



The LEWIN GROUP®



HEALTHCARE AND HUMAN SERVICES POLICY, RESEARCH, AND CONSULTING—WITH REAL-WORLD PERSPECTIVE.

Exploratory Study of the Global Outcomes of the Older Americans Act Programs and Services

Final Report

Prepared for: Department of Health and Human Services, Administration on Aging

Submitted by: The Lewin Group, Inc.

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Executive Summary

Overview of Study Design Process

In the process of creating this study design, the research team identified a number of strengths and limitations to conducting a global outcomes evaluation of the Older Americans Act (OAA). This report proposes a study design of OAA programs. This study will assist AoA in identifying actions needed to better position the states for participation in a nationwide evaluation.

Organization of Report

This report is organized as an executive summary that references appendices that are the major sections of the project: Appendix A – Literature Review; Appendix B – Study Design; Appendix C – Limitations and Recommendations.

Older Americans Act Title III Overview

Older American Act programs and services represent a significant federal investment in developing a comprehensive, coordinated, and cost-effective system of home and community-based services (HCBS) that enables adults to live independent and healthy lives in their homes and communities. The services under OAA Title III are described in the table below:

Table 1: OAA Title III Services

Title	Services
Title III-B: Supportive Services and Senior Center Programs ⁱ	Title III-B funds a broad array of services that enable seniors to remain in their homes for as long as possible. These services include but are not limited to: <ul style="list-style-type: none"> ▶ Access services, such as transportation, case management, and information and assistance; ▶ In-home services, such as personal care, chore, and homemaker assistance; and ▶ Community services such as legal services, mental health services, and adult day care. This program also funds multi-purpose senior centers that coordinate and integrate services for older adults such as congregate meals, community education, health screening, exercise/health promotion programs and transportation.

ⁱ Administration on Aging. Supportive Services and Senior Centers Programs. Retrieved from: http://www.aoa.gov/AoARoot/AoA_Programs/HCLTC/supportive_services/index.aspx.

Title	Services
Title III-C: Nutrition Services ⁱⁱ	<p>The purpose of the OAA Nutrition Program is to:</p> <ul style="list-style-type: none"> ▶ Reduce hunger and food insecurity ▶ Promote socialization of older individuals ▶ Promote the health and well-being of older individuals and delay adverse health conditions through access to nutrition and other disease prevention and health promotion services. <p>Congregate Nutrition Services and Home-Delivered Nutrition Services provide meals and related nutrition services to older individuals in a variety of settings including congregate facilities such as senior centers; or by home-delivery to older individuals who are homebound due to illness, disability, or geographic isolation. Services are targeted to those in greatest social and economic need with particular attention to low-income individuals, minority individuals, those in rural communities, those with limited English proficiency and those at risk of institutional care. Nutrition Services Programs help older individuals to remain independent and in their communities.</p> <p>The OAA authorizes and provides appropriations to the Administration on Aging (AoA) for three different nutrition programs under Title III:</p> <ul style="list-style-type: none"> ▶ Congregate Nutrition Services (Title III C1) ▶ Home-Delivered Nutrition Services (Title III C2) ▶ Nutrition Services Incentive Program (NSIP).
Title III-D: Disease Prevention and Health Promotion Services ⁱⁱⁱ	<p>Title III-D of the OAA provides grants to States and Territories based on their share of the population aged 60 and over for education and implementation activities that support healthy lifestyles and promote healthy behaviors. Health education reduces the need for more costly medical interventions. Priority is given to serving elders living in medically underserved areas of the State or who are of greatest economic need.</p>
Title III-E: National Family Caregiver Support Program ^{iv}	<p>The National Family Caregiver Support Program (NFCSP) provides grants to States and Territories, based on their share of the population aged 70 and over, to fund a range of supports that assist family and informal caregivers to care for their loved ones at home for as long as possible.</p> <p>The NFCSP offers a range of services to support family caregivers. Under this program, States shall provide five types of services:</p> <ul style="list-style-type: none"> ▶ information to caregivers about available services, ▶ assistance to caregivers in gaining access to the services,

ⁱⁱ Administration on Aging. Nutrition Services (Title III C). Retrieved from:

http://www.aoa.gov/AoARoot/AoA_Programs/HCLTC/Nutrition_Services/index.aspx.

ⁱⁱⁱ Administration on Aging. Disease Prevention and Health Promotion Services (Title III D). Retrieved from: http://www.aoa.gov/AoARoot/AoA_Programs/HPW/Title_IIID/index.aspx#purpose.

^{iv} Administration on Aging. National Family Caregiver Support Program (Title III E). Retrieved from: http://www.aoa.gov/AoARoot/AoA_Programs/HCLTC/Caregiver/index.aspx.

Title	Services
	<ul style="list-style-type: none"> ▶ individual counseling, organization of support groups, and caregiver training, ▶ respite care, and ▶ supplemental services, on a limited basis <p>These services work in conjunction with other State and Community-Based Services to provide a coordinated set of supports. Studies have shown that these services can reduce caregiver depression, anxiety, and stress and enable them to provide care longer, thereby avoiding or delaying the need for costly institutional care.</p>

Under this project, the Administration on Aging (AoA) seeks to study the impact of OAA programs and services, specifically services provided under Title III, on key outcomes, including HCBS use, health care use, community tenure, and long-term services and supports (LTSS) expenditures. OAA services and programs are diverse, often integrated and/or provided in combination with other services, funded through multiple funding streams, and administered and delivered by different state and local-level agencies with varying data collection capacity. Therefore, studying OAA-funded programs and services is inherently challenging.

Prior to developing this design, The Lewin Group (Lewin) conducted a literature review, developed and presented a study framework, and completed a study design. These steps are discussed below.

Literature Review

The development of a comprehensive OAA Global Outcomes Study Design required background research on prior studies about the impact of HCBS on the four outcomes of interest in this project: (1) HCBS Use; (2) Health Care Use; (3) Nursing Home (NH) Admission/Community Tenure; and (4) Cost Savings. To better understand potential study techniques and key variables related to these outcomes, Lewin conducted a review of the literature ([Appendix A](#)).

Methods and Overall Search Results

In order to conduct a thorough literature review, the Lewin team used articles from the Administration on Aging’s (AoA) literature collection of studies compiled by S³, previous literature reviews by the Lewin team, and a targeted updated search to identify new and additional relevant materials. After identifying approximately 900 articles, the Lewin team applied inclusion/exclusion criteria to identify:

- ▶ 19 key studies examining impacts of OAA services or new and useful findings on outcomes of interest related to OAA services, including HCBS use, health care use,

community tenure, NH admissions and costs used to inform the Findings and Lessons Learned Section;

- ▶ 100 additional studies and informational materials providing background information about OAA programs and services, key variables, and related outcomes; and,
- ▶ 21 key studies and papers from the program evaluation and social research literature. These studies, in combination with the 19 key studies, informed the methods for this design.

Elements and Relationships to Consider

LTSS presents a complex and fragmented delivery and financing system. A combination of federal, state and local sources fund a wide range of services to older persons residing in diverse communities and that require these services. To supplement these services, many older people rely on care provided by informal caregivers, caregivers paid out of pocket, or local agencies that provide services. Such a dynamic, multi-layered system requires tremendous coordination and constant adjustments to the changing policy environment and needs of the population. To study such a complex system requires understanding the challenges of defining constructs (e.g., funding, mix of services, unmet needs of individuals, etc.) and the means to measure these constructs (e.g., self-report, use of administrative records, standardized scales, the pros and cons of various proxy measures, and other considerations). Despite the inconsistencies in definition, we found a series of broadly defined variables that demonstrated statistical significance, or were previously found to have demonstrated significance in the studies' background research, with the four key outcomes of interest to this review: 1) HCBS service use, 2) health care use, 3) community tenure/NH use, and 4) LTSS expenditures.

We chose Andersen's Behavioral Model of Health Services Use (Andersen, 1995) to classify the variables into the domains listed below. This model has been widely used to determine variables tested in medical care studies (Andersen, 1995; Miller and Weissert, 2000). This model highlights predisposing, enabling, and need characteristics as variables that contribute to use of services, including HCBS, health care, and nursing home use. The literature review presented findings from numerous studies on how the characteristics, or variables, contribute to use of and/or cost of services. For each domain, we examined the impact the variables had on the aforementioned four key outcomes of interest.

▶ **Predisposing**

- **Demographic variables including:** Age, Sex/Gender, Race/Ethnicity, Education, Geographic Location, Living Alone, Marital Status, Having Children, and Spousal Use of Services

▶ **Enabling**

- **Demographic variables including:** Income/Wealth, Home Ownership, Payment Method
- **Informal Support:** Availability and Use of Informal Support
- **Caregiver Characteristics & Supports:** Available Support for Caregiver, Caregiver Age, Caregiver Burden, Caregiver Awareness of Services
- **Policy/Funding/Supply Level:** State/Medicaid HCBS Funding, Proportion of LTSS Spending on HCBS, Number of Home Health Agencies, County Supply of NH Beds, NH Diversion/Pre-admission Screening

▶ **Need**

- **Health characteristics variables including:** Perceived Unmet Need, General Poor Health, Alzheimer's/Cognitive Impairment/Dementia, ADL Limitations, IADL Limitations, Comorbidities, MH Health Status

▶ **Service Use, Mix and Spending Variables**

- **Acute:** Hospital Admissions/Use, Emergency Department Use
- **Post-Acute:** Case Management, Timing of Care, NH Use (short-stay)
- **LTSS:** HCBS Use, Volume of Services Received, Combination/Bundle of Services, Use of State/Medicaid/Medicaid Waiver Services, Use of OAA III-B, Use of OAA III-E, Use of Title III-C, Timing of Care, Case Management, IADL Assistance, NH Use (Long-Stay)

Lewin suggests that these variables be taken into consideration as part of the final study design.

Study Design Options and Issues/Considerations

Determining the outcomes attributable to a program or service presents a central challenge for any impact study. A study must not only use the best and most-efficient design, but it also must address the needs and values of persons served by the program and prove useful to informing policy and practice. Our review of previous HCBS studies and pertinent materials from the general evaluation literature identified several designs to consider in studying OAA programs and services:

- ▶ **Randomized field experiments**, considered the gold standard in research design for proving impact, offer a design most suited for new program models or service packages. This approach may be less appropriate for established and scaled up programs where no suitable control group exists or it might be unethical to withhold services from a control group. The literature indicates that randomized experiments are less informative when studying complex social interventions, such as OAA services and programs, with substantial variability in local applications.

- ▶ **Non-randomized comparison groups** measure outcomes for two or more groups, but do not randomly assign participants to service receipt. Several HCBS studies have constructed comparison groups using different populations and analytical methods. Significant advances have been made in analytic methods that address vulnerabilities of comparison group designs and researchers have argued that results of this design can be extremely rigorous and emulate results of randomized experiments when certain criteria are met (Shadish & Cook, 2009).

Various methodologies create comparison and treatment groups when using non-randomized comparison designs, such as regression discontinuity and propensity score matching. These methods control for systematic differences in the comparison groups that would otherwise bias the results in a non-randomized design. Additionally, depending on the specifics of the research question and the context of the study, a variety of analytic techniques, such as survival analysis and structural equation modeling, can be applied to understand the impact and pathway of the outcome.

The literature frequently recommends combining more than one analytic methodology. More than one strategy may be needed to answer all study research questions. Also, because all methods have limitations, synthesizing findings across multiple measures and methods may be needed to gain a full understanding of the program.

In addition to the complex challenges associated with designing a valid and reliable impact study, we must consider the dynamic nature of the LTSS delivery system. At times programs expand based on new policy guidance, while, at other times, they contract in response to budgetary constraints. Further, each State and locality has different funding systems, policies, practices, and client needs that must be accounted for in any design. Lewin compiled a list of key questions to ask states in order to develop a study design that could best take into account the variation within states. This list is included in the Study Design ([Appendix B](#)).

Findings and Lessons Learned from Past HCBS Studies

Our synthesis of previous HCBS studies suggests several key findings, lessons learned, and recommendations to consider in studying the impact of OAA and non-OAA HCBS programs. These findings suggest that designing a study that produces credible, solid evidence of results will be of critical importance to AoA, the Aging Network, and service recipients and families who rely on OAA and non-OAA programs and services. Increasingly, stakeholders seeking continued or expanded funding for health and social programs must be able to “make the business case” for the investment, with rigorous research demonstrating success in improving peoples’ lives and achieving more effective/appropriate use of economic resources. In addition to providing evidence of an impact, a study design that allows for exploration into the pathways through which

the impact is made (e.g., case management, targeting of services, individual belief about HCBS, etc.) will allow policy leaders to make informed decisions about how to allocate future funding in a way that results in the greatest possible impact on outcomes. The primary findings are listed below:

- ▶ OAA and non-OAA services work better when offered as part of a comprehensive system to meet individual needs.
 - Coordinated systems of care at the national, state, and agency level are important considerations when evaluating the effects of OAA and non-OAA social support activities;
 - New studies highlight the effectiveness of moderate services, including OAA home-delivered meals and IADL help;
 - Availability of services and resources in the community play an important role in affecting OAA and non-OAA HCBS outcomes.
- ▶ For OAA and non-OAA services, the greatest HCBS impacts have been on community tenure, rather than health care utilization.
- ▶ Community tenure is associated with family caregiver availability and individual characteristics of both the caregiver and the consumer.
- ▶ An assessment of HCBS outcomes must consider the effect of OAA services, controlling for the impact of non-OAA services.
- ▶ Service use is affected by many individual characteristics, some of which are difficult to measure (e.g., changing needs over time).
- ▶ Virtually every study concluded that further research is needed to develop understanding of the complexities inherent in the LTSS delivery system.

Available Data Sources and Data Elements

Our review identified numerous data sources that have been used in recent related HCBS studies, the types of data available from each source, and examples of studies using the data. These include OAA-specific, state, national and qualitative data sources. In addition, we provide examples of surveys of HCBS programs that could potentially be used to capture some types of program information that have been identified in the literature as important to consider, but are not included in existing data sets.

A high-quality study design hinges on valid and reliable data. Regardless of how well a study is designed, the outcome is only as good as the data used. While available data sources provide a cost-effective and efficient way for collecting data, all sources reviewed were found to have limitations in terms of the measures/indicators collected, the quality of the data, the frequency of the collection, or comparability of the measures/indicators over localities and states. Many studies have used supplemental surveys, questionnaires or interviews to collect additional data that complement the

data collected through regular reporting systems to allow for more robust evaluation results. While supplemental data collection methods may be costly, they are likely the only way to ensure the inclusion of high quality data on certain key variables (e.g., availability of informal caregivers, level of unmet need, functional status, etc.).

Study Design Framework

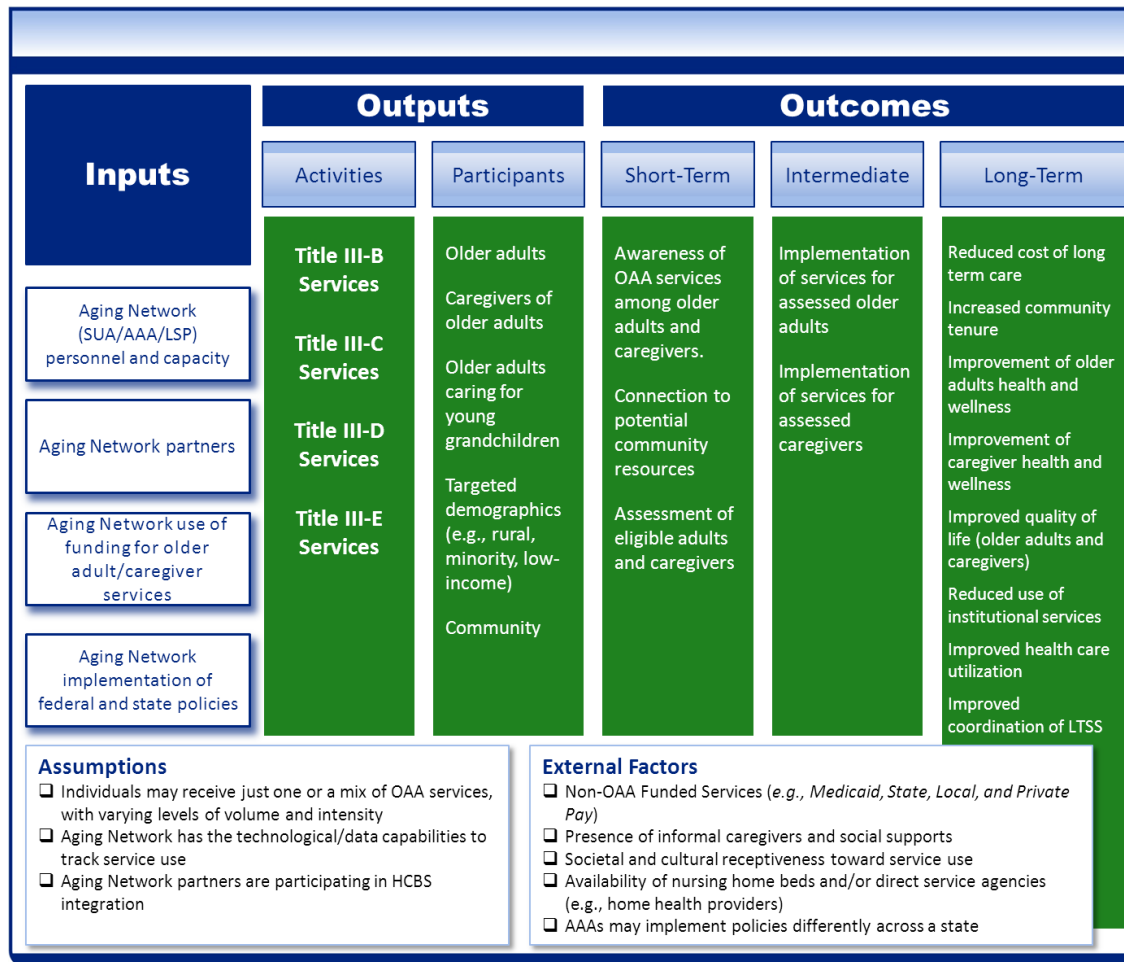
The Study Framework and Design (**Appendix B**) describes Lewin’s proposed approach for understanding the impact of OAA programs and services on the aforementioned outcomes of interest. Building off of the literature review, this document includes a discussion of the challenges and trade-offs that must be considered in the selection of variables, research questions, study design options and secondary data sources, in order for AoA to endorse a rigorous impact study of OAA programs and services.

This design focuses on the impact of services provided through OAA-funded HCBS programs authorized under Titles III-B, C, D, and E of the OAA. These programs include a range of supportive services, nutrition services, health promotion and disease prevention programs, as well as services for family caregivers. While the mix and type of services offered differ by state and locality, the vast majority of OAA funding is used for the provision of nutritional services.

Logic Model

To best understand how OAA program activities relate to short and long-term outcomes, a logic model was developed in collaboration with ACL staff (Figure 1). The logic model depicts the inputs, activities, outputs, and outcomes of OAA-funded HCBS programs and services. We have included “non-OAA funded activities” (e.g., informal services, state-funded HCBS, private pay) as these activities often occur in combination with OAA-funded activities and impact the key outcomes of interest for this project.

Figure 1: Logic Model



Research Questions

Based on the expected outcomes depicted in the logic model, we propose the following research questions. What is the impact of OAA-funded HCBS programs and services on:

- ▶ Community tenure
- ▶ Health care utilization
- ▶ Costs of care for older adults (e.g., LTSS, health care costs)
- ▶ Physical, mental, and emotional health and wellness (e.g., preventive measures) of care recipients and caregivers
- ▶ Unmet needs among older adults
- ▶ Caregivers (e.g., strain, burden, depression, health, etc.)
- ▶ Coordination of services (e.g., care management)

In addition to answering questions about the impact of service use on desired outcomes, we recommend that AoA consider a design that measures the strength of association of covariates/intervening variables on the key outcomes including, but not limited to, mix, type, and intensity of services. This step would answer the following sample questions:

- ▶ What is the impact of OAA services alone or in combination with services paid for by other sources?
- ▶ What is the impact of service mix and intensity on outcomes of interest? [if possible, we will isolate OAA services]
- ▶ What subgroups had the most favorable outcomes? (e.g., health conditions, demographics, functional status)

Defining the Scope of the Study

A critical methodological decision hinges on how non-OAA funded services are factored into the study design. For example, does the design consider the OAA service package alone or in combination with a similar service package that is funded by alternative sources? This decision will impact the comparison group, sample size, research questions and generalizability of the findings.

Another important issue discussed frequently in the literature, and one that we are confronted with in this design, is the level of exposure to HCBS services (i.e., mix, duration, intensity and timing). Consideration of this step will ensure that individual variations are factored into the final models. Several studies that were reviewed developed exposure algorithms that may be applicable for use in the final models to address this issue (NYSOA, 2010).

Furthermore, an important issue raised in the literature is the impact of certain policy or other contextual factors on individual outcomes (e.g., nursing home admission or HCBS use). These measures include the amount of state spending on Medicaid HCBS, the number of nursing home beds in a geographic area, availability of Waiver slots, the number of home health agencies in a particular area, and the use of pre-admission screening prior to NH use.

Several of the key variables proposed for the OAA study are well established measures (e.g., sex as male/female/unknown). However, the literature points to several limitations of many of the measures (e.g., informal care measures, ADL/IADL limitation measures), which must be considered prior to including them in the study.

Proposed Study Design

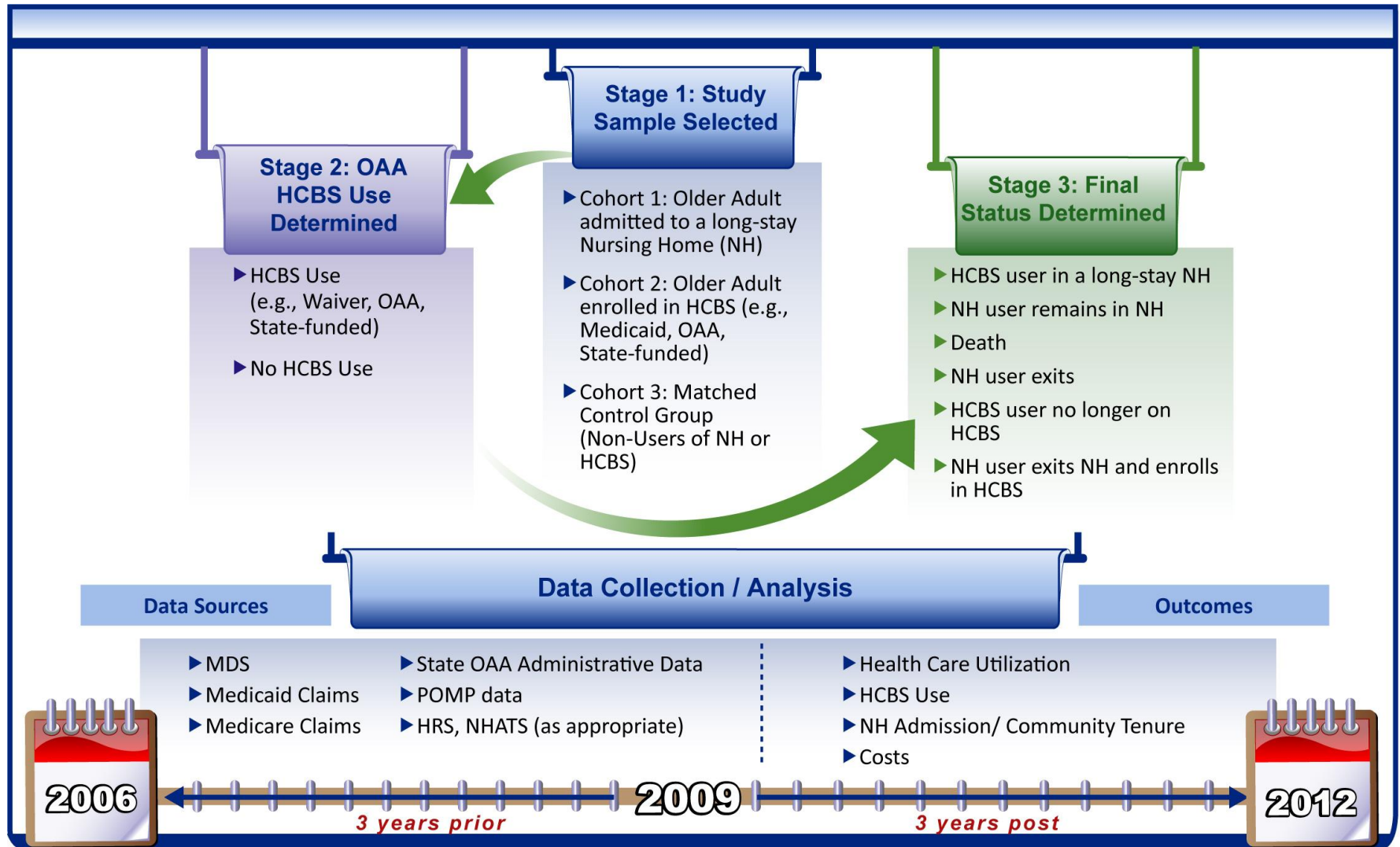
We suggest that the design approach with the greatest potential for delivering conclusive and actionable results would be a quasi-experimental design that includes: 1) a retrospective study component drawing on existing individual data from federal sources; and 2) a prospective study component using data to be collected during the study period. Evaluators of HCBS and other health and social service programs usually rely on quasi-experimental techniques as the best impact study design and most powerful alternative to random experiments. We know from the literature that demonstrating impacts on HCBS expenditures can take several years, with a lag between increased spending on HCBS expansion and savings from this investment (Kaye, LaPlante, & Harrington, 2009). Thus, we recommend a study period of seven years, a plausible option given the retrospective/prospective design option. This study period time can be modified depending upon time, data, or funding constraints.

To reduce bias and error in assessing program outcomes, we recommend incorporating multiple methods, measures, and data sources. In using a quasi-experimental design with a matched comparison group, a suggested method includes propensity score matching for constructing a matched comparison group in the final design. This will allow comparisons of older adults who had an outcome of interest with older adults who are matched on certain key characteristics relevant to the outcome, to determine whether OAA services contributed to the difference in outcome. The matching process will allow us to control for factors that are believed to contribute to different outcomes (e.g., gender, diagnosis, multiple chronic conditions, etc.).

The key to unbiased inference in this approach, as in any quasi-experimental design, is proper specification: choosing a set of key factors to be controlled so that uncontrolled variables are approximately random, i.e., not correlated with the controlled variables or the treatment (Achen, 1986). Knowledge about the factors that affect receipt of services and factors correlated with outcomes (*i.e., community living tenure and healthcare utilization*) identified in the literature review are essential to the success of the design.

The research team proposes using this design in a study of 3 states. A primary purpose of the study will be to identify a core set of variables that all states should collect. States have been granted great flexibility regarding program administration and data collection. As a result, states lack uniform and comprehensive data. Conducting this study, as discussed in the **Recommendations** section, can address that issue.

Figure 2: Proposed Study Design Image



Proposed Study Design Description

The above graphic depicts the proposed design for the Study of the Global Outcomes of Older American Act Programs and Services. The goal is to measure the impact/association of OAA service use by older adults on four key outcomes (health care utilization, HCBS expenditures, NH admissions and community tenure). Further, the design allows for the examination of various service use trajectories over time (e.g., HCBS user in a NH, NH user exits NH, etc.) and the extent to which OAA programs and services are associated with these trajectories. The details of the study design are discussed below.

Intervention: Receipt of OAA services, alone or in combination with other HCBS.

Target Population: The target population for this study is older adults age 60 and above (those eligible for OAA services). In the selection of the cohorts in stage 1, the sample will be selected and then connected back to those who received OAA services in stage 2 of the design. Those who have received OAA services are the treatment, or intervention, group and those who are not matched to OAA service use are the comparison group.

Pre-Stage: Three states will be selected through an RFP process to participate in this study design. The states will have the data capacity and availability to participate in the stages outlined below.

Stage 1: The proposed design takes place over a six-year study period and consists of three stages. In **Stage 1**, (depicted in the blue box in the middle), the study sample is selected using MDS, Medicaid/Medicare claims data, and OAA or state-funded services data, that cover a one-year period of time (2009-2010) and an entire state (e.g., Georgia). Three cohorts of older adults will be identified from this dataset: *Cohort 1* will be a sample of older adults who have been admitted to nursing homes; *Cohort 2* will be a sample of older adults enrolled in any HCBS [Medicaid, state-funded, or OAA]; and, *Cohort 3* will be a group of individuals who were not admitted to a nursing home and did not receive HCBS. This group will be matched to older adults in *Cohorts 1* and *2* on certain key variables to ensure comparability (propensity score matching). *Cohort 3* will serve as the comparison group.

Stage 2: During **Stage 2** of the study (represented in the purple box on the left), the HCBS service use by *Cohort* will be measured. This will be accomplished through the analysis of Medicare/Medicaid Claims, POMPS, State OAA administrative records, HRS and any other available sources. The study period covers 2006-2008. Data will be analyzed by service type, mix, and intensity of service use. A group of individuals will be non-users.

Stage 3: In the final stage of the study, **Stage 3**, (illustrated in the green box on the right), using the same combination of data sources, three additional years of service use

and client disposition – status post-intervention will be examined. In sum, the study will have a longitudinal data base (2006-2012 or the most current year available to us) that includes three unique cohorts of individuals: nursing home users at baseline, HCBS users at baseline, and non-users at baseline. This combination will allow for both within-group and between-group data modeling. Results will demonstrate if receipt of OAA services, whether alone or in combination with other services, will directly impact: health care utilization, HCBS expenditures, nursing home (NH) admissions and community tenure.

Limitations and Recommendations

The Administration on Aging (AoA) and The Lewin Group (Lewin) hosted an Expert Group meeting, conducted several key informant interviews with additional stakeholders and held calls with states about their Older Americans Act (OAA) data systems. This feedback yielded a better understanding of the limitations of this study design and the recommendations to address them ([Appendix C](#)).

Limitations

The following major limitations were identified in those discussions:

- ▶ **State Older Americans Act (OAA) Data:** A select group of states (FL, GA, MA, MN, and OH) were interviewed about their OAA data collection policies and procedures. These interviews highlighted some of the limitations of state OAA data, along with identifying states with more comprehensive data systems from our small sample. Specific limitations that impact the study design included:
 - The absence of Social Security Numbers (SSNs), which provide the most reliable method to match to Medicare and Medicaid claims.
 - Lack of information regarding the reasons for termination of services, which limits the ability to measure community tenure as an outcome.
- ▶ **Informal Caregiver Data:** As discussed in the expert group meeting and key informant interviews, difficulties will be encountered obtaining caregiver information, due largely to the non-existence of such data.
- ▶ **Private Pay Data:** This is a limitation for both the treatment and comparison groups. States do not uniformly collect information on private pay services received by OAA users. Therefore, this information would not be readily available for the proposed treatment or comparison groups.

Recommendations

While this study can be conducted, it will require complicated data gathering, cleaning and merging to overcome many of the data limitations. It will also be heavily

dependent on the strength of the chosen states' OAA data system and timeline when the states migrated to a statewide data system. Based upon the limitations of data sources available, and feedback from expert group participants and key informants, the recommended approach is outlined below:

Step 1: Issue RFP to conduct study

AoA issues an RFP to carry out the proposed study. The awarded research team would work with AoA to prepare for and conduct the study.

Step 2: Convene Technical Working Group

Within three months of the contract begin date, AoA in collaboration with the awarded research team establishes a Technical Working Group (TWG). A TWG can assist the research team in identifying the minimum key variables necessary for a retrospective/prospective design.

Step 3: Issue RFP to states

Prior to the completion of step 2, AoA issues an RFP identifying up to three states willing to participate in organizing existing data at the state level. Proposed criteria for this RFP are outlined in the **Limitations and Recommendations** document.

Step 4: Assist states / Collect available secondary data

Step 4 has two concurrent components that will begin upon awarding three states grants to conduct the study: (1) AoA and the research team will work with the three selected states in gathering and preparing their OAA administrative data; and (2) while the selected States are preparing and assisting in the collection of data, the research team should assist the states as necessary. In addition, the research team will begin preparations for linking the state-level data with other national datasets.

Step 5: Expand work to include primary data collection

Step 5 includes expanding the work described in steps 2-4 in the selected states to include primary data collection, as funds and time allow. Primary data collection will strengthen the data by gathering detailed information on such key aspects of caregiving as informal supports. This step could be accomplished through either a state-wide random selection of OAA participants, or targeted data collection that occurs with select AAAs in the chosen states.

Step 6: Design and field the study

The research team selected in Step 1 should work with AoA and the three participating states in finalizing the study design and fielding the study with data collected at the state and federal level. The proposed design in the **Study Framework and Design** should be the foundation for this design, and modified as appropriate given available state secondary data and any additional primary data.

Step 7: Reconvene TWG and present findings

Once the exploratory study is conducted in the three selected states reconvene the TWG and present results for feedback and discussion. TWG members, in collaboration with AoA and the research team, will define a core set of variables that AAAs will employ to ensure consistent data collection across agencies.

Step 8: Training & technical assistance for data collection

With changes to SPR data requirements, many states will require intensive T&TA as they make updates to their current data systems. However, some states will be more prepared than others or already collect the core variable requirements, while others will require a complete overhaul.

Conclusion

Conducting this study can position AoA to design and implement a more comprehensive evaluation of OAA services. As all states begin collecting newly required data elements, AoA might consider how this new data can be used in a national evaluation, or an evaluation conducted in a random selection of states. This evaluation could result in definitive conclusions providing a full picture of the impacts of OAA Title III services to date. Specifically, AoA will better understand the impact of OAA services across the board in promoting positive outcomes for service recipients, including increased community tenure and decreased health care use. This evaluation will also examine the potential cost savings of OAA service use. Additionally, it will enhance capacity for ongoing research and provide information about the programs that AoA and the Aging Network can use in future program planning.

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Appendix A: Literature Review

Introduction

This report presents The Lewin Group’s findings from the review of materials (Subtask 2.1 of the project to design an *Exploratory Study of the Global Outcomes of Older Americans Act Programs and Services*). In this overview, we describe our methods and present findings from our review of materials. These include findings related to: (a) a study design that may be suitable for assessing OAA program impacts, taking into account the complexity in measuring impact; (b) findings and lessons learned from past HCBS studies; (c) elements and relationships to consider in developing a program model and planning a study of HCBS impacts (including HCBS goals, policies, strategies, impacts, and research questions); and (d) available data sources identified for us in examination of these issues (**Appendix A-A**).

Methods and Overall Search Results

We found relevant studies, reports, and other published materials through a variety of methods. There were two phases to our search:

1. We utilized the collection of articles previously compiled for AoA by S³ and other materials provided by AoA. We augmented these study reviews with a targeted search for new and additional studies (published and unpublished) on the impacts of HCBS on community tenure, health care utilization, and/or economic/systems outcomes, through:
 - a. A search on PubMed and Google Scholar using key search terms related to this literature review, and
 - b. Browsing research articles and abstracts in the Clearinghouse for Home and Community Based Services (<http://www.hcbs.org/>).
2. Additional studies were obtained through other sources (e.g., email lists, reviewing sources cited in reviewed studies, other studies known to the research team, and recommendations from the expert group, key informants, and state OAA representatives).

From this, we scanned approximately 900 articles/studies and narrowed the review to the studies below. Inclusion criteria included:

- ▶ Materials providing background information about OAA programs and services.
- ▶ General review of HCBS studies that included extracting relevant information to inform this report: previous evaluations of OAA services and studies of HCBS use on community tenure, health care utilization, and/or economic outcomes were used. These studies were most directly relevant to this project.

- ▶ In-depth review of studies where we extracted information on the data sources, detailed findings for all outcome measures, and the authors' recommendations for future research.
- ▶ Two researchers read the full text of the studies and reviewed each entry. For evaluation methodologies, we paid particular attention to 19 studies that specifically examined impacts of OAA services or that provided new and useful findings to help inform a study design. The in-depth reviewed studies included:
 - Studies that specifically examined OAA programs and services, including research conducted as part of the Administration on Aging's Performance Outcomes Measurement Project (POMP), and related studies by the same authors that specifically examined outcomes of OAA services, along with other HCBS, in numerous states (e.g., Florida, New York, Georgia, and Rhode Island).
 - Findings from the Community Tenure study, which examined receipt of OAA services, along with other HCBS, and has been nationally recognized for its methods. This 5-year prospective study tracked older adults in Kansas who had applied for nursing facility admission and received a pre-screening admission assessment under the State's Client Assessment Referral and Evaluation (CARE) Program. The study tracked CARE participants' community tenure and outcomes when community tenure ended (Chapin et al., 2009).
 - Select studies of non-OAA HCBS that could be particularly useful in developing a study design. These were recent studies that: (a) measured the impacts of HCBS on community tenure and/or health care utilization; (b) used rigorous methods and large samples so that the results are reasonably generalizable; (c) examined a complex set of factors to rule out alternative explanations for program results; (d) examined relationships or factors not previously examined in the literature.
- ▶ Over 100 articles presenting background research, prior HCBS studies and evaluations, and research on factors predicting HCBS use, health care use, and nursing home utilization. These include meta-analyses that examined predictors of nursing home admission (Gaugler et al., 2007) or other adverse outcomes (Miller & Weissert, 2000). Other studies examined targeted groups experiences with the outcomes of interest, such as people with dementia, older adults in rural areas, and African American women.
- ▶ 21 relevant materials from the general program evaluation/social research literature. These materials were used to enhance understanding of evaluation design options suggested by the HCBS studies and to identify other potential design options that may be appropriate to consider. These evaluation design-related materials included: evaluation literature known to Lewin and AoA, materials recommended in OMB guides, and additional items found through targeted searches for materials about specific methodologies that appeared most relevant.

There were many studies that, while informative, did not meet our inclusion criteria for further review. These include:

- ▶ Studies of particular program strategies or interventions (e.g., adult day care, assistive technology, care management, participant direction, food assistance programs);
- ▶ Studies related to the direct service workforce, studies of informal/family caregivers;
- ▶ Overview articles/issue briefs;
- ▶ State specific program overviews;
- ▶ Research on demographic trends and predictors of health outcomes;
- ▶ Studies related to needs assessments;
- ▶ Studies related to medical, exercise or therapeutic home-based interventions;
- ▶ Studies not written in English and/or not conducted in the United States

We did not apply exclusion criteria based on the time in which the study was conducted or published to capture the early HCBS findings from the Channeling Demonstration.

Study Design Options

In this section, we summarize our findings from the reviewed HCBS studies and program evaluation literature on possible study design options for AoA to evaluate the impact(s) of the Older Americans Act (OAA) and services on older adults and caregivers. Additionally, we must account for the combination of OAA programs and services with non-OAA HCBS programs and services.

Strategies in Evaluating Aging and Disability Programs

A study that seeks to evaluate the effectiveness of a social program, frequently referred to as a program evaluation, is different from other types of research (Krause, 1996; Rossi, Freeman, & Lipsy, 1999). In what is sometimes described as “pure” research, social scientists start with hypotheses, gather data, and then try to form generalizations about the results. A search for theory is the primary function, and this quest for theory requires the use of research procedures in a fashion that often differs from what generally occurs within program evaluations. For example, correlations that might produce a scientific journal article could easily be meaningless to an agency director who is trying to decide whether to spend additional dollars on a particular program.

While the major focus of studies evaluating program outcomes is to determine whether outcomes can be attributed to the program (GAO 1991; GAO 2012), they are also

concerned with identifying any unintended outcomes and understanding how the program works with other programs (Treasury Board of Canada, 1998).

DIFFERENCE BETWEEN PROGRAM EVALUATION AND OTHER RESEARCH

***Program evaluation** is the use of social research procedures to systematically investigate the effectiveness of social intervention programs.—Rossi, Freeman, & Lipsey, 1999*

Program evaluation, or “evaluation research,” refers to the research procedures and techniques used to examine the effectiveness of social programs. Program evaluation, in other words, is a process that generates the information used to describe what a program is doing and how well it does it.” — Krause, 1996

GAO (2012) recommended that five key steps, similar to those presented by Krause (1996), should be taken into consideration before data are collected in a program evaluation:

1. Clarify understanding of the program’s goals and strategy.
2. Develop relevant and useful evaluation questions.
3. Select an appropriate evaluation approach or design for each evaluation question.
4. Identify data sources and collection procedures to obtain relevant, credible information.
5. Develop plans to analyze the data in ways that allow valid conclusions to be drawn from the evaluation questions.

Each of these steps is crucial and should not be overlooked. As a tool for understanding how program activities relate to short-term and long-term outcomes, evaluation materials typically recommend using a program logic model (GAO, 2012). A review of materials, along with discussions with program stakeholders, is essential to gathering the information needed to develop a successful program logic model and evaluation design. Content analysis or a summary of the content of existing materials, such as that undertaken in this report, has several applications in program evaluation (GAO, 1989). These include identifying program goals, describing program activities, and determining program results.

Research Designs

Research designs fall into several groups discussed in depth in this section: randomized; non-randomized comparison group; time series/longitudinal; and alternate causal explanation elimination.

A frequent recommendation in the evaluation literature is to combine two or more research designs. GAO (2009) recommended, “Since all evaluation methods have limitations, our confidence in concluding that an intervention is strengthened when the conclusion is supported by multiple forms of evidence” (pg. 28-29). Some of the HCBS studies cited used more than one type of design; for example, a survival analysis study was used with a matched comparison group in the Kansas Community Tenure Study (Chapin et al., 2002).

The Treasury Board of Canada (1998) advised that using more than one evaluation strategy is desirable to increase support for inferences about program impact. This is because, “Generally speaking, no single evaluation strategy is likely to yield enough evidence to answer unambiguously the questions posed by the evaluation” (Treasury Board of Canada 1998, p. 28). Because an evaluation study generally addresses several issues at a time, more than one strategy may be needed to answer all research questions (Treasury Board of Canada, 1998). Trochim (2006) noted that the currently prevailing philosophy in science recognizes that all observation is fallible and has error and that all theory is revisable. This view emphasizes the importance of multiple measures and observations, each of which may possess different types of error and the need for *triangulation* (i.e., synthesizing findings) across these multiple error-containing sources to try to gain a full understanding of the program.

Shadish and Cook (2009) described pattern matching designs, which “counter the unfortunate notion that researchers should choose from a small and fixed set of designs” (pg. 623). While researchers often focus on minimizing threats to validity, pattern matching designs “attend to a less often noticed piece of advice, to predict a diverse pattern of results whose strong testing might require multiple nonrandomized designs, each with different presumed biases” (pg. 623). Shadish and Cook (2009) quoted Campbell & Stanley’s 1963 advice that “the more numerous and independent the ways in which the experimental effect is demonstrated, the less numerous and less plausible any singular rival invalidating hypothesis becomes” (pg. 623). They recommended that when an ideally implemented experiment or quasi-experiment is not feasible, researchers assemble more than one design that predicts a pattern of causal results, because fewer alternative explanations are plausible if the results match the predicted pattern.

An example discussed by Shadish and Cook (2009) was measuring the same outcome via a randomized and nonrandomized comparison group design then comparing results. They referred to Cook et al. (2008), who suggested a stringent set of seven

criteria for good comparisons of results obtained from a randomly formed and a non-randomly formed control group.

1. The studies compare a randomly formed control group and a non-randomly formed control group.
2. The randomized and nonrandomized experiment both estimate the same estimator (e.g., average effect of treatment on the treated or intent to treat).
3. The randomized and nonrandomized groups should differ from each other only in method of assignment.
4. The person estimating results from the nonrandomized study should not know the results from the randomized experiment.
5. The randomized experiment should be an exemplar of its kind, not subject to large attrition or partial treatment problems.
6. The quasi-experimental design should similarly be an exemplar of its kind, without attrition or partial treatment problems, with focal local controls and good pre-test measurement of variables related to treatment and outcome.
7. A defensible standard for what counts as a match in randomized and nonrandomized results is used. "This is difficult both because reasonable people might disagree on substantive criteria that would make a difference to policy decisions and because statistical criteria will inevitably be subject to power problems" (pg. 622).

Cook and colleagues (2008) showed that when most or all of the seven criteria were met, results from different kinds of nonrandomized experiments matched results from randomized experiments. This was true for regression discontinuity designs, well-designed nonrandomized experiments with focal local controls and stable matching, and statistical analyses such as propensity scores.

Randomized Field Experiment

Many HCBS studies, using randomized assignment to test the effectiveness of a particular program, or of HCBS overall, have encountered serious implementation problems that lead to inconclusive results. The early HCBS studies revealed many limitations to the use of randomized experiments in the study of HCBS programs. These include: lack of clarity over whether the actual experimental intervention was likely to have its intended effect, small estimates of results due to similarities in services received

by treatment and comparison group members, and lack of generalizability of the results (Kane, 1988; Brown & Phillips, 1986).

Another limitation of randomized experiments is that results could show relatively small estimates of program impacts, even if the program is very effective, if only a fraction of the treatment group actually participated in program services or if a substantial proportion of the control group received similar services from existing agencies; this was an issue in the Channeling demonstration (Brown & Phillips, 1986) and in the Cash & Counseling demonstration (Applebaum, Seidl, & Austin, 1980). Another noted challenge to this design is that treatment and control groups may differ despite random assignment, as was the case in the evaluation of Georgia's Alternative Health Services program (Skellie, Mobley, & Coan, 1982). Several studies performed secondary analyses of Channeling demonstration data to address research questions not answered in the original demonstration project. Although their data is now outdated, these studies provide examples of the use of more sophisticated models to gain a better understanding of how and why specific program effects may or may not occur in HCBS programs (Rabiner, Stearns, & Mutran, 1994; Liu, McBride, & Coughlin, 1990; Greene, Lovely, & Ondrich, 1993; Green, Ondrich, & Laditka, 1998).

A recent article in an evaluation blog discussed the debate about the use of randomized experiments in evaluating social programs: "The promotion of experimental designs often has a polarizing effect: Proponents sometimes act as if it is the cure for all evaluative ailments; opponents sometimes act as if it is the root of all evil." / "Any design should be selected because it is the best way to answer a particular question, and the question to be answered should be directly related to the stage of the organization or program being tested. Not all questions in the field are best answered through an experimental design approach. But some are." (Buteau, February 17, 2012).

A 2009 GAO report described several circumstances in which random experiments are generally not well-suited. In particular, GAO (2009) advised: "the evaluation literature cautions that as social interventions become more complex, representing a diverse set of local applications of a broad policy rather than a common set of activities, randomized experiments may become less informative... In these cases, aggregating results over substantial variability in what the intervention entails may end up providing little guidance on what, exactly, works" (pg. 25).

However, Xu et al. (2010) recently recommended a different use for randomized experiments: to determine the effectiveness of increasing the volume of various types of formal HCBS on health outcomes and expenditures. This was based on their finding that receiving a greater volume of attendant care, homemaking services, and home-delivered meals was associated with a lower risk of hospitalization.

A 1990 paper in *Evaluation Review* (Dennis, 1990) noted that randomized field experiments can and often do encounter threats to the validity of their inferences about program results. In addition, because of their difficulty and expense, the author recommends that randomized field experiments “should be considered only when no simpler alternatives for evaluating the intervention can be found” (pg. 350).

However, several developments in the analysis of randomized experiments in recent years have led to more sophisticated randomized experiments (Shadish & Cook, 2009). Developments in analytical methods and computer software have occurred for coping with partial treatment implementation and potential attrition and the use of nested models. In nested models (often called group-randomized or cluster-randomized models), individuals are “nested” within aggregated groups, which are themselves nested within conditions. Examples include students nested within classrooms, clients nested within psychotherapy groups, or workers nested within worksites.

RECENT ADVANCES IN RANDOMIZED FIELD EXPERIMENTS

In recent years, more sophisticated randomized experiments have developed, as a result of developments in analytical methods and computer software for coping with implementation problems. One example is nested models, in which individuals are nested within aggregated groups, which are themselves nested within conditions. (Shadish & Cook, 2009)

Non-Randomized Comparison Group Designs

A non-randomized, often called “nonequivalent,” comparison group design measures outcomes for two or more groups but does not randomly assign participants to receive services or not (Shadish & Cook, 2009). The GAO (1991) described three different ways to form a non-randomized, or nonequivalent, comparison group for a program evaluation: matched comparison group; regression discontinuity/biased assignment, and naturally occurring comparison groups. These options are discussed below.

Matched Comparison Groups

A few of the studies reviewed in-depth for this report used matched comparison groups. These studies used a number of different populations from which to form the comparison group and different statistical techniques to match the groups, as summarized in **Table 1** below.

Table 1 : HCBS Studies With Non-Randomized Comparison Groups

Study	Comparison Group Populations	Analytical Methods
Felix et al., 2011	Arkansas Community Connector participants People receiving Medicaid in nearby counties where the Community Connector program was not operating	This longitudinal study used propensity score matching to compare the two groups. The Arkansas Community Connector Program used specially trained community health workers to identify people living in the community who have unmet LTC needs and who may be at risk for entering NHs in three disadvantaged Arkansas counties and connect them to Medicaid HCBS.
Shapiro & Loh 2007; Shapiro, Loh & Mitchell 2009	HCBS users in Florida People on waitlist	This study of five HCBS programs in Florida used propensity score matching to compare outcomes for HCBS users matched with individuals placed on the waitlist when program capacity has been reached. The user/waitlisted status was not expected to be determined by unobservable characteristics that potentially affect outcomes because, in Florida, persons with equivalent need for services and frailty are prioritized on a first-come, first-serve basis. Any differences in frailty that arise from group membership are accounted for through regular assessments that both users and waitlisted persons complete. The authors developed an algorithm that determined the differences in Medicaid expenditures between the two groups, producing an estimate of cost-savings. Second, the study used a linear panel model in which the difference-in-difference estimator was employed. This estimator represents the difference in the average outcome in the treatment group before and after treatment, minus the difference in the average outcome in the control group before and after treatment.
Shapiro & Loh, 2010	HCBS users in Florida (individuals who applied for and received any HCBS through DOEA during the month) Individuals not receiving services that month, including those on waitlist and those who stopped	Building on findings from Shapiro, Loh, & Mitchell (2009), this study of HCBS in Florida compared outcomes for three match comparison groups, as well as a naturally occurring comparison group (individuals in nursing homes). Three-stage-least squares estimators were used to produce the final estimates. The authors implemented several layers of controls to reduce potential bias due to differences between the groups. Multiple regression models were used to control for

Study	Comparison Group Populations	Analytical Methods
	receiving HCBS Individuals who did not apply for services Individuals in nursing homes	demographic differences and differences in ADL scores. They then estimated a set of fixed effect models to control for unobserved factors of Medicaid expenses that may correlate with the HCBS service status. The authors noted that employing propensity score matching using the CIRTS database may introduce selection bias. To account for this, they compared those in the CIRTS database with nursing home residents who were not in the CIRTS database in the study period.
Chapin et al., 2002; 2003; 2009; Macmillan et al., 2007	Older persons in Kansas who received a CARE assessment and were diverted from NH Those who received an assessment and were not diverted and entered a NH	This 5-year longitudinal study, tracked a cohort of older adults in Kansas for 18 months and 24 months who received CARE Assessment. Quantitative data analyses compared those who were diverted and those who were not diverted.

MATCHED COMPARISON GROUPS EXAMPLE

A study of HCBS users in Florida constructed 4 comparison groups by matching data from the state CIRTS system with MDS data (Shapiro & Loh, 2010):

- ▶ *Individuals who applied for and received any HCBS during the month (MDS II & CIRTS match)*
- ▶ *Individuals not receiving services that month, including those on waitlist and those who stopped receiving HCBS (MDS II & CIRTS match)*
- ▶ *Individuals who did not apply for services (MDS, no CIRTS match)*

Four techniques for improving the similarity between comparison groups are: (1) difference-in-difference design, (2) the use of instrumental variables, (3) propensity score matching, and (4) case matching (Duignan, 2009). Currently, the most popular method for matching the two groups to be as similar as possible is propensity score matching (Shadish & Cook, 2009). The Money Follows the Person (MFP) evaluation design proposed two comparison groups (Brown et al., 2008). One group comprised

Medicaid enrollees during a previous period who appear to meet MFP eligibility criteria and transitioned from institutional to community-based care. The other group included institutionalized Medicaid enrollees in the pre-MFP period who have the same observable characteristics as MFP participants, but did not transition to the community.

Many studies across a number of fields have tested the ability of matched comparison group designs to produce unbiased estimates by comparing them with estimates from randomized experiments. These studies generally suggested that matched comparison group designs can often produce misleading results. In 2003, the U.S. Department of Education discussed this literature and reported:

“There is persuasive evidence that the most common comparison-group designs produce erroneous conclusions in a sizeable number of cases. A number of careful investigations have been carried out—in the areas of school dropout prevention, K-3 class-size reduction, and welfare and employment policy—to examine whether and under what circumstances comparison group designs can replicate the results of randomized controlled trials. ...These investigations have shown that most comparison-group designs in education and other areas produce inaccurate estimates of an intervention's effect.....In a sizeable number of cases, the inaccuracy produced by the comparison-group designs is large enough to result in erroneous overall conclusions about whether the intervention is effective, ineffective, or harmful.” (p. 3)

However, more recent research suggests that valid results from statistically matched comparison group designs are possible. Shadish & Cook (2009) noted that significant advances have been made in addressing vulnerabilities in the design and analysis of nonrandomized comparison group experiments.

WHEN CAN MATCHED COMPARISON GROUP DESIGNS APPROXIMATE RESULTS FROM RANDOMIZED DESIGNS?

“Evidence suggests that nonequivalent comparison group designs can approximate answers from randomized designs when they use focal local controls, careful matching on stable covariates, and measure a rich set of pretest predictors of treatment and outcome that can be used in statistical adjustments such as propensity score analysis.” – Shadish & Cook, 2009, pg. 625

Several of the evaluation design articles we reviewed emphasized the importance of selecting comparison group members who are local to the participant group, not a national sample.

Regression Discontinuity Design

For many evaluations, the evaluator does not form the treatment and comparison groups (GAO, 1991). Rather, some people have naturally been exposed to the program and others have not.

NATURALLY OCCURRING COMPARISON GROUP

This design may be used when the evaluator does not form the treatment and comparison groups. Rather, some people have naturally been exposed to the program and others have not. Although this somewhat limits the evaluator's options, the general logic of the design is the same. (GAO, 1991)

An example in the studies we reviewed was Medicaid participants living in the community and in nursing homes. The regression discontinuity design, noted by the GAO (1991) and described below, can be used in situations where people are naturally assigned to either receive or not receive services based on known criteria. To our knowledge, no studies in the long-term services and supports field have used this lesser known approach to forming a comparison group, nor have we seen any HCBS studies mentioning this approach.

The Research Methods Knowledge Base website (Trochim, 2006, Design, Quasi-Experimental Design) describes regression-discontinuity design as “an important and often misunderstood alternative to randomized experiments, because its distinguishing characteristic--assignment to treatment using a cutoff score on pretreatment variable--allows us to assign to the program those who need or deserve it most.” Thus, the regression-discontinuity design does not require assignment of potentially needy people to a no-program comparison group in order to evaluate program effectiveness.

REGRESSION DISCONTINUITY DESIGN

In this design, participants are assigned to treatment using a cutoff score on a measured variable. This allows the program to be assigned to people who need or deserve it most. (Trochim, 2006)

Regression discontinuity studies have taken advantage of many naturally occurring cases of assignment to treatment using a cutoff. Examples include students to remedial writing training if they scored lower than a cutoff on a measure of writing skills and villages to receive social welfare assistance if they scored lower than a cutoff on a measure of village development. (Shadish & Cook, 2009)

In regression discontinuity design, the choice of cutoff value is usually based on one of two factors: (1) solely on the basis of program resources that are available (e.g., if a program has the capability of handling 25 people and 70 people apply, one can choose a cutoff that distinguishes the 25 most needy persons from the rest); or (2) substantive grounds, such as an indication of severity of illness (Trochim, 2006). To interpret the results, one must know the nature of the assignment variable, who received the program, and the nature of the outcome measure.”

According to Shadish et al. (2011), regression discontinuity design, sometimes called a cutoff-based experiment or cut-off based assignment, is close behind preference to random assignment in estimating unbiased treatment effects. The theory of regression discontinuity design is that it yields an unbiased estimate, like randomized experiments, because the assignment variable is completely known and measured. In a regression discontinuity design, a program effect is suggested when a “jump” or “discontinuity” in the regression lines is observed at the cutoff point (Trochim 2006). This is because units become more similar as they approach the cutoff from either side.

The Coalition for Evidence-Based Policy describes how this design addresses the challenge of self-selection and motivation bias:

“Among comparison-group studies, regression-discontinuity designs are particularly well-suited for constructing program and comparison groups with similar motivation. Such designs compare a program group comprised of individuals just above the threshold for program eligibility, with a comparison group of individuals just below (e.g., families earning \$19,000 per year versus families earning \$21,000, in an employment program whose eligibility cutoff is \$20,000). Because program participation is not determined by self-selection, and the two groups are very similar in their eligibility score, there is reason to believe they are also similar in motivation.”

The most common implementation problems in studies using this design occur when assignment to condition does not adhere strictly to the cutoff and when persons manipulate their assignment scores to receive or avoid treatment (Shadish et al., 2011). However, the authors noted, new analytic methods have been developed for modeling nonlinearities in regression discontinuity designs and coping with violations of assignment by cutoff score.

As with matched comparison group designs, several studies in the research methods literature have compared results from randomized experiments and regression discontinuity designs. Shadish et al. (2011) recently reviewed these studies and found that, as expected, most analyses suggested that bias was least when restricting the

sample to participants closest to the cutoff. Unlike most of the studies comparing matched comparison groups to randomized experiments, results from four studies reviewed by Shadish et al. (2011) generally supported the hypothesis that regression discontinuity design produces causal estimates similar to those from randomized experiments. Some of the comparisons did not yield the same results, but the authors noted this may have been because the studies used different statistical methods to identify the regression discontinuity design effect estimate, with different estimates producing different results. Shadish et al. (2011) corrected problems found in past studies by randomly assigning 588 participants to be in a randomized experiment or a regression discontinuity design in which they were otherwise treated identically. The authors compared results for the two designs estimating both the same and different parameters, using three different methods of modeling nonlinearities. Results suggested that estimates from regression discontinuity designs approximated the results of randomized experiments reasonably well. They noted that, in cases when the assignment variable moderates the effect of treatment, results for people at the cutoff would not represent results for people at other points on the assignment variable.

Also, Shadish et al. (2011) raised the question of how to interpret results of comparisons between results from randomized field experiments and quasi-experimental designs. They found that neither the randomized experiment results nor the regression discontinuity design results would adequately represent the interaction between treatment and assignment variable. In this sense, the regression discontinuity design has the advantage in that a graphical display of the relation between assignment and outcome is likely to make the potential interaction more salient than it would be in a randomized experiment in which the researcher might not even think to test the interaction. Thus, the authors suggested that, in comparing randomized experiments and regression discontinuity design, the matter is less about one design being better or worse than the other across the board and more a matter of understanding the competing strengths and weaknesses of the two designs in representing the treatment effect in the presence of the interaction.

Further, Shadish et al.'s (2011) study questioned what it means to claim that estimates from randomized experiments are the gold standard in social research. This term can imply either that the randomized experiment is generally the best design for causal inference or that the failure of a non-randomized estimate to match the randomized estimate is cause for questioning the nonrandomized one. The authors noted that widespread agreement that the first claim is true has perhaps led to uncritical acceptance that the second claim necessarily follows. However, the authors noted, differences between the two estimates could be due to sampling error, differences in implementation, or differences in the parameters estimated. Thus, they suggested, past authors of studies comparing randomized experiments with nonrandomized designs may have overstated the case when they interpreted their results as suggesting that nonrandomized designs may not well approximate results from randomized

experiments. The authors recommended that randomized experiments are still preferable to regression discontinuity design, because they have more power and fewer assumptions. They posit that if researchers do need to use a regression discontinuity design, they can be reasonably confident that their results are “an accurate estimate of the effects of treatments” (Shadish et al., 2011, pg. 190).

Time Series / Longitudinal Models

An alternative type of quasi-experimental design is a time series, or historical, design, in which “the basis for contrast is the same participants before program implementation” (GAO, 1991, p. 52). Similarly, the Treasury Board of Canada (1998) noted that a comparison group could be either a non-randomized “constructed group,” which was not exposed to the program (or was exposed to a different level of the type of services), or a “reflexive group,” namely the experimental group itself before exposure to the program. A historical design is an extension of a basic pre-program/post-program design that incorporates many measurements over time.

According to the Treasury Board of Canada (1998), an advantage of historical designs is that they are useful for analyzing programs that have time-dependent effects. “The authors state, “The longitudinal aspect of these designs can be used to address several questions: Is the observed effect lasting or does it diminish over time? Is it immediate or delayed, or is it seasonal in nature? Some type of historical design is called for whenever these types of questions are important” (pg. 49).

A frequently mentioned limitation in these studies was limitations in the available data. Another limitation in some studies was that other competing explanations may exist that were not accounted for in the study. The Treasury Board of Canada (1998) states, “Other threats remain--those related to history for example--because time series designs cannot eliminate the possibility that something other than the program caused a change between measurements taken before and after exposure” (p. 48). In addition, “Numerous data problems may exist with historical designs. In particular, the time series available are often much shorter than those usually recommended for statistical analysis (there are not enough data points); different data collection methods may have been used over the period being considered; and the indicators used may have changed over time.” Moffitt (1991, p. 61) discussed the challenge of data consistency in time series designs: “When measurements are made repeatedly, definitions and procedures may change. Care must be taken to see that time series are free of definitional and measurement changes, because these can be mistaken for program effects.”

However, recommendations have been made to strengthen time series designs. A more complete set of measures over time “allows the evaluator to eliminate many of these threats by analyzing pre- and post-program trends” (Treasury Board of Canada, 1998, p. 47). Another recommendation is to add one or more comparison groups (Treasury

Board of Canada, 1998). Because both the experimental and comparison groups should experience the same external factors, an observed change being caused by anything but the program is unlikely. "As with any design using a non-equivalent comparison group, however, the groups must be similar enough in terms of the characteristics of interest" (Treasury Board of Canada, 1998, p. 48) "With adequate time series data, this design can be fairly rigorous, ruling out many threats to internal validity, particularly maturation and testing effects" (Treasury Board of Canada, 1998, p.48).

Survival Analysis

Survival analysis is a statistical approach that evaluates whether an event occurs, when it occurs, and what factors contribute to it occurring (Singer & Willett, 1991). It provides a hazard rate (what is the distribution of risk of the outcome over time?) as well as a survivor function (what is the overall chance of an outcome occurring?). Also, the method is able to identify time periods on a continuum when individuals are most at risk of an outcome and compare patterns of risk for different subgroups. Survival models relate the time (survival time) that passes before some event occurs to one or more covariates (predictor or confounding variables) that may be associated with the survival time.

This methodology is versatile, in that it can use prospective or retrospective data, measure the outcome in either continuous or discrete intervals and be applied to various panel study designs (Singer & Willett, 1991). The only requirement is that data is collected over time, at intervals that are meaningful to the outcome and covariates being studied and precisely documents when the outcome event occurs.

Several recent studies have used various types of survival models to assess the impacts of HCBS on time to nursing home admission or hospitalization. One such model is the Cox proportional hazard model introduced by Cox in 1972. The Cox proportional hazards model is the most widely used method of survival analysis to study an individual's survival time to a particular outcome (New York State Office for the Aging, 2010). Many of the studies we reviewed used this method.

- ▶ The Cox proportional hazard model was used in the Kansas Community Tenure Study (Macmillan et al., 2007), which has been recognized nationally for its methods. This study tracked a cohort of NH applicants who received a CARE assessment and were diverted from NHs for five years to identify duration of community tenure.
- ▶ The New York State Office for the Aging, 2010 used the Cox proportional hazards model to study time to nursing home placement for participants in Aging Network Services in New York.
- ▶ As part of AoA's POMPS, Brock et al. (2007) examined the effect of the receipt of OAA services on the potential delay in NH placement among OAA service clients

age 60 and older. The authors conducted time-to-event analyses (time to NH placement) using the Cox proportional hazard model.

- ▶ In the Advanced POMP, Westat conducted time-to-event analyses (time to NH placement) using Cox proportional hazards regression models applied to client data from the participating states (Karuza et al., 2011).
- ▶ Miller et al. (1998) used a Cox proportional hazards model in a longitudinal, prospective study on the effect of health care system characteristics on time to nursing home admission for persons with Alzheimer’s disease. The authors noted that the Cox model can allow HCBS researchers to examine the influence of predictor values most proximal to the event of nursing home admission. The study used data from 28 states from a longitudinal survey.
- ▶ Xu et al. (2010) used the Cox proportional hazards model in a longitudinal study with a single cohort on interval from the initial HCBS placement until each hospital admission, by volume of Indiana Medicaid waiver HCBS. The authors noted that a strength of this method is that the methodology examines whether specific components of the HCBS program are associated with hospitalization.

COX PROPORTIONAL HAZARDS MODEL

This is the most widely used method of survival analysis to study an individual’s survival time to a particular outcome. Past studies have used this method to estimate:

- ▶ *Duration of community tenure (Macmillan et al., 2007)*
- ▶ *Time to nursing home placement (New York Office for the Aging, 2010; Brock, 2007; Karuza et al., 2011; Miller et al., 1998)*
- ▶ *Time to each hospital admission (Xu et al., 2009)*

Survival models are able to take into account the effect of time-varying covariates (e.g., deteriorating cognitive functioning) as well as censored data (i.e., data on study participants who have not experienced the outcome by the time study participation ends) (Singer & Willett, 1991). Additionally, the survival model can analyze an event as a risk factor for a subsequent event (e.g., if someone has two ER visits, are they at higher risk for the second ER visit because of the first). Each study participant has their own pattern of experiences. However, caution must be used, as pooled repeat spells can create bias.

As noted by Alecxih, Lutzky and Corea (1996), the effect of unique state factors--such as instituting certificate of need requirements or policies to promote HCBS, can be estimated by using a pooled time-series analysis technique. This methodology explains

changes in the dependent variable within each state (e.g., state changes in the number of HCBS care clients) by within-state changes or national regulatory changes. At the same time, the methodology holds constant all the many factors that vary substantially across states, but remain relatively fixed over time (e.g., geographic characteristics, the structure of the economy, racial and ethnic composition of the population). Pooled time-series analysis has two major advantages over analysis of time-series data for a single state. First, 50 times as many observations are available to provide information on the effects of the independent variables. Second, each state serves essentially as a comparison state for all other states, allowing researchers to more definitively assess the extent to which changes observed in one state after a change in its programs or policies are unique to that state or are also observed in other states that had no program or policy change.

DISCRETE TIME SURVIVAL ANALYSIS/POOLED LOGISTIC REGRESSION

Studies have used this approach to measure:

- ▶ *Odds of six outcomes (ER use, hospitalization, caregiver burden, death, NF use, and permanent NH placement), by dates of major policy and budget changes in Michigan (D'Souza et al., 2009)*
- ▶ *Risk of permanent NH relocation, by state, county, and person-level characteristics that change over time (Muramatsu et al., 2008)*
- ▶ *Risk of first long-term NH admission, by states' spending on HCBS (Muramatsu et al., 2007)*

Several studies used **discrete time survival analysis**. D'Souza et al. (2009) noted that this method is procedurally equivalent to pooled logistic regression.

- ▶ D'Souza et al. (2009) conducted a discrete time survival analysis of adjusted odds of six outcomes (emergency room use, hospitalization, caregiver burden, death, NH use, and permanent NH placement), controlling for demographics, functional status, and cognitive status. Using dates of major policy and budget changes in Michigan, the authors defined four distinct time periods to examine trends and outcomes. A longitudinal sampling scheme with adequate frequency provided the ability to analyze multiple outcomes over time while controlling for many covariates.
- ▶ Muramatsu et al. (2008) performed a discrete time survival analysis of the risk of permanent NH relocation (NH death), to examine how it is associated with state spending on HCBS, taking into consideration the timing of the NH relocation and state, county, and person-level characteristics that change over time.

- ▶ Another study by Muramatsu and colleagues (2007) was a discrete time survival analysis of first long-term NH admissions that occurred between 1995 and 2002, using Health and Retirement Study panel data. The study examined the effects of states' spending on HCBS on risk of first long-term NH admissions.

Interrupted and Short Interrupted Time Series

The GAO (1991) stated that the persuasiveness of the argument about the effect of a program on participants can be strengthened by using the interrupted series subtype of time series design. Also, administering these designs is “relatively easy.”

An interrupted time-series analysis compares trends in repeated measures of an outcome for a group before and after an intervention or policy is introduced, to learn if the desired change in outcome has occurred (GAO, 2009).

An interrupted time series design has about 100 observations on one unit, with treatment introduced at some known time (Shadish & Cook, 2009). Similar to regression discontinuity design, an effect is measured as a change in the slope or intercept of the time series at the point of treatment introduction.

Because researchers rarely have the opportunity to gather so many data points over time, recent years have seen more interest and progress in the design and analysis of short interrupted time series, having for example 10 to 50 time points (Shadish & Cook, 2009). Practice has moved toward interrupted time series designs with a control series, either created from units not participating in the intervention or from nonequivalent dependent variables – those that the intervention should not affect but that other alternative causes should affect.

During the 2000's, new analytic models have been developed in the use of pooled time series and multilevel models that can often estimate treatment effects when many independent short-time series assessing the same intervention on the same outcome are available (Shadish et al. 2009). Examples of the use of these designs include 20-40 schools or students that are each measured 4-8 times.

Exhaustive Alternative Causal Explanation Elimination Design

The Treasury Board of Canada (1998) recommended including a causal model as part of a program evaluation design. They state:

“An alternative way of addressing the issues of causal inference involves the use of a causal model: an equation that describes the marginal impact of a set of selected independent variables on a dependent [outcome] variable. While quasi-experimental designs focus on comparisons between program recipients and one or more control groups, causal models focus on the variables to be included in the model--both endogenous (intrinsic to the program) and exogenous (outside the program)--and their postulated relationships. In quasi-experimental designs, the program is of central interest; for causal models, the program is only one of several independent variables that are expected to affect the dependent variable” (pg. 56).

An exhaustive alternative causal explanation design works in situations where an outcome is observed, but whether the outcome was caused by the intervention or some other factor is unclear (Duignan, 2005-2009). Using this design involves listing all possible alternative explanations and then systematically eliminating each of them as having caused the improvement. This provides a reasonable basis for believing that the intervention is the cause of the improvement. This is sometimes described more as a “forensic-type” method than the quasi-experimental approaches described above.

Some of the HCBS studies that we reviewed used a **cross-sectional statistical model** to develop causal explanations for factors affecting HCBS outcomes.

- ▶ Chen and Thompson (2010) used a structural equation model to test a theoretical framework to predict the likelihood of older adults residing in the community.
- ▶ Miller (2011) combined data from many sources to conduct a state-level analysis of data from 2000 to 2007, using multivariate fixed effects models to examine the association between level of HCBS investment, other state and program characteristics, and state-level rates of NH use for working-age and older adults.
- ▶ Muramatsu and Campbell (2002) used a cross-sectional, hierarchical model. The study involved a two-level multinomial logistic regression analysis to examine effects of state expenditures on HCBS and the use of formal personal assistance and informal caregiving.

Muramatsu and Campbell (2002) noted that multi-level models are a set of related analytic approaches for exploring links between macro and micro levels of social

phenomena. The authors described several advantages of these models, also called contextual models, hierarchical linear models, or random coefficient models:

- ▶ First, they address the non-independence of observations engendered by the nesting of subjects within state.
- ▶ Second, they provide a useful means of linking macro level data to individual outcomes.
- ▶ Finally, they explicitly recognize the fact that the states represented in the sample are a subset of the 50 states and DC to which the study wishes to generalize. The authors used a new approach by putting a relatively well-researched individual-level model of use of personal assistance into a macro-level (state-level) context and by using a multi-level multinomial logistic regression analysis.

The Treasury Board of Canada (1998, p. 57) noted, “Causal models are best suited to situations where sufficient empirical evidence has confirmed, before the evaluation, the existence of a relationship between the variables of interest... In addition, statistical analyses can be used to control for selection or history biases....The main strength of simulation is that it allows the evaluator to estimate incremental effects in complex and uncertain situations. The main limitation of the technique is that it requires a sophisticated understanding of the dynamics of the program, as well as some skill in building quantitative models” (p. 97). They added, “Statistical models are often vital in identifying incremental effects.”

The Treasury Board of Canada (1998, p. 106) recommended, “Statistical models are versatile and, if properly constructed, will provide very useful estimates of program results. On the other hand, statistical models must be appropriately specified and validated to provide reliable results, which is not always as straightforward a task as it may at first appear. One weakness of statistical models is that the evaluator may not be able to draw inferences from them. For example, if the model covers only certain age groups or individuals in certain geographic areas, the evaluator may not be able to infer from his or her results the program's probable effects in other geographic areas or on other age groups.”

Most federal programs are larger programs, which normally produce large data sets and can therefore rely on regression-based ‘linear models’ to identify effects (Treasury Board of Canada, 1998, p. 105). “Regression analysis often is used “as the final confirmation and measurement of a causal relationship between the program and observed effects. In fact, it is important that the regression model be based on *a priori* reasoning about causality”. One way to determine if a model is probably robust is to “specify and calibrate the model using only half the data available and then see whether the model is a good predictor of outcomes shown in the other half of the data. If this is the case, then the model is probably robust.”

“In practice, most evaluators will want to use both causal and comparative approaches to determine program results” (Treasury Board of Canada, 1998). Quasi-experimental designs can be used to construct and manipulate control groups and, thereby, to make causal inferences about program results. Causal models can be used to estimate the marginal impact of variables that affect program success.” [refers to Bickman 1987 and Trochim 1986] (p. 56) “Regardless of the design chosen, it is desirable that the causal model approach be incorporated into the evaluation design, to the extent possible, to support the credibility of the findings.” (p. 59)

Findings from Early HCBS Evaluations

Many early evaluations of HCBS programs centered on the question, *Does HCBS save money?* For example, a frequently referenced early study is the National Long-Term Care Channeling Demonstration (“Channeling”). A recent fact sheet prepared for AoA by members of the Lewin team summarized findings and lessons learned from this demonstration, based on our review of many Channeling-related studies (The Lewin Group, 2012). This large-scale demonstration was a randomized experiment that tested the feasibility and cost-effectiveness of a community-based LTC delivery model integrating health and social services. The concept involved “channeling” people with LTC needs, i.e., matching them with appropriate LTC services (ASPE, 1991). Results from the Channeling demonstration did not show any significant differences between treatment and control groups in hospital use, nursing home (NH) use, or longevity.

Several early reviews of the literature on the impacts of HCBS, conducted from 1985 through 2006, found inconclusive evidence that it reduced nursing home utilization or saved costs (Hughes, 1985; Hedrick & Inui, 1986; Kemper, Applebaum, & Harrigan 1987; Weissert & Hedrick 1994; Doty 2000; Grabowski 2006) (see **Text Box**). This suggests the need to look at studies beyond this time period to understand the most recent available evidence. A frequently mentioned conclusion in these studies was that efforts to expand community-based LTC would need to be supported on the basis of other benefits they provided (e.g., meeting individual preference and improved life satisfaction), rather than on grounds of cost-effectiveness (Weisserts & Hedrick, 1994; Kemper, Applebaum, & Harrigan, 1987; Kemper, 1988; Thornton, Dustan, & Kemper, 1988). Nonetheless, policymakers were reluctant to fund HCBS for years after studies prematurely suggested that HCBS might not be cost-effective. Only in the past few years have studies using data from a longer time period and more sophisticated analytical models demonstrated the ultimate cost effectiveness of shifting funding from institutional care to HCBS, as our several recent reviews of the literature show.

Findings And Lessons Learned From Early HCBS Literature Reviews (1985-2006)

Several early reviews of the literature, conducted from 1985 through 2006, found inconclusive results and suggested the need to examine the multi-level factors affecting HCBS outcomes.

Hughes (1985) found “contradictory findings” in the community-based LTC literature. She suggested that “increased preoperational specification of underlying theory, increased sophistication in targeting services to high-risk groups, use of multivariate analysis, and the development of more relevant outcomes measures will improve the quality of future study findings, thereby contributing to theory and model building in this field.”

Hedrick & Inui (1986) found that, across studies, home care services either had no effect on hospitalization or tended to increase the number of hospital days. The cost of care either was not affected or increased. The author contended, “The critical need at present is for better-designed studies to test the effects of different types of home care, targeted at various types of patients, on the outcomes assessed in the existing studies, as well as other important outcomes such as family finances, quality of life, and quality of care.”

Kemper, Applebaum, & Harrigan (1987) found evidence that expanding publicly financed community services would likely increase costs. They recommended, “Policymakers should move beyond asking whether expanding community care will reduce costs to addressing how much community care society is willing to pay for, who should receive it, and how it can be delivered efficiently.”

Weissert & Hedrick (1994) found an absence of demonstrated cost-effectiveness of community-based LTC. They suggested, “It may be time to lay aside studies showing that home care is not cost-effective and get started on ways to make it become so.” (Weissert, 1990)

Doty (2000) found that in principle, personal care and waiver services could provide an alternative to NH placement, but limitations on the effectiveness of these programs in deterring NH admissions were experienced in practice. A major finding from this review was that, in contrast to LTSS for elderly persons and people with disabilities, state systems for people with intellectual and developmental disabilities had “evolved far beyond the traditional ‘cost-effective alternatives to institutional care’ paradigm. In that system, a totally different perspective was evident, in which “States do not make those desiring services demonstrate or contend that they will otherwise go into institutions; the states are on record as desiring that people are spared that debilitating experience.” Instead, states are faced with creating priorities for people

Findings And Lessons Learned From Early HCBS Literature Reviews (1985-2006)

waiting for community services, based on factors such as immediacy of need, severity of disability, and length of wait.

Grabowski (2006) conducted a review and reported that noninstitutional LTC services were generally associated with increased costs, but greater client and caregiver welfare. The review found that “most recent evaluations have relied on potentially confounded research designs, which leaves open the question of whether the findings relate to the programs or biased selection across the treatment and comparison groups” (pg. 3).

A frequently mentioned recommendation in the early HCBS literature was that, to demonstrate cost savings, HCBS would need to be better targeted to individuals most likely to benefit from the services (Weissert & Hedrick, 1994; Greene, Ondrich, & Laditka, 1988). On the other hand, Kemper, Applebaum, and Harrigan (1987), 25 years ago, contended that the important issue was not efficiency of targeting, but rather an issue of equity: “Who deserved the limited community care that society can pay for?” They recommended that the debate about HCBS “should move beyond asking whether expanded public financing of community care will reduce costs to addressing how much community care society is willing to pay for, who should receive it, and how a more efficient long-term care system can be designed” (Kemper, Applebaum, & Harrigan, 1987, p. 98). This was based on their review of previous community-based care demonstrations to examine “What have we learned?” Similarly, in 1988, Kane recommended the need for a “new paradigm” to replace the quest for cost-effective “alternatives” to nursing homes, contending that this quest may be counterproductive. A reason is that community-based LTC services include a wide array of service types, and research is needed to examine the effective design and targeting of each kind of community service.

Theoretical Considerations

Previous studies have used various models, or theoretical frameworks to guide research related to the effects of HCBS on community tenure. Several examples are described below, including a recent model known as an “outcomes model”, which establishes all steps necessary to achieve high-level outcomes for the program. The indicators are then monitored and mapped onto the visual model, along with evaluation questions.

Models and Theoretical Frameworks

A frequently used model is the Andersen model (Andersen, 1995, p. 2-3, cited in Chapin et al., 2002). The Andersen model, widely used to understand patterns of health service use of older adults, was selected for use in the Kansas Community Tenure Study

because it organizes factors leading to service use, thus matching the study's structure of examining factors predicting NH admission and mobilization of community supports (Chapin et al., 2002). In addition, Miller et al. (1998) used Andersen's Behavioral Model of Health Services Utilization (Andersen & Newman, 1973) as the conceptual framework for selecting and analyzing model variables in the study. In the version employed by Chapin et al. (2002), the model comprises six categories related to factors affecting the use of HCBS and NH services:

- ▶ Predisposing factors: factors that affect "the status of a person in the community, his or her ability to cope with presenting problems and commanding resources to deal with these problems"
- ▶ Enabling factors: "Health personnel and facilities must be available where

people live and work. Then, people must have the means and know-how to get those services....income, health insurance, a regular source of care"

- ▶ Need factors: "Perceived need is largely a social phenomenon...Evaluated need represents professional judgment about people's health status and their need for medical care"

Building on Andersen's model, Chen and Adams Thompson (2010) used the Health Behavioral Model (HBM) to construct an HCBS model with a longitudinal perspective, to predict and explain when use of HCBS facilitated remaining in communities. Their home and community based services (HCBS) model included the following categories and sub-categories:

- ▶ Personal factors
 - Predisposing factors
 - Social enabling and financial factors
 - Disability and perceived unmet need factors
- ▶ Service use
 - HCBS use
- ▶ Remaining in communities

D'Souza et al. (2009), in a study of the effects of financial strain on HCBS use and outcomes in Michigan, tested a conceptual framework for how budget environments affect resources, which may affect program staffing and services, ultimately impacting participant outcomes. Elements of the framework included:

- ▶ Change in medical/ functional eligibility, leading to increase in need for formal care
- ▶ Inflation, budget reductions, and program intake closure, leading to strain on program resources
- ▶ Decrease in direct services funding
 - Purchased services
- ▶ Decrease in administrative funding
 - Staffing
 - Monitoring
 - Service coordination
 - Outside funding sources

- ▶ Other factors
 - Agency-specific effects
 - Medical care environment
- ▶ Decline in hours of formal care per participant
- ▶ Decline in participant health
- ▶ Adverse outcomes

The research design for the evaluation of the Money Follows the Person (MFP) grant program (Brown et al., 2008) uses a model for MFP transition programs that includes the following outcomes and action steps:

- ▶ Outreach program: identify eligible enrollees, provide informed consent
- ▶ Institutionalized enrolled: characteristics affect likelihood of transition (age, level of need, types of conditions, type of institutional care/setting, length of institutionalization), receive transition services (housing assistance, service planning)
- ▶ Enrollees transitioned receive qualified HCBS, demonstration services, supplemental services
- ▶ Generate enhanced funds for rebalancing program
- ▶ Enrollee outcomes: increase number transitioned, increase length of community residence, decrease re-institutionalization, reduce Medicaid and Medicare expenditures, receive high quality of care, increase quality of life
- ▶ MFP rebalance initiative: Medicaid enrollees transition from institutional care to the community and receive HCBS, enhanced funds flow to state to reduce institutional care, support transitions, increase HCBS, strengthen infrastructure
- ▶ Institutional care: decrease number and types of beds, change budget allocation between institutional care and HCBS
- ▶ HCBS: Change mix of services, increase number and type of waiver programs
- ▶ System-level outcomes: Increase proportion of institutionalized Medicaid enrollees transitioned to community, increase average age/acuity level of entry to institutional care, increase absolute and relative total use of and spending on HCBS
- ▶ Decrease absolute and relative use of and spending on institutional care
- ▶ Decrease LTC spending per LTC recipient
- ▶ Increase ratio of HCBS expenditures to total LTC expenditures

Visual Outcomes Model

Generally, models used for program evaluation design connect inputs (resources invested in the program); program activities (what the program does and who it reaches); short-term, medium, and long-term outcomes; and influential factors in the environment (GAO, 2012).

A new, less well known and efficient way of building a model that can be used for evaluation planning and other purposes is to use a visual “outcomes model” of the project, program, or organization (Duignan, 2009). An outcomes model identifies all steps that are believed to be needed to achieve high-level outcomes for the program or organization. The indicators to be monitored can then be mapped onto the model, along with the evaluation questions that need to be answered. This approach, developed by

New Zealand evaluation expert Duignan, is called Duignan's Visual Monitoring and Evaluation Planning and DoView Results Roadmap Evaluation Planning. It provides a transparent model that can be used for other purposes, such as strategic planning and evidence-based practices, as well as impact evaluation.

OUTCOMES MODEL

An outcomes model can be used when implementing similar projects in a number of different settings. This is more efficient than all places "reinventing the wheel" when it comes to planning, implementing, monitoring, and evaluating their particular program. (Duignan, 2009)

Once the outcomes model is drawn, the links between steps and outcomes within the model can be examined to see what evidence exists for the link (Duignan, 2008a).

Any step or outcome can have one or more of the following features; it can be: "influencable" by a program, controllable by a program, measurable, attributable to a program, and/or accountable. In addition, outcomes models are distinguished by the following features (Duignan, 2008a):

- ▶ The steps and outcomes are not limited to those that are controllable or attributable to a particular program. They do not have to only include steps and outcomes that are measurable.
- ▶ They have no artificial limit on their size. The most common mistake in this regard, according to Duignan (2008a), is to attempt to fit a model onto a single printed page. This creates serious problems, because in all significant policy areas, drawing a comprehensive causal map will require more space than just one page.
- ▶ They allow for the possibility that any step or outcome can be causally connected to any other step or outcome in the model. The current standard method of visualizing causal links (a drawn line and arrow) has major disadvantages when it comes to visualizing models that have complex patterns of causality, Duignan observed. Often causal links between steps and outcomes are omitted from a diagram because the person drawing the diagram cannot see how they can fit an additional causal line into the diagram. Thus, models often end up being drawn in a "siloe" manner, such that any lower-level step is only allowed to contribute to a single higher-level outcome. Duignan noted that this indicates the need for a way of representing causal links between steps and outcomes in situations where they cannot be visualized as line and arrow links.
- ▶ They are not compromised by arbitrary constraints that make them harder to interpret. In particular, Duignan noted, evaluation studies sometimes require that models consist of a single layer of outputs, above them a single layer of intermediate outcomes, and above them a single layer of final outcomes. Duignan stated, "The

use of this constraint is reinforced by the unexamined acceptance of the one page limit on models.”

- ▶ They need to be able to be used in all parts of the decision-making process. While such a model could theoretically be developed using any software, a software called DoView facilitates this by making an outcomes model easily portable across different media, to be used in meetings with stakeholders and for other purposes. It is the only software we discovered that is designed for making large models with numerous steps showing very complex relationships crossing multiple pages. The user can add to each element in the model: notes, links to documents and websites, pictures, and questions. The model can be easily converted to poster size, turned into a web model, or projected on a screen.
- ▶ They can be divided up into an interconnected set of sub-modules. Each sub-module contains a set of conceptually related steps, for example, many types of programs can set out steps and outcomes at a national, regional, organizational, and individual level.

The findings included throughout this report could be used to develop a generic model for HCBS outcomes, “so that the evaluation is not approached as a novel exercise, with different evaluation plans laid out in very different formats” (Duignan, 2008b). Also, this model would make it easier for those planning evaluations to ensure that they have included all of the important elements needed in an evaluation plan. The model could be developed through discussions among AoA, stakeholders, and the Lewin study design team, using software to facilitate representation of the complex relationships across levels and outcomes. Some of these items can be measured using existing data sets, while some items would require new data collection efforts (e.g., surveys of older adults to ascertain their awareness of unmet needs or perceptions of functional abilities).

Findings and Lessons Learned from Past HCBS Studies

This chapter synthesizes key findings from our review of past studies of the impacts of OAA and non-OAA HCBS programs and services. The complex, fragmented, dynamic and unpredictable long-term care delivery system does not lend itself to traditional views of cause-and-effect that assume a linear relationship resulting in an additive model in which the output of a system is proportional to its inputs. Overlay the disjointed long-term care system with myriad service users, and we must consider a linked system filled with attributes that can be seen as both cause and effect, as well as additive and summative.

We decided to focus on variables that demonstrated significance with one of the four key outcomes of interest in this review: 1) HCBS service use, 2) health care use, 3) community tenure/NH use, and 4) cost impacts. These variables are both statistically

significant independent variables and control variables. It is presumed that the final study design will included a broad mix of variables. To best organize these variables, we used the Andersen Model, a widely-used framework among the studies analyzed.

Andersen Model

For this literature review, we chose to use the Andersen Health Behavioral Conceptual Model to frame our literature analysis. As mentioned previously, this model has been widely used to determine variables tested in health care studies (Andersen, 1995; Miller and Weissert, 2000). This model highlights predisposing, enabling, and need characteristics as variables that contribute to use of services, including HCBS, health care, and nursing home use. The exhibit below illustrates the way these variables relate to one another. Predisposing characteristics include demographics, social support, and health beliefs. Enabling characteristics include familial, facility, market, and policy resources. Finally, need includes perception of need, cognitive and physical function, and disease. The use of other services are also predictors of one another; for example, prior hospital use is a predictor of NH admission (D’Souza, 2009; Gaugler et al., 2007; Goodwin et al., 2011; Miller & Weissert, 2000; Sands et al., 2008; Xu et al., 2010). This literature review presents findings from numerous studies on how the aforementioned characteristics, or variables, contribute to use of services. The purpose of this section is to review the most important variables to include in a study of this kind.

Key Variables Table

Table 2 shows the key variables identified through the literature review and their association with the four outcomes of interest. A full table with sources can be found in Appendix A-B.

Table 2 : Key Variables

Independent Variables Included in Outcome Analysis	HCBS Use	Health Care Use	Community Tenure/NH Use	Cost Impacts
<i>Predisposing Variables</i>				
Age	√	√	√	
Education		√	√	
Gender	√	√	√	
Race/Ethnicity	√	√	√	
Geographic Location	√	√	√	
Living Alone	√	√	√	

Independent Variables Included in Outcome Analysis	HCBS Use	Health Care Use	Community Tenure/NH Use	Cost Impacts
<i>Marital Status</i>	√	√	√	
<i>Informal Caregiver Availability</i>	√	√	√	
<i>Having Children</i>	√		√	
<i>Social Support</i>			√	
Enabling Variables				
<i>Income</i>	√	√	√	
<i>Home Ownership</i>			√	
<i>Payment Method</i>	√		√	
<i>Caregiver or Spouse Age</i>			√	
<i>Support for Caregiver</i>			√	
<i>Caregiver Burden</i>			√	
<i>NH Bed Supply</i>			√	
<i>Number of Home Health Agencies</i>			√	
<i>Medicaid HCBS Spending</i>		√	√	
<i>State HCBS Spending</i>	√	√	√	
<i>Pre-admission screenings</i>			√	
Need Variables				
<i>Alzheimer's/Cognitive</i>	√	√	√	
<i>Comorbidities/Chronic Medical</i>	√	√	√	
<i>Psychiatric Issues/Problematic</i>			√	
<i>Worse ADL/IADL Performance in</i>			√	
<i>ADL Limitations</i>	√		√	
<i>IADL Limitations</i>	√		√	
<i>Self-health Ratings</i>			√	
<i>Perceived Unmet Need</i>	√	√	√	
Service Use Variables				
<i>Hospital Admissions/Use</i>	√	√	√	
<i>HCBS Use</i>	√	√	√	√
<i>NH Use</i>			√	√

Independent Variables Included in Outcome Analysis	HCBS Use	Health Care Use	Community Tenure/NH Use	Cost Impacts
<i>Paid Helpers</i>			√	
<i>Case Management</i>			√	
<i>Medicaid Waiver</i>			√	
<i>Timing of Care</i>			√	
<i>Volume of Services</i>		√	√	√
<i>Low-intensity HCBS</i>			√	√
<i>Combination of Services</i>			√	√
<i>Use of OAA III-B</i>				√
<i>Use of OAA III-C</i>	√		√	√
<i>Use of OAA III-E/Respite</i>			√	√

Predisposing Variables

Age

Many predisposing characteristics have been identified as contributing to **HCBS use**. Prior research has highlighted the effects of demographic variables on using HCBS. Some studies find that age is a strong predictor of service utilization (Liu, McBride, and Coughlin, 1994; Mitchell and Krout, 1998). In a study by Alkema et al. (2006), researchers found that age was only a significant predictor for one type of referral to service, suggesting that it may be more appropriate as a proxy variable, representing increasing needs due to disability and chronic care.

Similarly, increased age is one of the strongest predictors of **nursing home admission** (Bharucha et al., 2004; Cai, Salmon, & Rodgers, 2009; Chen & Thompson, 2010; Gaugler et al., 2007; Miller and Weissert, 2000; Muramatsu et al., 2007; Ness, Ahmed, & Aronow, 2004). Friedman et al. (2005) found that, for Programs for All-inclusive Care for the Elderly (PACE) participants enrolled from the community, those of greater age were at an increased risk of NH admission. Older age has also been associated with an increased risk of LTC placement after hospitalization (Goodwin et al., 2011). For those without dementia in Florida, Andel, Hyer, and Slack (2007) found that older age was associated with increased risk of NH admission. However, it is important to note that some studies found no association between age and NH admission (MacMillan, 2007; Sands, 2008).

Gender

Gender is a statistically significant predictor of **HCBS use**. One study found that being female, along with having lower educational attainment, is associated with using home safety services. Women were also more likely to use home modification and transportation services (Alkema et al., 2006). Laditka, Laditka, and Davis (2006) compared HCBS use by older African American, Hispanic, and Non-Hispanic White women and men. They found that, in comparison to non-Hispanic white women, non-Hispanic white men were *less* likely to use Personal Care Aides, Senior Centers, and Transportation. Additionally, in comparison to the same group, they use services less intensively.

In Miller and Weissert's (2000) meta-analysis of studies regarding adverse outcomes for older adults, they found that females were less likely to be **hospitalized**.

Female gender is another variable that has resulted in mixed findings for **NH admission**. Gaugler et al. (2007) stated that women appear less likely to enter a NH than men. This is supported by Cai, Salmon, and Rodger's (2009) finding that female gender was associated with less risk of NH admission. Conversely, Goodwin et al. (2011) report that female gender is a risk factor for LTC placement after hospitalization. Ness, Ahmed, and Aronow, in their study of 23 years of NH demographic and payment data, found that women were at an increased risk of NH placement from 1977-1999. Karuza and Wu (2011) discuss these inconsistent findings, pointing out that Miller and Weissert (2000) found that women were at less risk, but of the 47 articles using gender as a variable, 40 of them did not show significant findings. Noël-Miller (2010) analyzed the Health & Retirement Study – following couples who were living in the community in 1998 over 8 years. She found that widowed men's risk of nursing home entry doubled; however, risk was unchanged for women after spousal death.

Race and Ethnicity

Race and ethnicity is also a predictor of **HCBS use**. This variable has mixed findings. One study noted that among predisposing characteristics, age and race/ethnicity have been found to be the strongest predictors of service utilization (Liu, Mcbridge, & Coughlin, 1994). Mitchell and Krout's findings (1998) indicate that being African American is associated with increased discretionary service use. These services are considered to be more based on the choice of the eligible adult/caregiver, whereas less discretionary services are considered medical services, such as hospitalization, that are not the choice of the consumer. Sands (2008) found that HCBS users were more likely to be white than nursing home patients, suggesting that white older adults were more likely to remain in the community. Goins, Tincher, and Spencer (2003) examined awareness and utilization of HCBS by rural American Indian and White older adults who have co-

morbid diabetes. They found that American Indian respondents were more likely to both be aware of and use HCBS programs in comparison to white respondents.

Wallace et al. (1999) found that Black women in their study had greater health needs, however they use less formal services. Another study by Laditka, Laditka, & Drake (2006) found that African American women had higher odds, in comparison to non-Hispanic white women, of using Personal Care Aides, Transportation, Adult Day Centers, and Information & Referral. They conducted an intensity analysis and found that African American women used services more intensively than non-Hispanic white women. Casado, van Vulpen, and Davis (2010) found that black race/ethnicity was associated with having unmet HCBS needs.

Haller and Gessert (2007) examined the factors associated with **medical care utilization** at end of life in NH residents who had severe cognitive impairments. They found that non-white race was associated with high medical care utilization within 90 days prior to death.

Many studies have found that being white increases the risk of being **institutionalized** (Andel, Hyer, & Slack, 2007; Miller & Weissert, 2000; Gaugler et al., 2007, Cai, Salmon, & Rodgers, 2009). Stevens et al. (2004) found that African American care recipients were placed in NH significantly slower than White care recipients. However, other studies have found that being African American or Hispanic is significantly associated with an increased risk of NH admission (Muramatsu et al., 2007; Ness, Ahmed, & Aronow, 2004). Zhanlian et al. (2011) found that the number of NH residents of color has increased more rapidly than their overall demographic increases. They suggest that this may relate to unequal access to HCBS alternatives to NH admission.

Education

Alkema et al. (2008) found that level of education was significantly associated with **use of any HCBS** category – when controlling for other factors, every year increase in education resulted in 14% less likelihood of using any HCBS.⁵ Li (2006) found that less educational attainment within rural areas was a barrier to accessing homemaker services.

Some studies have shown that higher education is significantly associated with reduced **nursing home admission** (Muramatsu et al., 2007; Miller, 1998). However, Miller and

⁵ The authors did not anticipate this finding, given a lack of research on educational attainment's effect on service use. They posit that, given the fact that socioeconomic status is a proxy for education, lower income individuals may not have considered using these services (e.g., home modifications) before. But upon hearing of their benefit and potential affordability, they were more open to their use.

Weissert (2000) found that education did not appear to be a significant predictor of institutionalization.

Geographic Location

Geographic location is an important variable, especially with the increase in nonmetropolitan residents who are older adults⁶. Living in a rural area has been associated with **service use** (McAuley, Spector, Van Nostrand, & Shaffer, 2004; Mitchell & Krout, 1998). McAuley et al. (2004) found that using Medicare home health was significantly greater for residents in the most rural counties of their study, no matter what the individual's Medicaid coverage was. This was the same for Medicaid-covered residents in nonmetropolitan areas. Mitchell and Krout (1998) found that living in a rural or in a small town was associated with increased use of the most discretionary services. Another study by Sun (2011) reported that rural older adults in Alabama were *less* likely to use HCBS than their urban counterparts.

Older adults with cognitive impairments living in an urban location had an increased risk of high **medical care utilization** within 90 days prior to death (Haller & Gessert, 2007).

In an analysis of the Longitudinal Study on Aging (1984-1990), Coward, Home, and Peek (1994) found that older adults with urinary incontinence, who lived in less urbanized and thinly populated nonmetropolitan counties, were more likely to have **NH admission** than older adults with urinary incontinence in other residential areas.

Living Alone

Living alone has also been associated with more **service use** (Xu et al., 2010; Alkema et al., 2006; Wallace et al., 1999). Older adults living alone had a higher probability of using transportation services (Alkema et al., 2006) and Xu et al. (2010) found that those living alone were more likely to use more than 8 hours of formal attendant care. Weddle et al. (2012) found that African Americans who live alone are more likely to use congregate meal services. Many studies find that living alone also increases the risk of being **institutionalized** (Cai, Salmon, & Rodgers, 2009; Gaugler et al., 2007; Miller & Weissert, 2000).

Marital Status

Wallace et al. (1999) found that being widowed was associated with increased **service use**. In two systematic literature reviews, being married was found to be associated with

⁶ <http://www.ers.usda.gov/briefing/population/challenges.htm>

lower odds or reduced risk of **NH placement** (Gaugler et al., 2007; Miller & Weissert, 2000). Similarly, Borrayo et al. (2002) report not being married was associated with increased likelihood of being in a NF or ALF than using HCBS.

For older adults with dementia, Andel, Hyer and Slack (2007) found that married individuals were more likely to be placed in a NH. They found that widowed status *reduced* the risk of NH placement among older adults without dementia. They suggest that this may be due to the unique nature of this population. Having limited financial resources, a spouse may actually be a burden or an additional strain on resources. Another study found that being widowed was associated with a decline in NH placements from 1977 to 1999 (Ness, Ahmed, & Aronow, 2004).

Having Children

Gaugler et al. (2007) found that having children lowered the odds of **NH admission**. Muramatsu et al. (2007) also found that living close to or living with children was significantly associated with lower NH admissions. Noël-Miller (2010) found that having adult children reduced the risk of NH admission for wives, regardless of husbands' vital status. Adult children buffered husbands' risk only after their wives' death.

Informal Support

Older adults who receive unpaid caregiving support, and who have personal care needs, are less likely to use discretionary **services** and more likely to use nondiscretionary services than those who do not receive any formal assistance (Mitchell & Krout, 1998).

Having an informal caregiver was associated with increased risk of **hospitalization** (Miller & Weissert, 2000). Van Houtven and Norton (2004) found that informal care reduced home health care use.

The presence of an informal caregiver is also a variable that has mixed findings relating to **NH admission**. In their systematic literature reviews, both Miller and Weissert (2000) and Gaugler et al. (2007) found that caregiver availability increased risk/was associated with greater odds of entering a nursing home. Gaugler et al. (2007) points out that this contrasts with prior conclusions on informal care. In an analysis of PACE participants who had a caregiver, Friedman et al. (2006) found that caregiver presence did not change the older adult's institutional risk. In their analysis of the AHEAD study, Lo Sasso and Johnson (2002) found that receiving frequent assistance from children with their [older adults with a disability] basic personal care reduced the likelihood of NH use over a two year period by about 60%. Andel, Hyer, and Slack (2007) also found that caregiver presence reduced the risk of NH admission for older adults without dementia. Van

Houtven and Norton (2004) found, in an analysis of the HRS and AHEAD survey, that informal care reduced home health care use and delayed NH admission. Finally, on a similar note, less or worse social support was associated with increased risk of institutionalization (Bharucha et al., 2004).

Spouse Service Use

Having a spouse use services was positively related to older adults using CCRC **services** (Krout et al., 2000).

Enabling Variables

Income

Wolinsky and Johnson (1991) point out that income enables **service use**. Borrayo et al. (2004) found that Medicaid-eligible individuals were 26 times more likely to utilize Florida's Aged and Disabled Waiver program than other state-funded services. Another study found that concern over the affordability of services is associated with unmet HCBS need (Casado, van Vulpen, & Davis, 2010).

In Miller and Weissert's (2000) review, they found that most studies did not report income to be a significant predictor of **institutionalization** or **hospitalization**. Muramatsu et al. (2007) measured income and non-housing wealth using terciles. Income was not associated with risk of NH admissions. However, being in the high wealth tercile, as opposed to the low wealth tercile, did reduce the risk of NH admission.

Payment Method

Medicaid and private pay were found to be the most common payment sources in an analysis of the National Nursing Home Surveys from 1977-1999 (Ness, Ahmed, & Aronow, 2004). In the last year (1999), Medicaid payment was most prevalent among residents age 65-74, women, and African Americans. The CARE study, found that being a customer identified as potentially lower income at the time of the study was associated with higher rates of NH admissions than those not qualifying for Medicaid, and were identified as low-income (Macmillan et al., 2007). A higher percentage of those receiving Medicaid HCBS/FE services remained in the community in comparison to those who did not; however, this was not statistically significant. Muramatsu et al. (2007) caution that **Medicare** status is difficult to evaluate as a predictor of HCBS or NH admission, because virtually all people over 65 have Medicare. Borrayo, Salmon, Polivka, and Dunlop (2002) found that Medicaid eligibility was associated with higher use of nursing facilities in Florida. However, this was also associated with a higher likelihood of HCBS use, in comparison to ALF use.

Home Ownership

Home ownership has been associated with a delayed or decreased risk of **NH admission** (Cai, Salmon, & Rodgers, 2009; Gaugler et al., 2007).

Caregiver Characteristics, Burden, & Assistance

Casado, van Vulpen, and Davis (2010) reported that if a caregiver has substitute help, they report having less unmet **HCBS services**.

Regarding informal caregiving, enabling characteristics are associated with the caregiver's characteristics. Yaffe et al. (2002) found that caregivers being between the ages of 65 and 74 and older than 75 was associated with a greater risk of **NH placement**. If the caregiver receives greater support, Miller and Weissert (2000) found that was associated with a decreased risk of NH entry. Caregiver burden is a strong predictor of NH entry. Greater caregiver burden has been associated with increased NH placement in a number of studies (Gaugler et al., 2009; Miller, Rosenheck, & Schnieder, 2012; Spillman & Long, 2009; Yaffe et al., 2002).

Policy Variables: State Spending on HCBS

Muramatsu et al. (2007) used two variables to look at state HCBS spending and other state-level funding: One was per capita HCBS spending (total HCBS spending/population of 65 or older), which measures the absolute amount of money going towards HCBS; and (2) Percentage of LTC spending going to HCBS rather than nursing homes, which measures the extent of the state's LTC system orientation towards HCBS as compared with institutions. The study's interaction effect models showed that living in a state with higher HCBS spending reduced **NH admission** risk among childless seniors, but not among those with living children. Controlling for other characteristics, only 3% of the variance in NH admissions was between states, indicating that state-level factors played relatively small roles. However, the authors recommended that the allocation of HCBS resources requires careful consideration about fairness for individual older adults and their families, as well as cost-effectiveness. They noted, "Targeting HCBS resources to seniors without children would penalize those with children such that these seniors would have to continue to depend on their children, who would be locked into caregiving roles" (Muramatsu et al., 2007).

Miller et al. (1998) found that a higher percentage of Medicaid LTC spending on HCBS (versus institutional LTSS) was significantly associated with a longer time to NH admission for unmarried persons in the study, but not married persons.

Results of the Muramatsu et al. (2008) study on state HCBS spending and place of death among older Americans suggested that doubling per capita HCBS services would result in a 25% reduction in the risk of NH relocation for people on Medicaid. The effect was not significant for people without Medicaid. Higher state HCBS spending was associated with lower risk of NH relocation, especially among those with Medicaid.

Recent studies have also examined predictors of low-care NH residents (Hahn et al., 2011; Thomas & Mor, 2013 manuscript). One study found that a \$10,000 increase in per-enrollee HCBS Medicaid waiver expenditures was associated with a 3.5 percentage point reduction in prevalence of low-care resident prevalence in Florida counties (Hahn et al., 2011). Another study examined the relationship between OAA Title III state expenditures and the prevalence of low-care NH residents in those states (Thomas & Mor, 2013 manuscript). They found that increased spending on Title III was associated with fewer NH residents who had low-care needs, suggesting that increased state spending on this lower-intensity service could decrease low-care NH resident prevalence.

Policy Variables: Reduction in Resources

Regarding policy resources, D'Souza et al. (2009) found that reductions in resources for Medicaid home care were associated with increased probability of adverse outcomes including **hospitalization, ER use, and NF placement**.

Policy Variables: Home Health Agencies

Miller (1998) found that for married individuals, a greater number of home health agencies was associated with a longer time to **NH admission**. This may be related to easier access to services. On a similar note, one study found that having a primary care provider is associated with reduced odds of nursing home admission (Goodwin et al., 2011).

Policy Variables: Nursing Home Bed Supply

Miller and Weissert (2000) report that many studies found a positive relationship between nursing home bed supply and risk of **nursing home placement**. However, Miller (1998) found that this variable was not significant relating to NH entry when examining NH beds per 1,000 persons 85+. Borraro et al. (2002) examined predictors of NH, ALF, or HCBS use in Florida. They found that individuals who lived in north, central, and west Florida were more likely to be living in a NF than in an ALF or using HCBS. Those in south Florida were more likely to use HCBS than live in an ALF or NH setting. This is interesting to note because of the increased NH bed supply in those regions outside of south Florida and the increased HCBS program access in south Florida.

Policy Variables: Pre-admission screenings

Chapin et al. (2009) assessed the CARE program and found that, of the numbers of individuals diverted from the NH, there was almost an equal amount of older adults who died or who were placed in nursing homes, while 18% of the older adults were still living in the community. They suggest that providing HCBS information during a pre-admission screening could potentially permanently prevent **NH admission**.

Need Variables

Awareness of Need/Self-health Ratings

Older adults displaying characteristics of need is connected to **HCBS use**, whether it be awareness of need, ADL or IADL limitations, or poorer health overall. Perceived unmet need is important to both discretionary and nondiscretionary service use among families providing care to dependent older adults (Kosloski & Montgomery, 1994; Mitchell & Krout, 1998). Chen and Thompson found that awareness of need was associated with HCBS use (2010). Casado, van Vulpen, and Davis (2010) report that a lack of awareness, reluctance, and unavailability of HCBS were some of the main reasons for unmet HCBS needs.

Self-health ratings are associated with an increased risk of **NH admission** (Cai, Salmon, & Rodgers, 2009; Muramatsu et al., 2007). Muramatsu et al. (2007) found that worse self-rated health status was significantly associated with increased risk for NH admissions. A lower self-perceived health was associated with an increased risk of long-term stay nursing home admission (Cai, Salmon, & Rodgers, 2009).

General Poor Health

Poorer health and a greater number of illnesses were strong predictors of CCRC onsite **services** for respondents in Krout et al.'s 2002 study. In one study, greater overall care needs were associated with unmet HCBS needs (Casado, van Vulpen, & Davis, 2010). Among a study of African Americans in an urban congregate meal program, Weddle et al. (2012) found that nutrition risk was a significant influence on use of the service. Alkema et al. (2006) found that older adults with incontinence were three times more likely to use any service. Those who had sensory impairments had over five times greater odds of utilizing HCBS.

Variables that affected **hospitalization** and other adverse outcomes include *worse performance on physical function measures* not based on ADL, greater illness severity, and prior hospital use (Miller & Weissert, 2000).

Banaszak-Holl et al. (2004) found that models that excluded functional impairment showed that *chronic medical conditions* and dementia significantly affected the risk of **institutionalization**. Even in those models that controlled for functional impairment, dementia still had a strong effect, but chronic medical conditions did not. Friedman et al. (2005) found that IADL dependence and *bowel incontinence* were associated with a higher risk of nursing home admission or PACE participants who joined PACE from the community. Borrayo et al. (2002) reported that older adults with more *chronic diseases* were more likely to be in a NF or using HCBS than in an ALF. An del, Hyer, and Slack (2007) report that, among older adults without dementia, *diabetes, incontinence, and stroke* also contribute to an increased risk of NH admission.

Overall, Miller and Weissert (2000) highlight that worse performance on any measure of ADLs, IADLs, incontinence and disability was correlated with an increased risk of NH placement and hospitalization. *Lower physical functioning* is significantly associated with increased risk of NH admissions (Muramatsu et al. 2007).

Interestingly, among older adults without dementia in Florida, An del, Hyer, and Slack (2007) found that *arthritis and heart disease reduced* the risk of NH admission.

ADL Limitations

The strongest associations between need and service use is physical function. Research has found that ADL limitations and chronic disabilities are two of the strongest need-based predictors of **HCBS use** (Borrayo et al., 2002; Wolinsky & Johnson, 1991). According to Johnson & Wolinsky (1996), ADLs are significant predictors of using in-home health services among white females, but not black females.

For individuals who returned to the community from a recent **hospitalization** and had unmet ADL needs, their risks of readmission were increased. It was greater for those with unmet needs for new disabilities in comparison to those who were admitted with an existing disability (DePalma et al., 2012).

In a meta-analysis of studies on **NH admission** in the U.S., Gaugler et al. (2007) found that one of the strongest predictors of NH admission was having 3 or more ADL dependencies. Similarly, D'Souza et al. (2009) found that, when the ADL Index was used as a proxy for health status, functional impairment was positively associated with death and permanent NH placement. Borrayo et al. (2002) found that individuals needing ADL assistance were more likely to be in a NF than in an ALF or using HCBS.

IADL Limitations

Some studies have found that IADL limitations are associated with both **HCBS use and NH admissions** (Chen & Thompson, 2010; Chapin et al., 2002).

Many studies have found that IADL limitations are associated with HCBS use and NH admissions (Andel, Hyer, & Slack, 2007; Chen & Thompson, 2010; Chapin et al., 2002). Cai, Salmon, and Rodgers (2009) found that worse IADLs were associated with increased NH admissions; however, it is important to note that higher ADLs did not show a significant effect on NH admission. In a 12-year epidemiological study in the U.S., IADL disability was found to be a significant predictor of institutionalization (Bharucha et al., 2004).

Comorbidities

Sands et al. (2008) measured morbidities using a commonly used measure, the Charlson index (based on ICD-9 codes in 6 months prior to study period, in which a higher rating reflects greater number and severity of comorbid conditions). **HCBS waiver users** were more likely to have one or more comorbidities than NH patients.

Haller and Gessert (2007) found that having 3+ comorbidities was associated with high **medical care utilization** at end of life for NH residents with a cognitive impairment hospitalized within 90 days of death.

Alzheimer's Disease & Cognitive Impairment

Variables relating to need are strongly associated with **NH admission**, including cognitive and physical function. Many studies have found that Alzheimer's disease and cognitive impairment are strongly linked to NH admissions (Bharucha et al., 2004; Borrayo et al., 2002; Chen & Thompson, 2010; Gaugler et al., 2007; Miller & Weissert, 2002; Wolinsky & Johnson, 1991). Borrayo, Salmon, Polivka, and Dunlop (2002) reported that individuals with Alzheimer's diagnoses or a high cognitive impairment level were more likely to be in an institution (nursing facility or assisted living facility) than to use HCBS. Between the NF or ALF, they are also more likely to be in an NF. Gaugler et al. (2009) found that, for persons with dementia, some predictors of NH entry include: severity of cognitive impairment, Alzheimer's disease diagnosis, basic ADL dependencies, behavioral symptoms, and depression.

Mental Health Status

Psychiatric issues (Cai, Salmon, & Rodgers, 2009) and being disoriented/having problematic behavior (Miller & Weissert, 2000) was associated with an increased

institutionalization risk. Andrews et al. (2009) found that people with schizophrenia enter nursing homes earlier than persons with no mental illness; however, the median age of NH admission for those with schizophrenia is 65. This disparity was higher for those at middle age (40-65).

Service Use, Mix and Spending: HCBS, Health Care, and Nursing Home Outcomes

General Health Care Experiences

Wallace et al. (1999) found that previous health care experiences predicted **service use**.

Miller and Weissert (2000) found that more frequent doctor visits are correlated with increased risk of **hospital admission**. Additionally, taking more medications is associated with hospitalization risk.

Prior Hospital Use

As mentioned previously, prior hospital use is a significant predictor of **hospitalization**. The number of hospital days an individual has is also significantly related to an individual's impairment (Miller & Weissert, 2000).

Prior hospitalization is a significant predictor of **nursing home admission** (Miller and Weissert, 2000). Gaugler et al. (2007) found that this was associated with slightly greater odds of NH entrance. Hospital use and emergency room use has been linked to increased use of HCBS, increased health care utilization rates, and NH admission (D'Souza, 2009, Sands et al., 2008, Xu et al., 2010). One study found that NH patients, compared to HCBS users, were more likely to have been admitted to a hospital in the 6 months before receiving LTC (Sands et al., 2008). Goodwin et al. (2011) found that ¾ of new NH placements were precipitated by hospitalization. They state that being discharged from a hospital into a SNF was associated with increased odds of LTC admission.

Prior Nursing Home Use

Prior NH use was found to be a strong predictor of **NH admission** (Gaugler et al. 2007) and positively associated with future NH use (Miller & Weissert, 2000). PACE participants who enrolled from a NH vs. from the community were at a higher risk of having a 30 day NH admission (Friedman et al., 2005).

Prior Service Use

The effect of HCBS use on NH admission has resulted in mixed findings. In some cases, more HCBS services are associated with a greater risk of **NH admission** (Miller & Weissert, 2000; Karuza & Wu, 2011; NYSOA, 2011). Other studies indicate that HCBS use can delay NH admission (Brock et al., 2007; Karuza & Wu, 2011; Kosloski & Montgomery, 1995; Chen & Thompson, 2010; Chen et al, 2011; Gaugler et al., 2005; OPPAGA, 2010; Shapiro & Taylor, 2002). One study looked at the use of an HMO and found that it appeared to help at-risk older adults postpone NH placement (Fischer et al. 2003). Shapiro & Taylor (2002) conducted a randomized controlled trial where individuals on the waiting list for Florida’s Community Care for the Elderly program who were at “moderate risk” received services earlier than they would have. They found that the intervention group had higher subjective well-being and were less likely to enter an institution or die during the 18-month period than the comparison group. The types of services these studies researched varied and included the effect of services like paid helpers, case management, OAA III-E/ respite care, and State Medicaid Waiver. The studies also examined the effect of service delivery including volume of services and timing of care.

Volume of Services

Receiving a greater volume of attendant care, homemaking services, and home-delivered meals was associated with a lower risk of **hospitalization** (Xu et al., 2010).

Additionally, volume of services has an effect on **institutionalization**. In Rhode Island, individuals who received more than one service had increased community tenure (Brock et al., 2007; Karuza & Wu, 2011).

Timing of Care

Regarding service delivery, Gaugler et al. (2005) found that timing of care affected **institutionalization**. Caregivers of individuals with dementia who used in-home help services earlier in their caregiving experiences were more likely to delay institutionalization (Gaugler et al., 2005). In MacMillan et al.’s (2007) study period, at three months after assessment, 31.4% of diverted individuals used services (the highest proportion in the study). This further supports that timing of care is an important variable to consider in NH diversion research.

IADL Help

Miller and Weissert (2000) analyzed multiple studies that examined adverse outcomes for older adults. They found that having paid helpers was positively associated with **NH**

use. However, Chen and Adams-Thompson (2010) looked at various types of service use on adults' ability to remain in the community, including paid ADL/IADL personal care services and other HCBS. They found that the only service that supported older adults to remain in the community was paid IADL personal care services. The authors suggested that the studies should look at how IADL personal care services and other HCBS help older adults remain in the communities longer before their first NH visit or return home after institutional care. This would inform efficiency of service provision.

Supporting these findings, IADL limitations emerged in the New York POMP study as a significant factor predicting **NH risks** (New York Office for the Aging, 2010). Similarly, the Advanced POMP (Karuza & Wu, 2011) found that limitations in IADLs were more significantly associated with increased risk for NH placement than commonly recognized limitations in ADLs. This finding extended the knowledge base and suggested the importance of considering IADL limitations in the study of and delivery of OAA HCBS.

Case Management

A research recommendation emerging from the Advanced POMP (Karuza & Wu, 2011) was to explore the question: Is there an optimal strategy for program implementation and service delivery (role of case manager)? Shapiro & Loh (2009) found that cost savings for HCBS resulted from **reduction in use of NHs**. They posited that case management, which was used by all programs evaluated, helped to target the specific services to the needs of the client and increase the efficiency of HCBS programs. The author suggested that HCBS results in cost savings because the use of case management that targets specific services is tailored to the needs of the client, which is associated with a shift in client services from expensive care service (e.g., NH) towards less expensive services (e.g., prescriptions). In Rhode Island, utilization of case management services was associated with increased likelihood of NH admissions, but the authors suggested that this may be because use of case management services is an indicator of higher need (Brock, et al. 2007).

The New York POMP project (NYSOA, 2010) found that intensity of case management services was a statistically significant predictor for **NH placement** in two counties, controlling for other factors. To explain this association, a case study analysis indicates that users of case management were already very frail and in the highest need of services, likely explaining their need for NH services (NYSOA, 2011). Additionally, local county policies and procedures affected NH placement. In one county (for which case management was more significant), case managers assist clients with NH placement and they have a cap on personal care services.

OAA III-E / Respite Care

Georgia provided respite (OAA III-E) data in an analysis of their POMP data. This indicated that the relationship between service intensity and mean survival was flat for respite, but it was a significant predictor of decreased **NH placement** (Brock et al., 2007; Karuza & Wu, 2011). Kosloski and Montgomery (1995) found that there is a negative relationship between the amount of respite received and NH placement.

Medicaid Waiver

Pande, Laditka, Laditka, and Davis (2007) examined the frailty of older adults enrolled in South Carolina's Medicaid home care waiver program in 1995 and 2005. They found that older adults in 2005 were significantly more likely to have chronic conditions in comparison to those in 1995. Additionally, they were more likely to receive specific **services** in 2005. The authors suggest that this indicates older adults are remaining in the community longer and that Medicaid Waiver services may delay **institutionalization**.

Service Use, Mix, and Spending: Cost Savings Predictors

Cost savings is an important outcome to measure when examining the effects of HCBS on health care and NH use. A recent analysis of the available evidence for AARP (Mollica et al., 2009) concluded that "**HCBS is cost-effective**." The report found that "over time, states that invest in HCBS experience slower Medicaid expenditure growth than states with low HCBS spending." For example, Kaye, LaPlante, and Harrington (2009) analyzed state spending data over 10 years and found evidence that states with established HCBS systems controlled spending better than did states with lower levels of HCBS and less established HCBS systems. Several recent state-specific studies have also found evidence of **reduced total utilization and/or cost savings from HCBS** (Senecal, 2009; Weissert et al., 1997; GAO, 1994; Alecxih, Lutzky, & Corea, 1996; Shapiro & Loh, 2010; Shapiro et al., 2009).

One study looked at the effects of **OAA III-C services**. At the state-level, for every additional dollar spent per person over 60 in the non-institutionalized population, there is a decrease of approximately 6.6% in the rate of change in nursing home residency status for adults over 65. When overall state HCBS spending is accounted for, that effect disappears (Buys et al., 2011 manuscript).

Some studies examined state-specific services. Felix et al. (2011) found a net 3-year savings of \$2.619 million for Medicaid in Arkansas as a result of their Community Connector Program. This program trained community health workers to identify individuals in disadvantaged communities who are at-risk of NH placement and connect them with services.

Shapiro and Loh (2010) tracked services from five categories in Florida (Alzheimer's Disease Initiative, Community Care for the Elderly, Home Care for the Elderly, the Medicaid Waiver, OAA Title III B) – those that were larger in scale and had enough observations for a meaningful evaluation of cost avoidance. The limitation is that this is a nonrandom selection of HCBS programs in Florida. Cost avoidance varied widely among the five HCBS programs that were analyzed. The study gave the cost avoidance in dollar amounts but did not look at pathways. For all service types, the greatest cost avoidances were for NH expenses; impacts on other health care expenditures were relatively small. In some cases, the HCBS programs were associated with cost increases in some expense categories, including prescription drug expenses, and transportation.

- ▶ **OAA III-B:** Based on equation by equation OLS, Older Americans Act III-B enrollees spent \$65 less on NH care, \$20 more on long-term home health services, \$55 more on prescription drugs, and \$69 more on other expenses than nonusers monthly. Results for inpatient expenses, outpatient expenses, physician expenses, and transportation expenses were not statistically significant (Shapiro & Loh, 2010).
- ▶ **Alzheimer's Disease Initiative (ADI):** Results of the 3 stage-least-squares equation showed cost avoidance associated with ADI (per member per month) was \$781 less for NH expenses, \$569 more for prescription drug expenses and \$102 more for transportation expenses. Results for total inpatient expenses, total outpatient expenses, total physician expenses, total long-term home health, and total other expenses were not statistically significant. (Besides ADI, the study did not report 3SLS results for any other program because of the high correlation with the mental health assessment variable) (Shapiro & Loh, 2010). In general, the results did not seem sensitive to the multiple enrollments in programs. (Shapiro & Loh, 2010)
- ▶ **Community Care for the Elderly (CCE):** Based on OLS equation by equation, CCE service users spent \$12 less on inpatient care, \$4 less on outpatient care, \$2 less on physician expenses, \$175 less on NH care, \$3 less on transportation, \$9 less on prescription drug, and \$38 less on other expenses than nonusers monthly. Results for total long-term home health expenses were not statistically significant (Shapiro & Loh, 2010).
- ▶ **Home Care for the Elderly (HCE):** Based on OLS equation by equation, HCE users spent \$3 more on physician expenses, \$152 less on NH care, \$6 less on long-term home health services, \$3 more on transportation services, and \$65 more on prescription drugs than nonusers monthly. Results for total inpatient expenses, total outpatient expenses, and total other expenses were not statistically significant (Shapiro & Loh, 2010).
- ▶ **Medicaid Wavier (MW):** Based on OLS equation by equation, MW enrollees spent \$9 more on outpatient care, \$117 less on NH care, \$8 less on long-term home health services, \$12 more on transportation services, \$63 more on prescription drug, and \$364 more on other expenses than nonusers monthly. Results for total inpatient

expenses and total physician expenses were not statistically significant (Shapiro & Loh, 2010).

Shapiro & Loh's 2010 study found consistent evidence that HCBS use in Florida produced cost savings compared with applicant non-users and non-user/non-applicants. In 2006, NH residents who received HCBS saved \$373.94/month more than NH residents who did not apply for or receive services. This was a \$4,487 average annual savings. The largest and most consistent benefit of enrollment in HCBS was for Medicaid NH expenses.

Shapiro & Loh (2010) found that several HCBS programs, including CCE **and Older Americans Act III-B, III-C and III-E**, produced the most consistent and robust Medicaid cost savings relative to those in the non-user/non-applicant group. Isolating the effects of individual programs was difficult, because a substantial proportion of the study population was enrolled in multiple programs.

Several recent studies have emphasized the effectiveness of **lower intensity HCBS**. In a study by Smith and Frick (2008), high intensity HCBS use generally did not produce more Medicaid cost savings than moderate intensity HCBS use. Shapiro and Loh (2010) and Shapiro et al. (2009) found that low intensity HCBS users had the largest long-term care cost savings. They recommended that a re-examination of client service mixes within and between programs may be important to determine if some services may be redundant and/or less predictive of NH avoidance. Another approach would be to find ways to minimize the general revenue expenditures associated with higher intensity HCBS service mix.

Future Research Considerations

Several recent studies have recommended further research on the effects of national, state, and agency level policies and practices on HCBS outcomes, to help inform LTSS systems planning, such as eligibility and targeting policies. For example, a recommendation based on the POMP research (Brock et al., 2007) was to expand control variables in HCBS outcomes models to include service agencies' policies and structure. While some of these variables are outside of the scope of this study design, they are important to keep in mind.

Table 3 below displays variables that are especially important to consider in future work.

Table 3 : Variables Recommended for Future Exploration

Variables Recommended for Future Exploration	HCBS Use	Health Care Use	Community Tenure/NH Use	Cost Impacts
Federal level				
National LTSS targeting policies	●	●	●	●
National LTSS eligibility policies	●	●	●	●
Broader Environmental Factors (e.g., medical care environment over time)	●		●	
State level				
Cost control policies	●			●
Distribution of HCBS resources across state			●	
State target policies	●	●	●	●
State HCBS eligibility policies	●	●	●	●
Financing models	●			●
NH use rates			●	
Strength of NH industry	●			
Strength of home care labor unions	●			
County/Local Level				
Variance in available housing options			●	
Distribution of HCBS resources across county			●	
Agency Level				
Agency Characteristics (policies, structure, etc.)			●	
Agency home care policies/procedures			●	
Individual older adult/caregiver level				
Service monitoring/coordinating to meet persons' needs			●	

Variables Recommended for Future Exploration	HCBS Use	Health Care Use	Community Tenure/NH Use	Cost Impacts
<i>Perceptions of functional ability</i>			●	
<i>Awareness of unmet needs</i>			●	
<i>Characteristics of Older Persons not using OAA services</i>	●	●	●	●
<i>Health/needs of Caregiver</i>			●	
<i>Quality of Life improvements</i>	●			
<i>Demographic variables</i>			●	

Recent studies suggest that the following policy issues are especially important to consider.

Case-Control Evaluations

Karuza & Wu (2011) recommended several questions for future research, including, How do OAA clients compare to those who do not receive OAA services? The Advanced POMP studies did not include cases and controls from the general population of older adults. Similarly, Brock et al. (2007) recommended further comparisons with general populations of older persons to explore over a broader population the effectiveness of OAA services.

Intensity

The Kansas CARE study of participants in an Aging Network nursing home diversion program, (Macmillan et al., 2007) diverted customers with greater level of need (higher LTC threshold scores) and those customers were able to stay in the community longer. This was an unexpected result and more research is needed on why this may be the case. The LTC threshold score was measured at the beginning of the study and not over time. Diverted CARE participants generally received OAA and other HCBS shortly after diversion, but were able to stay in the community without receiving services continuously.

Distribution of HCBS Resources across the Aging Network

Miller et al. (1998) recommended that future studies pay attention to the issue of how the allocation and distribution of home care resources within a county (or a state) may

influence NH risk. Similarly, a recommendation for future research emerging from the POMP (Karuza & Wu, 2011) was to explore: Is there an optimal strategy for program implementation and service delivery (distribution of limited service resources across Aging Network)?

Miller et al. (1998) also recommended that future studies pay attention to the issue of how the allocation and distribution of home care resources within a state (or a county) may influence NH risk.

NH Diversion/Pre-Admission Screening

Miller et al. (1998) did not study the independent effect of preadmission screening on time to NH admission, but suggested that this variable be included in future, related studies. Chapin et al. (2009), reporting on the Kansas Community Tenure Study, recommended: "As more studies on diversion of older adults who are applying for NH admission are completed, it will be possible to present a clearer picture of the capacity for older adults with significant long-term care needs to successfully remain in the community. In addition, research focused on the utilization of community-based services will provide policymakers a better understanding of diverted older adults' ability to maintain community tenure given timely access to publicly funded home- and community-based services."

Cross-Program Effects and Outcomes on Multiple Domains

The literature suggests that, to provide a complete picture of HCBS impacts, evaluators must consider cross-program effects and outcomes on a range of domains.

D'Souza et al. (2009) found that efforts to decrease Medicaid HCBS spending appeared to have triggered downstream increases in permanent NH placement and greater utilization of acute care services, typically funded by Medicare. They recommended that policymakers give more consideration to the overall cross-program effects of state HCBS budget reductions on access to preferred care settings and health outcomes.

Shapiro, Loh, & Mitchell (2011) recommended that a full estimation of the value of these programs must also consider the value of quality of life improvements that can be attributed to these services. When combined with estimates of actual cost avoidance, these studies would provide a more comprehensive assessment of the value of HCBS programs.

Miller et al. (1998) recommended that future outcomes studies focus not only on NH entry, but also include other outcome such as death, entering into assisted living facilities, hospitalization, Medicaid spend-down, and changes in quality of life, etc., in order to demonstrate the impact of HCBS in general, and of Aging Network home care in particular.

Measure Limitations

Recent studies suggest that HCBS use is affected by individual traits and circumstances that are difficult to measure. Some commonly used measures may not always be accurate.

Some evidence suggests that self-reported ADLs and IADLs often overestimate a person's functional ability when compared to a performance-based test. Chen & Adams Thompson (2010) suggested that older adults' perceptions of their functional ability may be a more important indicator of community tenure than their actual physical abilities because they related to their awareness of their unmet needs, which is tied to service use.

Similarly, Chen & Adams Thompson (2010) noted that awareness of unmet need and ability/desire to seek assistance are related to cultures and values that are not often measured but understood to drive use of services.

One study of Aging Network CARES assessment participants in Kansas found that living alone, residing in assisted living, and having available support did not explain the difference in those who remained in the community versus admitted to NHs (Macmillan et al., 2007). However, qualitative analysis showed that most customers who lived alone had daily informal contact and support from family. This suggested that living alone cannot be used as a measure of social isolation, particularly if informal support is not being accounted for. These results illustrate the complexities of measuring caregiver availability.

These measurement limitations are further discussed in the [Study Design](#) report.

Conclusion

AHRQ released a systematic review of the comparative effectiveness of institutional versus home and community-based services (Wysocki et al., 2012). The review focused on two questions:

1. What are the benefits and harms of long-term care provided through Home and Community-based Services (HCBS) compared to institutions such as nursing homes (NH) for older adults aged 60 and over who need long-term care (LTC)?
2. What are the costs (at the societal and personal level) of HCBS and NH (per recipient and in the aggregate) for adults over age 60? (pg. ES-4).

The review protocol (AHRQ, 2011) acknowledged that meaningful comparisons must include services of roughly equivalent type, frequency, and intensity. In addition, the protocol noted that assessing LTC cost impacts requires attention to expenses associated

with several factors, including housing, specific services delivered, health care utilization (including acute care services such as hospitals, emergency departments), and costs incurred by recipients and their families. In conducting the review, the authors noted that there is very limited evidence, in addition to methodological limitations, of literature relating to the outcomes of interest. They suggest that “more and better research is needed to draw robust conclusions about how setting influences outcomes and costs of older adults using LTC” (Wysocki et al., 2012, pg. ES-14).

This review supports the need for designing a study that produces credible, solid evidence of results that will be of critical importance to AoA, the Aging Network, and service recipients and families who rely on OAA and non-OAA programs and services. Increasingly, stakeholders seeking continued or expanded funding for health and social programs must be able to “make the business case” for the investment, with rigorous research demonstrating success in improving peoples’ lives and achieving more effective use of economic resources. Congress and the Office of Management and Budget (OMB) at the federal level, as well as state and local governments, use program evaluation information to make budget decisions. A study with inconclusive results, or misleadingly suggesting a lack of impact or negative impact, can be quite damaging to efforts to demonstrate the need and gain support for HCBS programs.

Appendix A-A: Available Data Sources and Data Elements

Numerous secondary data sources exist and several of the studies combined data from multiple sources. For example, Miller et al. (1998) linked individual level data from a national longitudinal survey with state health care system data via the state of residence of each person. In Shapiro & Loh (2010), MDS records were matched with CIRTS records, using resident IDs to obtain Social Security Numbers (SSNs) from CMS, then matching CIRTS records with the SSNs.

For this project, the POMP may provide the most appropriate initial data source to consider. However, we are encountering numerous data inconsistencies across states. Lewin continues to explore the POMP data with AoA as many improvements in data integrity have been made in the last three years. The POMP data could be matched to other individual data if appropriate identifiers are available and it could also be matched to geographic policy or supply/demand related data.

Older Americans Act Program Data

Available data sources could potentially be used to examine OAA services at the individual level or the state or AAA level. Table 1 below provides examples of recent studies using OAA program data.

Table 1: Data Sets with OAA/Aging Network Specific Data

Database	Data elements	Study
<p>Florida CIRT Database, a comprehensive assessment database of community-dwelling candidates for LTC services in Florida.</p> <p>Florida CARES</p>	<p>Demographic and health variables from CIRT screening assessment (marital status, race, sex, IADL, ADL, mental health assessment). A full assessment takes place every 3 months.</p> <p>Although 15 programs were in the CIRT file (including OAA III-B, III-C, III-D, and III-E), only five programs that were larger in scale had enough observations for a meaningful evaluation: Older Americans Act III-C, Alzheimer’s Disease Initiative, Community Care for the Elderly, Home Care for the Elderly, Medicaid Waiver</p>	<p>Shapiro & Loh, 2010, 2007</p> <p>Shapiro, Loh, & Mitchell, 2011</p>
<p>Administrative data from the four New York State AAAs participating in POMP</p>	<p>The data included in this study was longitudinal data collected separately from each county 1/1/08 - 6/30/09. The data elements for the study included: older adults’ age, gender, ethnicity, marital status, income, living arrangement, ADL and IADL scores. Family support data were not included because a significant number of cases did not report this information. Health status variables, such as self-reports of incontinence, stroke, Parkinson’s disease, Alzheimer’s disease, and mental status/dementia, and health events such as hospitalization and ER use, were also included. Service use variables were also included.</p>	<p>New York State Office for the Aging, 2010</p>
<p>AAA/Kansas Department on Aging databases</p> <p>Kansas State Publicly Funded Services (SPFS) data</p>	<p>The Kansas Department on Aging provided CARE Assessment, Senior Care Act, Medicaid Home and Community-Based Services for the Frail Elderly, and Older Americans Act service data which were extracted from their KAMIS and MMIS data systems</p>	<p>Chapin et al., 2002, 2003, 2009</p> <p>Macmillan et al., 2007</p>
<p>Administrative data on OAA participants from Georgia, New York, North Carolina, and Rhode Island</p>	<p>Data varied by state. Georgia provided data on service clients from selected AAAs in the state. NY data consisted of all consumers of OAA services age 60 and older in four counties who received at least one service during a 1-year period. NC data included all OAA consumers age 60+ from two counties who received at least one registered Home</p>	<p>Karuza & Wu, 2011</p>

Database	Data elements	Study
	<p>and Community Block Grant Service for at least three months. Rhode Island data consisted of two data sets of OAA participants; the second dataset was similar to the first, but with some differences and more recent.</p>	
<p>Administrative service data from Rhode Island, Georgia, North Carolina, and New York</p>	<p>Data available for analysis varied by state:</p> <ul style="list-style-type: none"> • Receipt of various OAA HCBS • Demographics (age, gender, ethnicity, living arrangements) • Presence or absence of a caregiver (Georgia only) • Medicaid eligibility (NC only) • Marital status (Rhode Island only) • Measures of physical functioning (ADL, IADL) • Health and mental status variables: self-reports of incontinence, stroke, Parkinson’s disease, Alzheimer’s disease, and dementia (NY only) • Other health event variables, such as emergency room use (NY only) 	<p>Brock et al., 2007</p>
<p>Administration on Aging, AGID database</p>	<p>AGID is an online database created by AoA that provides information on clients served, providers of services, and expenditures for particular programs. Additionally, AGID includes population characteristics from the Census Bureau.</p>	<p>Buys et al. (draft manuscript currently under review)</p>
<p>Administration on Aging, 1995, 1996, 2004 Administration on Aging Survey 1995</p>	<p>State spending on Older Americans Act State HCBS expenditures in 1992, including expenditures for HCBS for the functionally impaired elderly supported by Medicaid, Older Americans Act, Social Services Block Grant, state source programs, and other funding sources</p>	<p>Muramatsu et al., 2007 Muramatsu et al., 2002</p>

State Data Sources

State datasets provide information on applicants for non-OAA services in a state, such as Medicaid waiver services. However, states are inconsistent in the data elements collected. Thus, these data may not be easily comparable across states (Table 2).

Table 2: Other State Specific Data Sets

Data Source	Data Element	Study
Indiana Medicaid data (Indiana Medicaid enrollment and claims and Insite databases)	Monthly data on people receiving HCBS vs. care in NHs, including: Gender, Age, Race, Alzheimer’s status, Comorbidities, Medicare status, Medicaid status, Marital status, Geographic region within state, Total Medicaid expenditures (includes inpatient, outpatient, pharmacy, long-term care, and other expenditures), Inpatient and ER use	Sands et al. 2008 Xu et al., 2010
Data Archive maintained by University of Michigan Institute of Gerontology Data Archive	Includes longitudinal assessment information for all individuals enrolled in the Michigan Choice waiver gathered using a comprehensive assessment instrument (Minimum Data Set for Home Care (MDS-HC ©, Morris et al., 1997). Assessments generally required at 90-day intervals. The data archive also contains administrative records. (Self-report data by patient/caregiver)	D’Souza et al., 2009
A services database provided by the Florida Department of Elder Affairs (DOEA) that can be used to track all individuals who received state-funded HCBS	Monthly charges for inpatient, outpatient, and physician services from the Medicaid claims data.	Shapiro & Loh, 2010 Shapiro, Loh, & Mitchell, 2011
Kansas Department of Health and Environment	Verification of death of study participants	Macmillan et al., 2007
Arkansas Medicaid	Variables included: age, sex, race, Medicaid eligibility category, dually	Felix et al., 2011

Data Source	Data Element	Study
eligibility and claims data	eligible for Medicare, enrolled in Medicaid in year prior to CCP, years enrolled in Medicaid, enrolled in HCBS waiver for older adults or adults with physical disabilities, comorbidity index score, prior-year Medicaid spending. Also Medicaid spending by service type.	

National Data Sets and Other Sources

The in-depth reviewed studies provide many examples of national datasets and other sources of data on HCBS policies, including state and regional characteristics.

Table 3: National Data Sets and Other Sources

Data Source	Data Elements	Example HCBS Studies
CMS Minimum Data Set II (MDS)	Data on all NH residents MDS records were matched with CIRTS records using resident IDs to obtain Social Security Numbers (SSNs) from CMS, then matching CIRTS records with the SSNs. Permanent nursing home admission information	Shapiro & Loh, 2010 Chapin et al., 2002 Chapin et al., 2003 Macmillan et al., 2007 Buys et al., manuscript under review
MDS-HC	Identifies the number of times over the prior 90 days (or since the last assessment) that an individual has been admitted to hospital with an overnight stay or visited the ER without an overnight stay	D'Souza et al., 2009
OASIS	Medicare home health assessment and service use data	Chapin et al., 2003
CMS Nursing Home Data Compendium	Per capita NH bed supply	Miller, 2011
CMS Office of Research, Demonstrations and	Annual data related to the number of certified home health agencies	Miller, 2011

Data Source	Data Elements	Example HCBS Studies
Information (email communication with William D. Saunders, CMS, June 17, 2009).		
Thomson Reuters	<p>Form 64 data as compiled by Thomson Reuters contains Medicaid LTC expenditures data; share of LTC dollars devoted to HCBS for all states and DC, except for Arizona. Because Arizona operates its LTC program under a 1115 demonstration waiver, HCBS-specific expenditure data was not available.</p> <p>Thomson Reuters also provides an annual report on “Medicaid LTC expenditures in FY 2007” (Burwell, Sredl, & Eiken, 2008).</p>	<p>Miller, 2011</p> <p>Buys et al., manuscript under review</p>
National Health and Nutrition Examination Survey (NHANES); the National Longitudinal Study of Aging	<p>The authors suggested that the use of large datasets, such as these two surveys, might be particularly well-suited to evaluate more comprehensively the effects of Title III Nutrition Services on NH entry as well as other relevant health outcomes.</p> <p>Buys et al. and AoA plan to use both NHANES data linked with Medicare claims data, for individual-level comparisons between participants in OAA Title III Nutrition Services and non-participants on health outcomes and NH entry.</p>	<p>Buys et al., manuscript under review</p>
Medstat (Burwell, 2001, 2003)	State Medicaid expenditures for home health, personal care, nursing home, and HCBS waiver (aged or disabled)	Muramatsu et al., 2007
HHS, 1999, 2000-2004, 2008	State spending on Social Services Block Grant	<p>Muramatsu et al., 2007</p> <p>Buys et al, manuscript under review</p>
Kassner & Williams, 1997; Summer & Ihara, 2004	State spending on state source programs	Muramatsu et al., 2007

Data Source	Data Elements	Example HCBS Studies
Census Bureau data sources, including annual Statistical Abstracts and the American Community Survey	State-level data on the share of the state population who are Black or Hispanic, Data on per capita income, Female labor force participation, State poverty rate, Housing affordability (household housing costs \geq 30% of income, %), Total state population	Miller, 2011
CDC Behavioral Risk Factor Surveillance Survey	Includes measures of disease prevalence and health status, state prevalence of activity limitations because of a physical, mental or emotional problem, percent of population reporting good or fair health	Miller, 2011
CDC annual HIV/AIDS Surveillance Reports	State-level AIDS prevalence	Miller, 2011
National Climatic Data Center, National Oceanic and Atmospheric Administration, U.S. Department of Commerce (1992)	Mean heating degree days	Miller et al., 1998
Institute for Health and Aging, University of California at San Francisco	Number of licensed residential care beds per 1,000 persons 65+ (Harrington, DuNah, & Bedney, 1993) Medicaid NH per diem (Swan, Keo de Wit, Pickard, & Clark, 1993)	Miller et al., 1998
Health Resources Publishing (1992)	Adult day centers per 100,000 persons 65+	Miller et al., 1998
Health and Retirement Study (HRS), a nationally representative longitudinal survey of older persons conducted by the University of Michigan Institute for Social Research	Variables such as physical functioning, receipt of services (home care by a medical professional and additional service, e.g., adult day care, social worker, outpatient rehabilitation, transportation, or meals), NH placement, and demographics	Muramatsu et al., 2007 Muramatsu et al., 2008 Brock et al., 2007

Data Source	Data Elements	Example HCBS Studies
Assets and Health Dynamics among the Oldest Old (AHEAD) survey, conducted from Oct 1993-July 1994	The survey examined the impacts and interrelationships of changes and transitions for older Americans in three domains: health, financial, and family.	Muramatsu et al., 2002
Second Longitudinal Study of Aging (LSOA II), a collaborative effort of the National Center for Health Statistics and the National Institute on Aging	Nationally representative longitudinal study of adults age 70+.	Chen & Thompson, 2010
Consortium to Establish a Registry for Alzheimer's Disease (CERAD) data	The CERAD project enrolled individuals between April 1987 and Jan 1995.	Miller et al., 1998
AARP	Annual report on "State-funded home and community-based services programs for older adults" (Mollica, Simms-Kaselein, Kassner, 2009), which provides data on state governments' spending on HCBS.	Buys et al., manuscript under review

Other Potential Information Sources

In the absence of consistent national data collection on state LTSS policies, recent surveys of state Medicaid agencies and aging and disability agencies may be an additional source for this data. In a February, 2012 AARP Public Policy Institute report, a survey of state aging and disability agencies (SADAs) and Medicaid agencies from 48 states and DC regarding LTSS policy trends reported (Cheek et al., 2012):

- ▶ Implementing or planning to implement Medicaid Managed LTSS
- ▶ Focusing on improving integration of Medicare and Medicaid services for dual eligibles
- ▶ Cuts made to aging and disability services programs (non-Medicaid) in FY 2011 or expecting to cut these programs in 2012
- ▶ Provider rate cuts
- ▶ Restrictions to some Medicaid services, such as personal care services

- ▶ Level of demand for ADRC services, information and referrals, and respite care in FY 2011
- ▶ Numbers of HCBS participants and Medicaid nursing facility residents in FY 2010 and 2011, and expected trends for 2012
- ▶ Changes in staffing of state officials
- ▶ Plans for using the new health care reform law to expand HCBS

An earlier study (Kitchener, Terence, & Harrington, 2004) reported on a survey of state Medicaid waiver programs, that asked about state use of eligibility criteria, caps, and waiting lists in various Medicaid waiver programs. The survey asked about all waiver programs regarding cost containment strategies used in 2002. Results indicated that, of the 76% of waiver programs responding, 57% used some type of financial cap. A third (33%) used more restrictive financial eligibility criteria than for institutional services, and the vast majority of states limited the number of waiver slots available. Overall, the waiver programs reported that 157,640 persons were on waiting lists in 2002. A limitation of the study was that no response was received for 58 waivers, and some states may have underreported or not responded due to fear of negative public reactions or legal action by advocacy organizations. Thus, the study recommended policy initiatives to require the systematic recording and public reporting of cost control techniques (e.g., waitlists) in use in public programs. The authors recommended that future studies examine the implications of states' use of waiver waiting lists and other cost controls. They recommended that this line of enquiry examine, for example, the scope, quality, and cost of services received by people enrolled in waiver programs compared with persons held on waiting lists.

Appendix A-B: Detailed Key Variable Table

Variables with Significant Relationships to Outcomes of Interest ⁷	HCBS Use	Health Care Use	Community Tenure/ NH use	Cost Impacts	HCBS Use	Health Care Use	Community Tenure/ NH use	Cost Impacts
Predisposing								
Age	9	1	12*	0	Muramatsu & Campbell, 2002; Shapiro et al., 2009; Shapiro & Loh, 2009;	Xu et al., 2010	Miller, 1998 Karuza & Wu, 2011; NYSOA, 2010; Friedman et al., 2005; Goodwin et al., 2011; An del Hyer, &	

⁷ An asterisk (*) indicates that this variable has yielded mixed findings in the literature.

Variables with Significant Relationships to Outcomes of Interest ⁷	HCBS Use	Health Care Use	Community Tenure/ NH use	Cost Impacts	HCBS Use	Health Care Use	Community Tenure/ NH use	Cost Impacts
					Shapiro & Loh, 2007; Felix et al., 2011; Alkema, Reyes, & Wilber, 2006; Liu, McBride, & Coughlin, 1990; Mitchell & Krout, 1998; Xu et al., 2010		Slack, 2007; Bharucha et al., 2004; Cai, Salmon, & Rodgers, 2009; Chen and Thompson, 2010; Miller & Weissert, 2000; Muramatsu et al., 2007; Muramatsu et al., 2008	
Education	0	2	4	0		Alkema, Reyes, & Wilber, 2006; Li, 2006	Muramatsu et al., 2007; Muramatsu et al., 2008; Miller, 1998; Chen & Thompson, 2010	
Gender	9	2	13	0	Muramatsu & Campbell, 2002; Shapiro et al., 2009; Shapiro & Loh, 2010; Shaprio & Loh, 2007; Xu et al., 2010; Sands, 2008; Felix et al., 2011; Alkema, Reyes, & Wilber, 2005; Laditka, Laditka, & Drake, 2006	Xu et al., 2010; Miller & Weissert, 2000	Muramatsu et al., 2008; Muramatsu et al., 2007; NYSOA, 2010; D'Souza, 2009; Karuza & Wu, 2011; Chen & Thompson, 2010; Macmillan et al., 2007; Miller, 1998; Sands et al., 2008; Goodwin et al., 2004; Cai, Salmon, and Rodgers, 2009; Miller & Weissert, 2000; Ness, Ahmed, and Aronow, 2004; Gauger et al., 2007	
Race/Ethnicity	13	2	14	0	Muramatsu & Campbell, 2002; Shapiro et al., 2009; Shapiro & Loh, 2010; Shapiro & Loh, 2007; Xu et al., 2010; Felix et al., 2011; Mitchell and Krout, 1998; Wallace et al.,	Haller & Gessert, 2007; Xu et al., 2010	Brock, 2007; NYSOA, 2010; Miller, 2011; Sands et al, 2008; Muramatsu et al., 2008; Karuza & Wu, 2011; Stevens et al., 2004; Muramatsu et al., 2007 Ness, Ahmed, & Aronow, 2004; Andel, Hyer, & Slack 2007;	

Variables with Significant Relationships to Outcomes of Interest ⁷	HCBS Use	Health Care Use	Community Tenure/ NH use	Cost Impacts	HCBS Use	Health Care Use	Community Tenure/ NH use	Cost Impacts
					1999; Goins, Tincher, & Spencer, 2003; Sands et al., 2008; Liu, McBride, & Coughlin, 1994; Laditka, Laditka, & Davis, 2006; Casado, van Vulpen, & Davis, 2011		Cai, Salmon, & Rodgers, 2009; Gaugler et al., 2007; Miller & Weissert, 2000; Feng et al., 2011	
Geographic Location	5	1	3	0	Muramatsu & Campbell, 2002; McAuley, Spector, Van Nostrand, & Shaffer, 2004; Mitchell & Krout, 1998; Sun, 2011; Li, 2006.	Haller and Gesset, 2007	Coward, Home, & Peek, 1995; Macmillan, 2007; Chapin et al., 2003	
Living Alone	4	1	8*	0	Weddle, Wilson, Berkshire, & Heuberger, 2010; Xu et al., 2010; Alkema et al., 2006; Muramatsu & Campbell, 2002	Xu et al., 2010	Muramatsu et al., 2008; NYSOA, 2010; Karuza & Wu, 2011; Macmillan, 2007; Chapin et al., 2003; Cai, Salmon, and Rodgers, 2009; Gaugler et al., 2007; Miller & Weissert, 2000	
Marital Status	5*	1	8*	0	Muramatsu & Campbell, 2002; Shapiro et al., 2009; Xu et al., 2010; D'Souza, 2009; Wallace et al., 1999	Xu et al., 2010	Miller, 1998; Muramatsu, 2007; Karuza & Wu, 2011; Gaugler et al., 2007; Miller & Weissert, 2000; Andel, Hyer, & Slack, 2007; Borrayo et al., 2002; Ness, Ahmed, and Aronow, 2004	
Informal	3	2	9*	0	Xu et al., 2010;	Van	Chen & Thompson,	

Variables with Significant Relationships to Outcomes of Interest ⁷	HCBS Use	Health Care Use	Community Tenure/ NH use	Cost Impacts	HCBS Use	Health Care Use	Community Tenure/ NH use	Cost Impacts
Caregiver Availability					Chen & Thompson, 2010; Mitchell & Krout, 1998	Houtven & Norton, 2004; Xu et al., 2010	2010; Chapin et al., 2003; Karuza & Wu, 2011; Miller & Weissert, 2000; Gaugler et al., 2007; Van Houtven & Norton, 2004; Friedman et al., 2005; Lo Sasso & Johnson, 2002; Andel, Hyer & Slack 2007	
Having children	1	0	3	0	Muramatsu & Campbell, 2002		Muramatsu et al, 2007; Muramatsu et al., 2008; Gaugler et al., 2007	
Social Support	0	0	1	0			Bharucha et al., 2004	
Enabling								
Income	6	1	6	0	Muramatsu & Campbell, 2002; Shapiro & Loh, 2007; Chen & Thompson, 2010; Casado, van Vulpen, & Davis, 2010; Wolinsky & Johnson, 1991; Borrayo et al., 2004	Miller & Weissert, 2000	Muramatsu et al., 2008; Chen & Thompson, 2010; Macmillan et al., 2007; Muramatsu et al., 2007; Karuza & Wu, 2011; Miller & Weissert 2000	
Home ownership	0	0	3	0			Muramatsu et al., 2007; Cai, Salmon, & Rodgers, 2009; Gaugler et al., 2007	
Payment method	2	0	6*	0	Muramatsu & Campbell 2002; Chen & Thompson; 2010		Muramatsu et al., 2008; Chen & Thompson, 2010; Macmillan et al., 2007; Sands, 2008; Ness, Ahmed, & Aronow, 2004; Borrayo, Salmon, Polivka, & Dunlop, 2002	

Variables with Significant Relationships to Outcomes of Interest ⁷	HCBS Use	Health Care Use	Community Tenure/ NH use	Cost Impacts	HCBS Use	Health Care Use	Community Tenure/ NH use	Cost Impacts
Caregiver or Spouse age	0	0	2	0			Muramatsu et al., 2007; Yaffe et al., 2002	
Caregiver support	1	0	1	0	Casado, van Vulpen, & Davis, 2010		Miller & Weissert, 2000	
Caregiver burden	0	0	4	0			Gaugler et al., 2009; Miller, Rosenheck, Schnieder, 2012; Spillman and Long, 2009; Yaffe et al., 2002	
NH bed supply	0	0	6	0			Miller, 1998; Muramatsu et al., 2008; Muramatsu et al., 2007; Miller, 2011; Miller & Weissert 2000; Borrayo et al., 2002	
Number HHAs	0	0	3	0			Miller 1998; Muramatsu et al., 2008; Miller, 2011	
Medicaid HCBS spending	0	1	1	0		D'Souza et al., 2009	D'Souza et al., 2009 Miller 1998	
State HCBS spending	2	1	2	0	Muramatsu & Campbell, 2002; Muramatsu et al., 2008	D'Souza et al., 2009	Muramatsu et al., 2008; D'Souza, 2009; Hahn et al., 2011; Thomas & Mor, 2013	
Pre-admission screening	0	0	3	0			Chapin et al., 2003; Macmillan et al., 2007; Miller, 1998	
Need								
Alzheimer's Disease/Cognitive impairment	2	1	11	0	Xu et al., 2010; D'Souza; 2009	Xu, 2010	Miller, 1998; NYSOA, 2010; D'Souza, 2009; Muramatsu et al., 2008; Muramatsu et al., 2007; Bharucha et al., 2004; Borrayo et al., 2002; Chen and Thompson, 2010; Gaugler et al., 2007;	

Variables with Significant Relationships to Outcomes of Interest ⁷	HCBS Use	Health Care Use	Community Tenure/ NH use	Cost Impacts	HCBS Use	Health Care Use	Community Tenure/ NH use	Cost Impacts
							Miller and Weissert, 2002; Wolinsky & Johnson, 1991	
Comorbidities / Chronic Medical Conditions	3*	2	4	0	Xu et al., 2010; Sands 2008; Felix et al., 2011	Xu et al., 2010; Haller & Gessert	Banaszak-Holl et al., 2004; Borrayo et al., 2002; Muramatsu, 2007; Sands, 2008	
Psychiatric issues / Problem behavior	0	0	3	0			Cai, Salmon & Rodgers, 2009; Miller & Weissert, 2000; Andrews et al., 2009	
Worse ADL/IADL performance in general	0	0	2	0			Miller & Weissert, 2000; Muramatsu et al., 2007	
ADL limitations	10	0	10	0	Muramatsu & Campbell, 2002; Shapiro et al., 2009; Shapiro & Loh, 2010; Shapiro & Loh, 2007; Xu et al., 2010; Chen & Thompson, 2010; D'Souza et al., 2009; Johnson & Wolinsky, 1995; Borrayo et al., 2002; Wolinsky & Johnson, 1991		Chen et al., 2010; D'Souza, 2009; Muramatsu et al., 2007; Muramatsu et al, 2008; NYSOA, 2010; Karuza & Wu, 2011; Miller 1998; Chapin et al.; 2002; Borrayo et al., 2002; Gaugler et al., 2007	
IADL limitations	5	0	7	0	Muramatsu & Campbell, 2002; Shapiro et al., 2009; Shapiro & Loh, 2007; Chapin et al. 2002; Chen & Thompson 2010		Miller, 1998; Karuza, 2011; NYSOA, 2010; Andel, Hyer, & Slack, 2007; Chapin et al., 2002; Chen & Thompson, 2010; Cai, Salmon, & Rodgers, 2009	
Self-health ratings	0	0	2	0			Muramatsu et al., 2007; Cai, Salmon, & Rodgers	

Variables with Significant Relationships to Outcomes of Interest ⁷	HCBS Use	Health Care Use	Community Tenure/ NH use	Cost Impacts	HCBS Use	Health Care Use	Community Tenure/ NH use	Cost Impacts
Perceived unmet need	4	1	1	0	Kosloski & Montgomery, 1994; Mitchell & Krout, 1998; Chen & Thompson, 2010; Casado, van Vulpen, & Davis, 2010	DePalma et al., 2012	Karuza & Wu, 2011	
Use								
Prior Hospitalization	2	1	6	0	D'Souza 2009; Sands et al, 2008	Xu et al., 2010	Sands et al., 2008; Goodwin et al., 2001; D'Souza et al., 2009; Xu et al., 2010; Gaugler et al., 2007; Miller & Weissert; 2000	
Prior NH Use	0	0	4	1			Muramatsu et al. 2007; Friedman et al., 2005; Miller & Weissert; 2000; Gaugler et al., 2007; Shapiro & Taylor, 2002; OPPAGA, 2010	Shapiro & Loh 2010
HCBS Use	1	1	12	4	Chen & Thompson, 2010	Xu et al., 2010	Chen & Thompson, 2010; Macmillan et al., 2007; Karuza, 2011; NYSOA, 2010; D'Souza, 2009; Brock et al. 2007; Gaugler et al., 2005; Kosloski et al., 1995; Chen & Thompson, 2010; Chen et al., 2004; Miller & Weissert 2000; Fischer et al., 2003	Shapiro et al 2009; Shapiro & Loh, 2010; Shapiro & Loh, 2007; Felix et al., 2011
Paid Helpers	0	0	2	0			Miller & Weissert, 2010; Chen & Thompson, 2010	
Case Management	0	0	2*				Karuza 2011; NYSOA, 2010	
Medicaid waiver	0	0	1	2			Pande, Laditka,	Shapiro

Variables with Significant Relationships to Outcomes of Interest ⁷	HCBS Use	Health Care Use	Community Tenure/ NH use	Cost Impacts	HCBS Use	Health Care Use	Community Tenure/ NH use	Cost Impacts
							Laditka, & Davis, 2007	et al., 2009; Shapiro & Loh, 2010
Timing of Care	0	0	2	0			Macmillan et al. 2007; Gaugler et al. 2005	
Volume of services	0	1	2	1		Xu et al., 2010	Brock et al., 2007; Karuza & Wu 2011	Shapiro & Loh, 2010
Low-intensity HCBS	0	0	0	0 1				Shapiro & Loh, 2010
Combination of services	0	0	3	1			Karuza & Wu, 2011; Brock et al, 2007; Chapin et al, 2003	Shapiro et al, 2009
OAA III-B	0	0	0	2				Shapiro et al, 2009; Shapiro & Loh, 2010
OAA III-C	1	0	1	2	Xu et al., 2010		NYSOA, 2010	Shapiro et al., 2009 Buys et al. 2011
OAA III-E/Respite	0	0	3	1			Brock, 2007; Karuza, 2011 Kosloski & Montgomery, 1995	Shapiro & Loh, 2009

Appendix A-C: Detailed Bibliography

HCBS Studies Selected for In-Depth Review, Data Extraction, and Analysis

The 19 HCBS studies selected for in-depth review are summarized below. These studies were selected for more in-depth review, data extraction, and analysis because they: (1) specifically examined OAA services (POMP and Kansas Community Tenure

Study/CARE related studies), and/or (2) provided useful information to inform the study design.

NO.	Study	Reason for Including /Summary
1	<p>Brock, D.B., Rabinovich, B., Severynse, J., Ficke, R.USDHHS, Administration on Aging. (2007). Risk factors for nursing home placement among OAA service recipients: Summary analysis of data from five sources. (233-02-0087)</p>	<p>The Performance Outcomes Measurement Project (POMP) in Rhode Island, Georgia, North Carolina, and New York</p> <p>The authors use data from the Performance Outcomes Measurement Project (POMP) in Rhode Island, Georgia, North Carolina, and New York to examine the effect of the receipt of OAA services on the potential delay in nursing home (NH) placement among OAA service clients age 60 and older. The OAA services across the states were similar, but there was still some variation state-to-state. They also analyzed the national Health and Retirement Study.</p> <p>The authors used a time-to-event analysis (time to NH placement) using the Cox Proportional Hazard Model.</p> <p>Among their findings, Rhode Island POMP data analysis showed that risk of NH admission decreased for clients receiving more than one service, as compared with only one service. Utilization of case management services was associated with increased likelihood of NH admissions, but the authors suggested that this may be because use of case management services is an indicator of higher need.</p> <p>A recommendation based on the results of POMP studies was to include personal and institutional health resources and characteristics, as well as area characteristics in future research.</p>
2	<p>Chapin, R., Baca, B., Macmillan, K., Rachlin, R., & Zimmerman, M. (2009). Residential Outcomes for Nursing Facility Applicants Who Have Been Diverted: Where Are They 5 Years Later? <i>The Gerontologist</i>, 49(1): 46-56.</p>	<p>CARE Study</p> <p>The authors use data from the Client Assessment and Referral Evaluation (CARE) program. This assessment is completed when individuals seek nursing facility (NF) admission (both Medicaid and private pay). In addition to CARE program data, the authors used data from publicly-funded community based services (Medicare, Medicaid, and state), NF admission data, and death records.</p> <p>This was a five-year prospective study – they tracked those who applied for NF admission and those who were diverted. They then tracked the</p>

NO.	Study	Reason for Including /Summary
		<p>diverted individuals over a period of five years.</p> <p>Those diverted received services (many types, including OAA-funded services) during the five-year period. The use of these services was intermittent.</p> <p>A notable finding from this study is that many of the individuals diverted from NF were diverted until death, not just until NF admission.</p> <p>Additionally, the characteristics of those diverted versus those not diverted were very similar; suggesting that more could be done to divert individuals from NFs.</p> <p>A limitation of this study is that they only tracked individuals over a period of 60 months. The authors recommend future studies track diverted individuals over the remaining life course.</p>
3	<p>Chapin, R., Zimmerman, M., Macmillan, K., Rachlin, R., Nakashima, M., Hayes, J., Oslund, P., Swaim, T., Burke, J., Shea, J., Reed, C. (2002) <i>Longitudinal study of customers diverted through the care program: Technical report</i>. School of Social Welfare Office of Aging and Long Term Care., University of Kansas , Lawrence, Kansas.</p>	<p>CARE Study</p> <p>This study reviewed whether Medicaid-HCBS/FE Waiver Program services contributed more to community tenure than other services. The Kansas Department on Aging (KDOA) was interested in learning how long diverted older adults remain in the community (after the CARE assessment) and how effective State Publicly Funded Services (SPFS) are in helping older adults increase community tenure and avoid NF admission.</p> <p>The Kansas Department on Aging provided CARE Assessment, Senior Care Act, and Medicaid Home and Community Based Services for the Frail Elderly and Older Americans Act service data. Data were extracted from the KAMIS and MMIS data systems.</p> <p>The authors conducted a survival analysis along with a matched comparison group. They also analyzed qualitative data from interviews with the customers or their personal caregivers.</p> <p>The authors found that the use of Medicaid HCBS/FE Waiver Program services, State General Fund (SGF), and/or OAA before a NF admission appeared to impact the length of stay – many of the short-term residents (64.9%) received SPFS compared to 42.9% of permanent Medicaid NF residents.</p>
4	<p>Chapin, R., Zimmerman, M., Chapin, R., Zimmerman, M.,</p>	<p>CARE Study</p> <p>The authors presented their analysis of community</p>

NO.	Study	Reason for Including /Summary
	<p>Macmillan, K., Rachlin, R., Reed, C., Hickey, A., Baca, B., Wiebold-Lippisch, L., Henning, E., Oslund, P., Hayes, J., Katz, B., & Shea, J. (2003). <i>Examination of the Use of Medicare Home Health Services and Informal Caregiving and Their Relationship to Successful Community Tenure and Appendices</i>. School of Social Welfare Office of Aging and Long Term Care. University of Kansas, Lawrence, Kansas.</p>	<p>tenure, risk factors for a NF admission, and cost benefits of SPFS compared to NF admission.</p> <p>This builds on the 2002 study and utilizes the same methodology. The analysis of this study for 2003 included Medicare Home Health Service use data (OASIS) and an additional six months of SPFS, Minimum Data Set (MDS), and death data. The authors also conducted interviews with older adults, and their caregivers, who received the CARE assessment.</p> <p>The authors found that SPFS are cost effective and diverted customers continued to have high rates of community tenure. This data confirms that State Publicly Funded In-Home Services, Medicare Home Health Services, and Informal Support contribute to diversion and community tenure.</p> <p>Regarding OAA services, they found that the annual savings for diverted CARE customers who received OAA services was \$441,524.16.</p> <p>To determine factors that contribute to community tenure, the authors used the Cox Proportional Hazards Model Analysis and Logistic Regression Analysis.</p>
<p>5</p>	<p>Chen, Y., & Adams Thompson, E. (2010). Understanding factors that influence success of home- and community-based services in keeping older adults in community settings. <i>Journal of Aging and Health</i>. 22(3): 267-291.</p>	<p>The authors researched factors that influence success of HCBS in increasing community tenure.</p> <p>This study addressed three dimensions—personal factors, services use, and remaining in the community--in temporal order. The study constructed a theoretical framework to predict the likelihood of older adults residing in the community. They tested the framework using a complex structural equation model and nationally representative sample from a longitudinal survey (The Second Longitudinal Study of Aging) with data for six years.</p> <p>The study examined many types of non-OAA HCBS (discretionary services, nondiscretionary services, paid ADL and IADL help, unpaid ADL and IADL help) and different frequencies, and amounts, of these services.</p> <p>The results revealed the importance of paid IADL personal care services, and of elders' awareness of their unmet needs. In the complex model that was tested, these two factors stood out as the only</p>

NO.	Study	Reason for Including /Summary
		<p>significant factors that supported older adults remaining in the community.</p>
6	<p>D'Souza, J.C., James, M.L., Szafara, K.L. & Fries, B.E. (2009). Hard Times: The Effects of Financial Strain on Home Care Services Use and Participant Outcomes in Michigan. <i>The Gerontologist</i>. 49(2): 154-165.</p>	<p>The authors investigated the effect of program resources on individuals' enrollment in the MI HCBS waiver program for elderly and disabled adults. These services include personal care, homemaker, meals, adult day care, private duty nursing, skilled therapies, volunteer, and total formal service time.</p> <p>The data source for this study was a data archive maintained by the University of Michigan Institute of Gerontology – this includes participant data collected as a part of the Minimum Data Set for Home Care.</p> <p>Using dates of major policy and budget changes, the study defined four distinct time periods over four years. Data for over 100,000 participants were used to examine temporal trends in informal care hours and the six outcomes (emergency room use, hospitalization, caregiver burden, death, NF use, and permanent NF placement), controlling for demographics, functional status, and cognitive status. The study obtained adjusted odds of outcomes using discrete-time survival analysis.</p> <p>The study investigated the effect of HCBS funding on participant outcomes.</p> <p>They found that as resources diminished, mean formal care hours decreased, and three adverse outcomes increased: hospitalization, ER use, and NF placement.</p>
7	<p>Felix, H.C., Mays, G.P., Stewart, N.C., & Olson, M. (2011). Medicaid savings resulted when community health workers matched those with needs to home and community care. <i>Health Affairs</i>. 30(7): 1366-1374.</p>	<p>The Arkansas Community Connector Program was the first US initiative to test a mechanism of identifying priority populations with unmet LTC needs, to help them gain access to HCBS. The study measured outcomes on growth in use of Medicaid HCBS and growth in overall Medicaid spending in program participants versus comparison group members</p> <p>Using a longitudinal, quasi-experimental design, the study compared 919 Medicaid recipients served by the Community Connector program for three years, in three intervention counties, with a statistically matched group of 944 Medicaid recipients in five nearby counties.</p> <p>This study examined participation in the Arkansas</p>

NO.	Study	Reason for Including /Summary
		<p>Community Connector Program, which used community health workers specifically for the purpose of providing targeted outreach to residents in need of HCBS, who may be at risk of entering NHs, and connecting them to HCBS.</p> <p>Results suggested that Medicaid realized a substantial return of nearly three dollars on each dollar invested in the program. The program also increased spending on HCBS and decreased spending on NHs.</p> <p>The findings suggest that it can pay to actively seek out people with unmet LTC needs and help them gain access to formal services.</p>
8	<p>Karuza, J. & I-Hsin, W. Administration on Aging. (2011). Cross validation of nursing home placement prediction models: Findings from the advanced performance outcome measurement project.</p>	<p><i>New York POMP Study</i></p> <p>The Advanced POMP initiative’s objective is to examine the effects of HCBS provided by the aging network on the risk of nursing home placement for older adults.</p> <p>The authors conducted a time-to-event analysis (time to NH placement) using Cox Proportional Hazards Regression Models applied to client data from the participating states. They examined administrative data on OAA participants from Georgia, New York, North Carolina, and Rhode Island</p> <p>The outcomes measured were: (1) remaining in the community; (2) permanent nursing home placement; (3) mortality; (4) loss to follow-up; and, (5) the end of the study period.</p> <p>Results showed that IADLs were more significantly associated with increased risk for NH placement than commonly recognized limitations in ADLs.</p> <p>The findings suggest that OAA funded services, when administered in combination, are more effective than single OAA services.</p>
9	<p>Macmillan, K.R., Rachlin, R., Chapin, R., Chandran, D., Leedahl, S., Baca, B., Zimmerman, M., & Oslund, P. (2007). <i>The Community Tenure Study: Community Tenure Status of CARE Assessment Customers 60 Months after Diversion</i>. School of Social Welfare</p>	<p><i>CARE Study</i></p> <p>This study updates the status of participants in Chapin et al’s studies in 2002 and 2003. The outcomes measured were: (1) The community tenure status of diverted customers in 3-month intervals; (2) The state publicly funded service utilization of diverted customers in 3-month intervals; and, (3) The demographic and other differences</p>

NO.	Study	Reason for Including /Summary
	<p>Office of Aging and Long Term Care. University of Kansas. Lawrence, Kansas.</p>	<p>between diverted customers who maintained community tenure and those who became permanent nursing facility residents.</p> <p>Macmillan et al. (2007) used several data sources to track diverted customers, including Kansas CARE Assessment, Senior Care Act, Medicaid HCBS/FE, and OAA service data (from the KAMIS and MMIS data systems). They also used Kansas Department of Health and Environment data to verify death and CMS MDS data to identify permanent NF admission information.</p> <p>The services their study examined included SPFS, Medicare Home Health Services, and Informal Support.</p> <p>Results of the care study indicate that being a customer identified as potentially lower income, at the time of the study, was associated with higher rates of NH admissions than those not qualifying for Medicaid.</p> <p>The Kansas CARE study of participants in an Aging Network Nursing Home Diversion Program reported that diverted customers with greater level of need (higher LTC threshold scores) were able to stay in the community longer</p>
<p>10</p>	<p>Miller, S.C., Prohaska, T.R., Furner S.E., Freels S., Brody J.A., & Levy P.S. (1998). Time to nursing home admission for persons with Alzheimer's disease: the effect of health care system characteristics. <i>Journal of Gerontology Series B.</i> 53(6):S341-53.</p>	<p>This study analyzed the effects of health care system characteristics on the time to NH admission for persons with Alzheimer's disease.</p> <p>Up to nine years of data from 639 individuals (the Consortium to Establish a Registry for Alzheimer's Disease (CERAD)) was merged with longitudinal data from 28 states, where CERAD individuals resided. The study used a Cox Proportional Hazards Model to examine risk factors associated with time to NH admission, taking into account characteristics of each state's LTC system.</p> <p>Services examined included the percent of state spending on HCBS and LTC, along with other enabling variables. This included availability of NH beds and availability of HCBS. They also examined marital status and education.</p> <p>A higher percentage of state spending on HCBS was associated with a longer time to NH admission for unmarried persons with Alzheimer's disease in the first three years. The authors also found that, for</p>

NO.	Study	Reason for Including /Summary
		<p>married persons, a higher number of home health aides per 100,000 persons age 65 and over resulted in a longer time to NH admission.</p>
<p>11</p>	<p>Miller, N.A. (2011). Relations Among Home-and Community-Based Services Investment and Nursing Home Rates of Use for Working-Age and Older Adults: A State-Level Analysis. <i>American Journal of Public Health</i>, 101(9): 1735-1741.</p>	<p>This study examined relations among state provision of Medicaid-funded HCBS and NH rates of use for working-age and older-adults. The study examined associations between state socio-demographic, economic, supply, and programmatic characteristics and rates of use.</p> <p>The author combined many existing data sources and used multivariate fixed effects models to examine state-level rates of NH use over a seven-year period (2000-2007). Data were from all states and DC, except Arizona.</p> <p>Miller examined states' relative investment in HCBS (the share of LTC dollars devoted to HCBS). LTC expenditures were determined by combining NF, home health, personal care, and 1915(c) expenditures for older and working age adults, individuals with traumatic brain injury, and individuals with HIV/AIDS.</p> <p>The study found that greater investment in HCBS, coupled with reduced NH capacity, was associated with reduced rates of NH care for adults age 65 and older, but not for working-age adults. Their use was associated with state socio-demographic characteristics, as well as chronic disease prevalence.</p>
<p>12</p>	<p>Muramatsu, N. & Campbell, R.T. (2002). State Expenditures on home and community based services and use of formal and informal personal assistance: a multilevel analysis. <i>Journal of Health and Social Behavior</i>. 43(1): 107-124.</p>	<p>The authors examined the use of formal HCBS and informal personal assistance among adults age 70 and older, living in the community, with functional limitations.</p> <p>The sample included respondents to a nationally representative survey of older adults (N=3,051) with at least one ADL or IADL limitation. They combined data from this survey (the Assets and Health Dynamics among the Oldest Old Survey) with state HCBS expenditure data. The study conducted a two-level multinomial logistic regression analysis of data on the survey population nested in 34 states. This approach explored links between macro and micro levels of social phenomena.</p> <p>The authors found that, controlling for demographic, socioeconomic, and care needs factors, states with</p>

NO.	Study	Reason for Including /Summary
		<p>higher HCBS expenditures had individuals who were more likely to use formal personal assistance, but still not less likely to use informal personal assistance. The probability of using any formal assistance increases when an individual has more ADL limitations and lives in a state with higher levels of HCBS spending.</p> <p>This was the first known study indicating that the association between ADL limitations and use of personal assistance depends upon the level of HCBS expenditures of the state where individuals reside. The study suggested that, to the extent that supportive formal services can reduce the stress on the caregiver, state spending on HCBS may strengthen the existing system of informal caregiving.</p>
<p>13</p>	<p>Muramatsu N., Hoyem R.L., Yin H, & Campbell R.T. (2008). Place of death among older Americans: does state spending on home- and community based services promote home death? <i>Med Care.</i> 46(8):829- 38.</p>	<p>This study examined the impacts of state spending on HCBS and on dying at home versus dying in a NH among older Americans.</p> <p>The sample for this study included 3,320 respondents to the Health and Retirement Study, born 1923 or earlier, and who died between 1993 and 2002 (age 70 and older).</p> <p>Discrete time survival analysis of risk of end-of-life NH relocation was performed to examine the association with states' HCBS spending.</p> <p>The authors examined total HCBS expenditures for the 65 and older population, and the percentage of LTC expenditures going to HCBS rather than NHs.</p> <p>The study found that living in a state with higher HCBS spending was associated with lower risk of end-of-life NH relocation. This was found especially among individuals on Medicaid. State support for HCBS increased the chance of dying at home by lowering the risk of end-of-life NH relocation.</p>
<p>14</p>	<p>Muramatsu N., Yin, H., Campbell R.T., Hoyem, R.L., Jacob, M.A., & Ross, C.O. (2007). Risk of nursing home admission among older Americans: Does states' spending on home- and community-based services matter? <i>Journal of Gerontology Series B.</i> 62(3):169-78.</p>	<p>The authors examined the effect of state HCBS spending on NH admission among older Americans.</p> <p>They performed a discrete time survival analysis of first LTC admissions (90 days or more) over seven years, using data from the Health and Retirement Study.</p> <p>The authors examined total HCBS expenditures for those 65 and older, and the percent of LTC</p>

NO.	Study	Reason for Including /Summary
		<p>expenditures going to HCBS rather than NHs.</p> <p>Living in a state with higher HCBS expenditures was associated with lower risk of NH admission among childless seniors, but was not found to be statistically significant among seniors with living children. Lack of information on existing targeting policies and practices prevented the study from exploring whether the lack of impact of HCBS among childless seniors reflected targeting of seniors who lack family, or the ineffectiveness of state HCBS support among that population.</p>
<p>15</p>	<p>New York State Office for the Aging (2010). Performance outcomes measures project (POMP): From home care to nursing home in New York: demonstrating the benefits of aging network services. Albany.</p>	<p><i>New York POMP</i></p> <p>The authors calculated the outcome variable “survival time” for each individual consumer as the difference (in months) between the date of the event (nursing home placement) or censoring (by death, movement out of the study area, end of the study period, or other loss to follow-up) and the date the consumer entered the aging network service system.</p> <p>The authors used administrative data from January 2008 - June 2009 from the four New York AAAs participating in POMP. They examined whether the receipt of OAA Cluster 1 services affected NH placement. They also used the data to identify risk factors that contributed to NH entry. The authors used the Cox Proportional Hazards Model as the method for survival analysis to study an individual’s survival time to a particular outcome.</p> <p>They examined OAA Cluster 1 Services, which include: personal care services; homemaker/chores services; home-delivered meals; adult day care services; and, case management services.</p> <p>The authors stated that the modeling of “time to nursing home placement” shows that aging network consumers’ relative nursing home risk can be reduced by total services and personal care. They found that intensity of case management services in two counties was a statistically significant predictor for NH placement, controlling for other factors.</p>
<p>16</p>	<p>Shapiro, A. & Loh, C.P. (2007). <i>Establishing Algorithms for the Cost-Benefit Analysis of In-Home Services for Elderly in Florida.</i></p>	<p><i>Florida POMP</i></p> <p>The purpose of this study was to examine the estimated cost savings of Medicaid HCBS in Florida. The authors studied five HCBS programs in Florida</p>

NO.	Study	Reason for Including /Summary
	<p>(Florida Department of Elder Affairs and Administration on Aging No. XQ648). University of North Florida: Report for Florida Department of Elder Affairs.</p>	<p>which were: 1) Alzheimer’s Disease Initiative (ADI); 2) Community Care for the Elderly (CCE); 3) Home Care for the Elderly (HCE); 4) Medicaid Waiver (MW); and, 5) Older Americans Act 3b (OA3B).</p> <p>The authors utilized Medicaid claim data (SFY 1999-2005) to use a propensity score matching procedure, which simulated random assignment of Florida Department of Elder Affairs (FDOEA) clients into matched treatment (HCBS users) and comparison (waitlist) groups. They produced an algorithm that determined differences in Medicaid expenditures between the HCBS and waitlist groups, which produced an estimated cost savings. They also performed telephone interviews with over 500 FDOEA clients to employ a “Willingness to Pay” procedure.</p> <p>Their results suggest evidence of Medicaid cost avoidance through the use of HCBS programs in Florida. In the five HCBS programs analyzed, the range was a cost overage of \$885/month and a cost savings of \$1558/month.</p> <p>They also found from their contingent valuation survey that older adults’ median estimates of the hedonic value of their quality of life is, on average, \$900/month across all service programs.</p>
<p>17</p>	<p>Shapiro, A., & Loh, C.P. (2010). Advanced performance outcome measures project (POMP): Estimates of Medicaid and general revenue cost-avoidance from HCBS utilization (Contract No. XQ867)</p>	<p>Florida POMP</p> <p>The authors examined the cost effectiveness of HCBS programs for Medicaid and General Revenue in Florida. They examined the same services from their 2007/2009 studies, which include: the Alzheimer’s Disease Initiative (ADI); Community Care for the Elderly (CCE); Home Care for the Elderly (HCE); Medicaid Waiver (MW); and, Older Americans Act 3b (OA3B).</p> <p>They used data from their 2009 project to estimate models of cost-effectiveness simultaneously to reduce the error of measurement. They then estimated Medicaid and General Revenue cost-savings of HCBS programs through the use of a sample of individuals who would be placed into NHs.</p> <p>The researchers found evidence that HCBS utilization produces cost savings when compared with costs from those on waitlists for services and non-applicants. The largest and most consistent HCBS enrollment benefit was found for Medicaid NH</p>

NO.	Study	Reason for Including /Summary
		<p>expenses. These NH cost savings ranged from \$1000-\$1400/month compared to the MDS group (depending on service use intensity). The low intensity HCBS users utilized the fewest general revenue expenses and generated the greatest overall cost savings, in comparison to the non-users and non-applicants.</p>
18	<p>Shapiro, A., Loh, C.P. & Mitchell, G. (2009). Medicaid Cost-Savings of Home-and Community-Based Service Programs for Older Persons in Florida. <i>Journal of Applied Gerontology</i>, 30(1): 3-21.</p>	<p>This study examined potential Medicaid cost savings that result from HCBS use by older Floridians. They examined the same services from their 2007study, which include: the Alzheimer’s Disease Initiative (ADI); Community Care for the Elderly (CCE); Home Care for the Elderly (HCE); Medicaid Waiver (MW); and, Older Americans Act 3b (OA3B).</p> <p>The authors used Medicaid claim data (SFY 2000-2005) to use a propensity score matching procedure to simulate random assignments of seniors into a matched treatment group (HCBS users), and a comparison (waitlist) group. They developed an algorithm that determined differences between the two groups in Medicaid expenditures – this produced an estimate of cost savings.</p> <p>The authors found that some Florida HCBS programs showed evidence of Medicaid cost-savings. The median savings varied, ranging from a cost overage of \$277 per member per month to a cost-savings of \$229 per member per month. This was especially apparent when examining nursing home costs.</p>
19	<p>Xu H., Weiner M., Paul S., Thomas J., Craig, B., Roseman M., Doebbeling, C.C., & Sands LP. (2010). Volume of home- and community-based Medicaid waiver services and risk of hospital admissions. <i>Journal of the American Geriatrics Society</i>, 58(1): 109-115.</p>	<p>This study examined the effect of type and volume of HCBS Medicaid Waiver services on the risk of hospital admissions. They used Indiana Medicaid claims data (June 2001-December 2004). The Medicaid HCBS services examined included attendant care, home making, and home-delivered meals.</p> <p>The authors used a Cox Survival Analysis to examine time to hospital admission since enrollment in the HCBS waiver. They adjusted for demographics, comorbidities, prior use of health services, and volume of HCBS received. The sample included 1,354 Indiana Medicaid recipients, who were enrolled over two years.</p> <p>They found that a greater volume of the Medicaid</p>

NO.	Study	Reason for Including /Summary
		Waiver HCBS that they examined was associated with a lower risk of hospital admissions. The authors note that this association diminished, and was no longer significant, around one year after program enrollment. The lowest risk of hospital admissions was seen among individuals receiving more hours of attendant care and homemaking services.

In addition to the above studies selected for in-depth review, many additional studies were reviewed that addressed some topics of interest to this project but did not meet the criteria for an in-depth review and extraction of information.

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Appendix B: Study Framework and Design

Overview

Older American Act (OAA) programs and services represent a significant federal investment in developing a comprehensive, coordinated, and cost-effective system of home and community-based services (HCBS) that enables adults to live independent and healthy lives in their homes and communities. Under this project, the Administration on Aging (AoA) seeks to design a rigorous study of the impact of OAA programs and services on key outcomes including HCBS use, health care use, community tenure, and long term services and supports (LTSS) expenditures. OAA services and programs are diverse, often integrated and/or provided in combination with other services, funded through multiple funding streams, and administered and delivered by different state and local-level agencies with varying data collection capacity. Therefore, a study of OAA funded programs and services is inherently challenging.

This Study Design describes The Lewin Group's proposed approach for understanding the impact of OAA programs and services on the aforementioned outcomes of interest. Building off of the literature review^{viii} and study framework,^{ix} this document includes a discussion of the challenges and trade-offs that must be considered in the selection of variables, research questions, study design options and secondary data sources, in order for AoA to endorse a rigorous impact study of OAA programs and services.

Purpose of the Study

Developing and designing a study that produces credible, solid evidence of results is of critical importance to AoA, the Aging Network, service recipients and families who rely on OAA services. Key policymakers, such as Congress and the Office of Management and Budget (OMB) at the federal level, as well as state and local governments, use program evaluation information to make budget decisions. Increasingly, funding for health and social programs is dependent on stakeholders' ability to make the business case for the investment, with rigorous research demonstrating success in improving peoples' lives and achieving more effective use of resources. A study with inconclusive results or a study that suggests a lack of impact when in fact the design prevented the impact from being detected can be detrimental.

^{viii} The Lewin Group (2012). Study of the Global Outcomes of the Older Americans Act Programs and Services- Review of the Literature Department of Health and Human Services, Administration on Aging.

^{ix} The Lewin Group (2012). Study of the Global Outcomes of the Older Americans Act Programs and Services – Study Framework. Department of Health and Human Services. Administration on Aging.

This study focuses on the impact of services provided through OAA funded HCBS programs authorized under Titles III-B, C, D, and E of the OAA. These programs include a range of supportive services, nutrition services, health promotion and disease prevention programs, as well as services for family caregivers. While the mix and type of services offered differ by state and locality, the vast majority of OAA funding is used for the provision of nutritional services.

Process for Developing the Study Design

To begin, the team conducted a thorough review of the literature to examine the methodology, findings, etc. of related studies. These studies informed the research questions, logic model, and initially proposed OAA global outcomes study design. Subsequently, AoA and Lewin held multiple meetings to discuss these documents. Following the development of a study design, AoA and Lewin engaged various stakeholders through:

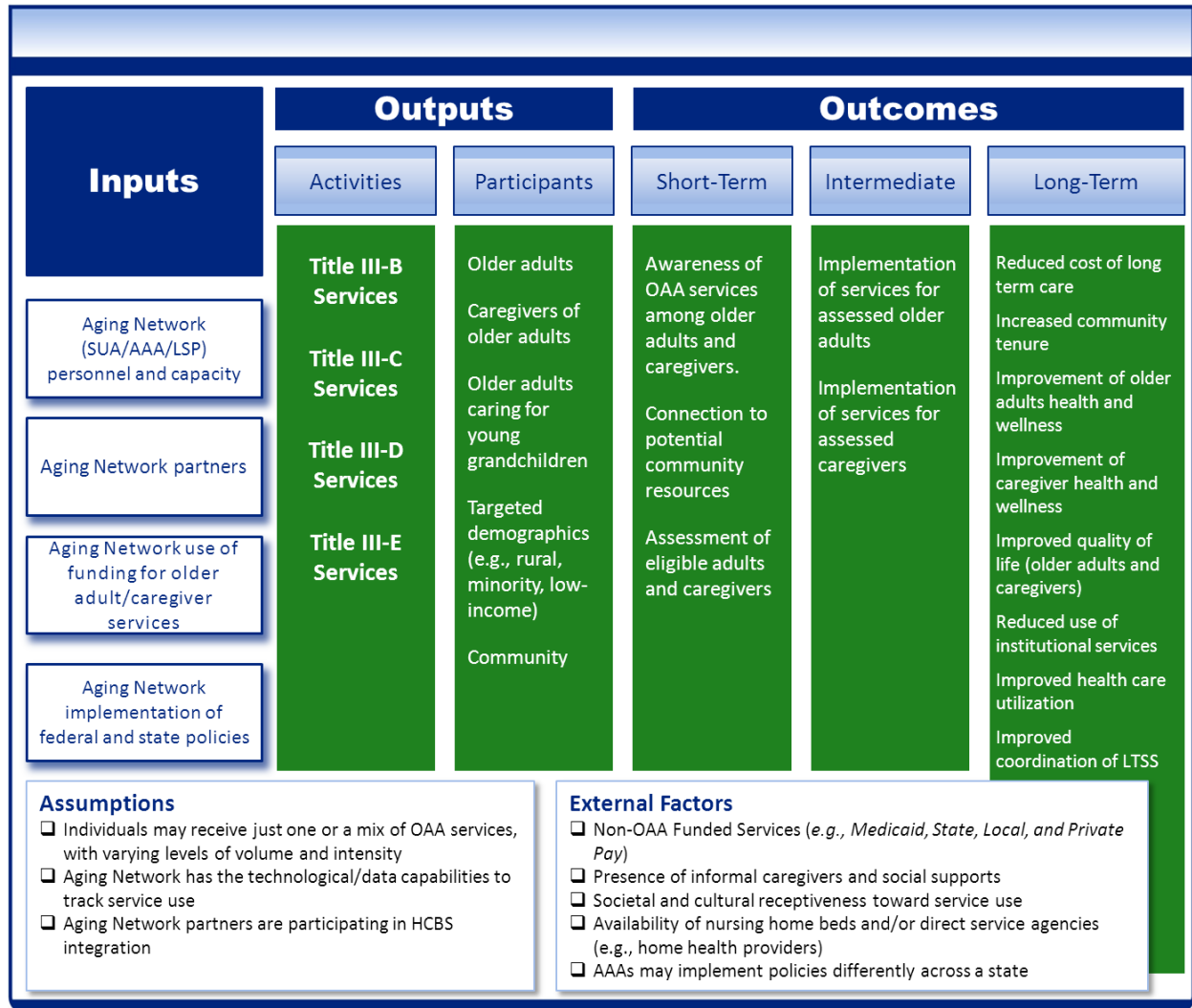
- ▶ Convening an expert group to provide feedback on the study design - with representatives from federal and state government, local agencies, and academia.
- ▶ Conducting key informant interviews with state representatives to better understand the available state administrative data for OAA, data collection and reporting processes.
- ▶ Conducting key informant interviews with selected expert group members to receive additional feedback and additional experts as needed.

Next steps based on feedback received are reflected in the **Limitations and Recommendations** document. In the process of designing this study, the research team identified a number of strengths and limitations to conducting a global outcomes study of the OAA.

Logic Model

The logic model below depicts the inputs, activities, outputs, and outcomes of OAA funded HCBS programs and services. We included “non-OAA funded activities” (e.g., informal services, state funded HCBS, private pay) as these activities often occur in combination with OAA-funded activities and impact the key outcomes of interest for this project. Assumptions and external factors are presented.

Figure 4: Logic Model



Research Questions

Based on the expected outcomes depicted in the logic model, the following research questions for an OAA global outcomes study were proposed. What is the impact of OAA funded HCBS programs and services on:

- ▶ Community tenure
- ▶ Health care utilization
- ▶ Costs of care for older adults (e.g., LTSS, health care costs)
- ▶ Physical, mental, and emotional health and wellness (i.e., preventive measures) of care recipients and caregivers
- ▶ Unmet needs among older adults
- ▶ Caregivers (e.g., strain, burden, depression, health, etc)
- ▶ Coordination of services (e.g., care management)

In addition to answering questions about the impact of service use on desired outcomes, it is recommended that AoA consider a design that measures the strength of association of covariates/intervening variables on the key outcomes including, but not limited to, mix, type, and intensity of services. This step would answer the following sample questions:

- ▶ What is the impact of OAA services alone or in combination with services paid for by other sources?
- ▶ What is the impact of service mix and intensity on outcomes of interest? [if possible, we will isolate OAA services]
- ▶ What subgroups had the most favorable outcomes? (e.g., health conditions, demographics, functional status)

Defining the Scope of the Study

A critical methodological decision hinges on how non-OAA funded services are factored into the study design. For example, does the design consider the OAA service package alone or in combination with a similar service package that is funded by alternative sources? This decision will impact the comparison group, sample size, research questions and generalizability of the findings.

Another important issue discussed frequently in the literature, and one that we are confronted with in this design, is the level of exposure to HCBS services (i.e., mix, duration, intensity and timing). Consideration of this step will ensure that individual variation (e.g., a caregiver that receives minimal exposure to respite care every week will likely respond differently than a caregiver who receives 24 hours of respite care

every week) are factored into the final models. Several studies that were reviewed developed exposure algorithms that may be applicable for use in the final models to address this issue (NYSOA, 2010).

Furthermore, another important issue raised in the literature is the impact of certain policy or other contextual factors on individual outcomes (e.g., nursing home admission or HCBS use). These measures include the amount of state spending on Medicaid HCBS, the number of nursing home beds in a geographic area, availability of Waiver slots, the number of home health agencies in a particular area, and the use of pre-admission screening prior to NH use.

Key Variables Supported by the Literature

Upon a review of the literature, articles were identified that support the association between the variables listed below and the key outcome variables of interest (LTSS expenditures, community tenure/NH use, health care use, and HCBS use). The list below also includes independent variables at the policy/funding level, as well as those related to characteristics of older adults and their service use. The variables are organized into the Andersen Health Behavioral Model’s predisposing, enabling, need, and use categories and shown in Table 2 below:

Table 5: Key Variables

Independent Variables Included in Outcome Analysis	HCBS Use	Health Care Use	Community Tenure/NH Use	Cost Impacts
<i>Predisposing Variables</i>				
<i>Age</i>	√	√	√	
<i>Education</i>	√	√	√	
<i>Gender</i>	√	√	√	
<i>Race/Ethnicity</i>	√	√	√	
<i>Geographic Location</i>	√	√	√	
<i>Living Alone</i>	√	√	√	
<i>Marital Status</i>	√	√	√	
<i>Informal Caregiver Availability</i>	√	√	√	
<i>Having Children</i>			√	
<i>Social Support</i>			√	
<i>Enabling Variables</i>				
<i>Income</i>	√	√	√	

Independent Variables Included in Outcome Analysis	HCBS Use	Health Care Use	Community Tenure/NH Use	Cost Impacts
<i>Home Ownership</i>			√	
<i>Payment Method</i>	√	√	√	
<i>Caregiver or Spouse Age</i>			√	
<i>Support for Caregiver</i>	√		√	
<i>Caregiver Burden</i>			√	
<i>NH Bed Supply</i>			√	
<i>Number of Home Health Agencies</i>			√	
<i>Medicaid HCBS Spending</i>		√	√	
<i>State HCBS Spending</i>			√	
<i>Pre-admission screenings</i>			√	
<i>Physician Access</i>		√		
Need Variables				
<i>Alzheimer's/Cognitive</i>	√	√	√	
<i>Comorbidities/Chronic Medical</i>	√	√	√	
<i>Psychiatric Issues/Problematic</i>		√	√	
<i>Worse ADL/IADL performance in general</i>		√	√	
<i>ADL Limitations</i>	√	√	√	
<i>IADL Limitations</i>	√		√	
<i>Self-health ratings</i>		√	√	
<i>Unmet need</i>	√	√	√	
Service Use Variables				
<i>Hospital Admissions/Use</i>	√	√	√	
<i>HCBS Use</i>	√	√	√	√
<i>NH Use</i>			√	√
<i>ADL/IADL Help</i>		√	√	
<i>Case Management</i>			√	
<i>Medicaid Waiver</i>			√	
<i>Timing of Care</i>			√	
<i>Volume of Services</i>		√	√	√

Independent Variables Included in Outcome Analysis	HCBS Use	Health Care Use	Community Tenure/NH Use	Cost Impacts
<i>Low-intensity HCBS</i>			√	√
<i>Combination of Services</i>			√	√
<i>Use of OAA III-B</i>				√
<i>Use of OAA III-C</i>	√		√	√
<i>Use of OAA III-E/Respite</i>			√	√

Variable Measure Considerations

Several of the key variables proposed for the OAA study are well established measures (e.g., sex as male/female/unknown). However, the literature points to several limitations of many measures, which must be considered prior to including them in the study. The considerations that were most frequently discussed in the literature are described below. Additionally, discussions with states also revealed related variable considerations, which are included in this section.

Predisposing Variables

Measures for Informal/Social Support

Studies identified measurement concerns regarding the amount or level of informal support, as well as concerns regarding proxy measures (living alone, marital status, and having children) used to represent this support. Results from these studies illustrate the complexities of measuring informal support.

Amount/Level of Informal Support: A study conducted by Xu and colleagues (2010) was limited by an inability to assess the amount of informal care provided. The researchers measured the existence of “informal help” with a yes/no response, but did not further examine the level of informal support. Similarly, a study by Sands and colleagues (2008) was not able to quantify the amount of formal or informal caregiving an individual received nor the influence the amount of that support may have on the inpatient use and/or expenditure for using HCBS waiver services. In state interviews, state representatives reported being able to measure the intensity of caregiving support (e.g., the number of hours a caregiver helps an older adult each week). However, other states did not require that their AAAs record and report this information. The existence of and availability of a caregiver may be recorded; however, the amount of hours they provide

informal support is not recorded or it is not reported consistently to the state. In some states, caregiver availability may not be recorded at all.

Living Alone: Living alone has been used as a proxy measure for social support (Krout et al., 2000). One study of the Aging Network CARES assessment of participants in Kansas found that living alone and having available support did not explain the difference in those who remained in the community versus those admitted to a nursing facility (Macmillan et al., 2007). However, additional qualitative analysis showed that most consumers who lived alone had daily informal support and contact from family members. This suggests that living alone may not be an appropriate proxy measure of social isolation, particularly if informal support has not been taken into account.

Marital Status: Similar to findings in the literature regarding living alone, marital status may not always serve as a proxy measure for informal caregiving and/or social support. In some cases, due to missing data, researchers have used marital status as a proxy measure for informal support (Miller et al. 1998). However, while two systematic reviews found an association between being married and lower odds or reduced risk of nursing facility placement (Gaugler et al. 2007; Miller and Weissert, 2000), findings from more recent research did not draw the same conclusion. For older adults with dementia, Andel, Hyer and Slack (2007) found that married individuals were more likely to be placed in a nursing home. The same study found that widowed status reduced risk of nursing home placement among older adults without dementia. The authors suggest that this may be due to the unique nature of this population. Having limited financial resources, a spouse may actually be a burden or an additional strain on resources that may lead to a nursing home placement. The highlighted studies demonstrate the importance of including marital status as a measure, but that it may not be an appropriate proxy measure for social support.

Having Children: A study by Gaugler and colleagues (2007) found that having children lowered the odds of nursing home admission. Muramatsu and colleagues (2007) also found that living close to or living with children was significantly associated with lower nursing home admissions. However, other studies found that the existence of children may not be a suitable proxy measure for social or informal support. One such study by Karuza & Wu (2011) argues that using proxy measures to quantify informal care is problematic if the geographic distance between parent and child(ren) and the child's level of involvement in providing care is not determined.

Enabling Variables

Income / Payment Method

Alkema and colleagues (2006) point out that education may be a proxy measure for socioeconomic status and has been used as such in sociological research. This method was used by Miller et al. (1998) in their study, where education level was used as a proxy for income. Another proxy measure for income is Medicaid status (Chapin et al. 2003) or welfare status (Casado et al. 2010), which includes receiving Medicaid, Social Security Supplemental Income, Temporary Assistance to Needy Families, and/or Supplemental Nutrition Assistance Program. However, these proxy measures do not capture everyone with low income because of the less than 100 percent (generally 50-70 percent) participation rates among those eligible for these programs (GAO, 2005).

Policy Variables

The literature supports the need to include policy variables in examining the impact of services on individuals. However, understanding how these variables are measured and their effect on/how they are affected by policy is important. They include:

- ▶ *State Spending on Medicaid HCBS*: Muramatsu et al. (2007) used two variables to look at state HCBS spending and other state level funding: One was per capita HCBS spending (total HCBS spending/population of 65 or older), which measures the absolute amount of money going towards HCBS; and (2) Percentage of LTC spending going to HCBS rather than nursing homes, which measures the extent of the state's LTC system expenditure for HCBS as compared to institutional settings. Some studies examined general Medicaid HCBS spending, but not per person spending (D'Souza et al., 2009; Miller, 1998) and found a potential association between the reduction in HCBS spending and an increase nursing home admissions.
- ▶ *Number of Home Health Agencies and Nursing Home Bed Supply*: Previous HCBS studies have identified a number of factors related to the availability of resources in the community that are important in HCBS outcomes. The New York Office for the Aging (2010) recommended, based on the lessons learned from the study, that future studies include community contextual factors, including the availability and accessibility of long-term care services. Contextual factors discussed in the literature may include the following:
 - **Number of home health agencies**. A study by Miller and colleagues (1998) found that for individuals who are married, a greater number of home health agencies is associated with a longer stay in the community.
 - **Right supply of nursing home beds**. Muramatsu and colleagues (2008) used county-level NH bed availability per person 65 or older to measure the variability of nursing home bed supply within a state as a proxy for long-term

care availability. While the nursing home bed supply may be a suitable proxy of nursing home use in some instances, the Maramatsu study also points out that the use of this variable as a proxy for long-term care availability should be done with care. Variations across states may exist because states with a smaller nursing home bed supply may be more likely to have a weaker nursing home industry and therefore be better positioned to lower nursing home utilization and HCBS funding than states with larger, more powerful nursing home industries.

- ▶ *Pre-Admission Screening*: A study conducted by Chapin and associates (2009) suggests that providing HCBS information during a pre-admission screening may have the potential to permanently prevent a nursing home admission. Findings from this study would suggest that examining the use and timing of a pre-admission screening is a variable to consider in the study of OAA services.
- ▶ *State Policies on Uniform Assessment Tools*: Some states may not require that their AAAs or local service providers use the same assessment tools, or even assess individuals at the same time intervals. This may be an issue in obtaining uniform data on OAA recipients across the state as well as tracking programs related to physical, emotional, and mental health.

Caregiver Characteristics, Assistance, & Burden

Connecting caregiver measures to individual outcomes may be difficult, specifically, measuring the amount of assistance the caregiver receives and the caregiver's burden and how these measures impact a consumer's outcomes. This relates to the discussion above regarding the measurement of informal and social support. As previously discussed marital status and having children may not be appropriate proxy measures for social support. Additionally, these measures do not capture the amount of informal and social support an older adult may receive and, therefore, possibly the burden placed on a caregiver providing support.

Casado, van Vulpen, and Davis (2010) reported that if a caregiver has substitute help, they report having less unmet HCBS services. A study conducted by Miller and Weissert (2000) found an association between the support a caregiver receives and the risk of nursing home entry. The study found that the greater the support a caregiver received, the risk of nursing home admission declined. More specifically, greater caregiver burden has been associated with increased nursing home placement in a number of studies (Gaugler et al., 2009; Miller, Rosenheck, Schnieder, 2012; Spillman and Long, 2009; Yaffe et al., 2002). However, when utilizing the caregiver burden variable, it is essential to examine data sets for consistent use of the measure.

An additional concern from state discussions is data collected related to the caregiver and the care recipient for those who are receiving Family Caregiver Support Program services. With only minimal data being collected on the care recipient, information might be lacking on the intensity of caregiving needed (e.g., the number of I/ADLs the caregiver has to assist with). Incomplete data may also prove to be problematic when tracking the same care-recipient over various OAA services.

Need Variables

ADL and IADL Limitations

Chen & Adams (2010) noted that awareness of unmet need and ability/desire to seek assistance are related to cultures and values that are not often measured but understood to drive use of services. Evidence suggests that self-reported ADLs and IADLs often overestimate a person's functional ability when compared to performance-based tests and therefore may not be omitted from research. However, the same study by Chen & Adams (2010) suggests that older adults' perceptions of their functional ability may be a more important indicator of community tenure than their actual physical abilities because an individual's perception of the functional ability is tied to their awareness of their unmet needs and their service use.

Additionally, for studies examining an individual over time, it is important to track whether ADL/IADL status changed over time. Xu and colleagues (2010) cited this as a limitation to their study because functional status was only obtained from the pre-admission screening used to determine functional eligibility for the waiver program and not once services had been received. This did not allow for an examination of the impact of waiver program services on functional status. As mentioned previously, this may be a concern, as various states have differing policies on which tool to use to conduct assessments and how often an individual is reassessed.

A study by Karuza & Wu (2011) examined the impact of OAA services on individual outcomes across four states. One state in the study used unmet need score as a proxy for ADL/IADL scores. However, Karuza and Wu point out that this is a limitation of the study and state, "the use of proxy measures to quantify client-based characteristics, e.g., limitations on Activities of Daily Living or Instrumental Activities of Daily Living, raises concerns with the validity and reliability of these measures, especially if the analyses use them as potential covariates or control variables".

While awareness of unmet need and self-perceived functional status may not be deemed appropriate measures for all studies, for the purposes of examining service use and the

impact of services on functional status over time, these measures should be considered without substitution by a proxy measure, if possible, in the OAA study.

Prior Use Variables

Prior Nursing Home Use / Defining Community Tenure

Prior nursing home stays has been a significant predictor of future nursing home admissions. However, prior nursing home stay was not measured consistently. For example, Muramatsu and colleagues (2008) defined “permanent” nursing home relocation as a stay at a nursing home or other health care facility at the time of death. However, for living study subjects, a long-stay nursing home admission was not defined in the Muramatsu study. Cai and associates (2009) identified a long-stay nursing home admission as “the stays after admission that exceed three months from the date of admission.” This measurement is consistent with prior research.

Chapin and colleagues (2003) interviewed nine state aging program representatives and found only two (Missouri and Connecticut) that routinely tracked community tenure and defined the measure. MO defined this as “Anyone who hasn’t chosen nursing facility” and CT as “to begin services and remain on the program without long-term placement.” Karuza & Wu’s (2011) analysis defined “survival” as any outcome that was not a permanent nursing facility placement. An additional state data concern is whether the state tracks the reasons for an OAA service recipient ending their service use. Some states may record the beginning and end date of service without tracking the reasons (e.g., death, NH admission, etc) for termination of services.

Measurement of Prior Service Use

Volume of Services: According to the literature, volume of services has an impact on institutionalization. In Rhode Island, individuals who receive more than one service have an increase in community tenure (Brock et al., 2007; Karuza & Wu, 2011). These studies did not have a control variable; therefore, they had to use receipt of one service as the control. Xu and associates (2010) posit that researchers need to track “the mechanism by which greater volume of formal services is associated with lower risk for hospitalization. It is possible that greater availability of services reduced risk for potentially preventable events”.

Service Intensity and Combination: A study by Shapiro and colleagues (2009) recommends that the intensity of services be examined, as that measure may impact outcomes, specifically cost-savings. They found that low intensity HCBS users utilize fewer general revenue expenses and generate the greatest overall cost savings, compared to non-users

(Shapiro & Loh, 2010). However, other studies show that costs savings related to service intensity may also be due to the combination of services received. For example, in the Shapiro (2009) study, when multiple services users were removed from the analysis, the Alzheimer's Disease Initiative (ADI) cost savings disappeared. Savings originally observed in the study from ADI may be a result of savings from the combination of ADI and other services.

Timing of Care: Regarding service delivery, Gaugler et al. (2005) found that timing of care impacted institutionalization. Caregivers of individuals with dementia who used in-home help services earlier in their caregiving experiences were more likely to delay institutionalization (Gaugler et al., 2005). In the MacMillan and colleagues' (2007) study, at three months after assessment, 31.4% of diverted individuals used services (the highest proportion in the study). This further supports that timing of care is an important variable to consider in nursing home diversion research. However, without data on when the receipt of services was first needed it may be difficult to measure the impact on institutionalization.

Case Management: One series of studies highlights the importance of understanding both state and local policies toward receipt of services. For example, Karuza & Wu (2011) found that intensity of case management services was a statistically significant predictor for nursing home placement in two counties, after controlling for select factors. Additional investigation into why this is the case (NYSOA 2010) revealed that local county policies and procedures impacted nursing home placement. In one county (for which case management was more significant), case managers who assist clients with nursing home placement and there is a cap on personal care services.

Cost of Service Use

Another data concern is whether a state can connect expenditures to the individual. Some states may only have the ability to report expenditures data in aggregate on the service level. This prevents researchers from accurately assessing the amount of money spent to provide OAA services at the individual level.

Proposed Study Design

We suggest that the study approach with the greatest potential for delivering conclusive and actionable results would be a quasi-experimental design that includes: 1) a retrospective study component drawing on existing individual data from federal sources; and 2) a prospective study component using data to be collected during the study period. Evaluators of HCBS and other health and social service programs usually rely on quasi-experimental techniques as the best impact study design and most

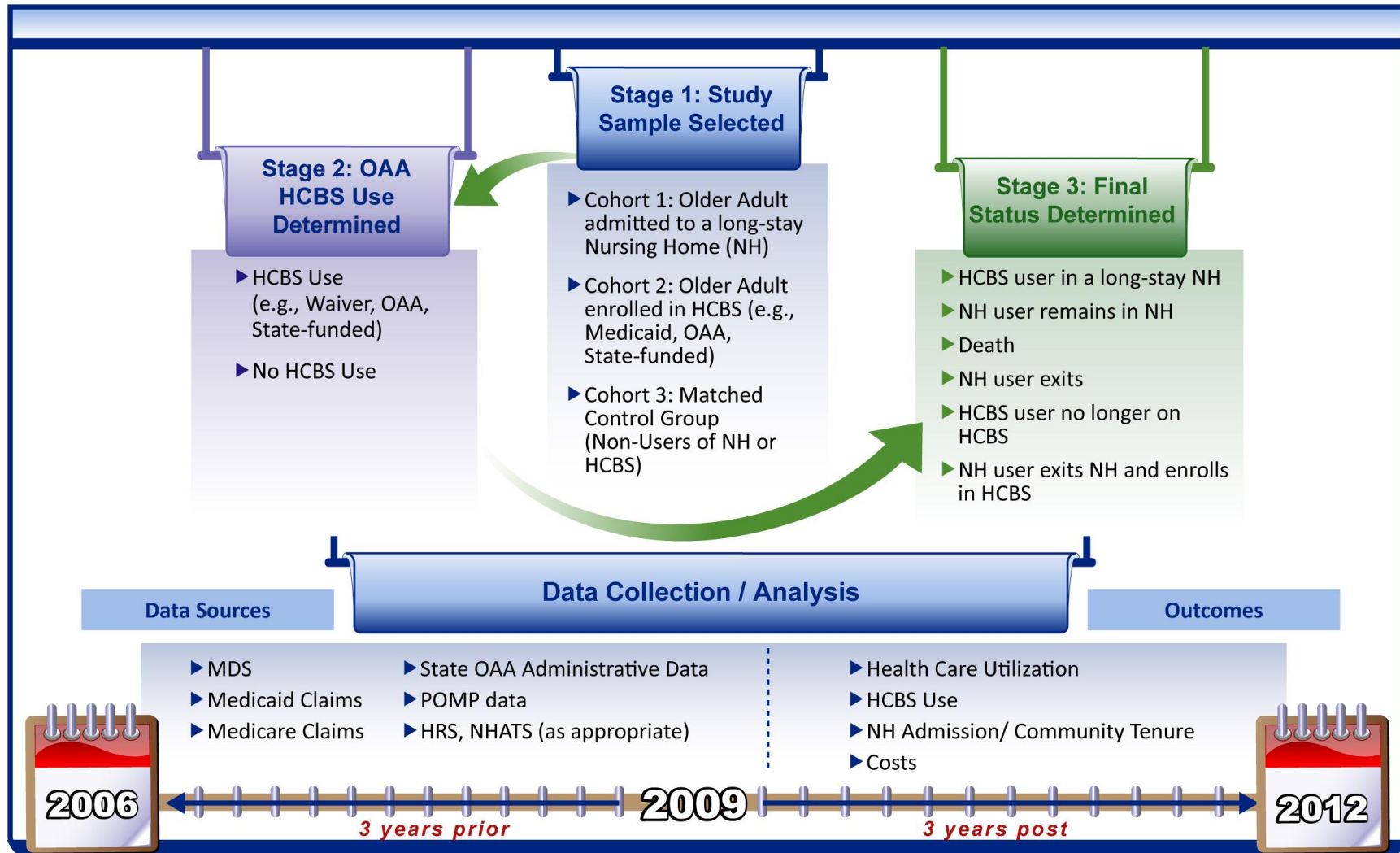
powerful alternative to random experiments. We know from the literature that demonstrating impacts on HCBS expenditures can take several years, with a lag between increased spending on HCBS expansion and savings from this investment (Kaye, LaPlante, & Harrington, 2009). Thus, we recommend a study period of seven years; a plausible option given the retrospective/prospective design option. This study period time can be modified depending upon time, data, or funding constraints.

To reduce bias and error in assessing program outcomes, we recommend incorporating multiple methods, measures, and data sources. In using a quasi-experimental design with a matched comparison group, we will explore different potential methods including propensity score matching for constructing a matched comparison group in the final design. This will allow us to compare older adults who had an outcome of interest with older adults who are matched on certain key characteristics relevant to the outcome, to determine whether OAA services contributed to the difference in outcome. The matching process will allow us to control for factors that are believed to contribute to different outcomes (e.g., gender, IADL status, etc.).

The key to unbiased inference in this approach, as in any quasi-experimental design, is proper specification: choosing a set of key factors to be controlled, so that uncontrolled variables are approximately random, i.e., not correlated with the controlled variables or the treatment (Achen, 1986). Knowledge about the factors that affect receipt of services and factors correlated with outcomes (i.e., community living tenure and healthcare utilization) identified in literature review are essential to the success of the design.

The research team proposes using this design in a study of 3 states. A primary purpose of the study will be to identify a core set of variables that all states should collect. States have been granted great flexibility regarding program administration and data collection. As a result, states lack uniform and comprehensive data. Conducting this study, as discussed in the **Limitations and Recommendations** report (**Appendix C**), can address that issue.

Figure 6: Proposed Study Design Image



Proposed Study Design Description

The above graphic depicts the proposed design for the Study of the Global Outcomes of Older American Act Programs and Services. The goal is to measure the impact/association of OAA service use by older adults on four key outcomes (health care utilization, HCBS expenditures, NH admissions and community tenure). Further, the design allows for the examination of various service use trajectories over time (e.g., HCBS user in a NH, NH user exits NH, etc.) and the extent to which OAA programs and services are associated with these trajectories. The details of the study design are discussed below.

Intervention: Receipt of OAA services, alone or in combination with other HCBS.

Target Population: The target population for this study is older adults age 60 and above (those eligible for OAA services). In the selection of the cohorts in stage 1, the sample will be selected and then connected back to those who received OAA services in stage 2 of the design. Those who have received OAA services are the treatment, or intervention, group and those who are not matched to OAA service use are the comparison group.

Pre-Stage: Three states will be selected through an RFP process to participate in this study design. The states will have the data capacity and availability to participate in the stages outlined below.

Stage 1: The proposed design takes place over a six-year study period and consists of three stages. In **Stage 1**, (depicted in the blue box), the study sample is selected using MDS, Medicaid/Medicare claims data, and OAA or state-funded services data, that cover a one year period of time (2009-2010) and an entire state (e.g., Georgia). Three cohorts of older adults will be identified from this dataset: *Cohort 1* will be a sample of older adults who have been admitted to nursing homes; *Cohort 2* will be a sample of older adults enrolled in any HCBS (e.g., Medicaid, state-funded, OAA); and, *Cohort 3* will be a group of individuals who were not admitted to a nursing home and did not receive HCBS. This group will be matched to older adults in *Cohorts 1* and *2* on certain key variables to ensure comparability (propensity score matching). *Cohort 3* will serve as the comparison group.

Stage 2: During **Stage 2** of the study (represented in the purple box), the HCBS service use by *Cohort* will be measured. This will be accomplished through the analysis of Medicare/Medicaid Claims, POMP, State OAA administrative records, HRS and any other available sources. The study period covers 2006-2009. Data will be analyzed by service type, mix, and intensity of service use. A group of individuals will be non-users.

Stage 3: In the final stage of the study, **Stage 3**, (illustrated in the green box), using the same combination of data sources, two additional years of service use and client disposition – status post intervention will be examined. In sum, the study will have a

longitudinal data base (2006-2012 or the most current year available to us) that includes three unique cohorts of individuals: nursing home users at baseline, HCBS users at baseline, and non-users at baseline. This combination will allow for both within-group and between-group data modeling. Results will demonstrate if receipt of OAA services, whether alone or in combination with other services, will directly impact: health care utilization, HCBS expenditures, nursing home (NH) admissions and community tenure.

Proposed Data Sources and Data Elements

A high-quality study hinges on valid and reliable data. Regardless of how well a study is designed, the study is only as good as the data utilized. While available data sources provide a cost-effective and efficient way of collecting data, all sources collected from the literature review were found to have limitations in terms of the measures /indicators collected, the quality of the data, the frequency of the collection, or comparability of the measures /indicators over localities and states. Many studies have used supplemental surveys, questionnaires or interviews to collect additional data that complement the data collected through regular reporting systems and allow for more robust study results. While supplemental data collection methods can be costly, they are likely the only way to ensure that high quality data is collected on certain key variables identified in the literature as critical for inclusion (e.g., availability of informal caregivers, level of unmet need, functional status, etc.).

Based on our understanding of the data sources available for use in a study of OAA programs and services, as well as the efficiencies needed by AoA in executing this study, the design will primarily utilize secondary data sources (which are discussed in more depth below). While it is feasible to use a study design that is solely based on secondary data sources, AoA must be keenly aware of and thoughtfully consider the trade-offs that are inherent in using a design that is solely based on secondary data.

In **Table 4**, the data sources proposed in the study design and how they are applicable and useful to the study design are identified. The purpose for using these secondary data sources in the OAA HBCS study is to compile a cadre of multiple independent, intervening, and outcome variables that are critical to building a reliable study model.

Numerous secondary data sources exist and several of the studies from the literature review combined data from multiple sources. For example, Miller et al. (1998) linked individual level data from a national longitudinal survey with state health care system data via the state of residence of each person. In Shapiro & Loh (2010), MDS records were matched with Florida CIRTS records, using resident IDs to obtain Social Security Numbers (SSNs) from CMS, then matching CIRTS records with the SSNs. Based on our proposed study design, we suggest using some of the data sets described below. We are proposing the use of Medicaid and Medicare claims data and exploring datasets similar to HRS, like NLTCs and NHATS.

Table 7: Suggested Data Sets

Data Source	Data Elements
<p>CMS Medicare Claims Data</p>	<p>The Medicare Claims Files contain information collected by Medicare to pay for health care services provided to a Medicare beneficiary. Data are available for each institutional and non-institutional claim type, which each record being a claim. Some of the information contained within these utilization files includes:</p> <ul style="list-style-type: none"> ▶ procedure and diagnosis information ▶ dates of service ▶ revenue center detail ▶ payment and charge amounts ▶ beneficiary demographic information ▶ limited professional provider and facility data (http://www.resdac.org/cms-data/file-family/Medicare-Claims)
<p>CMS Medicaid Claims Data</p>	<p>MAX Personal Summary File</p> <p>The Personal Summary File contains one record for every individual enrolled for at least one day during the year. The file contains demographic data (e.g. date of birth, gender, race), basis of eligibility, maintenance assistance status, monthly enrollment status, and a utilization summary. A small number of the records in the file are limited records for individuals who were assumed to be eligible, had a paid claim and then were ultimately determined to be ineligible. (http://www.resdac.org/cms-data/files/max-ps)</p>
<p>CMS Minimum Data Set (MDS)</p>	<p>“The CMS MDS is The Long Term Care Minimum Data Set (MDS) is a standardized, primary screening and assessment tool of health status which forms the foundation of the comprehensive assessment for all residents (regardless of payer) of long-term care facilities certified to participate in Medicare or Medicaid. The MDS contains items that measure:</p> <ul style="list-style-type: none"> ▶ physical, ▶ clinical, ▶ psychological, ▶ psycho-social functioning, and ▶ life care wishes” (http://www.resdac.org/cms-data/files/mds-3.0) <p>This dataset was used in prior HCBS studies (Buys et al manuscript; Chapin et al., 2002; 2003; Macmillan et al., 2007; Shapiro & Loh, 2010)</p>
<p>MDS-Home Care</p>	<p>This dataset identifies the number of times over the prior 90 days (or since the last assessment) that an individual has been admitted to hospital with an overnight stay or visited the ER without an overnight stay. It was used in a prior HCBS study (D’Souza et al., 2009). It also includes functional status, being used by 9 states for their Nursing Facility Level of Care Assessment.</p>

Data Source	Data Elements
Home Health Outcome and Assessment Information Set (OASIS)	<p>“The Home Health Outcome and Assessment Information Set (OASIS) contains data items that were developed for measuring patient outcomes for the purpose of performance improvement in home health care. OASIS assessments are collected at specified time points for adult (age 18 or over) Medicare and Medicaid patients. OASIS assessment instrument includes:</p> <ul style="list-style-type: none"> ▶ socio-demographic, ▶ environmental, ▶ support system, ▶ health status, ▶ functional status, and ▶ health service utilization characteristics”.(http://www.resdac.org/cms-data/files/oasis) <p>One study used this for Medicare home health assessment and service use data (Chapin et al., 2003)</p>
POMP – the Performance Outcomes Measures Project	<p>Original Performance Outcome Measure (POM) demonstration projects provided a core set of performance measurement tools to quantify the impact of OAA Title III services for consumers. The objectives of POM were to: develop performance measure across several program domains under Older American Act (OAA); to conduct sample surveys using POM instruments; and, to use data from the surveys to improve program management and to justify future program expenditures.</p> <p>This then grew into POMP and included Arizona; Florida; Georgia; Iowa; New York; North Carolina; Ohio; Rhode Island; and, South Carolina. Next Generation POMP and the Sentinel Project included more states. We examined multiple studies that used POMP data (Brock et al., 2007; Karuza & Wu, 2007; Shapiro & Loh, 2010).</p>
State OAA Administration Data	<p>We recommend the use of state OAA data from a state that uses a statewide database. Prior studies have used state data sources, like Florida’s CIRTS records (Shapiro & Loh, 2010). To determine the feasibility of using a state’s administrative data, we interviewed select states on their data collection and warehousing procedures.</p>
National Surveys related to Long Term Care	<p>The Health and Retirement Study</p> <p>The Health and Retirement Study (HRS) is an ongoing longitudinal panel study that surveys a representative sample of more than 26,000 Americans over the age of 50 every two years. (http://hrsonline.isr.umich.edu/)</p> <p>It collections variables such as physical functioning, receipt of services (home care by a medical professional and additional service, e.g., adult day care, social worker, outpatient rehabilitation, transportation, or meals), NH placement, and demographics. This survey has been used by prior HCBS studies (Brock et al., 2007; Muramatsu et al., 2007; 2008)</p>

Data Source	Data Elements
	<p>The National Long Term Care Survey (NLTCS)</p> <p>The NLTCS is a longitudinal survey designed to study changes in the health and functional status of older Americans (aged 65+) that was last fielded in 2004. It also tracks health expenditures, Medicare service use, and the availability of personal, family, and community resources for caregiving. (http://www.nltcs.aas.duke.edu/)</p> <p>The National Health and Aging Trends Studies (NHATS)</p> <p>The NHATS, first fielded in 2011, will gather information on a nationally representative sample of Medicare beneficiaries ages 65 and older. In-person interviews will be used to collect detailed information on activities of daily life, living arrangements, economic status and well-being, aspects of early life, and quality of life. (http://www.nhats.org/)</p>

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Appendix C: Limitations and Recommendations

Introduction

The Administration on Aging (AoA) and The Lewin Group (Lewin) hosted an Expert Group meeting on December 18, 2012. After this meeting, the team held several key informant interviews with additional stakeholders and calls with states regarding their Older Americans Act (OAA) data systems. This report addresses study strengths and limitations identified from the following:

- ▶ **Expert Feedback** – Suggestions of the expert group and key informants are included. AoA and Lewin considered ways to address these suggestions, while also recognizing the limitations of secondary data available.
- ▶ **State Feedback** – Discussions of the implications of state feedback on the exploratory study design are included. While some states, or AAAs within states, could be prepared to participate in the design proposed, there are still many limitations to consider based upon the site or state data collection policies and procedures.

Identified limitations are followed by a multi-step recommendation to prepare AoA and the states to conduct this OAA study.

Expert Feedback

To determine the feasibility of conducting this study using the proposed methodology, the research team discussed the design with a group of experts from various fields. The experts identified strengths and limitations of the study design, and some suggestions for moving forward. Below are the major action items that resulted from the meeting:

Research Questions & Measuring Impact

- ▶ Narrow the research questions to those answerable by this design, specifically, those that can be addressed using secondary data.
- ▶ Consider alternative variables to measure program impact. For example:
 - avoidable hospitalization instead of any hospitalization,
 - unnecessary ER visits,
 - improved access to primary care services.
- ▶ Be mindful in the findings that addressing unmet need may be correlated with increased service use; implying the program actually costs money as opposed to savings.

- ▶ Review additional literature including work done on Tailored Care (TCARE), which examines delayed institutionalization due to the provision of resources to caregivers^x.

Define Target Population

- ▶ Clearly define the target population and study sample. For example, the study design should note that residents in nursing homes in both the retrospective AND prospective design will be omitted from the analysis.

Defining a control group

- ▶ Attempt to include total non-users of services for the control group. A potential data source would be those on OAA waiting lists.

OAA Data limitations

- ▶ A potential data limitation is the inability to link claims data to OAA data (many states do not collect personal identifier information).
- ▶ In selecting a few individual states for this project, mindfulness must be given to the potential lack of minority representation.

Increased Focus on Post-Acute Services

- ▶ Consider including post-acute services as well as individuals living in assisted living in the study design to broaden the study sample.
- ▶ Consider examining the relationship between OAA expenditures to Medicare expenditures (e.g. does an increase in OAA expenditures lead to a decrease in Medicare expenditures by reducing the number of hospital readmissions?).

Concern over Private Pay & Informal Support

- ▶ Explore a means to capture the private pay HCBS user population.
- ▶ Explore a means to capture informal supports.
- ▶ Explore linking the Medicare users under Cohort 3 to national surveys (NLTCS, NHATS, and HRS). However, this may not be feasible at a state level.
- ▶ Explore linking housing data to service data. This would have capture residential care and assisted living consumers.

^x <http://www4.uwm.edu/tcare/>

Additional Data Concerns

- ▶ Use the CMS Chronic Condition Warehouse to capture a longitudinal trajectory. This would minimize some of the problems associated with annual claims data.

Items to Consider

- ▶ Reclassify this project as an exploratory study as opposed to an “evaluation design”.

State Discussions

To determine the feasibility of conducting this study across different states, the research team discussed specific questions and concerns about data with states that have state-wide databases for their OAA programs. The question template may be found in **Appendix C-A**. These questions were identified as key in determining a state’s suitability for being included in an exploratory study. The types of questions asked focused on whether:

- ▶ The state could provide the overall unduplicated service count;
- ▶ The state uses consistent data collection methods across the state;
- ▶ The state enacted policies relatively consistently across the state;
- ▶ The state collected the appropriate personal identifying information to connect state OAA administrative data to Medicare/Medicaid claims data; and
- ▶ The state tracked details about informal caregiving use among OAA clients.

The research team conducted interviews with Georgia, Florida, Massachusetts, Minnesota, and Ohio. Table 1 captures data challenges identified, as well as suggested mitigation strategies.

Table 8: State OAA Data – Risks and Mitigation Strategies

Risk	Mitigation Strategy
The state does not collect Social Security numbers for OAA service recipients, making linking state OAA datasets with CMS data difficult	Ensure that the state, if chosen for piloting this design, has other identifiers that can be used to link individuals to Medicare/Medicaid claims data (e.g., name, gender, DOB, address).
Longitudinal data tracking isn't available (uniformly) or reliable	We recommend excluding states lacking reliable longitudinal data. Some states may have migrated to a new system recently, in which case additional time would need to be spent cleaning and merging databases.

Risk	Mitigation Strategy
There is a lack of information on informal caregiving intensity for the intervention group	Ideally, this state would not be selected for the exploratory study; however, if the state has strong data otherwise, this will partially offset the limitation.
The state does not require use of a uniform assessment and re-assessment conducted over standard time intervals (e.g., re-assessed every six months)	Identify the necessary components from an assessment and ensure that these are collected. Determine the re-assessment time periods, if applicable.
The state cannot track expenditures data at the individual level	Ideally, this state would not be selected for the exploratory study; however, if the state has strong data otherwise, this will partially offset the limitation.
The state has some AAAs and providers collecting data at a more advanced level than other AAAs	If an exploratory study were conducted, these advanced AAAs could be chosen rather than conducting a study among all the state's AAAs.

Limitations of the Study Design

General Limitations

The use of secondary data can be economical, both in terms of cost and time. It can also allow evaluators to look at a much larger sample size than would often be feasible if primary data were collected. However, evaluators have less control over the quality, completeness, and consistency of secondary data. More specifically, below are a few of the challenges and questions that should be considered when utilizing and selecting secondary data sources for the OAA global outcomes study:

- ▶ **Validity** – Is the data collected, measured and documented accurately? Is it measuring what it was intended to measure?
- ▶ **Reliability** – Do all people collecting and entering data define, collect and document the data in the same way?
- ▶ **Change to Measures over Time** – Does the data get collected in the same way over time or do measure/indicators change over time?
- ▶ **Comparability/Consistency** – Are data collected in the same way across sources and across agencies/localities/states (e.g., does Indiana measure health status using the same scale as New York and do two counties within New York measure it the same way)?
- ▶ **Missing Data** – Are data sources complete? How often are data missing? Are data for individuals or agencies with certain characteristics more likely to be missing,

creating a bias? Are certain people not included at all in the data (e.g., caregivers under 50)? What methods can be used to account for missing or incomplete data?

- ▶ **Ability to Link Sources** – Are there ways to accurately link data in different sources? Is data in the different sources compatible (e.g., collected at the same frequencies, measured in the same way, etc.)?
- ▶ **Completeness of Data** – Do the various sources available include all or the majority of the key variables that need to be included in the model? Can the existing data serve as a proxy for what is being measured in the study?
- ▶ **Frequency/Length of Data Collection** – Is the data collected frequently enough to allow for measuring the outcomes of interest? If using retrospective data, has the data been collected long enough to evaluate long-term outcomes?
- ▶ **Sample** – Does the secondary data source collect information from a large enough sample of the population of interest? What are the implications of the sampling design on usability of the data for the study?

This list highlights some of the challenges that must be considered upfront when determining the use of secondary data sources and which sources to prioritize. Additionally, all of these issues must be considered when collecting primary data. However, an important difference between primary data collection and secondary data use is that the parties involved in developing the data collection tools and processes are able to control many of these factors upfront. This ensures that the data collected is suitable for the study design.

Study Design Limitations

The proposed study design recommends a method for examining the effect of OAA programs on service recipients, while also using a comparison group. The lack of an adequate comparison group in previous studies is a limitation of the HCBS impact literature (Grabowski, 2006; Shapiro & Loh, 2010). In the current design, the research team attempted to mitigate this limitation by identifying a control group using Medicare claims data; however, this design is limited in examining key variables for the treatment and control group. Specifically, this design's limitations include:

- ▶ **State Older Americans Act (OAA) Data:** A select group of states (FL, GA, MA, MN, and OH) were interviewed regarding their OAA Data Collection policies and procedures. These interviews highlighted some of the limitations of state OAA data, along with identifying states with more comprehensive data systems from our small sample. Specific limitations included that impact the study design included:
 - The absence of Social Security Numbers (SSNs), which provide the most reliable method to match to Medicare and Medicaid claims.

- Lack of information regarding the reasons for termination of services, which limits the ability to measure community tenure as an outcome.
- ▶ **Informal Caregiver Data:** As discussed in the expert group meeting and key informant interviews, difficulties will be encountered obtaining caregiver, due largely to the non-existence of such data.
- ▶ **Private Pay Data:** This is a limitation for both the treatment and comparison groups. States do not uniformly collect information on private pay services received by OAA users. Also, this information would not be readily available for the proposed treatment or comparison groups.

Research Questions

The following research questions for an OAA global outcomes study were proposed and further examined for feasibility to address the limitations identified. Currently, not every question can be answered by every state or organization. These questions may require modification depending upon the states and/or AAAs chosen by AoA to participate in an exploratory study (discussed in [Table 2](#)).

Table 9: Modified Research Questions

Original Question	Components to be Measured	Suggestion	Explanation
What is the impact of OAA-funded HCBS programs and services on community tenure?	<ul style="list-style-type: none"> ▶ OAA services by type, intensity, volume, and duration ▶ Community tenure (months remaining in the community; nursing home residency) 	This question may remain the same.	Most states track the beginning and end date of service use; however, not all states track the reasons for OAA service termination (e.g., NH admission). These reasons can be identified through Medicare and Medicaid claims data.

Original Question	Components to be Measured	Suggestion	Explanation
<p>What is the impact of OAA-funded HCBS programs and services on health care utilization?</p>	<ul style="list-style-type: none"> ▶ OAA services by type, intensity, volume, and duration ▶ Health care utilization (times hospitalized for potentially avoidable hospitalizations, visits to ER, nights spent in hospital, number of physician visits) 	<p>This question may remain the same.</p>	<p>Measures of health care utilization would be identified through Medicare and Medicaid claims data. Identifying outcomes would not be affected by OAA state data; however, it is important to choose a state with comprehensive data systems that may also keep detailed information on these outcomes for additional analysis.</p>
<p>What is the impact of OAA-funded HCBS programs and services on costs of care for older adults (e.g., LTSS, health care costs)?</p>	<ul style="list-style-type: none"> ▶ OAA services by type, intensity, volume, and duration ▶ LTC costs for both Medicaid and Medicare covered services 	<p>This question may remain the same; however, the state must already collect comprehensive individual expenditures data to best answer it or collect primary data as a part of this study design.</p>	<p>Some states can connect OAA expenditure data directly to the consumer (e.g., Mrs. Smith’s service use cost \$20,000 over 3 years). Others only report service expenditures in aggregate. Those states collecting individual-level expenditure data may be best able to answer this question.</p>
<p>What is the impact of OAA-funded HCBS programs and services on physical, mental, and emotional health and wellness (i.e., preventive measures) of care recipients and caregivers?</p>	<ul style="list-style-type: none"> ▶ OAA services by type, intensity, volume, and duration ▶ Physical health/wellness ▶ Emotional health/wellness ▶ Mental health/wellness 	<p>This question may remain the same; however, in order to be answered, the state must have a more comprehensive data system that tracks these measures uniformly, or the state must collect primary data as a part of this study design.</p>	<p>Not every state assess OAA clients consistently across the state (some states allow AAAs and providers to use their own assessment forms). Some of these assessments may be self-report, while others may be actual client-level evaluations. Additionally, time intervals for collecting this information vary considerably. No physical, emotional and mental health information will be available for the comparison group without primary data collection.</p>

Original Question	Components to be Measured	Suggestion	Explanation
<p>What is the impact of OAA-funded HCBS programs and services on unmet needs among older adults?</p>	<ul style="list-style-type: none"> ▶ OAA services by type, intensity, volume, and duration ▶ Measures in changes of perceived unmet need (self-report) ▶ Assessed unmet need 	<p>This question may not be feasible or may be difficult given available data. Only one state (GA) tracked this type of information. This could be answered if states collect primary data as part of this study design.</p>	<p>The suggested measure for this question is self-reported and assessed unmet need. Some states may assess unmet need (including when developing a service plan) but they do not compare the plan to the actual service delivered. Or, they do not re-assess the consumer if unmet need is a self-reported measure.</p>
<p>What is the impact of OAA-funded HCBS programs and services on caregivers (e.g., strain, burden, depression, health, etc.)?</p>	<ul style="list-style-type: none"> ▶ OAA services by type, intensity, volume, and duration ▶ Caregiver strain ▶ Caregiver burden 	<p>This is feasible if the state conducts more detailed caregiver assessments or if they collect primary data as a part of the study.</p>	<p>The research team must ensure the state assesses caregivers for these factors (strain and burden). Potential concerns are: Similar use of valid and reliable instruments. Frequency of administration.</p>
<p>What is the impact of OAA-funded HCBS programs and services on coordination of services (e.g., care management)?</p>	<ul style="list-style-type: none"> ▶ OAA services by type, intensity, volume, and duration ▶ Case management: effect of case management, review services received before and after case management ▶ Potentially preventable hospital readmission 	<p>This question may remain the same; however, the state must have a comprehensive data system that includes more detailed case management information that includes OAA services for the individual.</p>	<p>Some states may collect detailed case management information in their systems.</p>

Recommendations

While it is feasible to conduct this study, the rigorousness and generalizability of the study will depend on the data gathered, cleaned, merged and analyzed to overcome many of the data limitations described above. It will also be heavily dependent on the strength of the chosen state's OAA data system and timeline when the state migrated to a statewide data system. In addition, the time and funds allocated to conducting this study will also determine the study's validity and reliability.

Based upon the limitations of data sources available, and feedback from expert group participants and key informants, the research team recommends a multi-step approach outlined below.

Prepare for and Conduct an Exploratory Study

This recommendation will help AoA identify additional limitations with state data, test the feasibility of the current design, and recommend a set of core variables required to be collected uniformly across states for future program administration and evaluation. The steps below outline recommendations for approaching this study.

Step 1: Issue RFP to conduct study

AoA issues an RFP to oversee the proposed study. The awarded research team would work with AoA to prepare for and conduct the study.

Step 2: Convene Technical Working Group

Within three months of the contract begin date, AoA in collaboration with the awarded research team establishes a Technical Working Group (TWG). A TWG can assist the research team to identify the minimum key variables necessary for a retrospective/prospective design, as proposed in the **Study Framework and Design** document (**Appendix B**). From work conducted to date, these key variables may include those listed below. In many cases, states are collecting some of this information on service recipients already; however, the collection of this information across OAA service categories and AAAs is inconsistent.

- ▶ Social Security Number
- ▶ Date of Birth
- ▶ Gender
- ▶ Race/Ethnicity
- ▶ Address / Geographic Location
- ▶ Living Alone status
- ▶ Marital Status
- ▶ Informal Caregiver Availability
- ▶ Having Children
- ▶ Social Support
- ▶ Income
- ▶ Home Ownership

- ▶ Payment Method
- ▶ Caregiver or Spouse Age
- ▶ Support for Caregiver
- ▶ Caregiver Burden
- ▶ Physician Access
- ▶ Alzheimer's/Cognitive Impairment/Dementia
- ▶ Comorbidities/Chronic Medical Conditions
- ▶ Psychiatric Issues/Problematic Behavior
- ▶ ADL Limitations
- ▶ IADL Limitations
- ▶ Self-health ratings
- ▶ Unmet need measures
- ▶ Hospital Admissions/Use
- ▶ Prior / Current HCBS Use (OAA and non-OAA)
- ▶ Nursing Home Use

Service use should be tracked by a combination of services, timing of care, volume, and intensity. Additionally, collection of expenditures data on the individual level is an important variable for identifying cost savings.

It is also important to identify the effect of policy variables. The research team would be tasked with identifying and collecting this data, which should include:

- ▶ NH Bed Supply
- ▶ Number of Home Health Agencies
- ▶ Medicaid HCBS Spending
- ▶ State HCBS Spending
- ▶ Pre-admission screenings

Step 3: Issue RFP to states

Prior to the completion of step 2, AoA issues an RFP to identify up to three states willing to participate in organizing existing data at the state level. Criteria for this RFP should include that the state:

- ▶ use a statewide data collection system or has a statewide data collection protocol in place used consistently across AAAs. Ideally, the data collection system or protocol should be in place across the state for more than 5 years;
- ▶ collect Social Security Numbers (SSNs) across the states (personal identifying information). If not, state must collect name, DOB, and zip code to link data to Medicare/Medicaid claims;
- ▶ preferably collect personal identifying information for all services, including Title III-C and D services.
- ▶ collect detailed information on waitlisted individuals (if a waitlist is maintained), including demographic information, services needed, etc.;

- ▶ collect data beyond the standard National Aging Program Information Systems (NAPIS) State Program Reports (SPR) elements, such as:
 - Informal Caregiver Availability
 - Informal Caregiving Intensity
 - Consumer Private Pay Resources
 - Detailed data on an older adult in a caregiver dyad (where caregiver receives services)
 - Reason for service termination (community tenure)
 - Requiring case management notes be made available in an electronic format
- ▶ has standardized assessment protocols (e.g. tool and re-assessment intervals);
- ▶ report on volume of services received;
- ▶ differentiates services by program and funding source;
- ▶ report expenditures data at the individual-level;
- ▶ track difference between planned and actualized service delivery to measure unmet need; and
- ▶ is able to demonstrate data sharing relationships with partner agencies in their state (e.g. State Medicaid agency)

In this RFP, it should be noted that a future step/activity, if funded, would include statewide collection of primary data.

Step 4: Assist states / Collect available secondary data

Step 4 has two concurrent components that will begin upon awarding three states grants to conduct the study:

- 1) AoA and the awarded research team will work with the three selected states in gathering and preparing their OAA administrative data. As described in step 3, the selected states will have the data capacity to answer many of the study's posed research questions and will be able to quickly begin implementing this step. A vital component of data preparation is for the states to collaborate with partner agencies in their state (e.g., State Medicaid agency) to consider data systems integration and/or data use agreements for better use of state data.
- 2) While the selected States are preparing and assisting in the collection of data, the research team should assist the states as necessary. In addition, the research team will begin preparations for linking the state-level data with other national datasets. This will require that AoA facilitate a multi-agency collaboration, specifically, a strategic partnership with the Centers for Medicare and Medicaid Services (CMS) and other HHS agencies, Chronic Disease Warehouse (CDW), Housing and Urban

Development (HUD), and the Department of Transportation (DoT) to conduct a comprehensive evaluation of HCBS programs and services. Many older adults receive a combination of services, or experience a trajectory of service use that includes both AoA and CMS HCBS. They may also benefit from services provided through HUD, such as elderly and disabled-designated subsidized housing (Section 202 and Section 811). This option will better assess OAA services in combination with other service and the consumer's HCBS experience overall.

Step 5: Expand work to include primary data collection

Step 5 includes expanding the work described in steps 2-4 in the selected states to include primary data collection, as funds and time allow. Primary data collection will strengthen the data by gathering detailed information on such key aspect of caregiving as informal supports. This step could be accomplished through either a state-wide random selection of OAA participants, or targeted data collection that occurs with select AAAs in the chosen states.

As states begin collecting the primary data, AoA and the research team should facilitate additional interviews and/or focus groups with representatives (state and/or local level) in all 50 states and territories to identify deficits in data collection and access the landscape for implementing national requirements for data collection. In addition to feedback received from the TWG in step 2, step 5 will allow for the identification of potential variables classified as "mandatory" for ongoing, systematic data collection and better understand the challenges states may face in updating current data collection efforts to meet new national requirements.

Step 6: Design and field the study

The research team selected in Step 1 should work with AoA and the three participating states in finalizing the study design and fielding the study with data collected at the state and federal level. The proposed design in the **Study Framework and Design** should be the foundation for this design, and modified as appropriate given available state secondary data and any additional primary data.

Step 7: Reconvene TWG and present findings

Once the exploratory study is conducted in the three selected states reconvene the TWG and present results for feedback and discussion. TWG members, in collaboration with AoA and the research team, will define a core set of variables that AAAs will employ to ensure consistent data collection across agencies. It is recommended that results from the study, in addition to information collected in Step 5, be incorporated into core variable recommendations. Once the recommendations are finalized, AoA and the research team prepares an OMB package for approval of new SPR data requirements going forward.

Step 8: Training & technical assistance for data collection

With changes to SPR data requirements, many states will require intensive T&TA as they make updates to their current data systems. However, some states will be more prepared than others, or already do, collect the core variable requirements, while others will require a complete overhaul. Those states with little updates required should begin collecting and reporting the new SPR requirements as soon as possible. Other states that require more effort to update data collection systems should begin collecting and reporting the new SPR requirements as soon as they are able.

Suggestions for Future Research

Conducting this study can position AoA to design and implement a more comprehensive evaluation of OAA services in the future. Suggestions for future research are discussed below.

Comparison group data collection

Depending on funding availability, facilitating surveys among comparison groups of interest (e.g., private pay, Assisted Living) should be considered. These surveys would collect information on a representative sample of non-OAA service recipients to get a better understanding of their informal caregiving and private pay services and would address the limitation of only using claims data. AoA should work with the research team to prepare for this data collection, completing such tasks as:

- ▶ Developing survey tools
- ▶ Pre-testing survey tools
- ▶ Developing sampling procedure
- ▶ Identifying surveying method (i.e., phone, mail, etc.)

Additionally, to address the private pay limitation, one option involves partnering with a managed care provider company that offers a continuum of care (e.g., health care, medical home, personal care, long-term care insurance). This option gives the team the opportunity to link private insurer data with those identified for a comparison group.

Conduct an evaluation

As all states begin collecting newly required data elements, AoA might consider using this newly acquired data in a national evaluation. This evaluation could result in definitive conclusions providing a full picture of the impacts of OAA Title III services to date. Specifically, AoA will better understand the impact of OAA services across the board in promoting positive outcomes for service recipients, including increased community tenure and decreased health care use. This evaluation will also examine the

potential cost savings of OAA service use. Additionally, it will enhance capacity for ongoing research and provide information about the programs that AoA and the Aging Network can use in future program planning.

Appendix C-A: State Data Questions Guide

Interview Protocol

Interview Questions

1. Describe how your agency/organization collects data, i.e., is this handled by a contractor or the State itself? Do you assess data validity? How?
2. What are the State's current policies or criteria for services? (e.g. service caps; state vs. local service caps; eligibility requirements; waiting list policy)
 - a. What information do you collect on individuals on the wait list? Is this the same information for those receiving services?
3. What are the units of measure used for services in each Title III Category? Does your state use the SPR definitions or is there deviation from those units of measure?
 - a. III-B: Personal care, Home maker, Chore, Adult day care/ Adult day health, case management, assisted transportation, transportation, legal assistance, I&A, Outreach
 - i. Please be very clear on the I&A measures.
 - ii. Do you report adult day as respite?
 - iii. Is case management information collected electronically (i.e., case notes)?
 - b. III-C: Home-delivered meal, congregate meals, nutrition education, nutrition counseling, high nutritional risk, NSIP meals
 - i. Is there any potential confusion for how these may be measured? (e.g., meals served out of a senior center connected to an Assisted Living Facility – do the ALF residents get counted?)
 - ii. What meals count?
 - c. III-D: Health promotion [OAA – how much money spent / how many people are served]
 - i. What do you collect beyond OAA required collection?
 - d. III-E: Counseling/Support Group/Training, Case Management, Respite Care, Supplemental Services
 - i. Do you identify what the supplemental service is?
4. Do you track the volume of services received by each client? [be specific for which services and programs]
5. What data elements does your state collect? Included OAA, Waiver, etc... services. Of this data, what can you report?

- a. Do you have a data dictionary or a data list for these elements?
- b. What tools do you use for data collection? Is this consistent across the state?
- c. Are there consistent answer categories for variables across the state? (services, health, demographic)
- d. How integrated are your systems? Are state-funded and Waiver programs captured in the same system?
6. Do all AAAs collect the same or some of the same OAA data elements? Is the data collection process state-wide?
 - a. How does the state receive data from the local level? Is it at the individual level or the aggregate level?
 - b. Do you use a statewide database?
 - c. What is the timeline for local to state roll up of data, i.e., daily, monthly, annual?
 - d. Can the system produce an unduplicated count across services?
 - e. Does the system contain PII? Specifically, SSN or Medicare number?
 - f. Does the system track community tenure? What is the beginning point (referral, assessment, etc.) to termination (reason, nursing home, death, etc)?
 - g. Is state/local working with Medicare to track services utilization – care transitions, etc...?
7. Can your data be tracked longitudinally? [be specific for which services and programs]
8. What is the level of specificity for your OAA data? Do you separate OAA services out from similar non-OAA funded services (e.g., respite)?
 - a. How do you differentiate OAA services from non-OAA funded services (e.g., Medicaid)? Do you use consistent measures?
9. How do you track expenditures data?
 - a. Be clear on difference between expenditures and cost
10. How often do you collect data on the functional, physical, behavioral status of your OAA clients? Is that consistent across the state?
11. What demographic variables do you collect? Is this consistent across the state?
12. Do you track informal caregiving use?
13. Do you track unmet need?
 - a. Do you track utilization?
 - b. Do you track the difference between planned services delivery and actualized service delivery?
 - c. Do you have a system in place for ensuring that you are serving people in the underserved categories (rural, minority, etc)? Do you use targeting criteria?