom	Mean Barthel score; range 0-20, with lower scores indicating more dependency	HCBS: 14.8	11.0	NR	On average, HCBS recipients had less dependency
Nottingham Studies Rothera et al., 2003 ⁵⁷ United Kingdom	Median Barthel score; range 0-20, with lower scores indicating more dependency	HCBS: 13	7	p<0.001	On average, HCBS recipients had less dependency
Chappell et al., 2004 ³⁸ Canada	Functional Autonomy Measurement System score	Scores were not specified	Scores were not specified	Scores were not significantly different for HCBS and NH participants	HCBS and NH recipients had similar functional scores
Wodchis et al., 2003 ⁶⁶ Canada	Total dependence in mobility (percentage)	HCBS(a): 2% HCBS(b): 0%	28%	NR	HCBS groups had fewer individuals totally dependent in mobility

ADL = Activities of Daily Living; HCBS = Home and Community-Based Services; NH = Nursing Home; NR = Not Reported

Note: Table rows ordered by similar measures of physical function.

^aStudy focused on samples with dementia.

Table 6. Description of participant cognitive function: U.S. cross-sectional and longitudinal peer-reviewed studies

Study	Measure of Cognitive Function	HCBS/AL	NH	Significance	Summary
^a Beattie et al., 2005 ³⁴	Mean MMSE score; range 0–24, with lower scores indicating more impairment	AL: 8.40 (SD 7.06)	7.56 (SD 7.10)	Not significant	On average, AL residents did not differ significantly from NH residents in cognitive function scores (study focused on samples with dementia)
^a Edelman et al., 2005 ⁴⁰	(All participants had MMSE score of 10 or higher) Mean MMSE score; range 0–30, with lower scores indicating more impairment	AL: 11.1 (SD 6.8)	7.9 (SD 6.8)	p<0.01	On average, AL residents had higher cognitive function (study focused on samples with dementia)
Pruchno and Rose, 2000 ⁵⁴	Mean MMSE score; range 0–30, with lower score indicating more impairment	AL: 23.57 (SD 4.25)	23.09 (SD 4.06)	Not significant	On average, AL residents did not differ significantly from NH residents in cognitive function
Lee et al., 2001 ⁴⁶	MDS-COGS; range 0–9, with higher scores indicating more impairment	Scores were not specified	Scores were not specified	Mean score of HCBS participants was significantly lower than NH participants (p<0.05)	On average, HCBS recipients had higher cognitive function
Collaborative Studies of Long-Term Care subsample ^a Sloane et al., 2005 ⁶²	(All participants had diagnosis of dementia) Mean MDS-COGS score; range 0–10, with higher scores indicating more impairment	AL: 5.3 (SD 2.4)	5.7 (SD 2.3)	p=0.005	On average, AL residents had higher cognitive function (study focused on samples with dementia)
Borrayo et al., 2002 ³⁶	Mean cognitive impairment; range 0–3, with higher scores indicating more severe impairment Alzheimer's disease or other dementia (percentage)	HCBS: 1.72 (SD 1.23), 18% AL: 1.60 (SD 1.12), 42%	1.42 (SD 1.05), 56%	NR	On average HCBS recipients and AL residents had more cognitive impairment; HCBS and AL groups had fewer individuals with Alzheimer's disease or other dementia

Table 6. Description of participant cognitive function: U.S. cross-sectional and longitudinal peer-reviewed studies (continued)

Study	Measure of Cognitive Function	HCBS/AL	NH	Significance	Summary
Gaugler, 2006 ⁴³	Mean SPMSQ score; range 0–10, with higher scores indicating more impairment	HCBS: 3.02 (SD 2.67) AL: 2.30 (SD 2.20)	3.20 (SD 2.46)	Not significant	On average, HCBS recipients and AL residents were not significantly different from NH residents in cognitive function
^a Leon and Moyer, 1999 ⁴⁷	(All participants met criteria for probable Alzheimer’s disease) Mean CDRS score; range 0.5–6, with higher scores indicating more severe dementia	AL: 2.16 (SD 0.97)	2.72 (SD 0.97)	p<0.001	On average, AL residents had less severe dementia (study focused on samples with dementia)
Oregon Assisted Living Gaugler and Kane, 2005 ⁴⁴	Mean MSQ score; range 0–10, with lower scores indicating more impairment	AL: 7.07 (SD 2.30)	6.46 (SD 2.18)	p<0.001	On average, AL residents had higher cognitive function
^a Dementia Care Project Port et al., 2005 ⁵³	(All participants had diagnosis of dementia) Classified with mild, moderate, severe, or very severe dementia based on MMSE or MDS-COGS (percentage)	AL: 13.3% mild, 28.8% moderate, 23.8% severe, 29.2% very severe	8.0% mild, 13.3% moderate, 22.1% severe, 56.6% very severe	p=0.003	AL group had fewer individuals with very severe dementia (study focused on samples with dementia)
Kansas Medicaid Studies Shireman and Rigler, 2004 ⁶⁰	Diagnosis of Alzheimer’s disease or dementia (percentage)	HCBS: 6.1%	34.6%	p<0.01	HCBS group had fewer individuals with a diagnosis of Alzheimer’s disease or dementia
Reinardy and Kane, 1999 ⁵⁵	Dementia diagnosis (percentage)	HCBS: 15%	20%	Not significant	HCBS recipients did not differ significantly from NH residents in the number of individuals diagnosed with dementia
Collaborative Studies of Long-Term Care subsample Sloane et al., 2003 ⁶³	Moderate or advanced dementia at study enrollment (percentage)	AL: 38.6%	67.2%	p=0.001	AL group had fewer individuals with moderate or advanced dementia at study enrollment

Table 6. Description of participant cognitive function: U.S. cross-sectional and longitudinal peer-reviewed studies (continued)

Study	Measure of Cognitive Function	HCBS/AL	NH	Significance	Summary
Wieland et al., 2010 ⁶⁴	Diagnosis of dementia (percentage)	HCBS: 18.0% PACE: 80.9%	50.2%	p<0.001	HCBS group had fewer individuals than NH group with a diagnosis of dementia; PACE group had more individuals than NH group with a diagnosis of dementia
^a Mitchell et al., 2004 ⁵²	(All persons in sample had diagnosis of dementia and CPS of 5 or 6 at admission) CPS 6 versus 5 (percentage), with 6 indicating more cognitive impairment	HCBS: 34.6%	57.1%	p<0.001	HCBS group had fewer individuals with the highest cognitive impairment score (study focused on samples with dementia)
ASPE private LTC insurance cohort Doty et al., 2010 ³⁹	Cognitive impairment (percentage)	HCBS: 28% AL: 63%	64%	NR	HCBS group had fewer individuals than the NH group with cognitive impairment; AL group had similar number of individuals as NH group with cognitive impairment
Mehdzadeh, 2002 ⁵¹	Cognitively impaired (percentage)	HCBS: 16%	49%	NR	HCBS group had fewer individuals with cognitive impairment
Collaborative Studies of Long-Term Care subsample Zimmerman et al., 2003 ⁶⁷	Cognitive impairment indicated by diagnosis of dementia, MMSE score, or information on MDS (percentage)	AL(a): 42% AL(b): 35% AL(c): 23%	51%	NR	AL groups had fewer individuals with cognitive impairment

AL = Assisted Living; ASPE = Assistant Secretary for Planning and Evaluation; CDRS = Clinical Dementia Rating Score; CPS = Cognitive Performance Score; HCBS = Home and Community-Based Services; LTC = Long Term Care; MDS-COGS = Minimum Data Set Cognition Scale; MMSE = Mini-mental State Exam; MSQ = Mental Status Questionnaire; NH = Nursing Home; NR = Not Reported PACE = Program of All-Inclusive Care; SD = Standard Deviation; SPMSQ = Short Portable Mental Status Questionnaire

Note: Table rows ordered by similar measures of cognitive function.

^aStudy focused on samples with dementia.

Table 7. Description of participant cognitive function: international cross-sectional and longitudinal peer-reviewed studies

Study	Measure of Cognitive Function	HCBS/AL	NH	Significance	Summary
^a Boersma et al., 1997 ³⁵ The Netherlands	Mean MMSE score; range 0-28, lower scores indicate more impairment	HCBS(a): 14.8 HCBS(b): 13.6	5.5	NR	On average, HCBS recipients had higher cognitive function (study focused on samples with dementia)
^a Margallo-Lana et al., 2001 ⁴⁹ United Kingdom	Mean MMSE score; lower scores indicate more impairment	HCBS: 15.3	7.0	NR	On average, HCBS recipients had higher cognitive function (study focused on samples with dementia)
Challis et al., 2000 ³⁷ England	Median MMSE score; lower scores indicate more impairment	HCBS: 16	12	p<0.001	On average, HCBS recipients had higher cognitive function
Nottingham Studies Rothera et al., 2003 ⁵⁷ United Kingdom	Median MMSE score; range 0–30, with lower scores indicating more impairment	HCBS: 17	14	NR	On average, HCBS recipients had higher cognitive function
Resource Implications Study Group, 2000 ³² United Kingdom	Mean AGE CAT score; higher scores indicate more impairment	HCBS: 0.9	2.2	NR	On average, HCBS recipients had higher cognitive function
Wodchis et al., 2003 ⁶⁶ Canada	Severe cognitive impairment (percentage)	HCBS(a): 4% HCBS(b): 0%	34%	NR	HCBS groups had fewer individuals with severe cognitive impairment

AGECAT = Automated Geriatric Examination Computer Assisted Taxonomy; AL = Assisted Living; HCBS = Home and Community-Based Services; MMSE = Mini-mental State Exam; NH = Nursing Home; NR = Not Reported

Note: Table rows ordered by similar measures of cognitive function.

^aStudy focused on samples with dementia.

Table 8. Description of participant mental health: U.S. cross-sectional and longitudinal peer-reviewed studies

Study	Measure of Mental Health	HCBS/AL	NH	Significance	Summary
Marek et al., 2005 ⁴⁸	Mean score on MDS-based depression rating scale; range 0–21, with lower scores indicating less depressive symptoms	HCBS: 0.7 (SD 1.1)	1.1 (SD 1.9)	NS	On average, HCBS recipients did not differ significantly from NH residents in depressive symptoms
Pruchno and Rose, 2000 ⁵⁴	Mean CES-D score; higher scores indicate more depressive symptoms	AL: 13.92 (SD 10.85)	17.98 (SD 11.10)	p<0.05	On average, AL residents had fewer depressive symptoms
Collaborative Studies of Long-Term Care subsample ^a Sloane et al., 2005 ⁶²	Mean CSDD score; higher scores indicate more depressive symptoms	AL: 4.5 (SD 4.8)	3.6 (SD 4.6)	p=0.001	On average, AL residents had more depressive symptoms
^a Dementia Care Project Gruber-Baldini et al., 2005 ⁴⁵	CSDD score of 7 or greater indicating clinically significant depression (percentage)	AL: 23.9%	26.6%	NS	AL group did not differ significantly in number of individuals with clinically significant depression
^a Edelman et al., 2005 ⁴⁰	CSDD score of 7 or greater indicating depression (percentage)	AL: 36.4%	21.4%	NR	AL group had more individuals with a score indicating depression
Kansas Medicaid Studies Shireman and Rigler, 2004 ⁶⁰	Diagnosis of depression, any psychosis (percentage)	HCBS: 6.9%, 10.4%	9.8%, 24.6%	p<0.01, p<0.01	HCBS group had fewer individuals with a diagnosis of depression or a diagnosis of psychosis
Wieland et al., 2010 ⁶⁴	Diagnosis of anxiety/depression (percentage)	HCBS: 26.6% PACE: 26.2%	22.6%	NR	HCBS and PACE groups had more individuals with a diagnosis of anxiety/depression

Table 8. Description of participant mental health: U.S. cross-sectional and longitudinal peer-reviewed studies (continued)

Study	Measure of Mental Health	HCBS/AL	NH	Significance	Summary
Gaugler, 2006 ⁴³	Mean positive affect subscale score from the Dementia Quality of Life scale; higher scores indicate better psychosocial status	HCBS: 3.65 (SD 0.79) AL: 3.73 (SD 0.71)	3.83 (SD 0.71)	NS	On average, HCBS recipients and AL residents did not differ significantly from NH residents in psychosocial status
Oregon Assisted Living Frytak et al., 2001 ⁴²	Mean psychological well-being score from SF-36 mental health subscale; range 0–100, with higher scores indicating better psychological well-being	AL: 76.04	71.35	NR	On average, AL residents had better psychological well-being
Schroeder et al, 1998 ⁵⁹	Mean SWLS score; range 0–35, with higher score indicating higher life satisfaction	AL: 28.2 (SD 1.3)	29.5 (SD 1.0)	NS	On average, AL residents did not differ significantly in life satisfaction

AL = Assisted Living; CES-D = Center for Epidemiological Studies Depression Scale; CSDD = Cornell Scale for Depression in Dementia; HCBS = Home and Community-Based Services; MDS = Minimum Data Set; NH = Nursing Home; NR = Not Reported; NS = Not significant; PACE = Program of All-Inclusive Care; SD = Standard Deviation; SF-36 = Short-Form Health Survey; SWLS = Satisfaction with Life Scale

Note: Table rows order by similar measures of mental health.

^aStudy focused on samples with dementia.

Table 9. Description of participant mental health: international cross-sectional and longitudinal peer-reviewed studies

Study	Measure of Mental Health	HCBS/AL	NH	Significance	Summary
Nottingham Studies Rothera et al., 2003 ⁵⁷ United Kingdom	Median Geriatric Depression Scale score; lower scores indicate less depression	HCBS: 5	7	Categorical depression not significantly different between types of care	HCBS group did not differ significantly from NH group in number of individuals with depression
^a Boersma et al., 1997 ³⁵ The Netherlands	CAMDEX indicator for depression (percentage)	HCBS(a): 14.3% HCBS(b): 10.5%	16.2%	NR	HCBS groups had fewer individuals with an indicator for depression
Chappell et al., 2004 ³⁸ Canada	Terrible Delightful Scale and life satisfaction question	Scores were not specified	Scores were not specified	Scores were not significantly different for HCBS and NH participants, indicating they were comparable in terms of life satisfaction	HCBS group did not differ significantly from NH group in life satisfaction scores
Wodchis et al., 2003 ⁶⁶ Canada	Generally happy/free from worry (percentage)	HCBS(a): 53% HCBS(b): 84%	29%	NR	HCBS groups had more individuals that were generally happy/free from worry

CAMDEX = Cambridge Examination for Mental Disorders of the Elderly; HCBS = Home and Community-Based Services; MDS = Minimum Data Set; NH = Nursing Home;

NR = Not Reported

Note: Table rows order by similar measures of mental health.

^aStudy focused on samples with dementia.

Table 10. Description of participant clinical status: U.S. cross-sectional and longitudinal peer-reviewed studies

Study	Measure of Clinical Status	HCBS/AL	NH	Significance	Summary
Borrayo et al., 2002 ³⁶	Mean number of chronic diseases; range 0–16	HCBS: 3.34 (SD 1.80) AL: 2.01 (SD 1.25)	2.55 (SD 1.56)	NR	On average, HCBS recipients had more chronic diseases than NH users; On average, AL residents had fewer chronic disease than NH residents
^a Dementia Care Project Port et al., 2005 ⁵³ , Williams et al., 2005 ⁶⁵	Mean number of 11 comorbidities Score of 2 or more on PGC-PIS indicating pain (percentage)	AL: 2.0 (SD 1.5, range 0-7), 38.9% with pain	2.4 (SD 1.6, range 0-7), 25.0% with pain	NS; NS	On average, AL residents did not differ significantly from NH residents in the number of comorbidities; AL group did not differ significantly from NH group in number of individuals with pain
^a Edelman et al., 2005 ⁴⁰	Mean number of mild to severe comorbid conditions (out of 11 conditions) from the CIRS-g	AL: 3.6 (SD 2.0)	2.8 (SD 1.5)	p<0.05	On average, AL residents had more mild to severe comorbid conditions
^a Leon and Moyer, 1999 ⁴⁷	Mean CIRS-g Severity Index score excluding psychiatric illness; higher scores indicate more severity Has possible terminal conditions (percentage)	AL: 2.06 (SD 0.53), 34% (s.e. 0.04)	2.11 (SD 0.36), 54% (s.e. 0.04)	p<0.001 for terminal conditions	On average, AL residents had less severe conditions; AL group had fewer individuals with possible terminal conditions
Collaborative Studies of Long-Term Care subsample ^a Sloane et al., 2005 ⁶²	Mean number of comorbid conditions	AL: 3.6 (SD 2.3)	4.4 (SD 2.2)	p=0.001	On average, AL residents had fewer comorbid conditions
Kansas Medicaid Studies Rigler et al., 2004 ⁵⁶	CIRS-g summed disease burden score indicating disease categories but not severity (percentage)	HCBS: 27.4% score 0 or 1, 21.0% score 2 or 3, 21.0% score 4 or 5, 30.8% score ≥6	19.3% score 0 or 1, 39.7% score 2 or 3, 19.4% score 4 or 5, 21.6% score ≥6	NR	HCBS group had more individuals with diseases in many disease categories

Table 10. Description of participant clinical status: U.S. cross-sectional and longitudinal peer-reviewed studies (continued)

Study	Measure of Clinical Status	HCBS/AL	NH	Significance	Summary
Shugarman et al., 1999 ⁶¹	Mean Case-Mix Index score; higher scores indicate more resource intensive	HCBS: 0.84	1.03	p<0.001	On average, HCBS recipients were less resource intensive
Lee et al., 2001 ⁴⁶	Top 3 primary diagnoses for residents in each setting (percentage)	HCBS: 47.8% disease of circulatory system, 19.4% endocrine disorder, 10.4% disease of musculoskeletal system	29.9% disease of circulatory system, 28.4% disease of nervous system, 16.4% fracture	p<0.001	The most common primary diagnoses differed between HCBS recipients and NH residents
Mehdizadeh, 2002 ⁵¹	Number of diseases diagnosed, including cancer, diabetes, and/or other gland diseases; circulatory diseases; musculoskeletal diseases; and respiratory diseases (percentage)	HCBS: 36% with 0, 34% with 1, 22% with 2, 8% with 3, 0% with 4	31% with 0, 36% with 1, 25% with 2, 8% with 3, 0% with 4	NR	Individuals in HCBS group had similar number of diseases diagnosed as individuals in NH group
^a Mitchell et al., 2004 ⁵²	Diagnoses of cancer, congestive heart failure, and chronic obstructive pulmonary disease (percentage)	HCBS: 13.7%, 11.6%, 29.6%	11.4%, 15.6%, 29.6%	NS, NS, NS	HCBS group had similar number of individuals diagnosed with different diseases as NH group
Reinardy and Kane, 1999 ⁵⁵	Diagnoses of heart condition, stroke, skeletal-muscular (percentage)	HCBS: 21%, 19%, 16%	30%, 19%, 25%	p<0.05 for heart condition and skeletal-muscular	HCBS group had fewer number of individuals diagnosed with heart condition and skeletal-muscular condition
Wieland et al., 2010 ⁶⁴	Top 3 diseases/conditions for residents in each setting (percentage)	HCBS: 39.2% with diabetes, 27.1% with congestive heart failure, 26.6% with anxiety/depression PACE: 80.9% with dementia, 40.6% with stroke, 35.7% with diabetes	50.2% with dementia, 29.5% with diabetes, 23.5% with stroke	NR	The most common diseases/conditions was different for individuals in HCBS and PACE groups than for individuals in NH group

Table 10. Description of participant clinical status: U.S. cross-sectional and longitudinal peer-reviewed studies (continued)

Study	Measure of Clinical Status	HCBS/AL	NH	Significance	Summary
Collaborative Studies of Long-Term Care subsample Zimmerman et al., 2003 ⁶⁷	Diagnosis of heart condition (percentage)	AL(a): 38% AL(b): 49% AL(c): 48%	48%	NR	AL groups had similar number of individuals with a diagnosis of a heart condition as NH group
Oregon Assisted Living Frytak et al., 2001 ⁴² ; Gaugler and Kane, 2005 ⁴⁴	Mean pain and discomfort score from scale developed at RAND; higher scores indicate more pain and discomfort Mean subjective health impairment; range 0–4 with lower scores indicating better health	AL: 12.62 2.53 (SD 0.87)	12.97 2.73 (SD 0.92)	p<0.001 for subjective health	On average, AL residents had less pain and discomfort and better subjective health
Pruchno and Rose, 2000 ⁵⁴	Mean subjective health from 4-item scale from the MAI; higher scores indicate better health	AL: 8.86	8.07	p<0.05	On average, AL residents had better subjective health

AL = Assisted Living; CIRIS-g = Cumulative Illness Rating Scale-for Geriatrics; HCBS = Home and Community-Based Services; MAI = Multilevel Assessment Instrument; NH = Nursing Home; NR = Not Reported; NS = Not significant; PACE = Program of All-Inclusive Care; PGC-PIS = Philadelphia Geriatric Center-Pain Intensity Scale; SD = Standard Deviation; s.e. = Standard Error

Note: Table rows ordered by similar measures of clinical status.

^aStudy focused on samples with dementia.

Table 11. Description of participant clinical status: international cross-sectional and longitudinal peer-reviewed studies

Study	Measure of Clinical Status	HCBS/AL	NH	Significance	Summary
McCann et al., 2009 ⁵⁰ Northern Ireland	Limiting long-term illness (percentage) General health poor (percentage)	HCBS: 89%, 31%	99%, 64%	NR	HCBS group had fewer individuals with a limiting long-term illness and poor health
Wodchis et al., 2003 ⁶⁶ Canada	Severe pain (percentage)	HCBS(a): 6% HCBS(b): 4%	30%	NR	HCBS group had fewer individuals with severe pain

AL = Assisted Living; HCBS = Home and Community-Based Services; NH = Nursing Home; NR = Not Reported

Note: Table rows ordered by similar measures of clinical status.

Table 12. Description of participant physical function: U.S. cross-sectional and longitudinal grey literature studies

Study	Measure of Physical Function	HCBS/AL	NH	Significance	Summary
ASPE private LTC insurance cohort Miller et al., 2008 ⁷¹	Mean number of ADL limitations; range 0–6, with higher scores indicating more dependence	HCBS: 3.4 AL: 2.9	4.5	NR	On average, HCBS recipients and AL residents had fewer ADL limitations
Department of Elder Affairs, State of Florida, 2009-2010 ⁶⁹	Mean number of ADLs requiring assistance; range 0–8	HCBS: 3.54 Managed care HCBS: 5.06 AL: 4.35	5.15	NR	On average, HCBS recipients and AL residents had fewer ADLs requiring assistance
Ohio HCBS Waiver Mehdizadeh, 2007 ⁷⁰	Mean number of ADL impairments; range 0–6	HCBS: 3.0	4.4	NR	On average, HCBS recipients had fewer ADL impairments
Spillman et al., 2002 ⁷³	ADL or IADL impairments (percentage)	AL: 3.8% with no ADL/IADL, 32.5% with 1-2 ADL, 52.1% with 3 or more ADL, 11.1% with IADL only	2.2% with no ADL/IADL, 19.9% with 1-2 ADL, 74.4% with 3 or more ADL, 2.9% with IADL only	NR	AL group had fewer individuals with more ADL impairments

ADL = Activities of Daily Living; AL = Assisted Living; ASPE = Assistant Secretary for Planning and Evaluation; HCBS = Home and Community-Based Services; IADL = Instrumental Activities of Daily Living; LTC = Long Term Care; NH = Nursing Home; NR = Not Reported

Note: Table rows ordered by similar measures of physical function.

Table 13. Description of participant cognitive function: U.S. cross-sectional and longitudinal grey literature studies

Study	Measure of Cognitive Function	HCBS/AL	NH	Significance	Summary
Department of Elder Affairs, State of Florida, 2009-2010 ⁶⁹	Dementia (percentage)	HCBS: 32% Managed care HCBS: 63% AL: 62%	60%	NR	HCBS and AL groups had fewer or similar number of individuals with dementia compared with NH group
Ormond et al., 2006 ⁷²	Diagnosis of dementia (percentage)	HCBS(a): 12.9% HCBS(b): 20.3%	31.9%	NR	HCBS groups had fewer individuals with a diagnosis of dementia
Spillman et al., 2002 ⁷³	Alzheimer's disease and other dementia (percentage)	AL: 35.3%	46.1%	NR	AL group had fewer individuals with Alzheimer's disease and other dementia
Ohio HCBS Waiver Mehdizadeh, 2007 ⁷⁰	Cognitively impaired (percentage)	HCBS: 13.5%	70.7%	NR	HCBS group had fewer individuals with cognitive impairment

AL = Assisted Living; CPS = Cognitive Performance Score; HCBS = Home and Community-Based Services; NH = Nursing Home; NR = Not Reported

Note: Table rows ordered by similar measures of cognitive function.

Table 14. Description of participant mental health: U.S. cross-sectional and longitudinal grey literature studies

Study	Measure of Mental Health	HCBS/AL	NH	Significance	Summary
Ormond et al., 2006 ⁷²	Diagnosis of depression (percentage)	HCBS(a): 8.9% HCBS(b): 19.2%	20.4%	NR	HCBS groups had fewer individuals with a diagnosis of depression
Spillman et al., 2002 ⁷³	Mental disorder (percentage)	AL: 25.2%	28.9%	NR	AL group had fewer individuals with a mental disorder

AL = Assisted Living; HCBS = Home and Community-Based Services; NH = Nursing Home; NR = Not Reported

Note: Table rows ordered by similar measures of mental health.

Table 15. Description of participant clinical status: U.S. cross-sectional and longitudinal grey literature studies

Study	Measure of Clinical Status	HCBS/AL	NH	Significance	Summary
Ormond et al., 2006 ⁷²	Diagnosis of stroke; other cardiovascular; endocrine, nutritional and metabolic diseases and immune disorders; diseases of the nervous system and sense organs; respiratory system diseases (percentage)	HCBS(a): 11.3%, 70.7%, 41.0%, 22.4%, 14.3% HCBS(b): 16.6%, 79.1%, 41.1%, 19.8%, 17.3%	11.7%, 68.2%, 30.8%, 24.2%, 11.6%	NR	HCBS groups had few differences in the number of individuals diagnosed with different diseases
Spillman et al., 2002 ⁷³	Has diabetes; hip fracture; emphysema/asthma/COPD; stroke (percentage)	AL: 14.9%, 6.8%, 8.5%, 14.9%	19.7%, 5.4%, 9.6%, 21.5%	NR	AL group had fewer individuals diagnosed with different diseases

AL = Assisted Living; COPD = Chronic obstructive pulmonary disease; HCBS = Home and Community-Based Services; NH = Nursing Home; NR = Not Reported
 Note: Table rows ordered by similar measures of clinical status.

Table 16. Description of analysis and outcome domains: U.S. longitudinal peer-reviewed studies

Study	Sample/Intervention/Comparison	Analysis	Outcome Domains
ASPE private LTC insurance cohort Doty et al., 2010 ³⁹	Private LTC insurance policyholders including HCBS recipients, AL residents, and NH residents; longitudinal panel starting at initiation of services and followed for 28 months	Descriptive statistics; logistic regression was used to predict transitions	Satisfaction
Oregon Assisted Living Frytak et al., 2001 ⁴²	AL and NH residents in Oregon followed for 1 year	Hierarchical linear models were used to examine how setting (AL versus NH) affected growth trajectories for each outcome studied (ability to perform activities of daily living, psychological well-being, and pain and discomfort); models adjusted for resident characteristics, including health status variables, demographic variables, and social measures	Physical function, mental health, pain and discomfort
Oregon Assisted Living Gaugler and Kane, 2005 ⁴⁴	AL and NH residents in Oregon followed for 1 year	Used the Heckman two-stage approach to model the decision to move into an AL or NH setting and then used the information about the likelihood of choosing an AL or NH (Mills ratio) to correct for selection bias in the subsequent models; ANCOVA models were used, including the Mills ratio, to determine if resident activity varied among AL and NH respondents at baseline, 6 months, 1 year, for the change from baseline to 6 months and baseline to 1 year	Activity
Marek et al., 2005 ⁴⁸	Medicaid HCBS Aging in Place program participants and NH residents in Missouri followed for 30 months	Individually matched NH residents were compared with HCBS participants, with matching based on Medicaid eligible, ADLs (within 2 points), cognitive performance (within 1 point), age (within 4 years), and admission date (within 90 days); rank-based nonparametric methods were used for testing differences in outcomes; the baseline value of each outcome was used as the stratifying variable to further adjust for individual differences in initial status	Physical function, cognitive function, mental health

Table 16. Description of analysis and outcome domains: U.S. longitudinal peer-reviewed studies (continued)

Study	Sample/Intervention/Comparison	Analysis	Outcome Domains
^a Mitchell et al., 2004 ⁵²	A retrospective cohort of HCBS recipients and NH residents in Michigan with dementia; all persons in sample died within 1 year of admission to either HCBS program or NH	Bivariate analyses were used to compare end-of-life outcomes; logistic regression for end-of-life outcomes that differed significantly ($p < 0.05$) between settings in the bivariate analyses with age, race, sex, functional status, ethnicity, cognitive status (Cognitive Performance Score of 6 versus 5), and days between admission and death included as covariates in all multivariate models, with other potential confounders included as covariates in individual models depending on the outcome being examined	Utilization, advance care planning, nonpalliative treatments, symptoms, other treatments
Pruchno and Rose, 2000 ⁵⁴	All participants lived on a single LTC campus in Cleveland, Ohio; residents lived in AL or NH with followup for 15 months	Logistic regression was used to estimate effects of facility on mortality; repeated ANOVA was used for cognitive status, functional ability, and depression to estimate time, facility, and time by facility interaction effects	Physical function, cognitive function, mental health, mortality
Kansas Medicaid Study Rigler et al., 2004 ⁵⁶	Kansas Medicaid ambulatory cohort (community-dwelling older adults not receiving any HCBS or NH care during study year), HCBS cohort, and NH cohorts with follow-up for 1 year	Logistic regression was used to examine associations between level of disease burden and inappropriate medication use for each cohort separately without adjustment and with adjustment for sex, age, race, and mean total number of prescriptions per month	Harms
Kansas Medicaid Study Shireman and Rigler, 2004 ⁶⁰	Kansas Medicaid HCBS and NH cohorts with follow-up for 10–12 months	Multiple linear regression was used to test for differences in costs between the settings; all demographic and major chronic condition variables were included in the models	Expenditures

Table 16. Description of analysis and outcome domains: U.S. longitudinal peer-reviewed studies (continued)

Study	Sample/Intervention/Comparison	Analysis	Outcome Domains
Collaborative Studies of Long-Term Care subsample ^a Sloane et al., 2005 ⁶²	Residential care/assisted living facility (AL) residents stratified by (a) facilities with <16 beds; (b) facilities with ≥ 16 beds of the “new-model” type that provide nursing care and cater to an impaired population; and (c) “traditional” facilities with ≥ 16 beds not meeting the “new-model” criteria and NH residents with dementia in four states with follow-up for 1 year	Modeled functional change using generalized estimating equations; modeled rates of mortality, hospitalization, and incidence of new or worsening morbidity using generalized estimating equations; adjusted for baseline age, gender, race, education, marital status, length of stay, cognitive status, and number of comorbid conditions; to adjust for differential selection probabilities among the settings, they incorporated sampling weights into all outcome analyses	Physical function, cognitive function, mental health, mortality, utilization, behavior, social function, social withdrawal, morbidity
Wieland et al., 2010 ⁶⁴	Entrants into HCBS program, PACE program, and NHs in two counties in South Carolina with followup for 5 years	Kaplan-Meier curves tested with log-rank statistics for cohort survival comparisons (overall and stratified by mortality risk)	Mortality
Dementia Care Project ^a Zimmerman et al., 2005 ⁶⁸	Residential care/assisted living facility (AL) residents stratified by (a) facilities with <16 beds; (b) facilities with ≥ 16 beds of the “new-model” type that provide nursing care and cater to an impaired population; and (c) “traditional” facilities with ≥ 16 beds not meeting the “new-model” criteria and NH residents with dementia in four states with follow-up for 6 months	Linear mixed regression models with random effects were used to adjust the standard errors of the quality of life measures for clustering; estimated adjusted change in quality of life outcomes as the residual from regression of raw change on the baseline value	Quality of life

ADL = Activities of Daily Living; AL = Assisted Living; ANCOVA = Analysis of Covariance; ASPE = Assistant Secretary for Planning and Evaluation; HCBS = Home and Community-Based Services; NH = Nursing Home; PACE = Program of All-Inclusive Care

^aStudy focused on samples with dementia.

Table 17. Description of analysis and outcome domains: international longitudinal peer-reviewed studies

Study	Sample/Intervention/Comparison	Analysis	Outcome Domains
Resource Implications Study Group, 2000 ³²	Care-recipients receiving HCBS or NH care in the United Kingdom, with followup for 2 years	Tested significance of changes over time in General Health Questionnaire (GHQ) score of caregivers using <i>t</i> test for paired samples	Family caregivers' psychological morbidity
McCann et al., 2009 ⁵⁰	Residents in residential homes (referred to as HCBS group) and NHs in Northern Ireland, with followup for 5 years	Cox proportional hazards models were used to examine the relationship between resident and setting characteristics and risk of death during the 5-year followup adjusted for age, sex, general health, and marital status	Mortality
Nottingham Studies Rothera et al., 2002 ⁵⁸	Residents in residential homes (referred to as HCBS group) and NHs in the United Kingdom, with followup for 20 months	Survival function was calculated for the number of days survived within the 20-month period; univariate and multivariate Cox analyses controlling for age, gender, and prior placement were performed	Mortality

ADL = Activities of Daily Living; HCBS = Home and Community-Based Services; NH = Nursing Home; PACE = Program of All-Inclusive Care

Table 18. Description of analysis and outcome domains: U.S. longitudinal grey literature studies

Study	Sample/Intervention/Comparison	Analysis	Outcome Domains
ASPE private LTC insurance cohort Miller et al., 2008 ⁷¹	Private LTC insurance policyholders, including HCBS recipients, AL residents, and NH residents; longitudinal panel starting at initiation of services and followed for 28 months	Multivariate logistic regression predicting mortality, controlling for disability, medical conditions, and demographic characteristics at baseline; multivariate fixed effects model predicting expenditures on LTC, controlling for disability, demographic characteristics, and utilization	Mortality, expenditures
Department of Elder Affairs, State of Florida, 2009-2010 ⁶⁹	Medicaid LTC users in Florida in HCBS waiver, managed care HCBS program, AL program, and NHs for fiscal year 2009–10	Reports annual cost per client	Expenditures
Ohio HCBS Waiver Mehdizadeh 2007 ⁷⁰	Medicaid LTC users in Ohio in HCBS waiver and NHs	Reports annual Medicaid and other public expenditures for both settings	Expenditures

AL = Assisted Living; ASPE = Assistant Secretary for Planning and Evaluation; HCBS = Home and Community-Based Services; LTC = Long Term Care; NH = Nursing Home

Table 19. Physical function outcomes: U.S. longitudinal peer-reviewed studies

Study	Measure	Result	Risk of Bias Rating
Oregon Assisted Living Frytak et al., 2001 ⁴²	Functional ability, measured as need for assistance in ADLs, over 1 year	<p><i>Intercept coefficient:</i> -29.863, $p=0.000$ <i>Slope coefficient:</i> 0.656, $p=0.465$ The type of setting (AL vs. NH) was strongly related to functional ability at the start of the study, but it was not significantly related to individual growth rates.</p> <p>Conclusions: AL and NH residents experienced change in physical functioning over the study period, but the change was not related to the type of setting they lived in, so there were no significant differences in the trajectory of physical functioning between AL and NH residents.</p>	High
Pruchno and Rose, 2000 ⁵⁴	Mean MAI functional ability over 1 year; higher score indicates better function	<p>There was a significant main effect for facility (AL versus NH) in the repeated ANOVA analysis, indicating that AL residents had higher mean functional scores across time compared with NH residents. The interaction term for time versus facility was not significant, indicating that there were not different trends over time in functional ability for AL versus NH residents.</p> <p>Conclusions: Functional ability for AL and NH residents did not change at different rates.</p>	High
Collaborative Studies of Long-Term Care subsample ^a Sloane et al, 2005 ⁶²	Mean increase in ADL dependency per 12 months; measure based on MDS ADL items	<p>Residents with mild dementia: AL 4.29, NH 5.80, $p=0.059$ Residents with moderate or severe dementia: AL 0.87, NH 1.13, $p=0.807$</p> <p>Conclusions: Mean rates of decline in ADL dependency did not differ between AL and NH residents for the cohort with mild dementia or for the cohort with moderate or severe dementia.</p>	High
Marek et al., 2005 ⁴⁸	Mean impairment in ADLs; measured from MDS ADL items, with a range of 0–20, where higher scores indicate greater impairment	<p>6 months: HCBS mean 1.3, NH mean 3.2, $p=0.02$ 12 months: HCBS mean 1.7, NH mean 3.5, $p=0.04$ 18 months: HCBS mean 1.4, NH mean 3.8, $p=0.08$ 24 months: HCBS mean 0.8, NH mean 3.2, $p=0.00$</p> <p>Conclusions: ADL functioning was significantly better in the HCBS group compared with the NH group at all time periods except the 18-month time period.</p>	High

ADL = Activities of Daily Living; AL = Assisted Living; ANOVA = Analysis of Variance; HCBS = Home and Community-Based Services; MAI = Multilevel Assessment Instrument; MDS = Minimum Data Set; NH = Nursing Home

Note: Table 16 reports analysis performed in each study.

Note: Table rows ordered by analyses of AL versus NH then by analyses of HCBS versus NH.

^aStudy focused on samples with dementia.

Table 20. Cognitive function outcomes: U.S. longitudinal peer-reviewed studies

Study	Measure	Result	Risk of Bias Rating
Pruchno and Rose, 2000 ⁵⁴	Mean MMSE score over 1 year; range 0–30, with lower score indicating more impairment	There were no significant time, time by facility, or facility effects (for AL versus NH) in the repeated ANOVA analysis, indicating that AL and NH residents had similar trends in cognitive ability over time. Conclusions: Trends in cognitive ability for AL and NH residents were similar.	High
Collaborative Studies of Long-Term Care subsample ^a Sloane et al., 2005 ⁶²	Mean increase in cognitive impairment per 12 months; measure based on MDS-COGS	Residents with mild dementia: AL 0.41, NH 0.71, p=0.181 Residents with moderate or severe dementia: AL -0.13, NH 0.45, p=0.093 Conclusions: Mean rates of decline in cognitive function did not differ between AL and NH residents for the cohort with mild dementia or for the cohort with moderate or severe dementia.	High
Marek et al., 2005 ⁴⁸	Mean cognitive impairment; measured from MDS Cognitive Performance Scale, with a range of 0–6, where higher scores indicate greater impairment	6 months: HCBS mean 0.8, NH mean 1.4, p=0.00 12 months: HCBS mean 0.7, NH mean 1.8, p=0.00 18 months: HCBS mean 0.6, NH mean 1.8, p=0.00 24 months: HCBS mean 0.8, NH mean 2.1, p=0.38 Conclusions: Cognition was significantly better in the HCBS group compared with the NH group at the 6-, 12-, and 18-month time periods, but not at the 24-month time period.	High

AL = Assisted Living; ANOVA = Analysis of Variance; HCBS = Home and Community-Based Services; MDS = Minimum Data Set; MDS-COGS = Minimum Data Set Cognition Scale; MMSE = Mini-Mental State Examination; NH = Nursing Home

Note: Table 16 reports analysis performed in each study.

Note: Table rows ordered by analyses of AL versus NH then by analyses of HCBS versus NH.

^aStudy focused on samples with dementia.

Table 21. Mental health outcomes: U.S. longitudinal peer-reviewed studies

Study	Measure	Result	Risk of Bias Rating
Oregon Assisted Living Frytak et al., 2001 ⁴²	Psychological well-being, measured by SF-36 mental health subscale, over 1 year	<i>Intercept coefficient:</i> 2.197, $p=0.361$ <i>Slope coefficient:</i> 1.575, $p=0.235$ Average baseline levels of psychological well-being were similar across both settings (AL and NH), and individual growth rates were insignificant. Conclusions: AL and NH residents experienced no change in psychological well-being on average.	High
Pruchno and Rose, 2000 ⁵⁴	Mean CES-D score; higher scores indicate more depressive symptoms	There were no significant time, time by facility, or facility effects (for AL versus NH) in the repeated ANOVA analysis, indicating that residents in AL and NH had similar trends for depression over time. Conclusions: Trends in depression for AL and NH residents were similar.	High
Collaborative Studies of Long-Term Care subsample ^a Sloane et al., 2005 ⁶²	Mean increase in depressive symptoms per 12 months; measure based on CSDD	Residents with mild dementia: AL 1.33, NH 1.53, $p=0.753$ Residents with moderate or severe dementia: AL 1.52, NH 0.85, $p=0.409$ Conclusions: Mean rates of change in depressive symptoms did not differ between AL and NH residents for the cohort with mild dementia or for the cohort with moderate or severe dementia.	High
Marek et al., 2005 ⁴⁸	Mean score on MDS-based depression rating scale; range 0–21, with lower scores indicating less depressive symptoms	Baseline: HCBS mean 0.7, NH mean 1.1, $p=0.76$ 6 months: HCBS mean 0.5, NH mean 1.4, $p=0.00$ 12 months: HCBS mean 0.3, NH mean 1.5, $p=0.00$ 18 months: HCBS mean 0.5, NH mean 1.4, $p=0.14$ 24 months: HCBS mean 0.4, NH mean 1.3, $p=0.39$ Conclusions: Depression was significantly better in the HCBS group compared with the NH group at the 6- and 12-month time periods, but not at baseline, 18-, or 24-month time periods.	High

AL = Assisted Living; ANOVA = Analysis of Variance; CES-D = Center for Epidemiological Studies Depression Scale; CSDD = Cornell Scale for Depression in Dementia; HCBS = Home and Community-Based Services; MDS = Minimum Data Set; NH = Nursing Home; SF-36 = Short-Form Health Survey

Note: Table 16 reports analysis performed in each study.

Note: Table rows ordered by analyses of AL versus NH then by analyses of HCBS versus NH.

^aStudy focused on samples with dementia.

Table 22. Mortality outcomes: U.S. longitudinal peer-reviewed studies

Study	Measure	Result	Risk of Bias Rating
Pruchno and Rose, 2000 ⁵⁴	Mortality	Facility coefficient (NH versus AL): -1.50, s.e. 0.88 The type of facility (NH versus AL) had no effect on mortality after controlling for other demographic characteristics. Conclusions: Patterns of mortality were not significantly different for AL and NH residents.	High
Collaborative Studies of Long-Term Care subsample ^a Sloane et al., 2005 ⁶²	Mortality incidence rate per 100 participants per quarter	Residents with mild dementia: AL 3.2, NH 4.2, p=0.409 Residents with moderate or severe dementia: AL 3.7, NH 4.2, p=0.683 Conclusions: Mortality did not differ significantly between AL and NH residents for the cohort with mild dementia or for the cohort with moderate or severe dementia.	High
Wieland et al., 2010 ⁶⁴	Median survival	Median survival (unstratified): HCBS 3.5 years, PACE 4.2 years, NH 2.3 years	High

AL = Assisted Living; HCBS = Home and Community-Based Services; NH = Nursing Home; PACE = Program of All-Inclusive Care for the Elderly; s.e. = Standard Error

Note: Table 16 reports analysis performed in each study.

Note: Table rows ordered by analyses of AL versus NH then by analyses of HCBS versus NH.

^aStudy focused on samples with dementia.

Table 23. Mortality outcomes: international longitudinal peer-reviewed studies

Study	Measure	Result	Risk of Bias Rating
McCann et al., 2009 ⁵⁰ Northern Ireland	Median survival; mortality risk	Median survival: HCBS 4.51 years (3.92, 4.92), NH 2.33 years (2.25, 2.59) Mortality risk hazard ratios: Not in care home: reference HCBS: 1.63 (1.44, 1.85) NH: 2.17 (1.96, 2.41) Conclusions: Residents in nursing care homes had the highest mortality risk compared with those not in care homes.	NA
Nottingham Studies Rothera et al., 2002 ⁵⁸ United Kingdom	Mortality	Mortality over 20-month period: HCBS 23.3%, NH 39.1% Mortality (multivariate Cox): HCBS: reference NH: 1.85 (1.50, 2.23) Conclusions: Residents in nursing homes had higher odds of mortality than HCBS group.	NA

HCBS = Home and Community-Based Services; NH = Nursing Home

Note: Table 17 reports analysis performed in each study.

Table 24. Mortality outcomes: U.S. longitudinal grey literature studies

Study	Measure	Result	Risk of Bias Rating
Miller et al., 2008 ⁷¹ (ASPE private LTC insurance cohort)	Mortality over 28-month study period; examined characteristics at baseline (including service setting) that predict mortality	Mortality odds ratio: Not yet receiving LTC: reference HCBS: 1.497, p=0.039 AL: 1.329, p=0.147 NH: 1.822, p=0.013 The odds of mortality are highest for those receiving NH services at baseline (compared with those not yet receiving LTC at baseline).	NA

AL = Assisted Living; ASPE = Assistance Secretary for Planning and Evaluation; HCBS = Home and Community-Based Services; LTC = Long-Term Care;

NA = Not Applicable; NH = Nursing Home

Note: Table 18 reports analysis performed in each study.

Table 25. Utilization outcomes: U.S. longitudinal peer-reviewed studies

Study	Measure	Result	Risk of Bias Rating
Collaborative Studies of Long-Term Care subsample ^a Sloane et al., 2005 ⁶²	Hospitalization reported as incidence rate per 100 participants per quarter	Residents with mild dementia: AL 14.2, NH 8.4, p=0.009 Residents with moderate or severe dementia: AL 14.2, NH 10.0, p=0.115 Conclusions: Hospitalization rates were significantly higher among AL residents with mild dementia than among NH residents with mild dementia, but hospitalization rates were not significantly different between AL and NH residents with moderate or severe dementia.	High
^a Mitchell et al., 2004 ⁵²	Hospitalization in 90 days prior to last MDS assessment	Adjusted odds ratio: hospitalization HCBS: reference NH : 1.30 (0.98, 1.74) Conclusions: The odds of hospitalization did not differ between HCBS recipients and NH residents in the adjusted model.	High
^a Mitchell et al., 2004 ⁵²	Hospice referral any time prior to death	Adjusted odds ratio: hospice referral HCBS: reference NH: 0.26 (0.16, 0.43) Conclusions: The odds of hospice referral were significantly lower among NH residents compared with HCBS recipients in the adjusted model.	High

AL = Assisted Living; HCBS = Home and Community-Based Services; MDS = Minimum Data Set; NH = Nursing Home

Note: Table 16 reports analysis performed in each study.

Note: Table rows ordered by analyses of AL versus NH then by analyses of HCBS versus NH.

^aStudy focused on samples with dementia.

Table 26. Harms: U.S. longitudinal peer-reviewed studies

Study	Measure	Result	Risk of Bias Rating
Oregon Assisted Living Frytak et al. 2001 ⁴²	Pain and discomfort from scale developed at RAND; higher scores indicate more pain and discomfort	<i>Intercept coefficient:</i> -0.500, p=0.373 <i>Slope coefficient:</i> 0.615, p=0.419 <i>Slope² coefficient:</i> -0.378, p=0.293 Type of setting (AL versus NH) did not predict one's pain and discomfort score at baseline, individual variation in the growth rates for pain and discomfort, or the acceleration rate for pain and discomfort.	High
Kansas Medicaid Rigler et al., 2004 ⁵⁶	Inappropriate medication use defined as any paid claim for an unconditionally inappropriate medication during the study year based on Beers criteria	Overall rates of any inappropriate medication use: HCBS 48%, NH 38% Conclusions: The rate of any inappropriate medication use (unadjusted) was higher in the HCBS cohort compared with the NH cohort.	High
^a Mitchell et al., 2004 ⁵²	Whether or not subjects had feeding tube; pneumonia; daily or almost daily pain; shortness of breath; pressure ulcers; oxygen therapy in the 14 days prior to last assessment; in-dwelling bladder catheters; anti-anxiety agents in the 7 days prior to last assessment	Adjusted odds ratio feeding tube: HCBS reference, NH 1.70 (1.01, 2.84) Adjusted odds ratio pneumonia: HCBS reference, NH 2.86 (1.62, 5.04) Adjusted odds ratio daily or almost daily pain: HCBS reference, NH 0.38 (0.29, 0.50) Adjusted odds ratio shortness of breath: HCBS reference, NH 0.20 (0.13, 0.28) Adjusted odds ratio pressure ulcers: HCBS reference, NH 1.46 (1.04, 2.03) Adjusted odds ratio oxygen therapy: HCBS reference, NH 2.47 (1.51, 4.05) Adjusted odds ratio foley catheter: HCBS reference, NH 1.06 (0.73, 1.53) Adjusted odds ratio antianxiety medications: HCBS reference, NH 0.63 (0.44, 0.89)	High

AL = Assisted Living; HCBS = Home and Community-Based Services; NH = Nursing Home

Note: Table 16 reports analysis performed in each study.

Note: Table rows ordered by analyses of AL versus NH, then by analyses of HCBS versus NH.

^aStudy focused on samples with dementia.

Table 27. Expenditures: U.S. longitudinal peer-reviewed studies

Study	Measure	Result	Risk of Bias Rating
Kansas Medicaid Shireman and Rigler, 2004 ⁶⁰	Mean monthly total Medicaid expenditures (for inpatient services, outpatient services, prescription drugs, and LTC services)	Adjusted mean monthly expenditures for HCBS recipients were \$1,281 (p<0.001) lower per month than mean monthly expenditures for NH residents.	High

HCBS = Home and Community-Based Services; LTC = Long Term Care; NH = Nursing Home

Note: Table 16 reports analysis performed in each study.

Table 28. Expenditures: U.S. longitudinal grey literature studies

Study	Measure	Result	Risk of Bias Rating
ASPE private LTC insurance cohort Miller et al., 2008 ⁷¹	Monthly costs of care – LTC expenditures on either home health care, AL, or NH care estimated by using individuals' reported patterns of service use and cost information by zip code for a variety of service modalities taken from MetLife Market Surveys	Fixed-effect model coefficient results No paid LTC at baseline: reference HCBS: 0.557, p=0.000 AL: 0.618, p=0.000 NH: 1.133, p=0.000 HCBS recipients had 56%, AL residents had 62%, and NH residents had 113% higher monthly expenditures compared with individuals who were not receiving paid LTC at baseline.	NA
Department of Elder Affairs, State of Florida, 2009-2010 ⁶⁹	Annual Medicaid cost per client, FY 2009–10	HCBS: \$9,026 Managed care HCBS: \$18,504 AL: \$9,902 NH payments only: \$58,055	NA
Ohio HCBS Waiver Mehdizadeh, 2007 ⁷⁰	Medicaid expenditures per person, per year, October 2004–September 2005	HCBS: \$23,702 NH: \$55,571	NA

AL = Assisted living; ASPE = Assistant Secretary for Planning and Evaluation; HCBS = Home and Community-Based Services; LTC = Long Term Care; NA = Not Applicable; NH = Nursing Home

Note: Table 18 reports analysis performed in each study.

Discussion

Key Findings and Strength of Evidence

The literature base for head-to-head comparisons between recipients of Home and Community-Based Services (HCBS)—including assisted living (AL) residents—and residents of nursing homes (NHs) is limited. Although a considerable body of literature in the long-term care (LTC) field separately addresses HCBS and NH populations, few studies directly compare the two. Some literature examines the relative effectiveness of various HCBS programs in reducing admittance to NHs, thus assuming NH admission to be a negative outcome. Yet, in reality, some individuals may not benefit more from HCBS than from NH care, and HCBS may not justify increased private and public costs. (This is especially true if the individuals are unaware of their environments.) Moreover, NHs could have theoretical advantages in quality of care domains compared with HCBS programs.

This review addresses the direct comparison of HCBS and NHs. Included studies showed that on average NH residents were more impaired than HCBS recipients (including AL residents) in terms of physical and cognitive function, but results were mixed for mental health and clinical status measures. The distributions of HCBS recipients and NH residents on these measures overlapped. This overlap suggests that many people could be cared for by either approach. However, the difference in setting (HCBS versus NH, or AL versus NH) likely reflects other concerns, especially the availability of informal support for HCBS recipients, availability of housing (including residential homes), and state and provider policies that render HCBS flexible and affordable.

Table 29 summarizes the key findings and strength of evidence for the outcome domains addressed in the review. 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.

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 these outcomes 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 use of acute care for both the AL versus NH comparison and the HCBS versus NH comparison.

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

One study provided insufficient evidence that Medicaid expenditures were higher for HCBS recipients compared with NH residents, but other program and individual expenditures were not analyzed. No studies analyzed expenditures for AL versus NH residents.

Table 29. Summary of key findings and strength of evidence for outcome domains

Domain/Outcome	Key Findings/Strength of Evidence
<i>KQ 1b</i>	
Changes in physical function	<ul style="list-style-type: none"> • 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. • 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.
Changes in cognitive function	<ul style="list-style-type: none"> • 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. • 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.
Changes in mental health	<ul style="list-style-type: none"> • 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. • 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.
Mortality	<ul style="list-style-type: none"> • Two studies provided low-strength evidence (high risk of bias) that mortality did not differ between AL and NH residents. • 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.
Acute care utilization	<ul style="list-style-type: none"> • 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 to severe dementia group. • 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.
<i>KQ 1c</i>	
Harms	<ul style="list-style-type: none"> • 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. • 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.
<i>KQ 2</i>	
Costs	<ul style="list-style-type: none"> • 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. • Evidence was insufficient for comparing expenditures between AL and NH due to no studies examining this outcome.

AL = Assisted Living; HCBS = Home and Community-Based Services; KQ = Key Question; NH = Nursing Home; PACE = Program of All-Inclusive Care for the Elderly

Several factors must be considered in interpreting this body of evidence. Most studies did not sufficiently describe the settings and services received. Few studies specified the type, frequency, or intensity of services. For NHs and AL, particular settings studied will dictate the services available. However, individual variation in care plans remains possible (if not likely). In HCBS, the service variation is potentially much greater.

Policy debates about the relative merits of HCBS and NH have typically been presented as if NH and HCBS were simple, consistent concepts, and the populations served were homogeneous. However, the underlying empirical evidence requires closer examination. Specifically, comparisons between these modes of care are made more complicated by the considerable diversity in HCBS. The nature of HCBS clients and services can vary widely. Rarely do the analyses present complete descriptions of either. AL likewise varies widely in clientele and services. Analyses of the effectiveness of these modalities must describe both the clientele and the services in enough detail to provide necessary context and to allow for judging applicability.

Additionally, most studies did not report whether participants received any informal care or examine how informal care may have affected the type, frequency, or intensity of formal care services or how it may have interacted with outcomes. None of the studies examined recipients' or caregivers' experiences of care.

Most studies do 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 payment systems and policy environments. Issues of selection, case mix, and attrition complicate attempts to make indirect comparisons of the effects on trajectories. If not adequately addressed by the study design, these issues also impede direct comparisons.

Given the variation in clientele and the low likelihood of random assignment to HCBS versus NH, selection bias will continue to be a major concern, as it was with the studies reviewed here. Typical efforts to adjust for this bias, such as propensity scores, may be impeded by the large degree of heterogeneity, which reduces the accuracy of predictive equations. Multivariate analyses would encounter similar problems. Strong candidates for instrumental variables will be hard to identify.

One promising alternative may be to use “ideal types” as subgroups.⁷⁴ This approach uses frontier analysis to identify groups with specific clusters of key patient characteristics that pertain to a specific health issue. Patient subgroups identified in this manner are sometimes called “archetypes.” Frontier analysis techniques may be useful in addressing how variation in processes of care delivery—such as forms of HCBS or NH—combine with variation in patient characteristics to produce targeted health outcomes. Ideal types have been used in addressing diabetes care and could be applied here.⁷⁴

Distinguishing between long-standing and new LTC users is difficult with most data sources since individuals may not be followed across different providers or settings over time. Few studies used an admission cohort. Outcomes may differ for newcomers to the LTC system compared with those who have lived with limitations or received services for a long period of time. However, studies infrequently distinguished between the two. Related to this, followup times for tracing outcomes of interest were often short. Outcomes may not continue on the same trajectory over longer periods of time, so it is necessary to follow individuals over many years.

Most studies were not explicit about the composition of the people included within each group. For instance, most studies specified neither inclusion nor exclusion of individuals receiving postacute care (short-stay). 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 period of time. These groups may experience different outcomes and have different characteristics and preferences. Thus, investigators must be explicit about who is included or excluded.

The variation in outcome measures and data collection used across studies made it difficult to compare results. Any comparison of outcome trajectories must take into account the 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' activities of daily living (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

Applicability is limited. Many of the samples were not generalizable because they were often small or limited by geography or because they were drawn from specific programs that do not apply to populations outside the study.

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 at the policy level and perhaps at the consumer level. The paradigm for comparing HCBS and NHs has shifted over time. Initially, HCBS was seen as a potentially less expensive alternative to NHs. Increasingly, however, HCBS is 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.

HCBS and even NH services are in a state of rapid transition. However, competing trends may simply result in a continuation of the variability we have noted. One trend in HCBS is toward more flexible "consumer directed" services provided by self-employed "independent" providers. These developments may allow HCBS to offer more care at more flexible times. A slow but growing trend in NH services is toward either smaller settings in households within NHs or small self-contained houses licensed as NHs. Privately occupied rooms are becoming more available, as well. If these trends continue, we can hypothesize better quality-of-life outcomes for NHs than we would presently expect. The ever-shifting patterns of LTC settings make the careful measurement of the interventions even more important.

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.

Table 30 summarizes several issues for future research. Existing literature is difficult to review due to heterogeneity of services, settings, populations, and measures. Therefore, designs for future research should be prospective cohort studies, preferably with direct and comparable measurement and assessment in both settings.

Future research needs are extensive. They reflect both methodological issues and substantive clinical and policy questions, such as the tradeoffs individuals face in choosing one LTC setting over another. Addressing these issues will enable better analyses and will help consumers and policymakers make informed, evidence-based choices. Here we highlight important areas of future research, organized by Key Question (KQ), with specific needs for each.

Table 30. Summary of research gaps to address

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

Table 30. Summary of research gaps to address (continued)

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

AL = Assisted Living; HCBS = Home and Community-Based Services; LTC = Long-Term Care; NH = Nursing Home

KQ 1a: Similarity of Populations Served by HCBS and NHs

Studies that compare HCBS and NHs need to tease out differences in the intervention. Terms such as NH care, HCBS, and AL do not suffice. Studies must carefully describe the actual settings and services. Because of the considerable within-setting variation (in all settings, but especially HCBS), the descriptors of type, frequency, and intensity of service will vary with individual client characteristics. This necessitates larger sample sizes to allow for subgroup and interaction analyses. Additionally, studies must report whether participants received any informal care in order to increase understanding of how informal care affects the type, frequency, or intensity of formal care services and how it interacts with outcomes.

As AL continues to evolve, we may become more able to distinguish AL facilities that are essentially institutional in nature from those that are closer to community care. Refining such distinctions may mean that not all AL now counted as HCBS will be so counted in the future. For both AL and NH, we need to be able to discern the detailed nature of the setting in terms of privacy, autonomy, and independence-enhancing amenities. Reporting general characteristics of the setting does not suffice, because some residents in both NH and AL have no access to the features that render the setting less institutional. Cutler et al. developed a method of assessing the environment as it is actually experienced by each resident in an NH.⁷⁵ Such methods, although superior to global ratings of an NH environment or even an NH unit, are expensive to implement.

Studies should be explicit about the populations served in each setting. Postacute care delivered in NHs and home settings has increased sharply over the last several decades. Outcome trajectories will likely be affected based on the composition of the populations served in each setting. Despite the difficulty in doing so, studies should, when describing their populations, distinguish between individuals receiving short-term postacute care and long-term users.

NH residents are more disabled than HCBS recipients across certain domains. However, the measures used to characterize NH and HCBS populations may not always be comparable and the method of ascertainment often varies by setting and program. Disability measures in NH and HCBS environments should be similar. Measures should not be keyed to the supposed limitations of functioning in NHs in a misguided effort to provide “a level playing field.” For example, NH residents may have a lower level of disability on the bathing item because of availability of bathing equipment or help with bathing, and the solution may be to avoid that comparison. Similarly, instrumental activities of daily living (IADLs) are typically omitted in head-to-head comparisons of NH and HCBS. Presumably this is because investigators assume that NH residents will have no opportunity to prepare food, spend money, take medications, and the like, making it impossible to meaningfully assess IADLs in the NH. However, omitting ADLs such as bathing and most IADLs forces the comparable measures to conform to the low expectations about nursing homes, thereby suppressing the potential benefits of HCBS.

KQ 1b: Outcomes Among Those Served by HCBS Versus NHs

Given the differences in case mix, comparing outcome trajectories of older adults across HCBS and NHs presents numerous analytical challenges. Randomization can increase the likelihood that HCBS and NH populations are comparable on measured as well as unmeasured factors. However, randomization to HCBS versus NH or even to AL versus NH is precluded for practical and ethical reasons. Few persons with a strong preference for community care would accept an NH placement. In addition, many who believe they need NH care have already decided to leave the community.

Therefore, studies need to use statistical techniques to adjust for selection to ensure that the comparisons between groups are unbiased. As noted previously, these techniques include multivariate analysis, propensity scores, instrumental variables, or frontier analysis. Factors considered for adjustment should go beyond demographics, physical status, and cognitive status to include LTC attitudes held by both clinicians and consumers and availability of informal support. Studies should adjust for case mix and account for changes in the composition of HCBS and NH populations that result from deaths or transfers to different settings. In some cases, HCBS recipients may transfer to NHs. The impact of such transfers should be analyzed and interpreted.

Outcome measures should define and measure individual experiences of care provided in NHs and through HCBS across multiple domains, including quality of life and social functioning. Outcomes such as functioning and safety are obviously important. However, quality of life and social functioning often play a large role when individuals decide between care settings. Therefore, these outcomes should also be examined.

Resident report is necessary when using certain outcomes, including psychological well-being, social well-being, pain, and satisfaction, among others. Arguably, we may need more sensitive measures of outcomes. Attention should be paid to particular problems, including accurate measurement of outcomes for persons with dementia who cannot self-report, choice of a

reasonable proxy, and measures of the quality of dying and quality of life immediately before death. Care should be taken to use independent data collectors and identical instruments.

Studies of benefits tend not to examine constructs of increasing policy significance. One example of such a construct is community integration (meaning integration with a wider community than one's own home, AL, or NH). Community integration is an important policy goal under the Olmstead decision, which mandated access to community care whenever feasible. Measures of social support and family functioning are also weak. This is in part because of the tendency to rely on a single family member as the informant. Experience of care should be measured from both individual and family perspectives. Informal caregivers often play a large role in the lives of individual LTC recipients. Understanding how informal caregivers' needs are addressed is critical.

The characteristics of providers within each setting, as well across different services, may also impact the outcomes of HCBS and NH recipients. Future research should address how provider characteristics influence the outcomes of individuals receiving care through HCBS and in NHs.

Subgroup analyses, defined by such characteristics as diagnoses, race/ethnicity, and socio-economic indicators, could indicate whether outcomes for HCBS and NH recipients differ by groups. For instance, a growing use of NHs has been observed among minority populations.⁷⁶ We need more understanding about whether outcomes differ for these individuals based on the setting of care.

Ultimately, the choice between NH and HCBS involves competing goals and necessary tradeoffs (for example, between independence and safety). Comparing NHs and HCBS along multiple domains will provide LTC users with information that helps them to better evaluate NH or HCBS settings based on their needs, preferences, and values.

KQ 1c: Harms From HCBS Versus NHs

Studies of comparative harms must take into account psychological and social harms as well as physical and functional harms. For NH care (and perhaps some AL environments), hypothetical risks include loss of identity, helplessness, and depression. For HCBS, risks might include isolation, loneliness, anxiety about needing help, and depression. Yet, these outcomes are rarely looked at as harms. Indeed, investigators sometimes use depressive symptoms to risk-adjust away the impact of negative self-report when in fact the setting may cause the depressed symptoms. A distinction must be made between endogenous and situational depression. Studies should examine which settings better address psychological and social harms for individuals with similar impairments.

Also, studies will need to tease out harms attributable to treatment, such as over-, under- or inappropriate medication. For example, cognitive function becomes a reasonable outcome to examine if one considers the possibility that treatments and environments increase confusion.

KQ 1 Research Needs Summary

- HCBS and NH service packages need careful description.
- Studies should be explicit about the populations included in each setting, such as whether any distinctions are made between short-stay and long-stay individuals in these settings.
- Studies should use comparable measures to characterize NH and HCBS populations. Differences in disability in NH and HCBS settings should be measured in a way that allows for examining a full range of ADL and IADL outcomes in both settings rather

than suppressing outcomes to match the assumed limitations in NHs. The measures should allow for meaningful comparisons. For example, IADLs are typically not assessed in NHs and hence comparisons with HCBS are not possible.

- The timing of measurement—the point in LTC trajectory at which the populations are compared across settings—is as important as the type of measure used.
- Longitudinal studies should adjust for selection bias using statistical techniques such as multivariate analysis, propensity score methods, or instrumental variables. Studies should adjust for attrition as a result of resident deaths or transfers to other settings.
- Studies should follow admission cohorts through various stages of LTC service use and evaluate transfers between settings.
- Benefits and harms need to be measured fully. Studies should account for psychological and social benefits and harms as well as physical and functional harms. Quality of life, social functioning, community integration, experience of care, and satisfaction are important domains to examine.
- Subgroup analyses should capture major groups defined by diagnosis, functional capacity, socioeconomic indicators, and access to care.

KQ 2: Costs of HCBS Versus NHs

Costs of LTC are typically measured in terms of Medicaid expenditures. However, for two reasons, these expenditures represent only a portion of the total expenditures. First, LTC expenditures can be seen in both Medicare and private insurance (e.g., MediGap). Second, expenditures by public and private programs ignore several other sources of direct or indirect spending.

Thus, from a societal perspective, costs of LTC should include expenditures borne by (1) other public programs such as Medicare and (2) individuals and their families. This will enable policymakers to make true comparisons. It may also help them avoid shifting expenditures from one program to another, between state and federal funds, and from formal to informal care. True cost comparisons between HCBS and NHs should account for direct LTC expenditures and all other relevant expenditures on both sides of the HCBS/NH ledger including:

- Expenditures on room and board (included in expenditures for NH but not usually for HCBS recipients).
- Expenditures for other public subsidy programs such as housing subsidies and aging services through Older Americans Act (OAA) or Title XX (available to HCBS recipients but not to NH residents).
- Costs of informal care (financed by family members or provided as in-kind services) are often substantial and should be considered. This is especially true if family contributions and care negatively affect the caregiver. Family contributions occur in both HCBS and NHs, although they are likely greater in HCBS. Measuring and monetizing these contributions are both very difficult analytic steps, however. In addition, investigators may overestimate costs of family care if they rely on accounts of what family members do. This is because many of the activities of family members both in HCBS and NHs fall into the realm of familial relationship rather than care *per se* (e.g., visiting relatives, accompanying them on outings, and supplying food). Further, some contributions of family or informal caregivers are discretionary (e.g., laundering clothes for an NH resident in the family home to improve quality of laundering). Live-in relatives present an even more difficult conceptual problem when estimating the cost of family care in HCBS.

- Expenditures for hospital and emergency care and primary medical care (often covered by Medicare). Medicaid or individuals may also pay premiums, deductibles, and co-pays for these services, which are relevant expenditures.

Private pay clients should be further studied. Most of our information comparing expenditures for HCBS recipients and NH residents comes from the Medicaid population.

Notably, policymakers are also concerned about the aggregate costs to Medicaid. These aggregate costs are the product of both unit costs and volume. Additional concerns are raised by the “woodwork effect,” whereby the availability of more desirable HCBS may prompt some people to use the service who would otherwise forgo LTC in an institution. Some experts speculate that the “woodwork effect” could induce demand for LTC and ultimately raise expenditures. To the extent that HCBS induces use of LTC, the total Medicaid program expenditures could be higher even though the per-recipient expenditures are lower. However, the extent of this phenomenon has been a source of debate and is still being examined.⁷⁷⁻⁸⁰

KQ 2 Research Needs Summary

- Studies should compare direct LTC expenditures between NH and HCBS and other relevant expenditures. Costs should be viewed from a societal perspective and should include expenditures from public programs such as Medicaid and Medicare, as well as individual expenditures and family burden.
- Studies of expenditures for non-Medicaid LTC recipients are needed.

Current or Ongoing Studies

A study by a University of Pennsylvania team, headed by Mary Naylor, is currently underway. The study follows a cohort of older adults who recently began to receive LTC. The cohort is followed over 2 years. The final sample includes 468 English- and Spanish-speaking older adults (156 from nursing homes, 156 from assisted living facilities, and 156 from their homes), Data collection on the last few older adults enrolled in the study will be completed in summer 2012. Quarterly interviews are conducted with the study participants to elicit data regarding changes in multiple dimensions of health and quality of life. The data are supplemented by medical record data (e.g., use of health resources) and survey data (e.g., major organizational changes). In addition to a number of presentations, a paper on the conceptual model used to guide this effort is under review and an analysis of the first year of data is nearly complete.

Conclusions

The question of how the delivery of LTC through HCBS compared with NHs affects outcome trajectories of older adults is difficult to resolve based on limited evidence and the methodological limitations of studies reviewed. More and better research is needed to draw robust conclusions about how the setting of care delivery influences outcomes and costs for older adults using LTC.

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Abbreviations

ADL	Activities of daily living
AGECAT	Automated Geriatric Examination Computer Assisted Taxonomy
AHRQ	Agency for Healthcare Research and Quality
AL	Assisted living
CAMDEX	Cambridge Examination for Mental Disorders of the Elderly
CDRS	Clinical Dementia Rating Score
CES-D	Center for Epidemiological Studies Depression Scale
CHIP	Children's Health Insurance Program
CIRS-g	Cumulative Illness Rating Scale for Geriatrics
CMS	Centers for Medicare & Medicaid Services
COPD	Chronic obstructive pulmonary disease
CPS	Cognitive Performance Score
CSDD	Cornell Scale for Depression in Dementia
DRA	Deficit Reduction Act
EPC	Evidence-based Practice Center
HCBS	Home and Community-Based Services
IADL	Instrumental activities of daily living
LTC	Long-term care
MAI	Multilevel Assessment Instrument
MDS	Minimum Data Set
MDS-COGS	Minimum Data Set Cognition Scale
MDS-HC	Minimum Data Set – Home Care version
MMSE	Mini-Mental State Exam
MSQ	Mental Status Questionnaire
NH	Nursing home
NR	Not reported
NS	Not significant
OAA	Older Americans Act
PACE	Program of All-Inclusive Care for the Elderly
PGC-PIS	Philadelphia Geriatric Center-Pain Intensity Scale
PRISMA	Preferred Reporting Items for Systematic Reviews and Meta-Analyses
RCF	Residential care facilities
RCTs	Randomized controlled trials
RTI-UNC	RTI International-University of North Carolina
SF-36	Short-form Health Survey (Medical Outcomes Study Short-form 36)
SPMSQ	Short Portable Mental Status Questionnaire
SWLS	Satisfaction with Life Scale
TEP	Technical Expert Panel

Appendix A. Search Strategy

1 "long-term care".ti,ab
2 "day care".ti,ab.
3 "assisted living".ti,ab.
4 "adult day health center".ti,ab.
5 "adult day health care".ti,ab.
6 "adult foster care".ti,ab.
7 "independent living".ti,ab.
8 "board and care".ti,ab.
9 "home health care".ti,ab.
10 "group residential care".ti,ab.
11 "residential care".ti,ab.
12 "home and community based care".ti,ab.
13 "home and community based services".ti,ab.
14 "personal care services".ti,ab.
15 "aging in place".ti,ab.
16 "continuing care retirement communit\$".ti,ab.
17 "group residential care".ti,ab.
18 or/1-17
19 exp nursing homes/
20 institutionalization/
21 nursing home\$.ti,ab.
22 "institutional care".ti,ab.
23 (nursing adj home\$.tw.
24 (residential adj (aged or elderly or geriatric)).tw.
25 or/19-24
26 18 and 25
27 Randomized controlled trials as topic/
28 randomized controlled trial/
29 random allocation/
30 double blind method/
31 single blind method/
32 clinical trial/
33 clinical trial, phase i.pt.
34 clinical trial, phase ii.pt.
35 clinical trial, phase iii.pt.
36 clinical trial, phase iv.pt.
37 controlled clinical trial.pt.
38 randomized controlled trial.pt.
39 multicenter study.pt.
40 clinical trial.pt.
41 exp clinical trials as topic/
42 or/27-41
43 epidemiological studies/

44 exp case control studies/
45 exp cohort studies/
46 case control.tw.
47 (cohort adj (study or studies)).tw.
48 cohort analy\$.tw.
49 cohort analy\$.tw.
50 (follow up adj (study or studies)).tw.
51 (observational adj (study or studies)).tw.
52 longitudinal.tw.
53 retrospective.tw.
54 cross sectional.tw.
55 cross-sectional studies/
56 or/43-55
57 26 and 42
58 26 and 56
59 limit 57 to (english language and yr="1995-Current")
60 limit 58 to (english language and yr="1995-Current")
61 (case reports or comment or editorial or historical article or letter or news or newspaper
article or"review").pt.
62 59 not 61
63 60 not 61

Appendix B. Sources of Grey Literature

Federal and state agencies	<ul style="list-style-type: none">• Administration on Aging (AoA)• Agency for Healthcare Research and Quality (AHRQ)• Centers for Medicare & Medicaid Service (CMS)• Congressional Research Service (CRS)• Office of the Assistant Secretary for Planning and Evaluation (ASPE)• U.S. Government Accountability Office (GAO)• State Departments of Health or Health & Human Services• Veterans Administration
Research organizations, foundations, and advocacy groups	<ul style="list-style-type: none">• AARP• Abt Associates• Alliance for Health Reform• American Public Human Services Association Health Services Division• Center for Excellence in Assisted Living• Kaiser Family Foundation• LeadingAge• Mathematica Policy Research• Milbank Memorial Fund• National Academy for State Health Policy• National Association of Area Agencies on Aging• National Association of Medicaid Directors• National Center for Assisted Living• National Conference of State Legislatures• National Governors Association• National Investment Center• National PACE Association• PAS Center for Personal Assistance Services, UCSF• Robert Wood Johnson Foundation• RTI International• Scripps Gerontology Center• The Clearinghouse for Home and Community Based Services• The Commonwealth Fund• The Hilltop Institute• The John A. Hartford Foundation• The Lewin Group• The SCAN Foundation• Urban Institute• Visiting Nurse Service of New York

Appendix C. Excluded Studies

(Note that this set of references is different from those in the text, and the numbers are different.)
(Reason for exclusion shown in italics at the end of each reference.)

1. Andren S, Elmstahl S. Former family carers' subjective experiences of burden: a comparison between group living and nursing home environments in one municipality in Sweden. *Dementia* 2002; 1(2):241-54. *No relevant comparison*
2. Ashcraft AS, Owen DC, Feng D. A comparison of cognitive and functional care differences in four long-term care settings. *Journal of the American Medical Directors Association* 2006; 7(2):96-101; 16461251. *No relevant settings or sample*
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5. Biola H, Sloane PD, Williams CS, et al. Preferences Versus Practice: Life-Sustaining Treatments in Last Months of Life in Long-Term Care. *Journal of the American Medical Directors Association* 2010; 11(1):42-51. *No relevant settings or sample*
6. Boustani M, Zimmerman S, Williams CS, et al. Characteristics associated with behavioral symptoms related to dementia in long-term care residents. *Gerontologist* 2005; 45(Special Issue 1):56-61. *No relevant characteristics or outcomes*
7. Boyle G. Facilitating choice and control for older people in long-term care. *Health and Social Care in the Community* 2004; 12(3):212-20. *No relevant characteristics or outcomes*
8. Buck D, Gregson BA, Bamford CH, et al. Psychological distress among informal supporters of frail older people at home and in institutions. The Resource Implications Study Group of the MRC Cognitive Function and Ageing Study. *International Journal of Geriatric Psychiatry* 1997; 12(7):737-44; 9251936. *No relevant characteristics or outcomes*
9. Caprio AJ, Hanson LC, Munn JC, et al. Pain, dyspnea, and the quality of dying in long-term care. *Journal of the American Geriatrics Society* 2008; 56(4):683-8; 18266666. *No relevant settings or sample*
10. Castle NG, Lowe TJ, Lucas JA, et al. Use of resident satisfaction surveys in New Jersey nursing homes and assisted living facilities. *Journal of Applied Gerontology* 2004; 23(2):156-71. *No relevant characteristics or outcomes*
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Appendix D. Evidence Table

Author, Year, Project Name, Location, Study Type	Study Aim	Study Sample/Settings	Baseline Characteristics Reported	Outcomes Reported	Study Findings
Resource Implications Study Group 2000 ¹ United Kingdom Longitudinal	To examine psychological morbidity in informal caregivers of frail older people at home and in institutions. Predictors of psychological morbidity in caregivers and factors related to deterioration in their wellbeing over time were identified.	Care-recipients age 65 and older receiving care at home (HCBS) or NH care in the United Kingdom with follow-up for 2 years	Cognitive function	Family caregivers' psychological morbidity	No differences in GHQ scores between caregivers at home and visitors and no changes in GHQ score over time. Caregiver characteristics were stronger than those of care recipients in predicting psychological morbidity at follow-up and in predicting deteriorating well-being over time.
Department of Elder Affairs, State of Florida 2011 ² Florida Longitudinal Grey Literature	To present data on the Department of Elder Affairs Long-Term Care Community Diversion Pilot Project (Diversion), which is a model of managed HCBS for frail elders at risk of permanent NH placement.	Older Medicaid LTC users in Florida in HCBS waiver program, managed care HCBS program (Diversion program), AL, and NH for fiscal year 2009-10	Physical function, cognitive function	Expenditures	The average capitation rate per member per month for the Diversion HCBS managed care program is lower than Medicaid reimbursement for NH care.
Applebaum 2004 (Ohio HCBS Waiver) ³ Ohio Cross-sectional	To describe LTC use patterns for older adults in Ohio from 1992-1999.	Older Medicaid LTC users in Ohio in HCBS waiver and NH	Physical function	NA	Despite an increasing older population in Ohio over the time period, NH occupancy rates fell and in-home service and AL use increased.
Beattie et al. 2005 ⁴ U.S. Cross-sectional	To compare the wandering behavior of residents in AL and NH.	AL and NH residents age 65 and older in a metropolitan area of a midwestern state who had a diagnosis of dementia	Physical function, cognitive function	NA	There were no significant differences in wandering behavior between AL and NH residents.
Boersma et al. 1997 ⁵ The Netherlands Cross-sectional	To examine service utilization among patients with dementia and to examine whether	Individuals age 65 and older with dementia in The Netherlands who received no	Physical function, cognitive function, mental health	NA	82% of study subjects used one or more types of formal care and 55% were institutionalized. Age,

Appendix D. Evidence Table (continued)

Author, Year, Project Name, Location, Study Type	Study Aim	Study Sample/Settings	Baseline Characteristics Reported	Outcomes Reported	Study Findings
	sociodemographic and health-related variables are associated with care utilization.	professional/formal care at home, used one or more types of professional/formal care (HCBSa), residential living in a home for the aged(HCBSb), or a specialized NH			severity of dementia, somatic disorders, dependency in terms of activities of daily living, and marital status were predictors of higher levels of care.
Borrayo et al. 2002 ⁶ Florida Cross-sectional	To analyze consumers' predisposing, enabling, and need characteristics influencing their utilization of HCBS, AL, or NH.	LTC users age 60 and older in Florida including HCBS users, AL residents, and long-stay NH residents	Physical function, cognitive function, clinical status	NA	Need characteristics contributed the most to differential LTC use, with those with the most need more likely to be in NH or HCBS. Enabling characteristics, including Medicaid eligibility and geopolitical region of the state, were associated with higher NH use. Predisposing and enabling characteristics had a moderating influence on need.
Challis et al. 2000 ⁷ England Cross-sectional	To examine dependency and general health status of older individuals newly admitted to residential homes and NH for LTC.	New admits age 65 and older to residential homes (HCBS group) and NH in northwest England	Physical function, cognitive function	NA	31% of NH residents and 71% of HCBS group were 'low dependency.' In NH, low-dependency residents were more likely to be self-funding than those with higher dependency. A diagnosis of dementia was associated with NH admission rather than HCBS use.
Chappell et al. 2004 ⁸ Canada Cross-sectional	To examine the cost-effectiveness of home care as a substitute for institutional care for seniors needing LTC.	LTC users age 65 and older in Canada (Victoria, BC and Winnipeg, Manitoba) receiving LTC in the community or long-term care facilities (nursing	Physical function, mental health	NA	Costs were significantly lower for home care clients than for facility clients, regardless of whether costs only to the government were taken into account or whether both formal and informal costs were taken

Appendix D. Evidence Table (continued)

Author, Year, Project Name, Location, Study Type	Study Aim	Study Sample/Settings	Baseline Characteristics Reported	Outcomes Reported	Study Findings
		homes/intermediate care facilities)			into account. When informal caregiver time is valued at either minimum wage or replacement wage, there was a substantial increase in the average annual costs for both community and facility clients relative to when informal caregiver time was valued at zero.
Doty et al. 2010 (ASPE Private LTC Insurance Cohort) ⁹ U.S. Longitudinal	To profile individuals with private LTC insurance at the onset of using paid LTC services and to track their service use, satisfaction, and transitions over 28 months.	Private LTC insurance policyholders using HCBS, AL, or NH; longitudinal panel starting at initiation of services and followed for 28 months	Physical function, cognitive function	Satisfaction	About 96% of those filing claims were approved for payment. Few claimants reported that their policies restricted their choice of providers and most care costs were covered. Individuals using paid home care or assisted living had higher overall satisfaction than individuals in NH, and NH users had the greatest decline in their levels of satisfaction over the study period. The average number of care transitions was one, typically occurring within 4 months of baseline.
Edelman et al. 2005 ¹⁰ U.S. Cross-sectional	To compare three methods of assessing dementia specific quality of life.	Residents with dementia in AL facilities with dementia-specific programs and special care NH in a metropolitan area of the U.S.	Physical function, cognitive function, mental health, clinical status	NA	The relationship of staff quality-of-life measures to resident characteristics varied by care setting while no significant relationships were found for resident quality-of-life measures.
Franks 2004 ¹¹ Washington Cross-sectional	To compare perceived quality of life between matched AL and NH residents.	Residents age 65 and older in western Washington in AL and NH	Physical function	NA	After matching based on level of disability, matched pair t-tests revealed no difference in quality of life scores between AL and NH residents.

Appendix D. Evidence Table (continued)

Author, Year, Project Name, Location, Study Type	Study Aim	Study Sample/Settings	Baseline Characteristics Reported	Outcomes Reported	Study Findings
Frytak et al. 2001 (Oregon Assisted Living study) ¹² Oregon Longitudinal	To compare the outcome trajectories for the ability to perform activities of daily living, psychological well-being, and pain and discomfort between AL and NH residents.	AL and NH residents age 65 and older in Oregon followed for 1 year	Physical function, mental health, clinical status	Physical function, mental health, harms	There were differences in case-mix between AL and NH residents but no differences in outcome trajectories for activities of daily living, psychological well-being, and pain and discomfort. For activities of daily living and pain and discomfort, residents in both AL and NH on average experienced change over the study period. For psychological well-being, residents in AL and NH on average experienced no change.
Gaugler 2006 ¹³ Kentucky Cross-sectional	To examine the association between different dimensions of family involvement and resident psychosocial status for residents in family care homes, AL, and NH.	Residents in family care homes, AL, and NH in Kentucky	Physical function, cognitive function, mental health	NA	Facility family orientation and family involvement in care conferences were associated with great resident well-being (i.e., sense of aesthetics, or ability to appreciate beauty in one's surroundings), while families who transported residents to appointments outside of facilities had relatives with a lower sense of aesthetics.
Gaugler & Kane 2005 (Oregon Assisted Living study) ¹⁴ Oregon Longitudinal	To compare the activity of AL and NH residents over 1 year.	AL and NH residents age 65 and older in Oregon followed for 1 year	Cognitive function, clinical status	Activity	AL residents reported significantly higher activity compared to NH residents over time, but there was also considerable variability in activity across settings.
Gruber-Baldini et al. 2005 (Dementia Care Project) ¹⁵ U.S. Cross-sectional	To describe the prevalence, assessment, and treatment of depression and characteristics associated with	Residential care/assisted living facility (AL) residents stratified by (a) facilities with <16 beds; (b) facilities with ≥16 beds	Mental health	NA	23.9% of AL residents had depression and 26.6% of NH residents had depression. Depression was related to severe cognitive impairment, behavioral symptoms, pain,

Appendix D. Evidence Table (continued)

Author, Year, Project Name, Location, Study Type	Study Aim	Study Sample/Settings	Baseline Characteristics Reported	Outcomes Reported	Study Findings
	depression for residents with dementia in AL and NH.	of the “new-model” type that provide nursing care and cater to an impaired population; and (c) “traditional” facilities with ≥16 beds not meeting the “new-model” criteria and NH residents age 65 and older with dementia in four states with follow-up for 6 months			and for-profit NH residence.
Lee et al. 2001 ¹⁶ New York Cross-sectional	To explore factors affecting the choice of LTC setting among older adults.	Older Medicaid LTC users in New York City in a HCBS program and NH	Physical function, cognitive function, clinical status	NA	The results indicated that HCBS program use was characterized by a higher rate of being admitted from private homes, less cognitive impairments, less limitations in activities of daily living, and younger age than for NH residents. Health-related factors were found to be more important predictors than sociodemographic characteristics or support system for choice of different types of care.
Leon & Moyer 1999 ¹⁷ U.S. Cross-sectional	To estimate the potential cost savings from substituting AL for NH care for residents with Alzheimer's Disease that have health profiles that appear manageable within AL that specialize in dementia care.	LTC users in AL and NH across 9 states with probable Alzheimer's Disease	Physical function, cognitive function, clinical status	NA	Findings suggest that up to 13.9% of NH costs could be saved by substituting AL care for NH residents with Alzheimer's Disease that could be managed in AL.
Marek et al. 2005 ¹⁸ Missouri Longitudinal	To compare clinical outcomes (activities of daily living, cognitive function, depression,	Older Medicaid HCBS Aging in Place program participants and NH residents in Missouri	Mental health	Physical function, cognitive function, mental health	The HCBS Aging in Place group had statistically significantly better outcome in cognition at 6, 12, and 18

Appendix D. Evidence Table (continued)

Author, Year, Project Name, Location, Study Type	Study Aim	Study Sample/Settings	Baseline Characteristics Reported	Outcomes Reported	Study Findings
	incontinence, and pressure ulcers) between older adults who received services in the Aging in Place community-based LTC program to similar individuals residing in NH.	followed for 30 months			months, in depression at 6 and 12 months, in activities of daily living at 6, 12, and 24 months, and in incontinence at 24 months.
Margallo-Lana et al. 2001 ¹⁹ United Kingdom Cross-sectional	To determine the prevalence of behavioral and psychological symptoms among elderly individuals with dementia residing in care environments, the relationship with severity of dementia, and the pattern of psychotropic medication use.	Elderly individuals with dementia in the United Kingdom residing in social care facilities and NH	Physical function, cognitive function	NA	Overall 90% of study subjects had dementia with 79% of them having clinically significant behavioral and psychological symptoms in dementia and 58% receiving psychotropic medication. There was no difference in the prevalence of behavioral and psychological symptoms between social and nursing care.
McCann et al. 2009 ²⁰ Northern Ireland Longitudinal	To estimate mortality rates for residents in nursing and residential homes in Northern Ireland and analyze the variation by type of home and resident characteristics.	Residents in residential homes (HCBS group) and NH age 65 and older in Northern Ireland with follow-up for 5 years	Clinical status	Mortality	Median survival for residential home residents was 4.51 years, for NH residents was 2.33 years, and for dually registered home residents was 2.75 years.
Mehdizadeh 2007 (Ohio PASSPORT) ²¹ Ohio Longitudinal Grey Literature	To examine the costs of consumers in the PASSPORT program, Ohio's aged and disabled waiver program, compared to NH residents.	Medicaid LTC users in Ohio in HCBS waiver and NH	Physical function, cognitive function	Expenditures	On average, the total public cost (excluding Medicare) of caring for an individual in a NH was more than twice the cost of caring for them in the HCBS waiver.
Mehdizadeh 2002 ²² Ohio Longitudinal	To examine the health and LTC use trajectories of disabled older women dually eligible for Medicare	Disabled women age 60 and older using HCBS and NH services in Ohio; sample included those who remained in	Physical function, cognitive function, clinical status	NA	As sample members proceeded along their LTC career and their health and disability status worsened, there was a shift in the type

Appendix D. Evidence Table (continued)

Author, Year, Project Name, Location, Study Type	Study Aim	Study Sample/Settings	Baseline Characteristics Reported	Outcomes Reported	Study Findings
	and Medicaid.	the community the entire first year (HCBS) and those who remained in a NH the entire first year (NH)			of care needed from hospital and home care to NH care. There was also a shift in the major payer from Medicare to Medicaid.
Miller et al. 2008 (ASPE Private LTC Insurance Cohort) ²³ U.S. Longitudinal Grey Literature	To describe the demographic, health, and attitudinal profile of individuals with private LTC insurance at the initiation of LTC service use, understand the factors involved in the decision about how and why to use services in a particular setting, and to understand how and why people transition between care settings over time.	Private LTC insurance policyholders using HCBS, AL, or NH; longitudinal panel starting at initiation of services and followed for 28 months	Physical function	Mortality, expenditures	Compared to those not yet receiving paid care at baseline, NH residents at baseline had the highest odds of mortality during the study period, followed by those using home care at baseline and AL residents at baseline. Compared to people who were receiving paid care at baseline, individuals in home care had monthly expenditures that were 56% higher, NH residents had expenditures that were 113% higher, and AL residents had expenditures that were 62% higher.
Mitchell et al. 2004 ²⁴ Michigan Longitudinal	To compare the end-of-life care of older individuals with advanced dementia dying in home care and NH settings.	A retrospective cohort of home care and NH users age 65 and older in Michigan with dementia; all persons in sample died within 1 year of admission to either HCBS or NH	Physical function, cognitive function, clinical status	Utilization, advance care planning, nonpalliative treatments, symptoms, other treatments	NH residents dying with advanced dementia had greater functional impairment and more behavior problems compared to those in HCBS. Only 5.7% of NH residents and 10.7% of HCBS clients were referred to hospice, while 43.7% of NH residents and 31.5% of HCBS clients were hospitalized. End-of-life variables independently associated with NH versus HCBS care included hospice (adjusted odds ratio 0.26), life expectancy less than 6

Appendix D. Evidence Table (continued)

Author, Year, Project Name, Location, Study Type	Study Aim	Study Sample/Settings	Baseline Characteristics Reported	Outcomes Reported	Study Findings
Ormond et al. 2006 ²⁵ Texas Cross-sectional Grey Literature	To report on the transition process, participant characteristics, and service utilization and costs for Rider (a Money Follows the Person initiative for individuals to move from NH to community) participants.	Medicaid LTC users in Texas in the Community-Based Alternatives community care program, residents in NH, and participants in the Rider initiative for individuals moving from NH to the community	Cognitive function, mental health, clinical status	NA	months (adjusted odds ratio 0.31), advance directives (adjusted odds ratio 1.48), pain (adjusted odds ratio 0.38) shortness of breath (adjusted odds ratio 0.20) and oxygen therapy (adjusted odds ratio 2.47). Rider participants represented a wide range of NH residents, but individuals with certain characteristics were more represented in Rider participants compared to NH residents (such as those with the lowest care dependence).
Port et al. 2005 (Dementia Care Project) ²⁶ U.S. Cross-sectional	To compare the sociodemographics, self-rated health, and involvement of family caregivers for residents with dementia in AL and NH.	Residential care/assisted living facility (AL) residents stratified by (a) facilities with < 16 beds; (b) facilities with ≥ 16 beds of the “new-model” type that provide nursing care and cater to an impaired population; and (c) “traditional” facilities with ≥ 16 beds not meeting the “new-model” criteria and NH residents age 65 and older with dementia	Physical function, cognitive function, clinical status	NA	NH caregivers rated their health poorer than AL caregivers. AL caregivers rated their perception of involvement and burden higher than NH caregivers, and they engaged in more frequent monitoring of resident’s health, well-being, and finances than NH caregivers despite the reported time spent per week on care not differing.
Pruchno & Rose 2000 ²⁷ Ohio Longitudinal	To compare mortality rates, relocation, and trajectories of cognitive status, functional ability, depression, and subjective health of AL and NH residents.	Older adults in AL or NH living on a single LTC campus in Cleveland, Ohio with follow-up for 15 months	Physical function, cognitive function, mental health, clinical status	Physical function, cognitive function, mental health, mortality	Logistic regression results found that facility type (AL versus NH) was not a significant predictor of mortality or relocations due to declining health. The repeated ANOVA results

Appendix D. Evidence Table (continued)

Author, Year, Project Name, Location, Study Type	Study Aim	Study Sample/Settings	Baseline Characteristics Reported	Outcomes Reported	Study Findings
Reinardy & Kane 1999 ²⁸ Oregon Cross-sectional	To examine the decisions, circumstances, and perceived control of residents choosing adult foster homes and NH.	Residents in foster care and NH in Oregon	Physical function, cognitive function, clinical status	NA	found that trajectories of cognitive status, functional ability, depression, and subjective health of AL and NH residents did not change at different rates. There were statistically significant differences between foster care and NH residents in the characteristics of the setting that each group deemed important, the circumstances surrounding the decision, the people influencing it, and the perceived control over the decision.
Rigler et al. 2004 (Kansas Medicaid) ²⁹ Kansas Longitudinal	To examine the relationship between disease burden and inappropriate medication use in older Medicaid beneficiaries not receiving any HCBS or NH care (community-dwelling), receiving HCBS, and receiving NH care.	Medicaid beneficiaries age 65 and older in Kansas including an ambulatory cohort (community-dwelling older adults not receiving any HCBS or NH care during study year), HCBS cohort, and NH cohorts with followup for 1 year	Clinical status	Harms	Inappropriate medication use occurred in 21% of community-dwelling non-LTC cohort, 48% of HCBS cohort, and 38% of NH cohort. For the community-dwelling non-LTC and HCBS cohorts, inappropriate medication use increased as disease burden increased, but the rates of inappropriate medication use in the NH cohort showed little variation across disease burden.
Rothera et al. 2003 (Nottingham study) ³⁰ United Kingdom Cross-sectional	To examine the dependency and health status of older individuals admitted to residential care or NH and compare the findings with assessments conducted by social services departments prior to	Residents in residential homes (HCBS group) and nursing homes (NH) in the United Kingdom	Physical function, cognitive function, mental health	NA	Residents in NH had significantly higher cognitive impairment and physical disability, although a third of residents in residential care had substantial physical disability. 25% of NH residents had low dependency needs but these residents had greater

Appendix D. Evidence Table (continued)

Author, Year, Project Name, Location, Study Type	Study Aim	Study Sample/Settings	Baseline Characteristics Reported	Outcomes Reported	Study Findings
	placement.				cognitive impairment than residential home residents with the same level of dependency. Most residents had some behavioral disturbance (particularly nursing home residents) and more severe disturbance was associated with greater cognitive impairment and more depressed mood, but not physical disability.
Rothera et al. 2002 (Nottingham study) ³¹ United Kingdom Longitudinal	To examine life expectancy and mortality of older residents in nursing and residential homes and specific risk factors.	Residents in residential homes (HCBS group) and nursing homes (NH) in the United Kingdom with followup for 20 months		Mortality	One-year survival rates were 76% for HCBS group and 66% for NH residents. The odds ratio was 1.85 for NH residents for mortality compared with those in HCBS group.
Schroeder et al. 1998 ³² U.S. Cross-sectional	To compare functional ability, balance, strength, flexibility, life satisfaction, and physical activity between older adults in the community, AL, and NH.	Adults age 75-85 in the community (no assistance), AL, and NH	Physical function, mental health	NA	No difference was found among the groups in life satisfaction. NH residents had poorer functional ability, balance, strength, flexibility, and physical activity compared to individuals in AL and community non-LTC users.
Shireman & Rigler 2004 (Kansas Medicaid) ³³ Kansas Longitudinal	To examine the characteristics, health care utilization, and expenditures of Medicaid beneficiaries in HCBS waivers versus NH.	Medicaid beneficiaries age 65 and older in Kansas using HCBS or NH care with follow-up for 10-12 months	Cognitive function, mental health	Expenditures	After adjusting for demographic and clinical characteristics, mean monthly expenditures were \$1281 lower for the HCBS clients compared to NH residents.
Shugarman et al. 1999 ³⁴ U.S. Cross-sectional	To compare HCBS clients and NH residents on measures of resource utilization, activities of daily living, and overall case mix.	Admits to the Michigan Medicaid HCBS waiver program and to Ohio NH	Physical function, clinical status	NA	The HCBS and NH groups were similar across the resource utilization categories, but the NH group was more functionally impaired in activities of daily

Appendix D. Evidence Table (continued)

Author, Year, Project Name, Location, Study Type	Study Aim	Study Sample/Settings	Baseline Characteristics Reported	Outcomes Reported	Study Findings
Sloane et al. 2005 (Collaborative Studies of Long-Term Care sub-sample) ³⁵ U.S. Longitudinal	To compare the health and functional outcomes and utilization between individuals with dementia in AL and NH.	Residential care/assisted living facility (AL) residents stratified by (a) facilities with < 16 beds; (b) facilities with ≥ 16 beds of the “new-model” type that provide nursing care and cater to an impaired population; and (c) “traditional” facilities with ≥ 16 beds not meeting the “new-model” criteria and NH residents with dementia in four states with follow-up for 1 year	Physical function, cognitive function, mental health, clinical status	Physical function, cognitive function, mental health, mortality, utilization, behavior, social function, social withdrawal, morbidity	living functioning and overall case mix. Mortality rates, new or worsening morbidity, change in activities of daily living, cognition, behavioral problems, depressive symptoms, social function, and withdrawal did not significantly differ between AL and NH residents. Hospitalization rates were higher among individuals with mild dementia in AL. Due to death or transfer, about one half of individuals with mild dementia and one third of individuals with moderate or severe dementia remained in AL one year after enrollment.
Sloane et al. 2003 (Collaborative Studies of Long-Term Care sub-sample) ³⁶ U.S. Cross-sectional	To compare end-of-life care in AL and NH.	AL and NH residents from four states who died in or within 3 days after discharge from a study facility	Physical function, cognitive function	NA	Most decedants died in the facility where they had resided. Greater proportions of staff and family in NH knew that the resident's death was only days or weeks away. Both AL and NH residents experienced few highly negative moods and overall discomfort was low. Summary ratings of family satisfaction were significantly higher for the AL versus NH group.
Spillman et al. 2002 ³⁷ U.S. Cross-sectional Grey Literature	To describe the characteristics of elderly residents in AL and NH and the characteristics of the facilities.	Medicare beneficiaries age 65 and older in AL and NH	Physical function, cognitive function, mental health, clinical status	NA	AL residents were generally healthier and less disabled than those in NH.

Appendix D. Evidence Table (continued)

Author, Year, Project Name, Location, Study Type	Study Aim	Study Sample/Settings	Baseline Characteristics Reported	Outcomes Reported	Study Findings
Wieland et al. 2010 ³⁸ South Carolina Longitudinal	To compare the long-term survival of entrants into HCBS, PACE, and NH.	Medicaid beneficiaries age 55 and older entering HCBS waiver, PACE, and NH in two counties in South Carolina with follow-up for 5 years	Physical function, cognitive function, mental health, clinical status	Mortality	PACE entrants were older, more cognitively impaired, and had intermediate activities of daily living compared to HCBS and NH entrants. Unstratified median survival for HCBS was 3.5, for PACE was 4.2, and for NH was 2.3 years (p = 0.53). Accounting for risk, higher risk PACE entrants had higher survival compared to HCBS (moderate risk: PACE median survival 4.7 versus HCBS 3.4 years and high risk PACE median survival 3.0 versus HCBS 2.0 years).
Williams et al. 2005 (Dementia Care Project) ³⁹ U.S. Cross-sectional	To describe the prevalence, assessment, and treatment of pain and characteristics associated with pain for residents with dementia in AL and NH.	Residential care/assisted living facility (AL) residents stratified by (a) facilities with < 16 beds; (b) facilities with ≥16 beds of the “new-model” type that provide nursing care and cater to an impaired population; and (c) “traditional” facilities with ≥ 16 beds not meeting the “new-model” criteria and NH residents age 65 and older with dementia in four states	Clinical status	NA	Based on resident report, 38.9% of AL residents and 25.0% of NH residents had pain (p = 0.318). Pain was more commonly reported in for-profit facilities, and for those receiving professional assessment and treatment.
Wodchis et al. 2003 ⁴⁰ Canada Cross-sectional	To introduce a health-related quality-of-life measure based on the Minimum Data Set and the Health Utilities Index Mark 2 for community and institutional LTC users.	LTC clients in private households, supportive housing apartments, care facilities, and a chronic care hospital in Ontario, Canada	Physical function, cognitive function, mental health, clinical status	NA	The new health-related quality of life measure results provide preliminary evidence of good validity. Institutional populations had lower overall health-related quality of life scores than community populations.

Appendix D. Evidence Table (continued)

Author, Year, Project Name, Location, Study Type	Study Aim	Study Sample/Settings	Baseline Characteristics Reported	Outcomes Reported	Study Findings
Zimmerman et al. 2003 (Collaborative Studies of Long-Term Care sub-sample) ⁴¹ U.S. Cross-sectional	To compare AL and NH care and residents, identify different types of AL care and residents, and examine how AL case-mix relates to differences in care provision and/or consumer preference.	Residential care/assisted living facility (AL) residents stratified by (a) facilities with < 16 beds; (b) facilities with ≥ 16 beds of the “new-model” type that provide nursing care and cater to an impaired population; and (c) “traditional” facilities with ≥ 16 beds not meeting the “new-model” criteria and NH residents age 65 and older in four states	Physical function, cognitive function, clinical status	NA	NH report provision of significantly more health services and have significantly more lenient admission policies than AL, but they provide less privacy. They are similar to larger AL facilities in policy clarity or resident control. There are differences within AL types, with smaller and for-profit facilities scoring lower across multiple process measures. Resident impairment is substantial in both AL and NH, but differs by AL facility characteristics.
Zimmerman et al. 2005 (Dementia Care Project) ⁴² U.S. Longitudinal	To examine dementia care in AL and NH and its relationship to resident quality of life.	Residential care/assisted living facility (AL) residents stratified by (a) facilities with < 16 beds; (b) facilities with ≥ 16 beds of the “new-model” type that provide nursing care and cater to an impaired population; and (c) “traditional” facilities with ≥ 16 beds not meeting the “new-model” criteria and NH residents age 65 and older with dementia in four states with follow-up for 6 months		Quality-of-life	Change in quality-of-life was not related to facility type (AL versus NH).

NA = Not applicable

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Appendix E. Risk of Bias for Individual Studies

Study	Study Type	Overall Risk of Bias Assessment	Comments
Doty et al. 2010 ¹	Longitudinal	High	No correction for selection bias; no adjustment for confounders; non-generalizeable sample.
Frytak et al. 2001 ²	Longitudinal	High	No correction for selection bias; attrition bias.
Gaugler & Kane 2005 ³	Longitudinal	Moderate	Adjustment for selection bias using Heckman two-stage approach; adequate adjustment for other confounders.
Marek et al. 2005 ⁴	Longitudinal	High	Different measures used for HCBS and NH groups; attrition bias; no adjustment for other confounders.
Mitchell et al. 2004 ⁵	Longitudinal	High	No correction for selection bias; different measures used for HCBS and NH groups.
Pruchno & Rose 2000 ⁶	Longitudinal	High	No correction for selection bias; attrition bias; non-generalizeable sample.
Rigler et al. 2004 ⁷	Longitudinal	High	No correction for selection bias; limited confounders used in analysis; analyzed within groups but not across groups.
Shireman & Rigler 2004 ⁸	Longitudinal	High	No correction for selection bias; limited confounders used in analysis.
Sloane et al. 2005 ⁹	Longitudinal	High	No correction for selection bias.
Wieland et al. 2010 ¹⁰	Longitudinal	High	No stratified analysis comparing HCBS groups and NH.
Zimmerman et al. 2005 ¹¹	Longitudinal	High	No correction for selection bias; attrition bias.
Department of Elder Affairs, State of Florida 2011 ¹²	Longitudinal	NA	Grey literature studies not assessed for risk of bias.
Resources Implications Study Group 2000 ¹³	Longitudinal	NA	International studies not assessed for risk of bias.
Applebaum et al. 2004 ¹⁴	Cross-sectional	NA	Cross-sectional studies not assessed for risk of bias.
Beattie et al. 2005 ¹⁵	Cross-sectional	NA	Cross-sectional studies not assessed for risk of bias.
Boersma et al. 1997 ¹⁶	Cross-sectional	NA	Cross-sectional studies not assessed for risk of bias.
Borrayo et al. 2002 ¹⁷	Cross-sectional	NA	Cross-sectional studies not assessed for risk of bias.
Challis et al. 2000 ¹⁸	Cross-sectional	NA	Cross-sectional studies not assessed for risk of bias.
Chappell et al. 2004 ¹⁹	Cross-sectional	NA	Cross-sectional studies not assessed for risk of bias.
Edelman et al. 2005 ²⁰	Cross-sectional	NA	Cross-sectional studies not assessed for risk of bias.
Franks 2004 ²¹	Cross-sectional	NA	Cross-sectional studies not assessed for risk of bias.
Gaugler 2006 ²²	Cross-sectional	NA	Cross-sectional studies not assessed for risk of bias.
Gruber-Baldini et al. 2005 ²³	Cross-sectional	NA	Cross-sectional studies not assessed for risk of bias.
Lee et al. 2001 ²⁴	Cross-sectional	NA	Cross-sectional studies not assessed for risk of bias.
Leon & Moyer 1999 ²⁵	Cross-sectional	NA	Cross-sectional studies not assessed for risk of bias.
Margallo-Lana et al. 2001 ²⁶	Cross-sectional	NA	Cross-sectional studies not assessed for risk of bias.
McCann et al. 2009 ²⁷	Longitudinal	NA	International studies not assessed for risk of bias.
Mehdizadeh 2007 ²⁸	Longitudinal	NA	Grey literature studies not assessed for risk of bias.
Mehdizadeh 2002 ²⁹	Longitudinal	NA	Not included in longitudinal analytic set; not assessed for risk of bias.

Appendix E. Risk of Bias for Individual Studies (continued)

Study	Study Type	Overall Risk of Bias Assessment	Comments
Miller et al. 2008 ³⁰	Longitudinal	NA	Grey literature studies not assessed for risk of bias.
Ormond et al. 2006 ³¹	Cross-sectional	NA	Grey literature studies not assessed for risk of bias.
Port et al. 2005 ³²	Cross-sectional	NA	Cross-sectional studies not assessed for risk of bias.
Reinardy & Kane 1999 ³³	Cross-sectional	NA	Cross-sectional studies not assessed for risk of bias.
Rothera et al. 2002 ³⁴	Longitudinal	NA	International studies not assessed for risk of bias.
Rothera et al. 2003 ³⁵	Cross-sectional	NA	Cross-sectional studies not assessed for risk of bias.
Schroeder et al. 1998 ³⁶	Cross-sectional	NA	Cross-sectional studies not assessed for risk of bias.
Shugarman et al. 1999 ³⁷	Cross-sectional	NA	Cross-sectional studies not assessed for risk of bias.
Sloane et al. 2003 ³⁸	Cross-sectional	NA	Cross-sectional studies not assessed for risk of bias.
Spillman et al. 2002 ³⁹	Cross-sectional	NA	Grey literature studies not assessed for risk of bias.
Williams et al. 2005 ⁴⁰	Cross-sectional	NA	Cross-sectional studies not assessed for risk of bias.
Wodchis et al. 2003 ⁴¹	Cross-sectional	NA	Cross-sectional studies not assessed for risk of bias.
Zimmerman et al. 2003 ⁴²	Cross-sectional	NA	Cross-sectional studies not assessed for risk of bias.

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Appendix F. Overall Strength of Evidence Assessment

Outcome	Longitudinal Studies Examining the Outcome	Risk of Bias	Directness	Precision	Consistency	Strength of Evidence Rating
Physical Function						
AL vs. NH	Frytak et al., 2001 ¹ Pruchno & Rose, 2000 ² Sloane et al., 2005 ³	High	Direct	Imprecise (different measures)	Consistent	Low (no difference)
HCBS vs. NH	Marek et al., 2005 ⁴	High	Direct	Imprecise	Unknown	Insufficient
Cognitive Function						
AL vs. NH	Pruchno & Rose, 2000 ² Sloane et al., 2005 ³	High	Direct	Imprecise (different measures)	Consistent	Low (no difference)
HCBS vs. NH	Marek et al., 2005 ⁴	High	Direct	Imprecise	Unknown	Insufficient
Mental Health						
AL vs. NH	Frytak et al., 2001 ¹ Pruchno & Rose, 2000 ² Sloane et al., 2005 ³	High	Direct	Imprecise (different measures)	Consistent	Low (no difference)
HCBS vs. NH	Marek et al., 2005 ⁴	High	Direct	Imprecise	Unknown	Insufficient
Mortality						
AL vs. NH	Pruchno & Rose, 2000 ² Sloane et al., 2005 ³	High	Direct	Imprecise	Consistent	Low (no difference)
HCBS vs. NH	Wieland et al., 2010 ⁵	High	Direct	Imprecise	Unknown	Insufficient
Use of Acute Care						
AL vs. NH	Sloane et al., 2005 ³	High	Direct	Imprecise	Unknown	Insufficient*
HCBS vs. NH	Mitchell et al., 2004 ⁶	High	Direct	Imprecise	Unknown	Insufficient
Harms						
AL vs. NH	Frytak et al. 2001 ¹	High	Direct	Imprecise	(Sets of harms differed by intervention/comparator)	Insufficient
HCBS vs. NH	Rigler et al., 2004 ⁷ Mitchell et al., 2004 ⁶	High	Direct	Imprecise	(Sets of harms differed by intervention/comparator)	Low
Costs						
HCBS vs. NH	Shireman & Rigler, 2004 ⁸	High	Direct	Imprecise	Unknown	Insufficient

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Appendix G. Other Outcomes: Longitudinal Studies

Appendix Table G1. Other outcomes: U.S. longitudinal peer-reviewed studies

Study	Measure	Result	Risk of Bias Rating
Doty et al. 2010 ¹ (ASPE private LTC insurance cohort)	Question about satisfaction with services being received	Percent very satisfied at first and last wave: HCBS: 74%, 79% AL: 74%, 72% NH: 60%, 49%	High
Gaugler & Kane 2005 ² (Oregon Assisted Living study)	Resident social activity based on 5 items	AL residents engaged in more social activity than NH residents at baseline and 6 months, but type of setting was not significantly associated with activity at 1 year or change in activity over the 1 year period.	Moderate
^a Mitchell et al., 2004 ³	Whether or not subjects had an advance directive	Adjusted odds ratio advance directive: HCBS reference, NH 1.48 (1.11, 1.96)	High
^a Sloane et al. 2005 ⁴ (Collaborative Studies of Long-Term Care sub-sample)	Mean change increase in behavior problems per 12 months; mean change increase in social function per 12 months; mean change increase in social withdrawal per 12 months; new or worsening morbidity as the incidence of worsening of fracture, infection, stroke or paralysis, bleeding from the stomach or bowel, diabetes, heart condition, or skin ulcer reported as incidence rate per 100 participants per quarter	Behavior for residents with mild dementia: AL 1.08, NH 0.69, p = 0.604 Behavior for residents with moderate or severe dementia: AL: 1.72, NH 1.49, p = 0.809 Social function for residents with mild dementia: AL 1.55, NH 1.76, p = 0.568 Social function for residents with moderate or severe dementia: AL: 0.91, NH 1.44, p = 0.110 Social withdrawal for residents with mild dementia: AL 2.84, NH 2.24, p = 0.364 Social withdrawal for residents with moderate or severe dementia: AL: 2.55, NH 1.78, p = 0.307 New or worsening morbidity for residents with mild dementia: AL 23.5, NH 21.8, p = 0.574 New or worsening morbidity for residents with moderate or severe dementia: AL: 21.1, NH 21.7, p = 0.865 There were no significant differences between AL and NH residents in any of these outcomes.	High
^a Zimmerman et al. 2005 ⁵ (Dementia Care Project study)	Quality of Life in Alzheimer's Disease	There was no statistically significant difference in the adjusted change in quality of life score by facility type (AL or NH).	High

^aIndicates study focused on participants with dementia
HCBS = Home and Community-based Services; NH = Nursing Home; AL = Assisted Living; ASPE=Assistant Secretary for Planning and Evaluation, U.S Department of Health and Human Services

Appendix Table G2. Other outcomes: international longitudinal peer-reviewed studies

Study	Measure	Results	Risk of Bias Rating
Resource Implications Study Group 2000 ⁶	Family caregivers' psychological morbidity measured by General Health Questionnaire (GHQ) score	There were no significant changes over 2-year period in GHQ scores for any of the groups of caregivers for residents that remained in either HCBS or NH throughout the entire period, or for residents that transitioned from HCBS to NH during the study period.	High

HCBS = Home and Community-based Services; NH = Nursing Home

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