

FINAL REPORT

Evaluation Study Design for Long-Term  
Care Ombudsman Programs under the  
Older Americans Act:  
*Research Design Options*

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## 1.0 Executive Summary

In September 2011, the Administration for Community Living (ACL) awarded a contract to NORC at the University of Chicago (NORC) to develop an evaluation study design to better understand and assess the effectiveness of Long-Term Care Ombudsman Programs (LTCOPs). NORC was tasked with building the evidence base on LTCOPs in order to develop recommendations for a rigorous and comprehensive study design that investigates program efficiency and program effectiveness at multiple levels, including the resident/family, facility, local/state/program, and federal levels. The effort was led by NORC with extensive input and assistance from the ACL and a Technical Advisory Group (TAG) that was created to guide and inform the overall research objectives and design of the project. TAG members reflected a broad range of knowledgeable stakeholders, with particular expertise in the areas of ombudsman programs; aging program evaluation; elder abuse, neglect and exploitation research; and long-term care systems. The 14 TAG members included Rosemary Biggins, James Bulot, PhD, Toby Edelman, EdM, JD, Doni Green, Alice Hedt, Brooke Hollister, PhD, Rosalie Kane, PhD, MSW, Debi Lee, Yvette Lugo, Jackie Majoros, JD, Ana Potter, JD, William Scanlon, PhD, Lori Smetanka, JD, and Jean Wood. This document represents the culmination of that 16 month effort and describes approaches to evaluating the LTCOP that incorporates ongoing feedback from the ACL and TAG members. A list of participating TAG members and their affiliations can be found in **Appendix A**.

Key tasks of the design process involved the development of a family of four logic models and a set of overarching research questions to guide the evaluation, as well as the identification of data collection tools and data sources that inform those questions. The diversity of proposed activities reflects the ACL's goals for this evaluation, the commitment to a population health frame of reference, and seven critical LTCOP characteristics that influence design options. In an effort to address both the goals of the evaluation as well as uncertainty regarding future evaluation project funding, we have developed a multi-modal approach to evaluating the LTCOP that is highly scalable and features sufficient flexibility to handle an extensive or modest allocation of resources with a high degree of scientific rigor.

The evaluation study design for the LTCOP consists of two major groups of activities: a process evaluation and an outcomes evaluation. Both the process and outcome evaluations contain multiple cross-sectional and longitudinal data collection activities that combine existing data sources with new data collection that are both quantitative and qualitative. Several core sources of data include interviews (in-person and telephone), surveys, focus groups, case studies, and a cohort study. Collectively, these activities gather information from multiple perspectives, including residents, family members, facility

staff, ombudsmen (state and local), stakeholders, federal staff, and other individuals with interests in the program. Data collected as part of these evaluation activities can be used to support a number of analyses regarding the processes and outcomes of the program as well as cost analyses. It should be noted that while the process and outcomes evaluation activities are integrated and complementary (and sometimes combined), the components are separate and any one component can be pursued independently of the others. In the following report, we present greater detail on each LTCOP evaluation activity.



## 2.0 Introduction and Overview

In response to widely reported problems involving poor quality of care in nursing homes, the ombudsman program began in 1972 as a Public Health Service demonstration project in five states. The 1978 amendments to the Older Americans Act (OAA) established the LTCOP nationwide. Administered by the Administration on Aging (AoA) through grants to states and territories, LTCOPs currently operate in all 50 states, the District of Columbia, Puerto Rico, and Guam.

As mandated by the OAA, the LTCOP's main responsibilities are threefold (see **Appendix C** for Section 712 of the OAA). First and foremost, the LTCOP advocates on behalf of residents of long-term care facilities, including nursing homes, board and care homes, and similar adult care facilities. In this capacity, ombudsmen identify, investigate and resolve complaints about the care residents receive with respect to their health, safety, welfare and rights. Second, the program advocates for systems change by representing residents' interests before government agencies and analyzing, commenting on, and monitoring federal, state and local regulations, policies, and actions that potentially affect residents of long-term care facilities. Third, the ombudsman program provides information and consultation to facilities and residents and their families as well as collaboration with other agencies. Through education and outreach, the LTCOP aims to build capacity for advocacy in a number of ways. These include supporting family and resident councils, developing citizen organizations, and empowering residents and their caregivers to more effectively advocate on their own behalf.

The first national evaluation of the LTCOP was completed in 1995 by the Institute of Medicine (IOM). Since that time, significant changes have occurred in the long-term care environment, including an increase in consumer options in residential care and an increasingly older, frailer, and more diverse population of long-term care residents. While the LTCOP has historically filled a vital need for some of society's most vulnerable groups, these changes have placed greater and more complex demands on programs. In its fifth decade, the LTCOP operates in a very different socio-demographic, economic and political climate than was the case during its last comprehensive evaluation 18 years ago, making this an opportune time to re-assess the ability of the program to meet its legislative mandates.

## 3.0 Evaluation Study Design Goals

The ACL's four main goals for the evaluation of the LTCOP are:

1. Documentation of ombudsman practices, approaches, and processes, including analysis of the similarities and differences across state programs;
2. Provision of feedback to federal, state, and local program staff about what is working and areas for improvements in the LTCOP;
3. Documentation of the outcomes of the LTCOP; and
4. Measurement of program efficiency and the collection of program cost data to support program planning, continuation and/or expansions.

## 4.0 Characteristics of the LTCOP & Evaluation Designs

In developing an evaluation design for the LTCOP, key attributes of the program that influence potential study design options were considered. In particular, the following program characteristics and their design implications were taken into account:

### 4.1 Complexity of the Program and its Relationship to Measuring Outcomes

In multifaceted and complex programs such as the LTCOP, it is challenging to establish a clear and causal relationship between inputs, outputs, and outcomes while also taking into account contextual factors that may influence these relationships. The LTCOP's outcomes have multiple determinants, are moderated by myriad contextual factors, and may take several years or more to become apparent. The program's goal of improving residents' quality of life and quality of care are outcomes that are difficult to observe and not easily attributable to the program. Even absent concerns about demonstrating causality, significant time would be required to observe any cause and effect relationships that do exist. The inter-relationships of cause and effect, the strength of these associations, and follow-up time required to observe them must be understood when considering evaluation design options for the LTCOP.

**Implications for the evaluation design:** A realistic and relevant assessment of the program will focus on meaningful measures over which the LTCOP has a reasonable amount of control. These include short-term and to a limited extent, medium-term outcomes that reflect progress toward reaching the program's overarching, long-term objectives. This involves defining outcomes in a way that limits their scope to factors over which the LTCOP has direct influence. Further, these outcomes must be interpreted in the context of the LTCOP's resources and other contextual factors, which vary considerably.

### 4.2 Decentralization and Diversity of Program Implementation

Although states are tasked with ensuring that state-level programs meet specific requirements that flow down from the OAA, they also exercise considerable discretion in fulfilling program functions in a manner that best serves their elderly populations. States' ability to expand program responsibilities and their broad flexibility in administering the program (e.g., organizational location at both the state and local levels, sources of funding) means that great variations exist in the structure, operation, and effectiveness of ombudsman programs across states. Although the resulting diversity of program characteristics tailored to local contexts is a strength of the program, the same heterogeneity poses challenges for developing sound research and evaluation designs. Against this backdrop, however, there appears to be sufficient uniformity in goals and programs across states to be able to talk meaningfully about a set of common programmatic elements that define a single LTCOP.

**Implications for the evaluation design:** The proposed approach will include a set of core variables that addresses program elements that are common across all states, as well as a series of customized modules that will focus on specific topics which apply only to selected states, such as home-based care. This approach permits us to gather standardized information on fundamental LTCOP program features while also collecting information on important characteristics that are not uniform across states.

### 4.3 Consistency of Data

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Although the National Ombudsman Reporting System (NORS) currently collects information on a common set of variables for the LTCOP nationwide, its ability to consistently and reliably describe ombudsmen activities has raised concerns. Given the decentralized implementation of the program, the collection of high quality data can be challenging. Further, variability in interpretation of data items and the diversity of data collectors across sites (threats to inter-rater reliability) introduce additional concerns regarding the utility of this data set as a viable source of program information that can inform effectively on programmatic outcomes. For example, the large number of complaint codes (133) makes consistency in interpretation difficult across and within programs. Data provided by NORS on the extent of long-term care ombudsman (LTCO) activities, moreover, are likely to be incomplete. For example, the informal work performed by ombudsmen that does not rise to the level of being classified as “complaints” or “consultations” (as judged by ombudsmen themselves), may go undocumented. As a result of these examples, any use of NORS quantitative data must be used with caution.

Since the inception of NORS, the extent to which the data are employed as the AoA intended and the degree to which they meet federal, state, and local needs, remains unknown. The Office of the Assistant Secretary for Planning and Evaluation (ASPE) recently assessed the reliability of NORS based on a review of 2008 NORS instructions and data. ASPE identified several concerns with respect to inconsistencies in reporting, concluding that the “NORS data fails to meet the need of the Administration on Aging to understand and describe the activities of ombudsmen across the country” (n.d.).

**Implications for the evaluation design:** Any use of existing NORS data for LTCOP evaluation purposes will first require a careful review of data elements. The examination will help to better identify ways to fill critical knowledge gaps needed to better understand and/or analyze the issues surrounding data collection, use and consistency, as well as inform any potential revisions to NORS in the future. This would entail an examination of the data itself as well as interviews with ombudsmen regarding the process by which data are collected and quality assurances practiced.

Limitations aside, NORS remains potentially useful for informing proposed evaluation activities that rely on aggregate data, such as the ecological study on systems advocacy (described in more detail in Section

8.3.2). The narrative sections of NORS can also be valuable for identifying systems advocacy efforts across states for the proposed commissioned paper on legislative accomplishments of the LTCOP, as well as case studies on systems advocacy. Data collected at the local and state levels can be used for the outcomes evaluation where case-level information is needed. For example, the proposed analysis of ombudsman and nursing home complaint data (Section 8.3.1) rely on information that is collected at the local and state level which is not forwarded to the AoA.

Any new data collection effort, although it would require a significant investment of time and resources, must incorporate guidance materials, training, and ongoing technical support to ensure sound quality measurement and meaningful collection, reporting, and use of program data.

#### 4.4 Full-coverage and the Problem of Comparison Groups

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Programs that are intended to serve all members of a target population present one of the most difficult challenges for designing a rigorous evaluation. If a program is fully implemented, by definition there is no comparison group. In the case of the LTCOP, consumer advocacy, which is one of the key program responsibilities, is intended to benefit all older residents of nursing home facilities and licensed board and care homes, including assisted living. In 12 states and the District of Columbia, the LTCOP is also responsible for home-based long-term supports and services. Given that the main thrust of the LTCOP is targeted to all older residents of long-term care facilities, identifying a comparison group is especially challenging. Because the program has been in existence since 1972 serving essentially the same purpose, furthermore, there is no opportunity for a pre-post comparison at the program level.

**Implications for the evaluation design:** One strategy to develop a comparison group of non-LTCOP users is to identify residents/consumers who pursue complaint handling with agencies other than the LTCOP. Another way to address evaluating outcomes that are intended to benefit an entire population is to first identify programs that are "stronger" and "weaker" on certain parameters related to, for example, consumer or systems advocacy, and compare outcomes between stronger and weaker programs. Lastly, it is possible to employ a pre-post design examining changes in facility and consumer status based on a specific LTCOP intervention. The intervention, in this case, would not apply to complaint investigation (given that complainants can only be identified after the fact) but to education/outreach or systems advocacy activities that ombudsmen initiate. The effort, moreover, would need to be identified prior to deployment, reflect federal mandates, and have the potential to have a demonstrable impact at the consumer or systems level.

## 4.5 Hybrid Nature of the Program

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In addition to the hybrid *role*<sup>1</sup> that ombudsmen play (resembling the classical ombudsman model but without the neutral stance the position has historically assumed), the LTCOP itself can be understood as a hybrid *program* when we view its advocacy activities across different levels. At the individual/consumer level, advocacy is provided in the form of direct services that are typical of human service delivery programs. These services are offered through consultations, referrals, complaint handling, and via education and outreach activities to build the capacity for advocacy among long-term services and supports (LTSS) residents and their caregivers. At the systems level, the LTCOP engages in more traditional advocacy activities common to advocacy organizations such as monitoring and commenting on laws, regulations, government policies and action, and mobilizing stakeholders toward collective action to support person-centered care practices and policies. Despite their shared “advocacy” name, consumer advocacy (service delivery) and systems advocacy are profoundly different activities in the case of the LTCOP. Another related challenge concerns whether the state LTCO, local level entities, or both participate in systems advocacy work. Significant variations exist among states related to their practices and policies of *who* is doing the systems level work and the role that the state LTCO plays in leading that effort.

**Implications for the evaluation design:** Given the distinction between consumer and systems advocacy, a sound evaluation design requires developing individually tailored evaluation approaches that reflect the hybrid nature of these program features. This also points to a need to carefully define terms so that disparate activities that fall under the same term (e.g., “advocacy”) or activities with different names or audiences but which are similar, are not confused by researchers and respondents. The IOM report, for example, noted that, as operationalized by some ombudsmen, advocacy can blur roles among ombudsmen, regulators, adult protective services, and services. TAG members, furthermore, advised prefacing questions to residents regarding advocacy work in accessible language when describing the activities performed by ombudsmen.

## 4.6 Reliance on Trained Volunteers

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An important feature of the LTCOP in most states is its heavy reliance on trained volunteers. In 2010, 8,813 certified volunteer ombudsmen supported the program, a figure representing 88 percent of all ombudsmen nationwide. Given the significant role volunteers play in the LTCOP’s operations, design options must recognize the tremendous contribution of these individuals and be adaptable to their work flow and logistics. In addition, there are differences across states in how they use their volunteers which

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<sup>1</sup> p.42, Institute of Medicine. (1995). *Real people real problems: An evaluation of the long-term care ombudsman programs of the Older Americans Act*. J. Harris-Whelung, J. Feasley, C. Estes, (Ed.). Washington, DC: National Academy of Sciences.

may allow for important comparisons across programs in terms of both program efficiency and effectiveness.

**Implications for the evaluation design:** The design will need to account for possible differences between volunteers and paid staff such as the responsibilities assigned to each group, their respective motivation to perform, and expectations for training and performance. In addition, the use of volunteers is a particularly important element in cost analyses. Monetizing the value of volunteer labor (in addition to other in-kind resources) can demonstrate the ability of the LTCOP to leverage donated resources for implementing the program.

#### 4.7 Variability in Who is Served

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The three broad categories of long-term care settings include nursing homes, board and care homes (inclusive of assisted living and similar adult care homes), and home-based care. Unlike the other settings, nursing homes are heavily regulated by the federal government. The other two settings are either less heavily regulated, or are regulated to a greater degree by individual states. This results in a greater relative degree of homogeneity among nursing home service provision than among service provision in other long-term care settings. Moreover, the OAA authorizes responsibility for ombudsmen to serve residents who live in only nursing and board and care facilities while responsibility for individuals receiving in-home services (where ombudsman services to these individuals exist at all) is mandated by states.

**Implications for the evaluation design:** Ideally, evaluation activities that aim to make inferences about programmatic outcomes will involve collection of information from programs that are as homogenous as possible with respect to fundamental operational elements. In this way, the impact of contextual factors that may inhibit the ability to draw conclusions about LTCOP outcomes will be minimized. Nursing homes are considerably more uniform than other long-term care settings for LTCOP evaluation activities. Further, knowledge about how long-term care is provided in board and care facilities across states is limited, and the same holds true for in-home care. Given the variability in settings and populations, any analyses that are performed will be specific to the type of facility under investigation (data for all settings would not be aggregated). In addition, because the evaluation focuses on mandates outlined in the OAA, state mandates – such as for in-home care – will be studied insofar as they affect the ability of programs to carry out federal responsibilities.

## 5.0 Use of CDC Framework

The proposed design has a population health orientation, following guidance presented in the Centers for Disease Control and Prevention’s Framework for Program Evaluation in Public Health<sup>2</sup> and the W. K. Kellogg Foundation Logic Model Development Guide<sup>3</sup>. For this effort, NORC carried out the three steps outlined in the CDC Framework for conducting an evaluation design. These include:

- Engaging stakeholders, through convening of a TAG to offer input and feedback on all aspects of evaluation design;
- Describing the program, both through narrative and through logic model(s); and
- Focusing the evaluation design, through identification of key concerns, research questions, prospective data sources, and methods.

For each step in the evaluation, the CDC Framework offers a set of 30 criteria for assessing the quality of evaluation activities across the domains of utility (are the information needs of users met?), feasibility (are plans realistic, prudent, diplomatic, and frugal?), propriety (are activities both ethical and legal?), and accuracy (is technically accurate information revealed and conveyed?).

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<sup>2</sup> Centers for Disease Control and Prevention. Framework for program evaluation in public health. MMWR 1999;48(No. RR-11):[inclusive page numbers].

<sup>3</sup> W.K.Kellogg Foundation. 2004. W.K. Kellogg Foundation Logic Model Development Guide.



## 6.0 Use of Program Logic Models

The foundation for the LTCOP evaluation design is a set of program logic models that were developed in consultation with the ACL and the TAG. The logic models are intended to provide a common understanding of how the LTCOP operates and to clarify how program elements and their associated activities translate to desired short-, medium- and long-term outcomes. The family of logic models is presented in **Appendix D** and includes outcomes that were revised and refined in concert with the ACL and TAG.

For the evaluation study design of the LTCOP, we have focused on the short-term outcomes and a select number of medium-term outcomes in the logic models. Within this context, we consider outcomes at all levels, including consumer<sup>4</sup>, facility, local/state/program, and federal. While outcomes in the overarching logic model are currently described as increasing or decreasing on a given measure, it may be useful to provide national benchmarks or state equivalent benchmarks on various indicators as a means to provide feedback to states on their performance. **Appendix I** presents recommendations from the TAG on how to potentially measure these outcomes and where to locate available data sources. In addition to this feedback, the development of measures for the evaluation would benefit from building on measures used in previous studies of the LTCOP, such as those carried out by the IOM, the Helen Bader Report, Carroll Estes and her colleagues, as well as other LTCOP researchers. Data-related efforts that would also serve as useful references include the work of the National Association of State Long-Term Care Ombudsman Programs' (NASOP) standing data committee that is specifically tasked with examining NORS data.

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<sup>4</sup> Consumers refer to residents, families, and their representatives.

## 7.0 Overarching Research Questions

Several sources guided the development of the evaluation’s overarching questions. In addition to the logic models, we referred to the ACL’s goals for the evaluation design (outlined above), the OAA’s Section 206 specifications on evaluations of programs authorized by the Act, the IOM’s 1995 report, and ongoing discussions with the ACL.

Using these sources, we propose that the national evaluation of the LTCOP address the following overarching questions:

### Process Evaluation Questions

1. How is the LTCOP structured and how does it operate at the local, state, and federal levels?
2. How do LTCOPs use existing resources to resolve problems of individual residents and to bring about changes at the facility and governmental (local, state and federal) levels that will improve the quality of services available/provided?
3. With whom do LTCOPs partner, and how do LTCOPs work with partner programs?
4. How does the LTCOP provide feedback on successful practices and areas for improvement?

### Outcomes Evaluation Questions

1. Are the critical functions, including federally mandated responsibilities, of the LTCOP at the local, state, and federal levels carried out effectively and efficiently?
2. How effective is the LTCOP in ensuring services for the full range of residents of LTSS facilities, including individuals with the greatest economic and social needs?
3. How cost-effective is the LTCOP at the local and state levels?
4. What impact do LTCOPs have on long-term care practices, programs, and policies?
5. What impact do LTCOPs have on residents’ health, safety, welfare, and rights?

## 8.0 Evaluation Design Options

There are a number of options for evaluating the LTCOP, each with varying costs, scope, implementation, and complexity. Given the uncertainty with respect to funding for future evaluation activities, we have developed a **scalable**, **flexible**, and **multi-modal** study design for a comprehensive evaluation of the LTCOP that addresses the approved research questions. This design has a number of appealing features.

- The design is **scalable** because each information gathering activity can involve larger or smaller sample sizes (e.g. numbers of people, organizations).
- The design is **flexible** because we can incorporate larger or smaller numbers of distinct information gathering activities (e.g. number of focus groups, number of surveys).
- The design is **multi-modal** because it involves data collection using both qualitative (e.g. focus groups) and quantitative (e.g. surveys, cohort study) methods.

These design features and data collection strategies consider program efficiency, including cost and resource utilization, and program effectiveness at multiple levels, including the consumer, facility, local/state, and national levels. Collectively, the approach can be expanded or contracted depending on available resources and needs, making it adaptable to future resource availability.

As noted above, the evaluation design consists of two major groups of activities: a process evaluation and an outcomes evaluation. Both the process and outcome evaluations contain multiple data collection activities, some of which are qualitative and some quantitative. All quantitative data collection activities are targeted at gathering data that are currently not available or deemed potentially unreliable in existing data sources. In contrast, qualitative data can be collected to supplement and provide context for quantitative data and can be particularly helpful in addressing research questions involving program processes as well as outcomes that are not amenable to quantitative approaches.

Table 1 below summarizes the proposed LTCOP evaluation activities. It should be noted that while the process and outcomes evaluation activities are integrated and complementary (and sometimes combined), the components are separate and any one component could be pursued independently of the others. However, we strongly recommend that the *Core Process Data Collection* and the *Modular Process Data Collection* occur simultaneously. Separating the two data collection activities in time would not only decrease scientific rigor (e.g., the same set of respondents may not be able to participate at two distinct

time points) but also increase costs (re-fielding surveys, repetition of fixed costs, etc.). Adding modular sections to the core data collection, moreover, can be done at marginal cost.

With respect to the order in which the activities are rolled out, we strongly recommend that the *Detailed Review of Existing Data Sources* and the *Core and Modular Process Data Collection* come first. There is, however, some flexibility in sequencing the remaining activities. While process-related data collection efforts generally precede the outcomes evaluation, outcomes-related activities that draw on existing data sources or are not informed by the *Core and Modular Process Data Collection* can be pursued earlier in time.

**Table 1**

Process or Outcomes Evaluation (or both)?	Activity	Qual	Quant	New Data? Yes/No/Maybe	Evaluation Goal
Process	Detailed Review of Existing Data Sources	X	X	No	1
Both	Core Data	X	X	Yes	1,2, 3, 4
Both	Modular Data	X	X	Yes	1,2, 3
Both	Commissioned Papers	X	X	Yes	1,3
Both	Case Studies	X	X	Yes	1,2, 3
Outcomes	Analysis of Ombudsman and Nursing Home Complaint Data		X	No	3
Outcomes	Ecological Study		X	No	3
Outcomes	Cost Analyses		X	Yes	2, 4
Outcomes	Cohort Study	X	X	Yes	3

Three appendices have been included to assist the reader in understanding how the proposed evaluation activities can be carried out. **Appendix E** is a matrix of the evaluation’s goals, its associated evaluation questions, data sources, data collection methods, and logic model outputs/outcomes. **Appendix F** and to a limited extent **Appendix I** (which are confined to outcomes) outline various data elements (not an exhaustive list) that would be collected from respondent classes (discussed further in Sections 8.1 through 8.4.3) and the multiple approaches that will be used to collect those data.

## 8.1 Process Evaluation: Existing Data

### 8.1.1 Detailed Review of Existing Data Sources

The process evaluation will address program implementation and context, i.e. the fidelity with which states implement their LTCOPs, given the program’s federal legislative, and grant requirements.

Activities would encompass a review of existing program data sources that can be used to provide context

for the program, including local and state ombudsman complaint data, NORs, Minimum Data Set (MDS), Certification and Survey Provider Enhanced Reporting system and the Quality Improvement Evaluation System (CASPER/QIES) – previously Online Survey and Certification and Reporting (OSCAR), and state level data (such as the LTSS Scorecard, etc.). The review will be conducted with an eye toward linking existing data to new data collection efforts that are described below. **Appendix H** presents an annotated bibliography of existing data collection tools and data sources that can potentially support the LTCOP evaluation.

## 8.2 Process Evaluation: New Data Collection

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To supplement the process evaluation activities described above, we propose collection of new data using a tailored approach that involves "core" data that will be collected from all states as well as "modular" data that will collect additional information on specific strata (defined below) of interest in subsets of states. Core data will focus on variables that apply to all states, regardless of organizational structure, use of volunteers, and so forth. These data will describe the breadth of variables of central interest for the ACL as they apply across the board in all states. In contrast, modular data will be collected based on identification of key characteristics or "strata" that differ across states and that are hypothesized to impact programmatic effectiveness. These strata, for example, may include whether programs are responsible for home-based care or dedicate a significant amount of time to systems advocacy. Multiple modules can be developed, each with its own set of questions aimed at understanding key practices that vary by key strata.

Ideally, the evaluation design will include core data for each state as well as modular data for all modules that apply to that state. Thus, it is anticipated that some states would have a great deal of modular data while others would have little. Resources may dictate that core data elements and both the number of modules and modular data elements will need to be prioritized, thus resulting in less-than-comprehensive data collection on variables of interest for this objective. This approach recognizes programmatic heterogeneity and is both scalable and amenable to both small and large budgets.

***Importantly, the process evaluation core data collection serves four key purposes. The activities (1) describe the structure and operations of the program, (2) inform subsequent evaluation activities including the commissioned papers, case studies, and cohort study, (3) identify relevant sites for case study selection and (4) serve as "predictor variables" for the outcomes evaluation.***

### 8.2.1 Process Evaluation Core Data

Core process-related data will likely be cross-sectional, involve both qualitative and quantitative information, and will constitute the backbone of this part of the LTCOP evaluation. Core data will reflect both the breadth and depth of characteristics that are shared by all LTCOPs. It is possible that resource constraints will require prioritizing of core data topics or the number of elements within each topic. If this is the case, it should be expected that some universally-applicable topics will receive limited or no attention at all. Once again, this approach permits flexibility and scalability without compromising rigor.

Process evaluation core data will address evaluation goals 1 and 4, and relate to understanding the structure and operations of the LTCOP; determining the resources necessary to carry out responsibilities; assessing the ability of the program to meet mandated responsibilities; identifying how states carry out the program relative to the logic model that was developed; and determining how core activities of the program can be improved, among other areas of investigation. In terms of the logic model, the process evaluation will collect information regarding the programs' inputs, activities, outputs and to a limited extent, outcomes (in the case of ombudsmen respondents). Respondents for the process evaluation focus on program staff at the local, state, and federal levels as well as local and state ombudsmen associations. Additional respondent classes that need to be considered are State Units on Aging and other host agencies at the state and local levels (such as Area Agencies on Aging) that play a role in the how programs are structured and operate. These stakeholders have been identified for the outcomes evaluation but there may be a need to seek their input earlier as part of the process evaluation, especially if cost data are to be collected (Section 8.3.2).

#### 8.2.1.a Sampling

Process evaluation core data will be collected in a standardized manner at the state level from all states and from a random sample of local programs (i.e., census).

#### 8.2.1.b Respondent classes

At least four respondent classes (e.g. groups) will participate in the process evaluation core data collection; different data elements will be collected *across* classes, but in all states, identical data will be collected *within* each class

*Class 1:* Federal ACL staff, Centers for Medicare and Medicaid (CMS), National Ombudsman Resource Center, National Association for States United on Aging and Disability (NASUAD), NASOP, National Association for Local Long Term Care Ombudsman (NALLTCO) (data collected from all)

*Class 2:* State ombudsmen (data collected from all)

*Class 3:* Local, paid staff (random sample from each state based on size of program/number of paid staff)

*Class 4:* Volunteers (random sample based on size of program or number of staff; sampling can be done on state level by identifying a list of all volunteers, or within local programs according to local program size; other options are available and depend on securing comprehensive, accurate volunteer lists.)

### 8.2.1.c. Topics to be Covered

Core process data collection will solicit information on resources/inputs (including costs) as well as activities and outputs identified in the logic models. It is anticipated that these core data will cover a variety of topics. Our approach, which utilizes respondent classes, permits collection of data on the same or similar topics from diverse perspectives, and also accommodates collection of information that applies to only one class of respondents.

While not an exhaustive list, the following are examples of critical information that we propose for inclusion in the process evaluation core data set, sorted by respondent class:

*Class 1:* Federal staff and national associations— program operations, feedback to and monitoring of state programs, adequacy of resources, barriers to effective operation, interactions with state programs, inter-organizational relationships, use of program data for strategic planning.

*Class 2:* State ombudsmen – program operations, organizational placement, interactions with local programs, state mandates, program autonomy, adequacy of resources, inter-organizational relationships, political context, main activities, successful programmatic approaches, barriers to effective operation, ombudsmen characteristics, program size, data management systems, budget information, funding sources, disclosure confidentiality, legal counsel, resident transitions to less restrictive settings, designation of local programs, access to client records, feedback to and monitoring of local programs, leadership.

*Class 3:* Local, paid staff – program operations, organizational placement, interactions with state program, adequacy of resources, inter-organizational relationships, main activities, ombudsmen characteristics, training, skills and qualifications, clarity of roles, data management systems, budget information, rural vs. urban placement, lines of authority.

*Class 4: Volunteers* – ombudsmen characteristics, training, clarity of roles, skills and qualifications, level of support from both local and state office, knowledge of office of state LTCOP.

#### **8.2.1.d Data Collection**

Ideally, data will be collected via in-person and telephone interviewing as well as computer-assisted surveys. Records review will also be incorporated into the data collection. Of particular interest in the program records review is the availability of information in the following areas: characteristics of paid and volunteer staff (including demographics, skills, qualifications, level of effort/FTE and tenure), training and management of staff, cost data, funding sources, and organizational placement at the state and local levels.

#### **8.2.1.e Analysis Overview**

In addition to qualitative data, process evaluation core data will yield four "rectangular" data sets. That is, all elements should apply to, and be collected from each of the four respondent classes. It is anticipated that state will be the first "clustering" variable because Class 3 and 4 will be related to one another (i.e., not independent) because they are grouped within states and local programs. We expect that most analyses will be conducted within each respondent class. However, if there are programmatic features for which data are collected for more than one respondent class, comparisons across these groups will be possible. It is anticipated that the smallest number of respondents will be in Class 1, followed by Classes 2, 3, and 4. It should be emphasized that because Classes 3 and 4 are clustered within state, the clustering of these data will need to be taken into account in the analysis. In addition, it is anticipated that the number of respondents for Classes 3 and 4 will differ across states depending on size, whether local programs exist, and possibly according to how sampling is conducted for these classes.

On the basis of data collection focusing on the structure and operations of the program (in addition to existing data sources at the state- levels), we expect to identify key issues affecting program effectiveness. In addition to providing descriptive statistics on the LTCOP, the process evaluation will also facilitate the analysis of similarities and differences between state programs.

#### **8.2.2 Process Evaluation Modular Data**

Program evaluation modular data will likely be cross-sectional, involve both qualitative and quantitative information, and act as a targeted, tailored supplement to process evaluation core data for topics and programmatic features that are heterogeneous within and between states. Ideally, modules will be developed for all LTCOP strata that differ across states and that can reasonably be expected to impact program effectiveness. When possible, program evaluation modular data should be collected at the same time as program evaluation core data.



### 8.2.2.a Sampling

Ideally, strata-specific modules will be administered in all states to which the module applies. For instance, a module targeting issues associated with LTCOP complaint handling in home-based care will be administered in all states where the LTCOP supports in-home care. It is possible that resource constraints will require either prioritizing the number of modules that are developed and deployed and/or the need to deploy modules in less than the complete set of states in which they apply.

### 8.2.2.b Respondent Classes

The large number of potential strata upon which modules will be developed will require different respondent classes. Even in cases where modular data can be collected effectively from one respondent class, it will be useful to collect parallel data in multiple classes if different perspectives are desired. Ideally, program evaluation modular data will be collected from the same classes and the same individuals as those that participate in the program evaluation core data collection.

### 8.2.2.c Topics to be Covered

Modules can be developed for any LTCOP stratum that (1) differs by state and (2) is hypothesized to impact program effectiveness. Through the modular data collection, we will obtain information on mandates that vary across states. It should be noted however, that state mandates will be studied only to the extent that they support or detract from federal responsibilities. Potential strata include:

- Home care responsibility
- HCBS affecting both home care and board and care homes
- Levels of time devotion to systems advocacy work
- Nursing home closures
- Natural disasters (Hurricane Katrina, wild fires, earthquakes, etc.)
- Consumer financial protection
- Efforts at culture change
- Responsibility for serving as a primary finder of fact for abuse, neglect and exploitation reports in long-term care facilities
- Absence of volunteers, and
- Senior Medicare Patrol (SMP) collaboration

#### 8.2.2.d Data Collection

While data collection methods will vary somewhat based on the topic and classes of respondents, in general, it is recommended that data be collected via in-person and telephone interviewing as well as computer-assisted surveys. This approach assumes that respondents have Internet access and that email addresses or other means of delivering the URL can be identified. Ideally, process evaluation modular data collection will occur concurrently with the process evaluation core data collection, and will utilize the same individual respondents within each respondent class.

#### 8.2.2.e Analysis Overview

Process evaluation modular data will be cross-sectional, and will supplement core data in a number of ways. Data will be pooled with core data and examined to understand LTCOP operations in states that share a key characteristic of interest. These states can also be compared to "control" sites that do not share the variable of interest or analysts can statistically adjust the data from states that do not share the characteristic, or to a variety of control groups that can be constructed from the core data set. In addition, modular data may also be used to inform and develop case studies around certain topics.

### 8.2.3 Commissioned Papers

Commissioning formal background papers offers an opportunity to provide in-depth understanding and analysis on specific issues. Two potential topics for commissioned papers include a review of the legislative accomplishments of the LTCOP since the last IOM study 18 years ago and an examination of barriers to full inclusion of board and care facilities under the ombudsmen umbrella. Additional topics for commissioned papers may pertain to use of, and adequate access to, legal counsel. Given the flexibility of this design element, other subject areas may be suggested by the ACL as study resources permit.

#### 8.2.3.a Commissioned Paper: Legislative Accomplishments

The time horizon to realize successful systems advocacy efforts is often several years if not decades and the process is frequently indirect, complex, and non-linear. Any meaningful evaluation of systems advocacy needs to focus on proximate and traceable results of progress. For these reasons, the new data collection we propose on systems advocacy (see Section 8.2) is limited to a focus on immediate and intermediate outcomes.

In order to take a much longer view of the program's systems advocacy efforts, we recommend undertaking a commissioned paper on the federal-, state-, and local-level legislative and policy achievements to which the LTCOP contributed. Because the time period against which advocacy accomplishments can be measured is often shorter than ideal, pairing new data collection with a longer, retrospective examination of the program through a structured paper can be a fruitful way to capture both

the requisite characteristics for successful advocacy (including strategic capacity and adaptability to changing, unpredictable circumstances) and the full potential of the program’s systems advocacy activities.

Possible questions to be answered include:

1. How do LTCOPs approach legislative and policy change efforts?
2. What supports and barriers are in place related to the achievement of legislative or policy change?
3. What topics are most commonly the subject of legislative and policy change efforts?
4. Are there common catalysts that prompt legislative or policy change efforts?
5. What outcomes have been achieved through these efforts?
6. What level of effort is required of LTCOPs to achieve specific legislative or policy changes and over what period?

To date, the extent to which successful advocacy efforts have been systematically recorded is not clear. The Nursing Home Reform Law which passed as part of the Omnibus Budget Reconciliation Act of 1987 is often cited as an accomplishment to which the LTCOP contributed<sup>5</sup> but there are likely other policies and practices in which the LTCOP played a role since the last IOM study. For the commissioned paper, a document review can be conducted, and include newspapers, annual reports, the NORC narrative section on systems advocacy, and the Ombudsmen Resource Center’s publications. Data can also be drawn from interviews and surveys with ombudsmen (independently or within the process evaluation) and staff at the National Ombudsman Resource Center who are an important resource of the program’s history.

### **8.2.3.b Commissioned Paper: Barriers to Advocacy for Residents Living in Board and Care and Similar Adult Care Homes**

Under the OAA, LTCOPs are responsible for serving residents in skilled nursing facilities, nursing facilities, board and care facilities, and any other similar adult care homes, including assisted living facilities. In the OAA, a “board and care home” is defined as an institution regulated by a state pursuant to section 1616(e) of the Social Security Act, which requires states to enforce standards for any category of institutions, foster homes, or group living arrangements in which a significant number of supplemental security income benefit recipients reside. These regulations vary by state as does the use of the term

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<sup>5</sup> National Long Term Care Ombudsman Resource Center, Hunt, S. June 2002. “Ombudsman Best Practices: Using Systems Advocacy to Improve Life for Residents.” Retrieved from <http://www.ltcombudsman.org/sites/default/files/norc/systems-advocacy-paper.pdf>

“board and care home,” which could be used interchangeably or separately from “residential care homes” or “assisted living facilities,” depending on the state.

Although many states have begun covering assisted living services costs through Medicaid waivers, most residents pay privately or through long-term care insurance policy. Board and care facilities vary greatly in terms of size and the services they provide. On average, these facilities are larger in number than nursing homes but house fewer residents. As a consequence of this geographic spread and volume of facilities, the capacity of ombudsmen to provide a regular presence in board and care facilities can be more challenging than in nursing homes. Despite the fact that the OAA expanded ombudsman coverage to include board and care homes in 1981 (and “assisted living facility” was added to the definition of “long-term care facility” in 2006), NORS data suggest that LTCOPs do not visit board and care homes as regularly as they visit nursing homes. At the same time, the ACL has never defined full implementation of the mandate to provide “regular access”.<sup>6</sup>

A commissioned paper could examine barriers to and opportunities for effective service for individuals who live in board and care and similar adult care homes. Compared to nursing homes, we know less about the extent to which the LTCOP is involved in board and care facilities, how ombudsmen address the needs of board and care consumers, and whether serving residents of these facilities pose different challenges than serving nursing home residents. Potential topics for further investigation include Medicaid-funded home and community based services (HCBS) consumers who reside in board and care facilities, the ability of LTCO programs to influence state laws and policies related to these settings, the physical and social environment of board and care homes that may not be conducive to protecting complainants’ privacy or other barriers to making complaints, and the potential lack of guidance on advocating for special populations (such as those with developmental disabilities or mental illness). The data collection effort would draw on state laws and regulations, LTCOP policies and procedures, and surveys and interviews of state and local ombudsmen.

#### 8.2.4 Case Studies

Whereas modular data will be collected from all states that share a key characteristic (home care responsibility, etc.), case studies will enable us to examine certain issues requiring more focused, in-depth study. We propose two possible topics: best practices and systems advocacy. Other areas for study may be identified from the process evaluation. Regardless of the topics that are pursued, this general approach allows great flexibility and scalability. It should be underscored that careful identification of appropriate

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<sup>6</sup> According to NORS Instructions, the ACL defines facility coverage as “the number of facilities (unduplicated count) covered on a *regular basis*, not in response to a complaint, by paid and volunteer Ombudsmen. ***Regular basis means no less frequently than quarterly.*** Note that the information requested is the unduplicated number of facilities visited, not the number of visits.” (pp. 11-12)

sites around the given topic areas is critical to the success of case studies. In what follows, we offer a starting point for considering the criteria upon which states can be selected. Input from the ACL will help inform the validity and relevance of the data sources and help determine their utility or whether other sources of information (existing or new) would be more applicable.

#### 8.2.4.a Case Study: Best Practices

One potential topic for case study is an examination of best practices of successful ombudsman programs. For this effort, the IOM's identification of "exemplary practices" with respect to elements of program infrastructure and functions serves as useful starting point for selecting states. The remaining two ideal types of practices include "essential practices" and "unacceptable practices." Although 18 years have passed since they were first developed, the standards still serve as an important guide to ombudsman work today. For many ombudsmen, these model practices offer a basis for both measuring compliance with legislative mandates and a standard to which ombudsmen programs aspire.

In the 1995 report, the IOM developed the following prerequisites for effective ombudsman program performance: location of the office that maximizes the program's strengths (taking structure into account); qualifications of representatives; legal authority; resources (financial, information management, legal, and human – FTE : bed ratio, FTE : volunteer ratio); unified, integrated, and cohesive program operations; individual resident advocacy services; systemic advocacy work; and educational services. Exemplary practices in these areas are a composite of the most successful elements that existed in state and local programs. In order to achieve the status of exemplary practices, all essential practices need to be in place and be reflected in the states' activity and performance. At the time the IOM study was carried out, the committee did not seek nor did it locate, a program that adopted all elements of exemplary practice. If the IOM standards are employed, data on each element of exemplary practices may be collected from the process evaluation to identify sites for selection.

An alternative for selecting programs for case study may be to draw on input from ombudsmen and experts in the field. The Office of Inspector General's (OIG)<sup>7</sup> report, "Effective Ombudsman Programs: Six Case Studies," for example, selected states (CA, MA, MI, and OH) based recommendations from ombudsmen regarding the best overall programs and frequent citation by experts in the field and in the review of the literature. Two additional highly regarded states (DC and NJ) were selected because of their unique and outstanding features with respect to a strong enforcement focus and extensive legal support. An earlier OIG study found that successful ombudsman programs were characterized by high visibility

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<sup>7</sup> Office of Inspector General. (1991). *Effective ombudsman programs: Six case studies*. (Report No. OEI-02-90-02122). Washington, DC: U.S. Department of Health and Human Services.

through the use of both paid and volunteer staff. Programs handled complaints expeditiously, were highly publicized, secured adequate financial resources, and effectively recruited, managed, and retained volunteers.

Other possibilities for selection include states' ability to regularly visit both nursing facilities and board and care homes and/or states with high percentages of consumer satisfaction with respect to complaint resolution. To begin considering states for case studies, we present in **Appendix G** a ranking of states based on various indicators, using data from the 2010 NORS. Other criteria for successful practices or outcomes can be applied and discussed with the ACL.

#### 8.2.4.b Case Study: Systems Advocacy

A second proposed topic for case study is an in-depth exploration of systems advocacy, a core function of LTCOPs specified by multiple legislative mandates under the OAA. In this role, ombudsmen “must address and attempt to rectify the broader or underlying causes of problems for residents of LTC facilities. When working on the systems level, ombudsmen advocate for policy change by evaluating laws and regulations, providing education to the public and facility staff, disseminating program data, and promoting the development of citizen organizations and resident and family councils.”<sup>8</sup> Ombudsmen typically fulfill this responsibility through legislative, judicial, or administrative advocacy. Limited resources, however, often prevent systems advocacy work to be fully implemented across programs, resulting in significant variation in systems advocacy activity from state to state and locality to locality. According to 2010 NORS data, the time devoted to monitoring/working on laws, etc. (distinct from education and outreach) among state ombudsmen ranged from 0 percent to 65 percent.

A focused investigation of this critical aspect of ombudsmen's work is essential to understanding the LTCOP's overall functioning and effectiveness and the heterogeneous nature of systems advocacy make it well-suited for a case study approach. Unlike the ombudsman complaint handling function which is universal, the agenda for systems advocacy changes from jurisdiction to jurisdiction, and derives from complaint handling trends and particular circumstances related to the provision of long-term care in a given area. The window or opportunity for systems change is also unpredictable and the time course or arc of action from agenda setting through realization of systems advocacy objectives can span multiple years. A case study of systems advocacy efforts can tell us what, in addition to more funding and resources, can improve the efficiency and effectiveness of the LTCOP in fulfilling its responsibilities. The

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<sup>8</sup> p.72, Institute of Medicine. (1995). *Real people real problems: An evaluation of the long-term care ombudsman programs of the Older Americans Act*. J. Harris-Whelung, J. Feasley, C. Estes, (Ed.). Washington, DC: National Academy of Sciences.

approach offers a process-oriented focus on *how* selected state and local LTCOs engage in practices identified in the 1995 IOM report (pp.180-183) as exemplary in the area of systems advocacy, related to

- Agenda development and modification, and communication on agenda development between state and local LTCOs
- Capacity building among residents and their caregivers, through participation in and leadership of stakeholder coalitions,
- Regular, meaningful, and pro-active collaboration with regulatory agencies, legislators and stakeholders to leverage an agenda that supports resident rights and consumer protections through regulatory, legislative and legal actions, and
- Recognition of role of the Office of LTCO and authority to represent.

A case study's more fine-grained, narrative analysis of systems advocacy will rely on constructs and tools developed in the advocacy evaluation literature. Raynor et al.<sup>9</sup>, for example, provides a construct for assessing critical organizational capacities for advocacy that includes domains to measure multiple characteristics of LTCO leadership, internal management of LTCO programs, adaptation of state and local LTCOs to changing needs and partnerships, and the skill set of LTCO staff. Coffman<sup>10</sup> offers a set of interim outcomes related to policy (e.g., awareness, salience, attitudes/beliefs, public will, political will, constituency or support base growth, media coverage, issue reframing) and to advocacy capacity (organizational capacity, partnerships/alliances, collaboration and alignment, including messaging; new advocates, new champions, organizational visibility/recognition, new donors, more or diversified funding). Policy goals are differentiated to enable measurement of interim steps in the systems change process, from development of a proposed change and success in placing the change on the policy agenda, through adoption or blocking of the proposed change, and on to implementation, monitoring, and maintenance of a change.

Using these constructs and measures in a case study of systems advocacy in selected states and localities would require additional data gathering, involving:

- Additional respondent classes, such as state legislators, nursing home and board and care/assisted living associations, and judges involved in elder justice or bankruptcy cases. These respondents would vary depending on the specific topic or topics chosen for the case study.

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<sup>9</sup> Raynor J, York P, Shao-Chee S (TCG Group). 2009. *What Makes An Effective Advocacy Organization? A Framework for Determining Advocacy Capacity*. Los Angeles, CA: The California Endowment.

<sup>10</sup> Coffman, J. 2009. *A User's Guide to Advocacy Evaluation Planning*. Cambridge, MA: Harvard Family Research Project.

- Additional data instruments such as media tracking (to identify trends in coverage and content in print or social media over the course of an advocacy campaign), policy tracking (in addition to legislative history, monitoring of trends in regulatory and administrative decision making by public agencies and courts, as well as decision making and implementation at the level of residential care facilities) and structured interviews with policy or thought leaders (to gauge the influence of LTCO priority issues among the range of LTC issues in a jurisdiction or to query for a ranking of issues).
- Additional analytic tools, such as network mapping or social network analysis (to characterize the extent and strength of coalitions in which LTCOs participate or take a leading role). This approach to analysis would identify active participants in systems advocacy in addition to the LTCO, counting the frequency of task force participation (to give one example), the quality of participation as measured in provision of information, staff or financial support for task force activities, or dissemination of task force findings through communications, testimony, and other advocacy tasks.

Case studies can provide thoughtful snapshots of current activities at the time of data collection, along with a retrospective look-back at factors contributing to the current status of systems advocacy.

Selection of states that would be examined in various case studies will require discussions with the ACL to identify states that are employing successful systems advocacy strategies while balancing other responsibilities. For example, states may be selected based on a significant amount of time dedicated to systems advocacy work (expressed, for example, by the ability to meet a minimum 50% threshold as indicated in NORS). Employing this approach, however, would first require determining the meaning behind the NORS numbers to ensure that selected cut points (sensitivity analyses) are both valid and programmatically meaningful.

### 8.3 Outcomes Evaluation: Existing Data

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The second major set of activities in the evaluation design involves collecting and analyzing program outcomes using both existing as well as new data collection tools and sources.

#### 8.3.1. Analysis of Ombudsman and Nursing Home Complaint Data, Comparing LTCOP and non-LTCOP Users

Given that the LTCOP is targeted to all nursing home and board and care facilities, identifying a comparison group for a rigorous study design is challenging. Nonetheless, we have identified approaches that take this challenge into consideration.



Although the LTCOP is available to residential consumers, not all elect to utilize this resource when an issue arises. An alternative is to file a complaint with the state certification agency or other mechanism that regulates and enforces grievances, including those provided by facilities<sup>11</sup>. One approach to assessing the LTCOP is to compare consumer complaint outcomes between LTCOP users and state certification agency (non-LTCOP) users. An advantage of this evaluation activity is the use of existing data sources, including ombudsman and nursing home complaint data. However, it should be noted that it will be difficult to find comparable complaints or complaint situations, especially since the role of the LTCO is distinct from those of regularly agencies.

A recent study by Troyer and Sause<sup>12</sup> illustrates this approach and may serve as a guide for an evaluation design that pursues this line of investigation. Drawing on complaint data from the North Carolina Division of Health Service Regulation (the state certification agency) and the LTCOP from 2002 to 2006, as well as facility measures from CASPER/QIES (then OSCAR), the authors found significant differences in substantiation rates between the two agencies. Whereas 91 percent of ombudsmen complaints were verified, less than half (48 percent) of the state certification agency's complaints were substantiated. In addition, the study revealed that the two agencies were not duplicating efforts when examining matched categories of complaints.

Among other methodological issues that needed to be considered with this design are selection biases. At the same time, the selection biases themselves (while an issue for ensuring rigorous, meaningful comparisons) can provide information on differential use patterns in the ombudsman program, relative to other complaint resolution strategies. For example, it is possible that younger, more able bodied, residents pursue alternative, formal channels of reporting complaints while older, relatively more vulnerable residents may find the LTCOP to be more accessible and culturally appropriate because of its less formal approach.

### 8.3.2 Ecological Study

In an ecological study, the unit of analysis is a *population* or other aggregate measure of individuals. This is in contrast to other designs such as a cohort study where the individual is the unit of analysis. Because ecological studies require the availability of aggregate data describing both exposures and outcomes, NORS data may be potentially useful in this setting. An ecological study on systems advocacy (or other activity or event with potential outcomes at the aggregate level) offers the possibility to leverage over 15

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<sup>11</sup> In some states, programs do not serve residents under 60 years of age. These younger residents may register complaints with facilities, regulatory agencies, or other grievance mechanism.

<sup>12</sup> Troyer, J. L., & Sause, W. L. (2011). Complaints against nursing homes: Comparing two sources of complaint formation and predictors of complaints. *Gerontologist*, 51(4), 516-529.

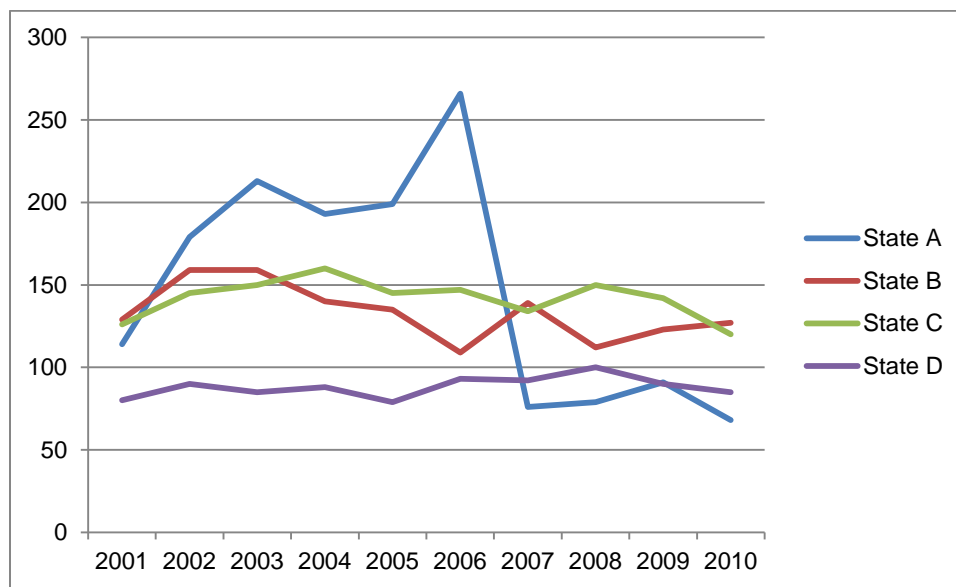
years of aggregated NORS data as a research resource. In this context, we propose conducting one or more ecological studies in which information relevant to systems advocacy can be used as "predictor" variables and NORS data used as outcomes.

As with all designs, ecological studies have strengths and weaknesses. The hypothetical example that follows is intended to illustrate the strengths and weakness of one potential application of the ecological study design in evaluating the impact of systems advocacy carried out by the LTCOP. This scenario involves a successful statewide initiative targeting the increase in problems related to theft and loss in long-term care facilities. Based on unfavorable trends in theft and loss complaints observed in the program's NORS data, State A requests facilities to submit copies of their policies on theft and loss. State A compares these policies to requirements in state law to determine how many facilities are meeting these requirements. In collaboration with facilities, a Theft and Loss Prevention Tip Sheet is developed and distributed to residents and families in all facilities in State A. Distribution of the Tip Sheet to residents and families is also incorporated into admission procedures in State A.

In this example, the unit of analysis is the state. NORS data can be used to describe the outcome (number of complaints regarding financial property, aggregated by state), and the predictor variable (distribution of tip sheet or some related effort targeting the prevention of theft/loss) is a simple yes/no variable. In order to demonstrate how the initiative impacted financial property complaints on the aggregate level, NORS data are examined over a period of 10 years in several states that did and did not undertake the initiative.

Figure 1 shows 10 years of aggregate data on financial property complaints in four hypothetical states. In 2006, State A (described above) undertook an initiative to reduce theft and loss in long-term care facilities. The three other states in Figure 1 did not initiate such a program. Aggregated NORS data on financial property complaints indicate that complaints for theft and loss decreased dramatically in 2006 shortly after the Tip Sheet began to be distributed in State A. Reductions in theft and loss continued to remain low several years after. In the three states that did not undertake the initiative, the total number of financial property complaints stayed relatively steady from 2000 to 2010, suggesting that the change in frequency of complaints could be related to advocacy efforts that resulted in the development and distribution of the Tip Sheet.

**Figure 1:** Total number of financial property complaints between 2001 and 2010 in four states



At the same time, it must be stressed that we cannot conclude that fewer reports of theft and loss decreased on the *individual level* or that any reductions in theft or loss were *caused* by the initiative. In an ecological study, we can only say that there is a strong suggestion that problems with theft and loss decreased on the aggregate level in a manner that appears to involve the facility-based prevention initiative. This is because ecological studies do not "connect" exposures and outcomes on the individual level or in a causative manner; they can only provide insight into relationships that occur at the population level. In fact, it is possible that other, unrelated issues were occurring in State A at the same time as Tip Sheets were distributed to residents and families. For example, it is possible that in 2006, there was a high-profile case involving theft or loss in State A that heightened awareness of this problem in a manner that increased vigilance among residents and families in State A. It is possible that other such factors, and not the Tip Sheet, were actually responsible for reductions in theft and loss in State A. These factors are called "secular trends" and they represent an important methodological issue that must be considered when drawing conclusions from an ecological study. This is especially true in situations where aggregate data on secular trends are absent or where identification of potentially troublesome secular trends is difficult. Nevertheless, ecological studies are a relatively inexpensive strategy that could be utilized to examine the impact of LTCOP systems advocacy on the population level.

An additional limitation of using ecological studies concerns the availability of data that are relevant to systems advocacy work. The potential outcomes of certain successful advocacy efforts may not be collected in NORS or other established data sources. For instance, initiatives related to increasing

personal care needs allowances or improving nursing home complaint handling by licensing and certification do not have relevant outcomes captured in NORs. Any assessment of the effects of these policies would require new, tailored data collection efforts examining outcomes before and after implementation of the policy. Another challenge pertains to the level of aggregation in NORs. In the example provided above, tracking the complaint code “financial, property” across states was relevant for examining the impact of the Tip Sheet intervention. While a complaint code exists for problems regarding theft and loss, the broad category of “financial, property” also contains other types of complaints that are not directly relevant to the intervention. Examples include billing/charges and personal funds that are not disaggregated. These data, however, may be available at the state and local levels.

Where data are available and relevant, however, NORs has the potential to complement other proposed evaluation activities such as the commissioned paper on systems advocacy (Section 8.2.3.a) and offer a more comprehensive understanding of systems advocacy efforts by employing different approaches and sources of data. Implementation of an ecological study in tandem with a commissioned paper can tell us not only whether a piece of legislation was successfully passed (while an achievement in and of itself), but whether that legislation had a positive impact on the residents it was intended to help. LTCOPs have collected NORs data for over 15 years and these data, when used in an ecological study, may potentially address the role that programs play in preventing problems in long-term care facilities. While the number of complaint investigations is often used to demonstrate the effectiveness of ombudsman programs, ombudsmen also play a critical role in preventing problems from occurring and prevention of these problems is difficult to measure and therefore goes unrecognized. The prevention of problems, however, is likely to be realized through broad systems advocacy efforts whose impact could be explored using one or more ecological studies. In the Tip Sheet example above, we see that in State A, there was a clear trend of increasing complaints for theft and loss, and the frequency of these complaints decreased dramatically following deployment of the Tip Sheet. It can be argued that the data in the figure can be used to estimate the number of prevented theft and loss complaints, thereby providing an opportunity to “measure” problem prevention. Ecological studies that utilize aggregate data from NORs or another source such as nursing home deficiency data could examine a variety of questions related to the impact of systems advocacy, assuming that the appropriate exposure and outcome data were available at the aggregate level for relevant periods of time.

Using this approach, we may identify variables in the NORs data that are suitable for use as outcomes in an ecological study. If this is the case, we can examine these outcomes in one or more states, either in a single year or over time. Likewise, we can think about aggregated data that are potentially related to systems advocacy such as funding levels, and use that information as the “exposure” or predictor variable

in this type of study. In this way, we can identify shifts or drifts in advocacy-related variables and relate them to relevant outcomes in NORS. For example, if there was a sudden change in a federal or state policy that might impact outcomes of the LTCOP, we could use NORS data to examine if there were any meaningful changes in key outcomes after this policy change.

## 8.4 Outcomes Evaluation: New Data Collection

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A key series of activities in the outcomes evaluation design involves leveraging data collected in the process evaluation and using them as "predictor" variables. These predictor variables will then be used in the outcomes evaluation, which will focus on collection of impact or "outcome" data. For the outcomes evaluation, our approach once again involves collection of "core" and "modular" data, but this stage of the design focuses on outcomes, rather than program characteristics and processes. Core outcome data apply to all LTCOPs regardless of state, program structure, etc., and to parallel classes of stakeholders in each state. In contrast, modular outcome data involve endpoints that pertain to a subset of states as a result of heterogeneity in strata, as described above. Core data will be collected in all states from several classes of respondents as resources permit. These respondents should ideally be the same as those described in the process evaluation activities, with the addition of complainants, LTSS residents and representatives, facilities, and stakeholders. In addition to core data, multiple, tailored modules will be developed that aim to assess heterogeneous outcomes that are linked to key strata. Respondents for these modules may also vary, but within a module, respondents will be uniform across states. As with the process evaluation, not all modules will apply to each state, and for modules that do apply, multiple classes of respondents can be engaged to provide a fuller understanding of each topic.

Whereas the process evaluation will collect information from program staff (discussed in Section 8.2), the outcomes evaluation will focus on program recipients (residents, facilities) and others who collaborate with or have an interest in the program, including stakeholders. With respect to the logic model, the outcome evaluation will collect information regarding the program's outcomes at the consumer, facility, state/local, and federal level. As noted earlier, outcomes related to ombudsmen themselves, however, will be collected as part of the process evaluation. Rather than conducting interviews or fielding surveys with ombudsmen at two points in time, carrying out these efforts simultaneously will result in not only cost-effectiveness but methodological rigor.

### 8.4.1 Outcomes Evaluation Core Data

Core outcome data can be cross-sectional or longitudinal, depending on resources and timelines. While cross-sectional outcome data can provide a "snapshot" of key outcomes at one point in time, longitudinal data are superior for a number of reasons, including the ability to capture trajectories and the ability to

collect data on diverse programmatic outcomes that may not all "appear" at one point in time. Thus, longitudinal data collection can not only allow for more complex, sophisticated descriptions of outcomes, they can also reduce the risk of failing to identify programmatic benefits that may occur at later points in time. Core outcome data will involve both qualitative and quantitative information, and they will constitute the backbone of the LTCOP outcome evaluation. Ideally, outcome evaluation core data will reflect both the breadth and depth of impacts that the LTCOP can reasonably be held accountable for, and for which rigorous measures can be identified and deployed. It is possible that resource constraints will require prioritizing of core outcomes that will be examined, or of the number of specific data elements that will be collected for each topic. If this is the case, it should be expected that some universally-applicable outcomes will receive limited or no attention at all.

#### 8.4.1.a Sampling

Data will be collected in a standardized manner from all states (i.e., census).

#### 8.4.1.b Respondent Classes

At least 5 respondent classes can be identified/recruited for outcome evaluation core data collection; different data elements will be collected *across* classes, but identical data will be collected *within* each class. Obtaining multiple perspectives on LTCOP processes and outcomes is critical for providing context to data collected as well as ensuring a variety of vantage points. For example, several TAG members expressed reservations about the accuracy of facility-based surveys. There was concern over whether responses on certain outcomes, particularly the management and allocation of LTCO resources, would be skewed because of facilities' self-interest. With the many misunderstandings related to LTCOPs, furthermore, TAG members advised that questions are prefaced with definitions of terms or descriptions of LTCO responsibilities and are expressed in accessible language. These issues are important not only for residents who may not be familiar with the term "ombudsman", for example, but also facility administrators who do not fully understand the LTCO's role.

*Class 1: LTCOP complainants*

*Class 2: LTSS residents and their representatives*

*Class 3: Former residents of long-term care facilities*

*Class 4: Facilities – staff and administrators at the facility itself as well as the corporate level where there are nursing home chains, trade associations*

*Class 5:* Stakeholders (SUA directors, AAA directors, surveys and certification, APS, consumer groups, etc.)

Ideally, respondents will come from areas/live in facilities that were surveyed in the process evaluation to allow for matching between the process and outcome data.

#### **8.4.1.c Topics to be Covered**

It is anticipated that outcome evaluation core data will cover a diversity of topics. Our approach permits collection of data on the same or similar topics from diverse perspectives, and also accommodates collection of information that applies to only one class of respondents.

*Class 1:* LTCOP complainants – complaint handling, consumer satisfaction with LTCOP, etc.

*Class 2:* LTSS residents and representatives – awareness of resident rights, LTCOP, and LTCOP advocacy, accessibility and availability of services (consultations, complaint handling), council participation and support, consumer confidence in raising issues.

*Class 3:* Former residents of long-term care facilities – prevention of problems, LTCO role in transitions out of facilities

*Class 4:* Facilities – administrators/staff interactions with ombudsmen programs, complaint resolution process, visiting and consultation process, educational activities, role of ombudsmen, facility size, type of facility, awareness of resident rights, ombudsman functions and program goals, awareness of prevention of problems due to LTCO intervention, perceived professionalism and helpfulness of ombudsmen to residents and families, ombudsmen provision of information and resources to support person-centered care, coalition/stakeholder engagement.

*Class 5:* Stakeholder knowledge of resident rights and LTCOP, inter-organizational relationships, collaboration.

#### **8.4.1.d Data Collection**

Ideally, outcome evaluation core data will be collected via in-person and telephone interviewing as well as computer-assisted surveys. However, the latter approach is often not realistic for many older adults, particularly those in skilled nursing. Thus, in-person interviews or focus groups may be necessary in order to capture consumer-level information. Online data collection may be more feasible for facility staff, and perhaps also for family members of consumers.

#### 8.4.1.e Analysis Overview

In addition to the availability of extensive qualitative information, outcome evaluation core data can generate a number of rectangular data sets representing diverse information from a variety of respondents. It is anticipated that state will be the first "clustering" variable because all classes of respondents will share programmatic characteristics that are defined to a large extent by the states in which they live or operate. We therefore expect that most analyses will be conducted within each respondent class. However, if there are programmatic features for which data are collected for more than one respondent class, comparisons across these groups will certainly be possible.

#### 8.4.2 Outcomes Evaluation Modular Data

Modular outcomes evaluation data can be cross-sectional or longitudinal. This information will involve both qualitative and quantitative information, and act as targeted, tailored supplements to outcome evaluation core data for topics and programmatic features that are heterogeneous across states. Ideally, modules will be developed for all LTCOP strata that differ across states and that can reasonably be expected to impact program effectiveness. Identification of modules will be conducted with the assistance of the ACL.

##### 8.4.2.a Sampling

Ideally, strata-specific outcome evaluation modules will be administered in all states to which the module applies. For instance, a module targeting outcomes associated with LTCOP operations in home-based care will be administered in all states where offering in-home ombudsman services. It is possible that resource constraints will require either prioritizing of the number of outcome modules that are developed and deployed and/or the need to deploy outcome modules in less than the complete set of states in which they apply.

##### 8.4.2.b Respondents

The large number of potential strata upon which outcome evaluation modules can be developed will require a corresponding variety of respondents. Even in cases where modular outcome evaluation data can be collected effectively from one respondent class, it may be useful to collect parallel data in multiple classes if different perspectives are desired. Ideally, modular outcome evaluation data will be collected from the same classes and the same individuals as those that participate in the core outcome evaluation data collection activities.

##### 8.4.2.c Topics to be Covered

Outcome evaluation modules can be developed for any LTCOP stratum that: (1) differs by state and (2) is hypothesized to impact program effectiveness. A preliminary list of these strata was presented above in



the process evaluation section of this document. Topics related to any of those strata can be developed and deployed in states to which they apply, and be administered to one or more respondents, depending on applicability.

#### **8.4.2.d Data Collection**

Ideally, outcome evaluation data will be via a secure, web-based data entry application. This approach assumes that respondents have Internet access and that email addresses or other means of delivering the URL can be identified. As noted above, this is unlikely to be the case in most resident-level data collection, but is likely to be more feasible with facility staff. In-person interviewing, whether computer-assisted or with paper, is possible, but will be costly, especially if repeated (longitudinal) outcome measures are desired. Ideally, modular outcome data collection will occur concurrently with core outcome evaluation data collection, and will utilize the same individual respondents within each respondent class.

#### **8.4.2.e Analysis Overview**

Modular outcome evaluation data can be cross-sectional and/or longitudinal, and will supplement universal outcome data in a number of ways. For instance, modular outcome data for a given stratum or strata can be pooled and examined to understand LTCOP operations in states that share a key characteristic of interest. These states can also be compared to states that do not share the characteristic, or to a variety of control groups that can be constructed from other strata.

### **8.4.3 Cost Analyses**

#### **8.4.3.a Measuring and Valuing the Full Costs of the LTCOP**

A critical component of demonstrating the value of the LTCOP rests on economic analysis. An economic evaluation or cost analysis of the LTCOP can assess whether the services delivered by the program offer a good return on investment. These analyses also can provide a means to compare the program's benefits relative to alternatives.

In a cost analysis, we begin by estimating the full economic costs of operating the LTCOP. Three steps are involved in deriving this estimate. These include identifying resources (both explicit and implicit costs), measuring their use, and monetizing the value of those resources. While expenditure data are available on the program (in FY2010 total program expenditures from all sources were \$87,677,013<sup>13</sup>), this figure does not capture implicit costs, particularly the use of volunteer time. A key strength and defining characteristic of the LTCOP, however, is its base of trained and dedicated volunteers. Of the total number of ombudsmen who carried out the responsibilities of the program in 2010, 88 percent were

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<sup>13</sup> [http://www.aoa.gov/aoa\\_programs/elder\\_rights/Ombudsman/index.aspx](http://www.aoa.gov/aoa_programs/elder_rights/Ombudsman/index.aspx)

unpaid. As a result of this basic programmatic feature in most states/territories, neglecting to include this unique segment of the LTCOP workforce obscures the full costs involved in operating the program. Other implicit costs that need to be considered include transportation used for facility visits, as well as shared or donated resources such as space, and potentially, equipment. These costs may be particularly relevant for programs located within State Units on Aging (and local/regional entities located within area agencies on aging or other multi-service agencies) where personnel, office space, and equipment may be shared, donated, or borrowed.

While assigning a dollar value to each program's explicit costs is relatively straightforward, calculating the implicit costs of established federal programs such as the LTCOP poses unique challenges. Since its inception, states have been accorded broad latitude in implementing their respective programs, a consideration that results in great diversity in program structure, approach, and operations, including utilization of human resources. The consequence of this variation for valuing resources in dollar terms for implicit costs is considerably more complex.

In the case of explicit costs, resources are easily monetized. The challenge is to allocate costs appropriately between the LTCOP and other personnel, space, or equipment that are potentially shared at agencies where programs are located. After determining the division of resources, if any, on a state-by-state basis, labor, fixed, and variable costs can be calculated by using budget and expenditure data that are available from each program. Using standard accounting principles, costs for equipment, such as computers, can be amortized over time.

Time and space are the primary types of implicit costs that need to be valued. Given the underlying variation in program components and structure across state and local programs, the calculation of some costs is subtle while others have an uncertain dollar value. This is especially true for monetizing volunteer services because of the wide variation in roles that volunteers play. Whereas some programs use volunteers largely as friendly visitors, others task volunteers with the same work that paid ombudsmen perform, including complaint investigation and systems advocacy. Other programs may have volunteers play an ever larger variety of roles. Further, LTCOPs in four states serve as the primary finder of fact for of abuse, neglect and exploitation reports in long-term care facilities. This may be a time-consuming responsibility which is outside the scope of the OAA functions.<sup>14</sup> Each of these roles demands a different level of skill and responsibility and valuing these roles must reflect those clear and sometimes subtle

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<sup>14</sup> In some states, other responsibilities that go beyond OAA-described functions include witnessing advance directives and convening ethics panels. Some states have additionally provided authority to LTCOP programs to serve populations beyond those identified by the OAA. Examples include services to individuals receiving in-home services, transition or follow-up services to Money Follows the Person demonstration projects, services to residents of ICF/MRs or other settings primarily serving younger individuals with disabilities.

differences. As a result, assigning a dollar value to the contribution of volunteers will likely be neither uniform across or even within states, nor will it be the same for all types of volunteers. In some instances, the equivalent salaried job category of paid staff (factoring in experience) may be used for this purpose.<sup>15</sup> Where no comparable substitute exists and the dollar value is unknown, other strategies have been employed to quantify volunteer services, including assigning market rate salaries or average state hourly rates. A sufficiently wide scope of salary comparisons, however, should be employed, given the diverse roles the ombudsmen play. Whatever methods are ultimately used, state and local variations in factors such as how volunteers are used and cost of living must also be considered. These issues apply, moreover, to staff as well as volunteers.

Another category of implicit costs to be valued include space or other equipment donated to the LTCOP. The extent to which LTCOPs rely on in-kind contributions varies by program and is expected to be partly determined by program structure. For example, the location of a program within SUAs presents potential benefits to programs. These include administrative support, ongoing professional training, use of shared facilities as well as supplies and clerical support. We anticipate that much of the calculation of implicit costs will require securing tailored information on each program that will facilitate valuation of in-kind resources in dollar terms. In addition to records review, this information can be collected as part of the process evaluation from state ombudsmen, as described in Section 8.2 in this report.

Once all explicit and implicit costs have been identified and calculated, the cost analysis for the LTCOP will not yield a single figure, but a range of figures. Several key decisions involving plausible alternatives for measuring and valuing resources must be made at various points in the analysis. These decisions will relate in large part to estimating the value of volunteer time. As a result, calculating a figure for each of the competing assumptions and presenting a range of estimates is recommended. Estimates on the total costs of the LTCOP can then be compared to existing calculations of total program expenditures that do not consider implicit costs. The resulting difference between the two figures represents the ability of the LTCOP to leverage donated resources for implementing the program. In the absence of volunteers and other implicit costs, programs would likely incur greater costs in order to provide the same level of service. By calculating the total costs of the LTCOP, cost analyses can effectively demonstrate the value of volunteers and other donated resources to the program.

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<sup>15</sup> A consideration using this approach is that paid ombudsmen may not be funded fully. Existing wages may be low despite the complex work that is involved.

#### 8.4.3.b Measuring and Valuing Cost Effectiveness

Having calculated the LTCOP's total costs, the range of cost estimates can serve as a foundation for additional cost analyses. To address how the LTCOP's relative costs and outcomes compare to alternative approaches, cost-effectiveness analysis (CEA) can be used. CEA examines the costs of a program and weighs them against various outcomes by calculating a ratio of costs to "units of effectiveness." Units of effectiveness measure a quantifiable outcome that is central to the program's objectives. It should be noted that while all states would be required to participate in the calculation of the LTCOP's total costs, the application of CEA need not be equally comprehensive. CEA can be applied to any number of state or local programs, depending on available resources and can be used to highlight certain features of the LTCOP.

One strategy to evaluate the cost-effectiveness of the LTCOP is to divide total program costs by a meaningful measure of effectiveness such as "number of complaints resolved" to determine a cost per successful investigation. Additional examples of potential cost effectiveness analyses using other quantifiable outcomes include:

- Cost per consumer reached (including complaints and consultations)
- Cost per consultation
- Cost per complaint resolved
- Cost of monitoring facilities (regular visits and responding to complaints and other requests)
- Cost per volunteer (taking into account the cost of training/managing volunteers compared to the type of work they perform; compare to cost of paid staff doing similar work)

Given that all program expenditures are unlikely to be devoted to any single task, whether it be complaint handling, consultations, systems advocacy, education or other activity, we anticipate that one methodological challenge will be isolating expenditures dedicated to complaints (or other specific activity) and determining the cost per complaint resolved.

A cost-effectiveness analysis must look at the marginal costs and benefits of a program compared to the *status quo*, i.e. what would have occurred if there were no LTCOP. In the absence of the LTCOP, would other programs fill the void, possibly at a higher cost because so much of the LTCOP workforce consists of volunteers? Would consumer needs go unmet? One potential analysis to address these questions would compare the cost-effectiveness of certain ombudsmen services to that performed by other agencies employing a different service delivery model.

#### 8.4.3.c Measuring and Valuing the Costs of Leaving Problems Unresolved

Another possibility in approaching cost analyses involves measuring the cost of leaving problems unresolved. Although it is difficult to measure the costs associated with avoiding a problem, there may be some types of complaints with tangible costs that can be measured. These may include problems related to abuse, neglect and exploitation or unresolved health issues. While it may be possible to capture these outcomes with hospitalization rates or some other indicator, attributing the outcome to the LTCOP may itself pose challenges, before any attempt at monetizing the measure is even considered.

One of the first steps in considering cost analyses is ensuring that valid data are available and standardized definitions are employed. Before any calculations can be made, it will be necessary to examine the validity of existing data sources that are used in cost analyses. For example, currently, the LTCOP in Texas calculates a number of cost ratios, including average program cost per staff ombudsman and average program cost per certified ombudsman (staff or volunteer). Other states are likely to do so as well. The ability to provide valid data, however, is likely to vary by state as will the reporting tools that are used across states. Methods used would then need to be standardized across states under study. Much of this information can be garnered through the proposed process evaluation to identify states where use of these tools for costs studies may be most promising. If existing data (program records) are deemed unreliable, using data that are collected as part of the proposed cohort study (Section 8.4.4) may be an option for securing high quality information for cost analyses.

#### 8.4.4 Cohort Study

One of the fundamental measures used to define program effectiveness in the LTCOP is complaint resolution. Investigation and resolution of complaints on behalf of long-term care residents is at the heart of the LTCOP and complaint handling and its associated outcomes are most directly and tangibly tied to the program. The percentage of complaints that programs resolve during the year is also one of only two data items in NORS that is considered a performance outcome measure by the AoA (the other being the number of complaints per long term care facility).

The calculation of the complaint resolution percentage, however, does not in fact refer to the status of complaint dispositions as the name suggests. Rather, it measures the percentage of complaints that are *resolved to the satisfaction* of the resident or complainant. It is therefore a measure of consumer satisfaction with ombudsmen complaint outcome. Importantly, it includes complaints that may or may not have been fully or even partially resolved. To a large extent, this measure reflects issues that are within the control of ombudsmen's work. Because the program advocates for services delivered by facilities, government agencies, and other third parties, it is not directly responsible for the provision of these

services. At the same time, it is important to know not only the levels of satisfaction with the resolution of a complaint investigation but also the actual complaint resolution, and to account for whether resolution lies within or outside of an ombudsman's control. While NORS collects some of these data, the categories used appear to intermingle outcomes.

Although using the percentage of complainant satisfaction with complaint resolution to quantify programmatic effectiveness has been in place for some time, NORS does not capture important complexities that characterize the LTCOP and its clients. As a result, the annual percentage of resolved complaints may not be an accurate reflection of programmatic effectiveness. Further, this measure provides no information about programmatic efficiency. If only the percent of resolved complaints are examined, programs that operate under especially challenging conditions may be perceived as underperforming relative to their more resource-rich counterparts (e.g. programs with more volunteers, funds, better partnerships, etc.).

In moving toward designing a rigorous and policy-relevant design for the LTCOP, it is critical to consider how to address the challenge of measuring complaint resolution in a manner that "levels the field" and permits a clear, and thoughtful assessment of program performance across a wide range of programmatic environments. One way to do this involves not only measuring complaint resolution as a percentage (as does NORS), but also measuring it as a rate. Including complaint resolution rate into our data collection plans enables us to evaluate efficiency because time is incorporated into our study of complaint resolution. Together with the complaint resolution percentage, studying complaint resolution rate can provide a fuller picture of the ability of the LTCOP to fulfill its responsibilities.

In order to rigorously and fairly assess the effectiveness of the LTCOP's complaint investigations and obtain information on complaint resolution rates, a cohort study is essential. A cohort study is a form of longitudinal or observational study that follows a group of people who share a similar characteristic over a specified period of time. For the LTCOP evaluation, we propose establishing a cohort of complainants in a select number of programs who would be followed from the time they initiated a grievance to the point at which their grievance was resolved. This cohort will be used to study LTCOP outcomes that require follow-up on individuals and which are not feasible using either the outcome evaluation core or modular data.

The cohort study would be carried out concurrently with NORS but would refine certain NORS elements (such as distinguishing consumer satisfaction from complaint resolution) and include new data items (such as demographic and health/disability characteristics of residents, the complexity of the complaint,

as well as facility information for data linking purposes). Data collection for the cohort study would focus on identifying new complaints that are opened during a specific interval (the “enrollment period”). As with NORS, these complaints would be followed through to their resolution. In order to determine the appropriate timeframe for this data collection effort, it is necessary to examine the duration of complaints (from initiation to resolution) and obtain measures of central tendency (e.g. mean, median, quartile ranges) on complaint data. Ideally, the enrollment period and follow up needs to be long enough to cover the duration of 80 – 90 percent of complaints. That is, we need to define a follow-up period in a manner that permits collection of complete data on a majority of complaints that are opened and resolved during the study.<sup>16</sup>

By assessing complaint resolution rates as well as relevant information on complaints and programs with a cohort study, we can more accurately assess program effectiveness under various conditions. Unlike percentages, rates allow us to consider time when evaluating complaint resolution. For example, one program may resolve complaints 90 percent of the time whereas another may resolve complaints only 50 percent of the time. The additional information on rates may reveal that despite its lower complaint resolution percentage, the amount of time the seemingly poorer performing program takes to resolve its complaints is the same as the higher performing program.

A cohort study also enables us to take confounding factors into account through “adjusted rates” (discussed further in section 8.4.4.a), another advantage that percentages do not offer when interpreting complaint resolution. Adjusted rates can account for time, organizational placement, staffing levels or mix, turnover rates, and other factors that might affect the speed with which programs resolve their complaints. By identifying these confounders and understanding their role in influencing complaint resolution rates, recommendations can be made about specific features of the LTCOP, and/or specific features of complaints that are likely to impede program efficiency. Such conclusions are possible to draw from data collected in a well-designed cohort study that allows calculation of rates in addition to percentages, but they cannot be drawn from existing NORS data alone.

Given the intensity of the proposed cohort study effort and the anticipated reliance on ombudsmen to collect study data, fielding a pilot study in a few sites prior to expanding the effort to a greater number of programs is advised. Piloting, and eventually deploying, the cohort study evaluation instruments would likely require the provision of incentives as well as training to ensure consistent, high quality reporting in

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<sup>16</sup> The beginning of the study period is the enrollment period. Subsequently, there would be a period of time when new complaints are added to the study until a target is reached. The enrollment period would then close and we would follow this cohort of people for the duration of the study period. The period between the point of enrollment and the end of the study period is the ‘follow up time’ and it will be longest for the people who are enrolled first and shortest for the people who are enrolled last. However, if resolutions occur quickly, this should not matter because the full duration for most enrolled people will be captured.

this decentralized evaluation environment. If such a function is desired, the cohort study can also serve as a model for future modifications in the NORS system.

Another important consideration is the individual-level demographic information that we seek to obtain. One of the defining characteristics of ombudsmen work is protecting resident confidentiality. Residents trust ombudsmen with sensitive information not only about their complaint but also about themselves. There may be concerns among residents – or even ombudsmen – regarding the disclosure of individual-level data to researchers and it deserves emphasizing that resident participation is voluntary. One of the advantages to a cohort study is that participants would provide informed consent prior to enrollment. This consent would give permission for the sharing of personal information that might otherwise not be available to researchers. Thus, the cohort study would be a regulated research activity that would be distinct from the service provision that LTCOPs routinely provide. These and other data stewardship issues will be addressed using the most conservative approaches available, and in consultation with the ACL and the evaluation sites.

If available evaluation funding precludes the implementation of a cohort study, a less methodologically rigorous alternative for obtaining data on complaint handling is to use state or local level data elements that are collected. In considering this option and its associated methodological issues, it is necessary to determine whether the data elements of interest are currently collected. These data items include:

- Demographic and health information on complainants
- Demographic information on ombudsman who handled the complaint
- Volunteer or paid status of the ombudsman
- Role of ombudsman in program
- Manner of complainant accessing the ombudsman/how learned of LTCOP
- Ease of contacting the ombudsman
- Type of complaint
- Complexity of the complaint
- Time to initiate processing of complaints
- Resolution times
- Result of complaint investigation
- Consumer satisfaction with services



- Willingness to use LTCOP services again
- Willingness to recommend services to someone else with a related issue to resolve
- Availability of other options to pursue complaint
- Perception of effectiveness of ombudsman
- Type of facility
- Size of facility and
- Facility ID code (to link with other data sources)

In addition to establishing the availability of these data elements, the reliability and validity of the data must also be systematically assessed. Some states collect a number of but not all data elements listed above. Another consideration is the ease with which disaggregated data can be obtained. In relying on retrospective data, we may not only be restricted analytically to what data are available, but also to the programs that collect these data. While state or local data elements are an option for examining complaint handling, the available data are unlikely to effectively serve the needs of a thorough evaluation of the program’s complaint resolution function.

Through an example in the following section, we provide background information on rates, how they differ from percentages, why we believe a cohort study that includes rate measurements has the potential to provide clear, policy-relevant information on LTCOP performance, and how this information can be used for informed decision-making as the program continues into the future.

#### 8.4.3.a Example of Rates Versus Proportions

The table below illustrates the experiences of 10 hypothetical complainants, i.e., one or more individuals who either initiated a complaint (complaints 1, 2, 3, 4, 5, 6, 8, and 9) or had an ongoing complaint that continued from the previous year (complaints 7 and 10) during a hypothetical year. These people were all clients in program A. It should be noted that the example is only roughly modeled off of NORS. There are a number of codes not represented here; we retained only those necessary for illustrative purposes.

**Figure 5:** Program A

Complaint number	Month											
	Jan	Feb	Mar	Apr	May	Jun	Jul	Aug	Sep	Oct	Nov	Dec
1		I	X	X	R							
2	I	X	X	X	X	X	R					
3					I	X	X	X	X	X	X	X
4											I	X
5				I	X	X	R					
6						I	X	X	X	R		
7	C	X	X	X	X	X	X	X	X	X	X	X
8			I	X	X	X	X	X	X	R		
9			I	X	D							
10	C	X	X	X	X	X	X	X	X	X	D	

I= a month in which the complaint was **I**nitiated  
 C=a case that **C**ontinued from the previous year.  
 R=a month when a case was successfully **R**esolved.  
 D= a case that was determined not to be pursued, or was **D**ropped for some reason  
 Cases with an "X" in December are still open at the end of the year.

As shown in Figure 5, 10 complainants had a complaint open at some point during the year in Program A, 2 of whom had complaints that were continuing from the previous year. Of the 10 complainants, 50 percent (5 complainants) had their complaints fully resolved, 20 percent (2 complainants) had an open complaint at some point during the year that was dropped for some reason, and 30 percent (3 complainants) still had an open complaint at the end of the year. These numbers represent *proportions*. They are percentages of complainants with various complaint dispositions. The percentages say nothing about how long the complainants were followed, when their complaints were open, when they closed, and so forth. Percentages also fail to incorporate the complexity of the complaint, available resources, the number of staff the LTCOP had during the year, or other factors that might influence how quickly this program resolves its complaints.

Valuable information can be provided by calculating a rate. In the same group of complainants, there were a total of 64 months during which these 10 complainants opened a complaint, continued to have an open complaint, or during which a complaint was dropped or resolved. The 64 months is called "person-time", which is the amount of time that all complaints were monitored during this hypothetical year. Of all the months that complainants were monitored, 28 months were among complainants whose complaints were resolved during the year, 14 months were among complainants whose complaints were dropped, and 22 months were among complainants whose complaints were still open at the end of the year. Complaint

number 10 contributed 11 person-months to the total, but complaint number 4 contributed only 2. While the disposition of these complaints was different, their time is counted in the same way regardless of what happens to their complaints. A rate is a number of events that occurs per unit time. Rates are expressed as fractions or decimals, with the number of complaints (events) in the numerator, and the amount of person-time in the denominator. In the above example, the *overall complaint resolution rate* for the hypothetical year was 5 complaints per 64 person-months ( $5/64=0.078$ ).

There are many statements we can make about all complaints, subsets of complaints or other combinations using rates. In order to compare rates to each other, rates must be expressed in terms of a common denominator. The choice of denominator is arbitrary, but is often chosen based on the amount of time that people are followed. In this example, we use 100-person months (a denominator of 1000 or even 1,000,000 is also possible). Therefore, the overall complaint resolution rate could be expressed as 7.8 cases per 100 person-months (0.078 multiplied by 100).

**Figure 6:** Program B

Complaint number	Month											
	Jan	Feb	Mar	Apr	May	Jun	Jul	Aug	Sep	Oct	Nov	Dec
1	I	X	X	X	X	X	X	X	X	X	X	X
2	X	X	X	X	X	X	X	X	X	X	R	

In program B, there are only 2 complainants with a complaint open during the year, and 50 percent of these complaints (1 person) had their complaint resolved. The complainants in program B contribute 23 person-months of time in this example. *Despite the smaller number of complainants and the same proportion of resolved complaints, the rate of complaint resolution is lower than Program A:  $1/23=0.043$ , or 4.3 complaints per 100 person-months.* In fact, the complaint resolution rate in program A is almost twice the rate of program B:  $7.8/4.3=1.81$ . Because NORS does not permit calculation of rates, however, the type of information in this example is not available.

The experience of these two programs illustrates the added value of looking at complaint resolution in terms of rates in addition to looking at this outcome in terms of percentages. Unlike percentages, rates allow us to take time into account when we evaluate complaint resolution. On the surface, a 50 percent resolution in Programs A and B appear to be "the same," but we see that program A resolved its complaints faster this year than Program B despite its higher load. There may be a variety of reasons that account for this outcome.

Program B may have fewer volunteers and more complex complaints such that resolution of certain complaint types is more challenging; Program A might have stronger partnerships with stakeholders that are critical for speedy complaint resolution. Factors like these that might influence the complaint resolution rate (or other LTCOP outcomes of interest that are related to time) are called "confounding variables." That is, they can "confound" or confuse interpretation of rates and other quantitative measures if they are not taken into account. This is especially true if confounding factors occur much more in one program than in another.

Currently, NORS neither permits calculation of rates, nor allows confounding variables to be taken into account when interpreting complaint resolution. This is in large part because (1) many variables that are likely to act as confounders are not collected in NORS, (2) the data are not constructed in a way that permits confounding variables that are collected to be examined in relation to complaint resolution, and (3) NORS precludes disaggregated analysis of data elements. As a result, our ability to use NORS as the primary tool for rigorously evaluating the LTCOP's performance (at least with respect to complaint resolution rate) cannot be achieved with this data source. Thus we propose conducting a cohort study in which person-time will be collected as well as information on a host of potentially confounding variables that can be taken into account when we examine complaint resolution rate. In the proposed cohort study we would examine a number of outcomes that reflect how quickly cases are resolved and look at percentages (the "traditional" approach), complaint resolution rates, and also "adjusted" rates.

"Adjusted rates" are calculated with statistical techniques that factor in person-time, complaint disposition, and confounding variables. That is, they are complaint resolution rates that "adjust" the rates for the confounders. These confounding variables can be on the program level (staff, budget, geographic distance, state-level policies that impact case adjudication, etc.) as well as the complaint level (complaint type, first or repeat complaint, etc.). The statistical procedures can describe how long cases take to resolve in a particular state or program in relation to confounding factors, thereby yielding the adjusted rates described above. Thus, our approach will involve several strategies to evaluate complaint resolution. It should be stressed that the newer, more complex strategies can paint a much more accurate (and potentially much more favorable) picture of LTCOP performance, especially for programs that have severe challenges such as the combination of extremely high case loads and very low staffing levels. Adjusted rates can take these challenges into account, thereby "evening the field" across programs in a way that is not currently possible with NORS data.

Using Program B's complaint resolution rate of 4.3 per 100 person-months as an example, it is possible that if we adjust this program's rate for the fact that it has no volunteers, and that all the complaints that

come into this program are extremely complex, we might see that Program B's complaint resolution rate is actually 7.2 cases per 100 person-months. This highlights the role that confounding factors play in impeding the program from its central goal of speedy complaint resolution. Perhaps more importantly, adjusting the rates changes our perception of the program's performance from one that was not as good as program A, to one that is very similar to program A, "all things considered."

## 9.0 Summary

The LTCOP is a unique and multifaceted program that does not readily lend itself to traditional evaluation approaches. In this report, we have presented a number of design options for a rigorous evaluation of the LTCOP that accounts for the program's distinctive features while addressing the ACL's fundamental research questions. In large measure, the strategies proposed in this report are the result of ongoing collaboration and feedback from both the ACL and TAG.

Collectively, the process and outcomes evaluation activities proposed here are designed to describe the structure and activities of the LTCOP and to assess its programmatic outcomes at multiple levels, including the resident/family, facility, as well as local/state/program and federal levels. While drawing on existing data sources, the proposed evaluation of the LTCOP relies heavily on new data collection efforts. These include interviews, surveys, focus groups, case studies, and a cohort study. Using our strategies, both existing data and new data collection can then be used to inform or support additional evaluation activities, including commissioned papers, case studies, analyses of ombudsman and nursing home complaint data, cost analyses, and ecological studies. The synergies that this approach offers are numerous and contribute to the efficiency of the overall evaluation design.

Of the evaluation activities that are proposed in this report, the cohort study and cost analyses are perhaps the most promising for demonstrating the value of the LTCOP. The cohort study in particular can provide the most direct evidence of the program's impact on clients while also leveling the field across programs. Measuring and valuing the LTCOP in the proposed cost analyses would represent the first time that the total costs of the program are calculated and a clear picture obtained of the value of the volunteer workforce upon which the program relies. In effect, the analyses would demonstrate the cost of the program in the absence of volunteers.

Because it is unlikely that each proposed evaluation activity will ultimately be undertaken, we have developed and proposed a set of scalable, flexible, and multi-modal activities. The scope of our approaches can be expanded or contracted depending on resources and needs, making it adaptable to a range of funding contingencies. Moreover, the components of the overall evaluation design are distinct and can be pursued independently of the others. While the order in which the evaluation activities are carried out is generally flexible, it is essential that the process evaluation's core and modular data collection come first. Greater flexibility, however, exists for sequencing remaining activities. Analyses that draw on existing data sources or those that do not hinge on the process data collection can commence

at any time. Commissioned papers, for example, can precede or follow the process evaluation, or it may take place both before and after. The timing and number of activities largely depend on whether clear priorities and funding resources exist. Some topics for investigation may be predefined but promising areas for research may also be identified based on what is learned from the process evaluation. The same option holds true for the case studies.

While many of the design elements can stand on their own, however, it is highly recommended that multiple evaluation activities are undertaken to ensure a rigorous assessment of the program. Only in this way can we obtain a comprehensive picture of the LTCOP and its impact for residents and their families, facilities, programs, and systems.

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## Appendix B: Glossary

**Assisted living facility:** Assisted living communities provide “housing with services,” including assistance with activities of daily living (ADLs), such as bathing, dressing, toileting, and medication administration. Some facilities provide specialized services for people with Alzheimer’s disease.

**Board and care homes:** A congregate living arrangement for people who cannot live independently but do not require skilled nursing care. This residential setting is also referred to as a “group home.” These arrangements provide residents with help with activities of daily living (ADLs) such as eating, bathing, and using the bathroom.<sup>17</sup>

Under the OAA, a “board and care facility” means an institution regulated by a State pursuant to section 1616(e) of the Social Security Act. Section 1616(e) of the Social Security Act states, “Each State shall establish or designate one or more State or local authorities which shall establish, maintain, and insure the enforcement of standards for any category of institutions, foster homes, or group living arrangements in which (as determined by the State) a significant number of recipients of supplemental security income benefits is residing or is likely to reside.”<sup>18</sup>

**Case:** Each inquiry brought to, or initiated by, the ombudsman on behalf of a resident or group of residents involving one or more complaints which requires opening a case and includes ombudsman investigation, strategy to resolve, and follow-up.<sup>19</sup>

**Certification and Survey Provider Enhanced Reporting system and the Quality Improvement Evaluation System (CASPER/QIES):** Formerly the Online Survey Certification and Reporting (OSCAR) file, the Certification and Survey Provider Enhanced Reporting (CASPER) system and the Quality Improvement Evaluation System (QIES) replaced the CMS’s OSCAR administrative database in July 2012. Maintained by CMS in cooperation with state survey agencies, CASPER/QIES includes detailed information on all institutional health care providers certified to provide services under either Medicare and/or Medicaid. It represents the most comprehensive source of information on facilities, patient characteristics and regulatory compliance of nursing homes.

**Cohort study:** A study which tracks two or more groups across time to assess causal relationships. This type of study can be done by going forward in time from the present (prospective cohort study) or,

<sup>17</sup> <http://www.medicare.gov/longtermcare/static/BoardCareHome.asp>

<sup>18</sup> [http://www.aoa.gov/AoA\\_programs/OAA/oa\\_full.asp](http://www.aoa.gov/AoA_programs/OAA/oa_full.asp)

<sup>19</sup> [http://www.aoa.gov/AoA\\_programs/Elder\\_Rights/Ombudsman/docs/Form\\_final2015.pdf](http://www.aoa.gov/AoA_programs/Elder_Rights/Ombudsman/docs/Form_final2015.pdf)

alternatively, by going back in time to comprise the cohorts and following them up to the present (retrospective cohort study). The defining characteristic of all cohort studies is that they track people forward in time from exposure to outcome.<sup>20</sup>

**Complaint:** A concern brought to, or initiated by, the ombudsman for investigation and action by or on behalf of one or more residents of a long-term care facility relating to health, safety, welfare or rights of a resident. One or more complaints constitute a case.<sup>21</sup>

**Complainant:** An individual or a party (i.e., husband and wife; siblings) who files one or more complaints made by, or on behalf of, residents with the ombudsman program.<sup>22</sup>

**Consultations:** Providing information and assistance to an individual or a facility that does not involve investigating and working to resolve complaints (i.e., a consultation is not a case). If the ombudsman refers someone with a concern to another agency and is not actively involved in investigating and working to resolve the problem, it is not an ombudsman case or complaint. Rather, it is considered a consultation.<sup>23</sup>

**Ecological study:** Aggregate data on exposures are compared with aggregate data on outcomes. The unit of analysis is a group, not an individual. It may also be used to study the effects of group-level constructs such as laws (e.g. the impact of a seatbelt law) or services (availability of a suicide prevention hotline). They do not allow causal inferences to be drawn since the data are not associated with individuals and are therefore for traditional hypothesis testing.<sup>24</sup>

**Focus group:** A type of group research, whose interview topics are limited to a small number of issues. The contemporary focus group interview generally involves 8 to 12 individuals who discuss a particular topic under the direction of a moderator who promotes interaction and ensures that the discussion remains on the topic of interest.<sup>25</sup>

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<sup>20</sup> <https://research.chm.msu.edu/Resources/4%20cohort%20studies.pdf>

<sup>21</sup> NORS

<sup>22</sup> Ibid

<sup>23</sup> <http://www.ltombudsman.org/sites/default/files/ombudsmen-support/training/NORS-Training-Three-Cs-09-08-11.pdf>

<sup>24</sup> Kirch, Wilhelm. (Ed.). (2008). Ecological Study. *Encyclopedia of Public Health*. (vol. 1, p 315). Springer.

<sup>25</sup> Stewart, D. W., Shamdasani, P.N., Rook, D.W. (2007). Focus groups and the research toolbox. In L. Shaw, D. Foster, & R. Holm (Eds.), *Focus groups: Theory and practice*. (p. 37). Thousand Oaks, CA: Sage Publications, Inc.

**Home and community based care:** Formal services that are provided to patients at home or community-based settings (e.g., adult day service programs, senior centers). These services can be paid for from either private or public funds.<sup>26</sup>

**Home and community based long-term services and supports (HCBS):** HCBS is a long-term service and support (LTSS) under Medicaid. Refers to assistance with activities of daily living (ADLs) like bathing and dressing and instrumental activities of daily living (IADLs) such as grocery shopping and money management. Assistance of the kind is generally meant to help older adults and people with disabilities remain independent in the community. A significant amount of care for individuals in need of ADL and IADL assistance is informal, and provided by family members. State-level programs are available to assist older adults and the services they offer vary by state.<sup>27</sup>

**Inter-rater reliability:** The measure of reliability or consistency among observers/raters in settings where observations are performed by multiple people using the same tools. Assessments are considered reliable when patients receive roughly the same score, regardless of who administers the assessment. In practice, two or more raters score episodes of behavior which are then used to compute a measure of agreement.<sup>28</sup>

**Logic model:** A systematic way of presenting a picture of how a program works: the theory and assumptions underlying the program; how it is expected to work; what activities need to come before others; and how desired outcomes are achieved.

**Long-term services and supports (LTSS):** The services and supports used by individuals of all ages with functional limitations and chronic illnesses who need assistance performing routine daily activities such as bathing, dressing, preparing meals, and administering medications.<sup>29</sup> Under Medicaid, “long-term services and supports” includes both institutional care and HCBS.

**Long-term care facility:** A skilled nursing facility, nursing facility, board and care facility, rehabilitation facility, or similar adult care home (including assisted living facility) that provides extended (although not necessarily permanent) care to patients.<sup>30</sup>

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<sup>26</sup> <http://aspe.hhs.gov/daltcp/reports/hcucus.htm> As of 5/7/2012, CMS concluded that further discussion and consideration of a definition for home and community based care was necessary. A new proposed regulation is set to be issued that will establish setting criteria for the definition.

<sup>27</sup> AARP, “Home and Community-Based Long-Term Services and Supports for Older People: <http://assets.aarp.org/rgcenter/ppi/ltc/fs222-health.pdf>

<sup>28</sup> Gliner, J. and Morgan, G. 2000. *Research Methods in Applied Settings*. Mahwah: Laurence Earlbaum Associates.

<sup>29</sup> <http://www.hilltopinstitute.org/publications/LTSSChallengesandOpportunitiesforStatesindifficultBudgetTimes-December2011.pdf>

<sup>30</sup> *The Older Americans Act, Section 102:* [http://www.aoa.gov/AoA\\_programs/OAA/oa\\_full.asp](http://www.aoa.gov/AoA_programs/OAA/oa_full.asp)

**MDS (Minimum Data Set):** Part of the federally-mandated process for clinical assessment of all residents in Medicare or Medicaid certified nursing homes. Provides a comprehensive assessment of each resident’s functional capabilities and helps nursing home staff identify health problems.<sup>31</sup>

**NORS (National Ombudsman Reporting System):** The ombudsmen complaint reporting system, which collects the information that SLTCOPs (State Long-Term Care Ombudsmen Programs) record in respective information systems.<sup>32</sup>

**Nursing home:** Nursing homes provide total care for their residents including room and board, social and dietary needs, as well as medical care. These facilities must be licensed and staffed by licensed nurses and certified nursing assistants. State Medicaid programs are required to provide nursing home services to eligible individuals over 21. Nursing homes accept a variety of payment methods, such as private pay (which includes insurance), Medicaid, and Medicare.

**Nursing facility:** A nursing home certified to participate in Medicaid. These long-term care facilities provide three types of services:

*Skilled nursing* or medical care and related services;

*Rehabilitation* due to injury, disability, or illness;

*Long-term care* health-related care and services (above the level of room and board) not available in the community, needed regularly due to a mental or physical condition.<sup>33</sup>

**Outcomes evaluation:** An assessment that involves collection of data on the short-term or immediate results of a project. Short-term results describe the immediate effects of the project on the target audience (e.g., percent of the target audience showing increased awareness of the subject). Information from such evaluation can show results such as knowledge and attitude changes, short-term or intermediate behavior shifts, and policies initiated or other institutional changes.<sup>34</sup>

**Person centered care** ensures an individual’s right to choose what help they want, need, or desire. This approach presents all options; honors and respects an individual’s choices and preferences and recognizes

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<sup>31</sup> <http://www.cms.gov/apps/mds/default.asp>

<sup>32</sup> [http://www.nasuaad.org/documentation/ombudsman/LTCOP\\_ReportingSystems.pdf](http://www.nasuaad.org/documentation/ombudsman/LTCOP_ReportingSystems.pdf)

<sup>33</sup> <http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Delivery-Systems/Institutional-Care/Nursing-Facilities-NF.html>

<sup>34</sup> <http://minorityhealth.hhs.gov/Assets/pdf/Checked/1/EvaluationProtocol.pdf>

the individual as the expert in her or his own life; and understands an individual's wholeness – physically, emotionally, and spiritually.<sup>35</sup>

**Process evaluation:** Examines whether a program is being executed as planned, including fidelity to the tasks and procedures involved in implementation. These include the administrative and organizational aspects of the program activities, delivery procedures involved in the efforts, and whether the target population is being reached. Process evaluations are a form of monitoring to ensure feedback during the course of the program or project instead of after its conclusion.

**Strata:** In this report, key characteristics that differ across states and that are hypothesized to impact programmatic effectiveness. Examples include whether programs dedicate a significant amount of time to systems advocacy.

**Substantiated complaints:** Complaints investigated and substantiated by the state survey agency in a long-term care facility. This involves providing adequate factual information to verify that the circumstances described in the complaint are accurate and true. Substantiation is used for purposes of regulatory or law enforcement action.

**Verified:** determined after work (interviews, record inspection, observation, etc.) that the circumstances described in the complaint are generally accurate.<sup>36</sup>

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<sup>35</sup> Michigan ADRC's August 2011 presentation to the Northsky non profit

<sup>36</sup> NORS

## Appendix C: Older Americans Act

According to Section 712 of the Older Americans Act, the functions of the Office of the State Long-Term Care Ombudsman are as follows:

- (A) identify, investigate, and resolve complaints that—
  - (i) are made by, or on behalf of, residents<sup>37</sup>; and
  - (ii) relate to action, inaction, or decisions, that may adversely affect the health, safety, welfare, or rights of the residents (including the welfare and rights of the residents with respect to the appointment and activities of guardians and representative payees), of—
    - (I) providers, or representatives of providers, of long-term care services;
    - (II) public agencies; or
    - (III) health and social service agencies;
- (B) provide services to assist the residents in protecting the health, safety, welfare, and rights of the residents;
- (C) inform the residents about means of obtaining services provided by providers or agencies described in subparagraph (A)(ii) or services described in subparagraph (B);
- (D) ensure that the residents have regular and timely access to the services provided through the Office and that the residents and complainants receive timely responses from representatives of the Office to complaints;
- (E) represent the interests of the residents before governmental agencies and seek administrative, legal, and other remedies to protect the health, safety, welfare, and rights of the residents;
- (F) provide administrative and technical assistance to entities designated under paragraph (5) to assist the entities in participating in the program;
- (G)
  - (i) analyze, comment on, and monitor the development and implementation of Federal, State, and local laws, regulations, and other governmental policies and actions, that pertain to the health, safety,

<sup>37</sup> “Resident” is defined as “an older individual who resides in a long-term care facility [Sec. 711(6)]

welfare, and rights of the residents, with respect to the adequacy of long-term care facilities and services in the State;

(ii) recommend any changes in such laws, regulations, policies, and actions as the Office determines to be appropriate; and

(iii) facilitate public comment on the laws, regulations, policies, and actions;

(H)

(i) provide for training representatives of the Office;

(ii) promote the development of citizen organizations, to participate in the program; and

(iii) provide technical support for the development of resident and family councils to protect the well-being and rights of residents; and

(I) carry out such other activities as the Assistant Secretary determines to be appropriate.

According to Section 102 of the Older Americans Act, the term “long-term care facility” means—

(A) any skilled nursing facility, as defined in section 1819(a) of the Social Security Act (42 U.S.C. 1395i–3(a));

(B) any nursing facility, as defined in section 1919(a) of the Social Security Act (42 U.S.C. 1396r(a));

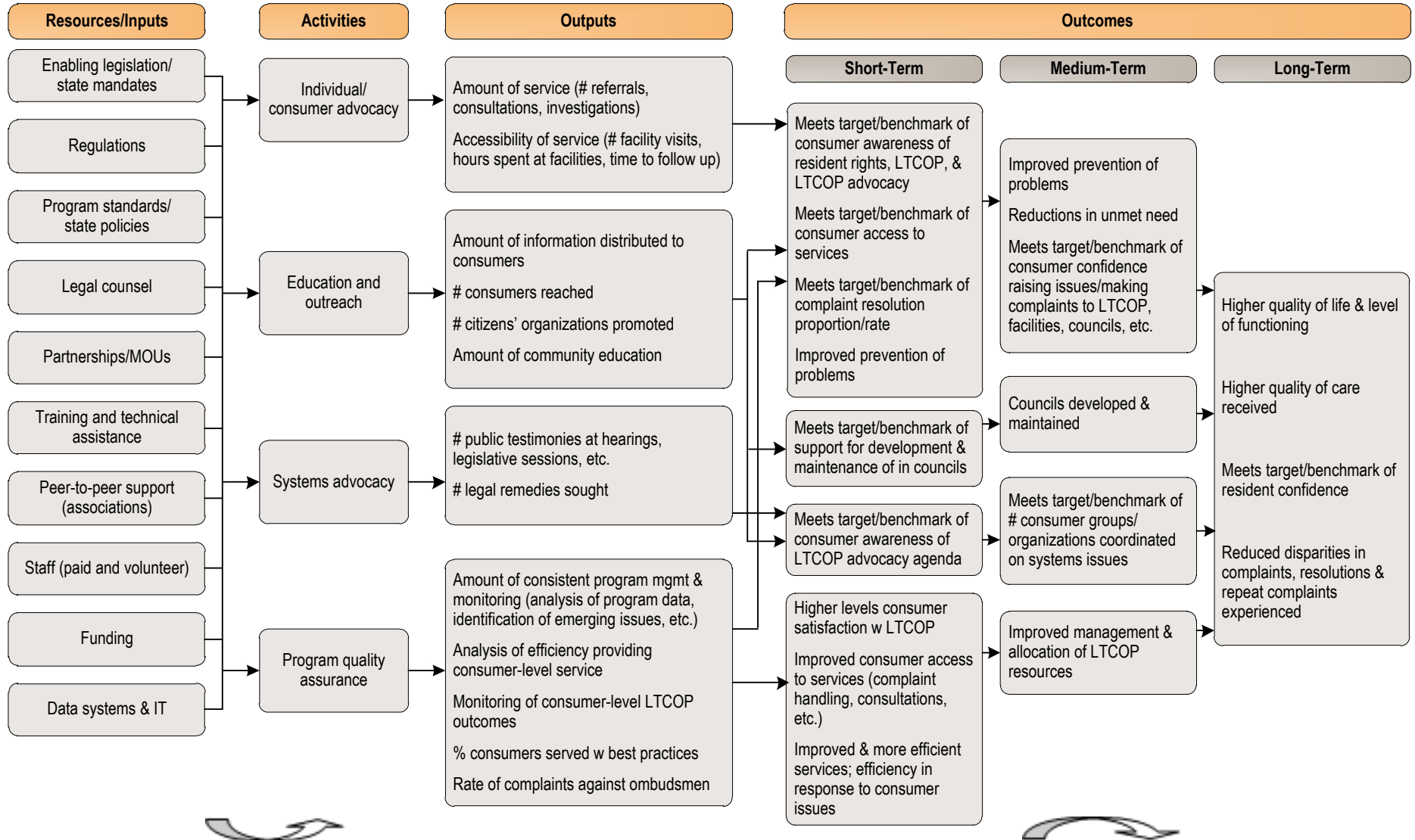
(C) for purposes of sections 307(a)(12)<sup>11</sup> and 712, a board and care facility; and

(D) any other adult care home, including an assisted living facility, similar to a facility or institution described in subparagraphs (A) through (C).

# Appendix D: Logic Models



**Long-Term Care Ombudsman Program**  
**CONSUMER-LEVEL Logic Model**

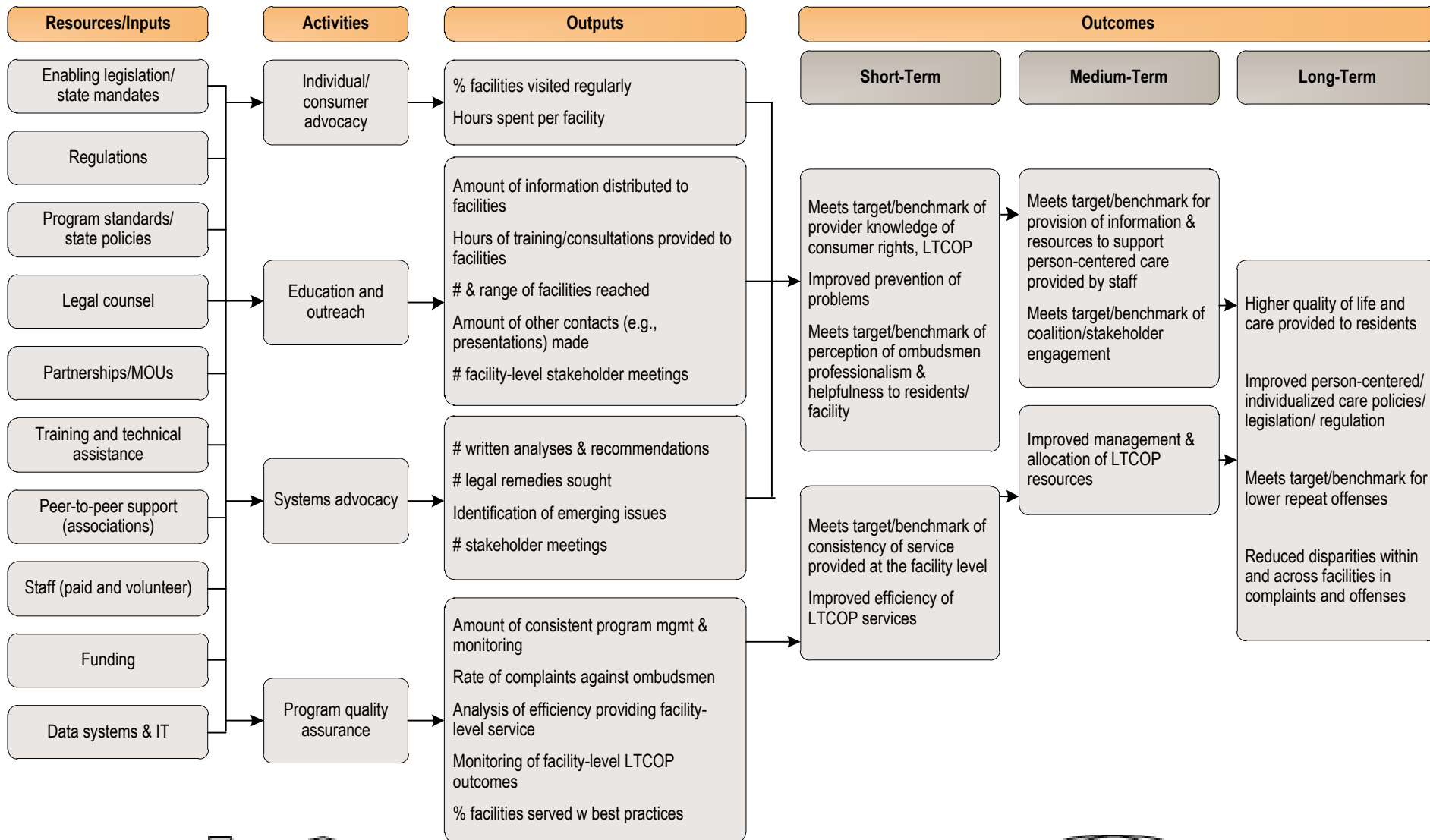


**Contextual Factors**

program autonomy and conflicts of interest (related to organizational placement, access to legal counsel, willful interference); personal characteristics of LTCOP staff (leadership, management, advocacy, negotiation skills); relationship with stakeholders; social, political and fiscal climate of the state; financing, number, and type of LTC facilities, services and supports; demographic, socioeconomic, geographic, and health and disability characteristics of consumers, populations and communities

– See list of enabling/limiting factors for an expanded set of variables. –

**Long-Term Care Ombudsman Program**  
**FACILITY-LEVEL Logic Model**

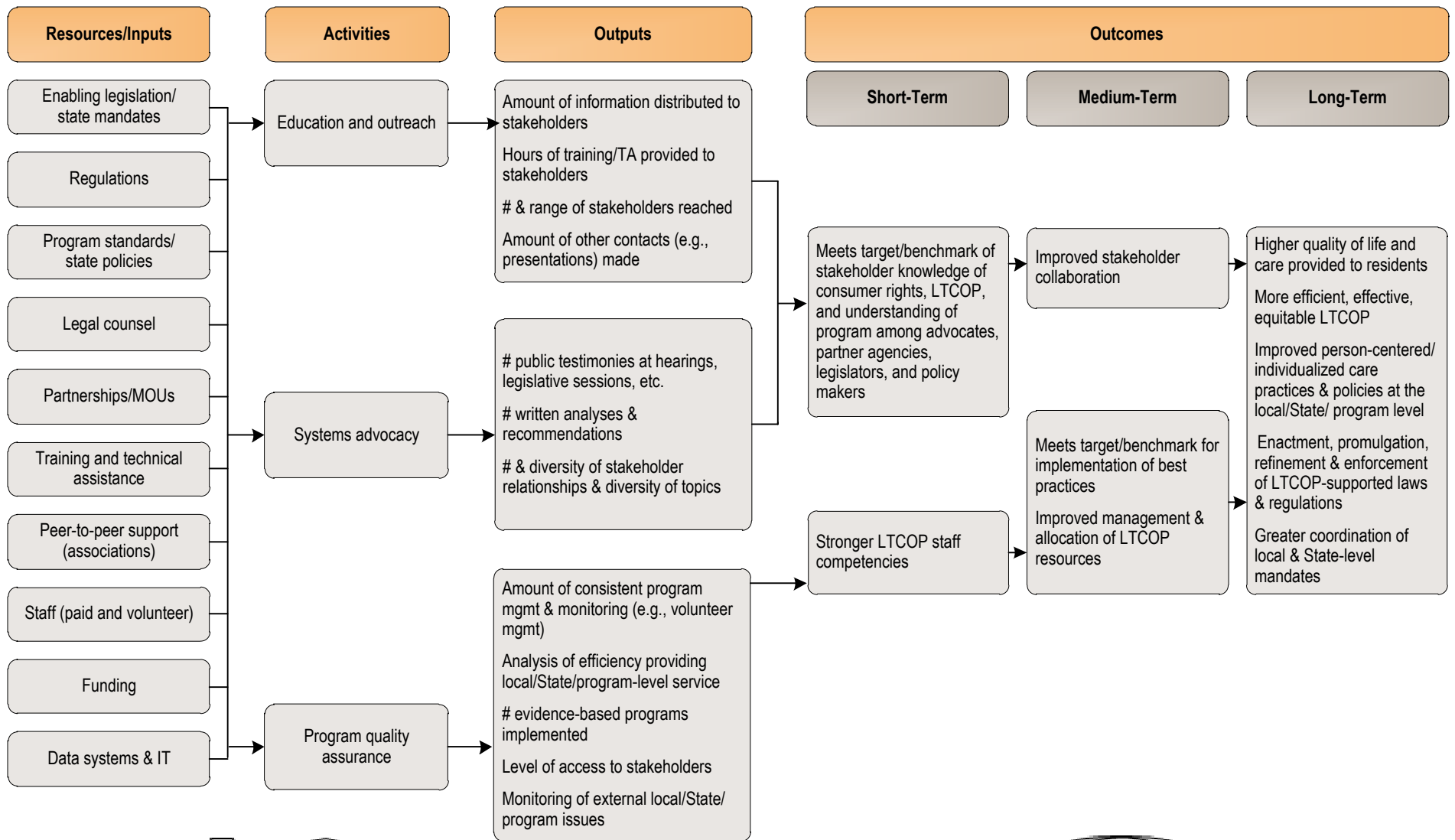


**Contextual Factors**

program autonomy and conflicts of interest (related to organizational placement, access to legal counsel, willful interference); personal characteristics of LTCOP staff (leadership, management, advocacy, negotiation skills); relationship with stakeholders; social, political and fiscal climate of the state; financing, number, and type of LTC facilities, services and supports; demographic, socioeconomic, geographic, and health and disability characteristics of consumers, populations and communities

– See list of enabling/limiting factors for an expanded set of variables. –

**Long-Term Care Ombudsman Program**  
**LOCAL/STATE/PROGRAM-LEVEL Logic Model**

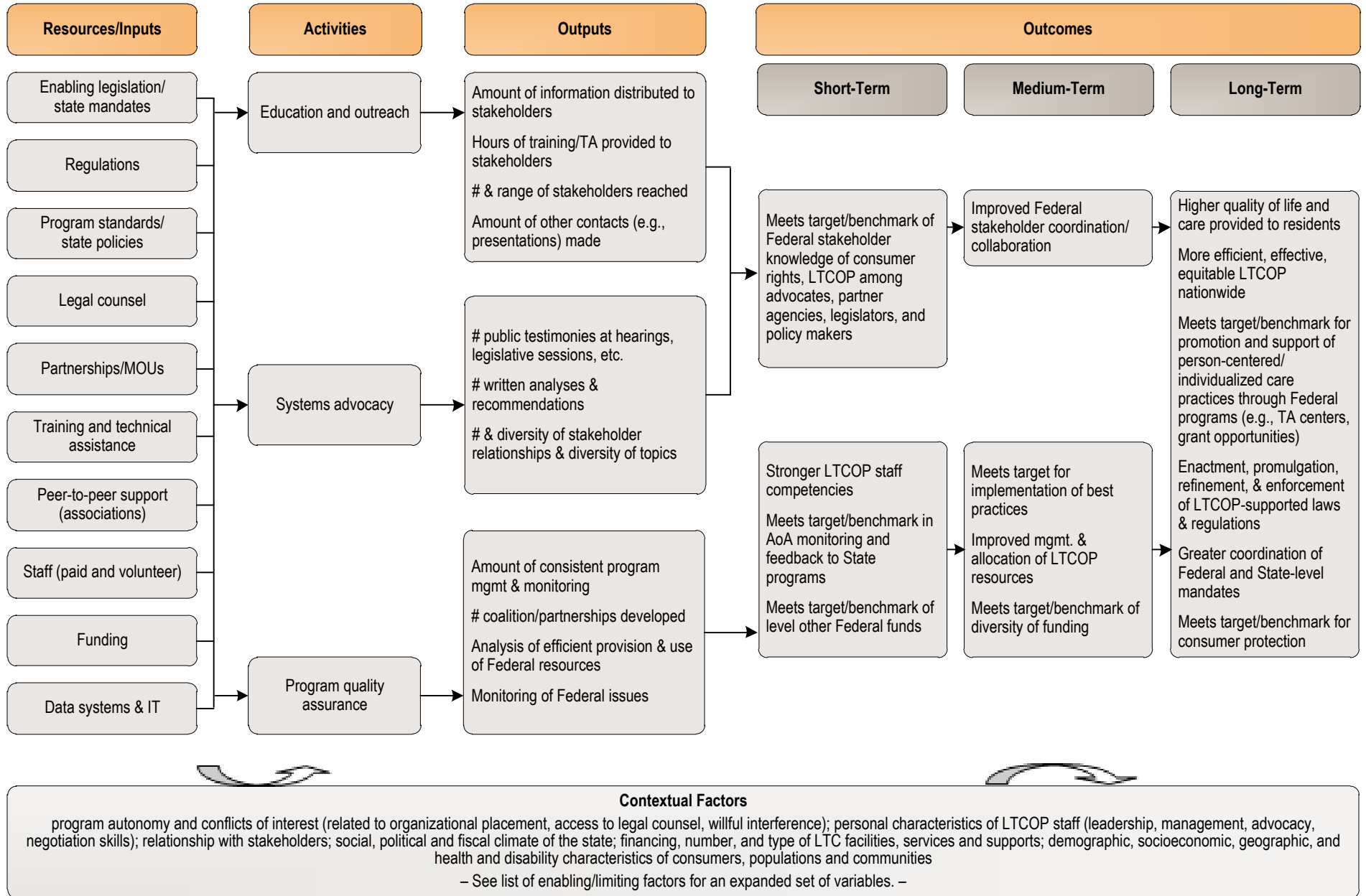


**Contextual Factors**

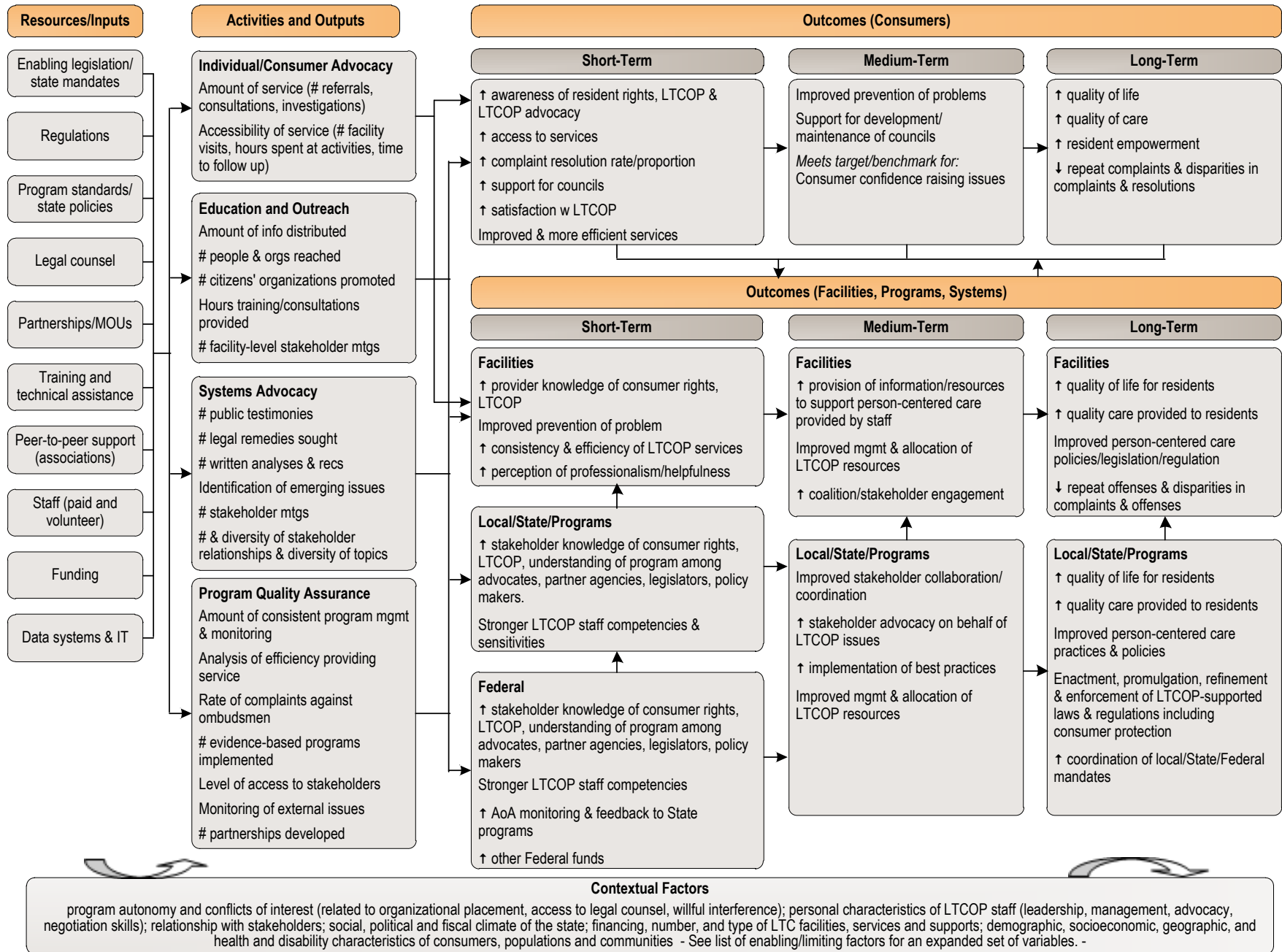
program autonomy and conflicts of interest (related to organizational placement, access to legal counsel, willful interference); personal characteristics of LTCOP staff (leadership, management, advocacy, negotiation skills); relationship with stakeholders; social, political and fiscal climate of the state; financing, number, and type of LTC facilities, services and supports; demographic, socioeconomic, geographic, and health and disability characteristics of consumers, populations and communities

– See list of enabling/limiting factors for an expanded set of variables. –

**Long-Term Care Ombudsman Program  
FEDERAL-LEVEL Logic Model**



**Long-Term Care Ombudsman Program**  
**Overarching Logic Model**



## Appendix E: Cross Walk Matrix

Evaluation Goal	Evaluation Question	Respondents/Data Sources	Data Collection Method	Outputs/Outcomes Captured
<p>(1) Documentation of Ombudsman practices, approaches and processes, including analysis of the similarities and differences across State programs</p>	<ul style="list-style-type: none"> <li>• How is the LTCOP structured and how does it operate at the local, State and Federal levels?</li> <li>• How do LTCOPs use existing resources to resolve problems of individual residents and to bring about changes at the facility and governmental (local, State and Federal) levels that will improve the quality of services available/provided?</li> <li>• With whom do LTCOPs partner with and how do LTCOPs work with partner programs?</li> </ul>	<ul style="list-style-type: none"> <li>• Local, State, and Federal LTCOP staff</li> <li>• LTCOP volunteers</li> <li>• Program partners</li> <li>• Facilities</li> </ul>	<p>Records review</p> <ul style="list-style-type: none"> <li>• Program records</li> <li>• Publications</li> <li>• Existing data sources</li> </ul> <p>Commissioned papers</p> <p>Core &amp; Modular Process Data</p> <ul style="list-style-type: none"> <li>• Interviews</li> <li>• Surveys</li> <li>• Focus groups</li> </ul> <p>Modular Process Data</p> <ul style="list-style-type: none"> <li>• Media tracking</li> <li>• Policy analysis</li> </ul> <p>Case Studies</p> <p>Ecological Study</p>	<p>Individual/Consumer advocacy</p> <ul style="list-style-type: none"> <li>• Amount of service (referrals, consultations, investigations)</li> <li>• Accessibility of services (# facility visits)</li> </ul> <p>Education and Outreach</p> <ul style="list-style-type: none"> <li>• Amount of info distributed</li> <li>• # of people &amp; orgs reached</li> <li>• # citizens' organizations promoted</li> <li>• Hours training/consultations provided</li> <li>• # facility-level stakeholder mtgs</li> </ul> <p>Systems Advocacy</p> <ul style="list-style-type: none"> <li>• # public testimonies</li> <li>• # legal remedies sought</li> <li>• # written analyses &amp; recs</li> <li>• # stakeholder mtgs</li> <li>• # &amp; diversity of stakeholder relationships &amp; diversity of topics</li> </ul> <p>Program Quality Assurance</p> <ul style="list-style-type: none"> <li>• Amount of consistent program mgmt and monitoring</li> <li>• Analysis of efficiency providing service</li> <li>• Rate of complaints against ombuds</li> <li>• # evidence-based programs implemented</li> <li>• # partnerships developed</li> </ul>

Evaluation Goal	Evaluation Question	Respondents/Data Sources	Data Collection Method	Outputs/Outcomes Captured
(2) Provision of feedback to Federal, State and local program staff about what is working and areas for improvements in the Long-Term Care Ombudsman Program	<ul style="list-style-type: none"> <li>How does the LTCOP provide feedback on successful practices and areas for improvement?</li> </ul>	<ul style="list-style-type: none"> <li>Local, State, and Federal LTCOP staff</li> <li>LTCOP volunteers</li> </ul>	Core & Modular Outcomes Data <ul style="list-style-type: none"> <li>Interviews</li> <li>Surveys</li> </ul>	<ul style="list-style-type: none"> <li>ACL monitoring and feedback to State programs</li> <li>Improved, consistent, national reporting system</li> </ul>
(3) Documentation of the outcomes of the Long-Term Care Ombudsman Program	<ul style="list-style-type: none"> <li>Are the critical functions, including mandated responsibilities, of the LTCOP at the local, State and Federal levels carried out effectively and efficiently?</li> <li>How effective is the LTCOP in ensuring services for the full range of residents of LTC facilities, including older individuals with the greatest economic and social needs?</li> <li>What impact do LTCOPs have on LTC practices, programs and policies?</li> <li>What impact do LTCOPs have on residents' health, safety, welfare and rights?</li> </ul>	<ul style="list-style-type: none"> <li>Consumers</li> <li>Facility staff</li> <li>Local and State LTCOP staff</li> <li>Staff of partner agencies/orgs</li> <li>Staff of advocacy/consumer groups</li> <li>Associations</li> <li>Resident &amp; family councils</li> </ul>	Records review <ul style="list-style-type: none"> <li>Policy documents, testimony, comments on laws, etc.</li> <li>State and local records</li> </ul> NORS data <ul style="list-style-type: none"> <li>Interviews</li> <li>Surveys</li> <li>Focus groups</li> </ul> Modular Outcomes Data <ul style="list-style-type: none"> <li>Media tracking</li> <li>Legislative history</li> </ul> Cohort Study <ul style="list-style-type: none"> <li>Ecological Study</li> </ul>	<ul style="list-style-type: none"> <li>Awareness of resident rights, LTCOP, and LTCOP advocacy</li> <li>Consumer access to services</li> <li>Complaint resolution proportion/rate</li> <li>Support for development and maintenance of resident/family councils</li> <li>Consumer satisfaction with LTCOP</li> <li>Efficiency of services</li> <li>Consumer confidence raising issues</li> <li>Prevention of problems</li> <li>Provider knowledge of consumer rights</li> <li>Facility perception of LTCO professionalism and helpfulness to residents and facility</li> <li>Consistency and efficiency of LTCOP services</li> <li>Facility perception of LTCO provision of information and resources to support person-centered care provided by staff</li> <li>Coalition/stakeholder engagement</li> <li>Facility perception of management and allocation of LTCOP resources</li> <li>Facility coalition/stakeholder engagement</li> <li>Stakeholder knowledge of consumer rights and LTCOP</li> <li>Stakeholder collaboration</li> <li>Strong LTCOP staff competencies &amp; sensitivities</li> <li>Optimal mgmt. &amp; allocation of LTCOP resources</li> </ul>

Evaluation Goal	Evaluation Question	Respondents/Data Sources	Data Collection Method	Outputs/Outcomes Captured
<p>(4) Measurement of program efficiency and the collection of program cost data to support program planning and to justify program continuation and/or expansions</p>	<ul style="list-style-type: none"> <li>• Are the critical functions, including mandated responsibilities, of the LTCOP at the local, State and Federal levels carried out effectively and efficiently?</li> <li>• How effective is the LTCOP in ensuring services for the full range of residents of LTC facilities, including older individuals with the greatest economic and social needs?</li> <li>• How cost-effective is the LTCOP at the local and State levels?</li> </ul>	<ul style="list-style-type: none"> <li>• LTCOP staff</li> <li>• Facility staff</li> <li>• Staff of partner organizations/ agencies</li> <li>• Staff of consumer/ advocacy organizations</li> </ul>	<p>Records reviews (cost and performance)</p> <p>Cost analyses</p> <p>Core Outcomes Data</p> <ul style="list-style-type: none"> <li>• Interviews</li> <li>• Surveys</li> </ul>	<ul style="list-style-type: none"> <li>• Consistent national reporting system</li> <li>• Efficiency in response to local/State/program issues</li> <li>• Optimal management &amp; allocation of LTCOP resources</li> <li>• Diversity of funding (non-federal, non-governmental)</li> </ul>



## Appendix F: Data Elements

Data Elements	Existing Data				New Data						
	Program Records	NORS	MDS	CASPER	In-person Interview	Telephone Interview	Survey	Focus Group	Media Tracking	Policy Analysis	Cohort Study
<b>Process Core</b>											
<i>Federal: ACL Staff</i>											
Program operations					x						
Feedback to and monitoring of state programs					x						
Adequacy of resources					x						
Barriers to effective operation					x						
Interactions with state programs					x						
Inter-organizational relationships					x						
Use of program data for strategic planning					x						
<i>Federal: National Ombudsman Resource Center</i>											
Role/relationship with LTCOP					x						
Interactions with state programs					x						
Interactions with local programs					x						
Successful programmatic approaches					x						
Barriers to effective operation					x						
<i>Federal: NASOP/NALLTCO/NASUAD</i>											
Role/relationship with LTCOP					x					x	
Definition of systems advocacy issues					x					x	
Opportunities, challenges for systems advocacy					x					x	
Extent of involvement in LTCO-led systems advocacy					x					x	
<i>Federal: CMS</i>											
Role/relationship with LTCOP					x						
<i>State Ombudsmen</i>											

Data Elements	Existing Data				New Data						
	Program Records	NORS	MDS	CASPER	In-person Interview	Telephone Interview	Survey	Focus Group	Media Tracking	Policy Analysis	Cohort Study
Program operations						X					
Organizational placement	X					X					
Interactions with local programs						X					
State mandates	X					X					
Program autonomy						X					
Conflicts of interest						X					
Adequacy of resources (funding, staffing)						X					
Inter-organizational relationships						X					
Capacity building						X					
Political and fiscal context						X					
Main activities by type of facility						X					
Successful programmatic approaches						X					
Barriers to effective operation						X					
Ombudsmen characteristics	X					X					
Data management systems						X					
Cost data	X					X					
Funding sources	X					X					
Designation of local programs	X					X					
Legal counsel						X					
Access to resident, records, facility						X					
Feedback to and monitoring of, local programs						X					
Transition to less restrictive settings						X					
Use of program data for strategic planning						X					
Management and allocation of resources						X					
Disclosure confidentiality						X					
MOUs						X					
Adequate access to or control over program resources, budget and expenditures						X					

Data Elements	Existing Data				New Data						
	Program Records	NORS	MDS	CASPER	In-person Interview	Telephone Interview	Survey	Focus Group	Media Tracking	Policy Analysis	Cohort Study
Ombudsmen characteristics (tenure, etc.)	x					x					
Leadership						x					
Barriers to effective operation						x					
Legislative activities (briefings, drafting legis/reg, comments on legis/reg)	x					x			x	x	
Testimony prepared/delivered, setting/context	x					x			x	x	
Written policy analyses/reports prepared, disseminated	x					x			x	x	
Advocacy partners/stakeholders, identity & frequency of contact	x					x			x	x	
Work group participation/leadership	x					x			x	x	
Media contacts/interviews, press releases	x	x				x			x	x	
Training related to systems advocacy						x			x	x	
<i>Local Ombudsmen and Paid Staff</i>											
Program operations							x				
Ombudsmen characteristics	x						x				
Organizational placement	x						x				
Interactions with state programs							x				
Adequacy of resources							x				
Inter-organizational relationships							x				
Supervision of ombudsmen							x				
Main activities by type of facility							x				
Clarity of roles							x				
Access to residents, records, facility							x				
Data management systems	x						x				
Cost data	x						x				
Program size							x				
Rural vs. urban placement							x				
Location in AAA or other							x				

Data Elements	Existing Data				New Data						
	Program Records	NORS	MDS	CASPER	In-person Interview	Telephone Interview	Survey	Focus Group	Media Tracking	Policy Analysis	Cohort Study
Management and allocation of resources							x				
Assignment to type of LTC facility							x				
Lines of authority							x				
Barriers to effective operation							x				
Legislative activities (briefings, drafting legis/reg, comments on legis/reg)	x						x		x	x	
Testimony prepared/delivered, setting/context	x						x		x	x	
Written policy analyses/reports prepared, disseminated	x						x		x	x	
Advocacy partners/stakeholders, identity & frequency of contact	x						x		x	x	
Work group participation/leadership	x						x		x	x	
Media contacts/interviews, press releases	x	x					x		x	x	
Training related to systems advocacy	x						x			x	
<i>Volunteer Ombudsmen</i>											
Ombudsmen characteristics	x						x				
Training	x						x				
Skills	x						x				
Qualifications	x						x				
Clarity of roles							x				
Assignment to type of LTC facility							x				
Location in AAA or other							x				
Guidance on advocating for special populations							x				
Supervision of volunteers							x				
Lines of authority							x				
Relationship with facility staff							x				
Barriers to effective operation							x				
Legislative activities (briefings, drafting legis/reg, comments on legis/reg)	x						x		x	x	

Data Elements	Existing Data				New Data						
	Program Records	NORS	MDS	CASPER	In-person Interview	Telephone Interview	Survey	Focus Group	Media Tracking	Policy Analysis	Cohort Study
Testimony prepared/delivered, setting/context	x						x		x	x	
Advocacy partners/stakeholders, identity & frequency of contact	x						x		x	x	
Work group participation/leadership	x						x		x	x	
Media contacts/interviews, press releases	x	x					x		x	x	
Training related to systems advocacy	x						x		x	x	
<i>Facility administrators and staff</i>											
Interactions with ombudsmen programs							x				
Visitation and complaint resolution process							x				
Educational activities							x				
Consultations							x				
Perceived role of ombudsmen							x				
Perceived role of volunteers							x				
Type of facility							x				
Size of facility							x				
Medicare/Medicaid							x				
Workforce issues							x				
Participation in resident and family councils							x				
Role/relationship with LTCOP							x			x	
Definition of systems advocacy issues							x			x	
Opportunities, challenges for systems advocacy							x			x	
Extent of involvement in LTCO-led systems advocacy							x			x	
<i>Resident &amp; Family Council Members, LTC consumers &amp; caregivers</i>											
Role/relationship with LTCOP								X		x	
Definition of systems advocacy issues								X		x	
Opportunities, challenges for systems advocacy								X		x	

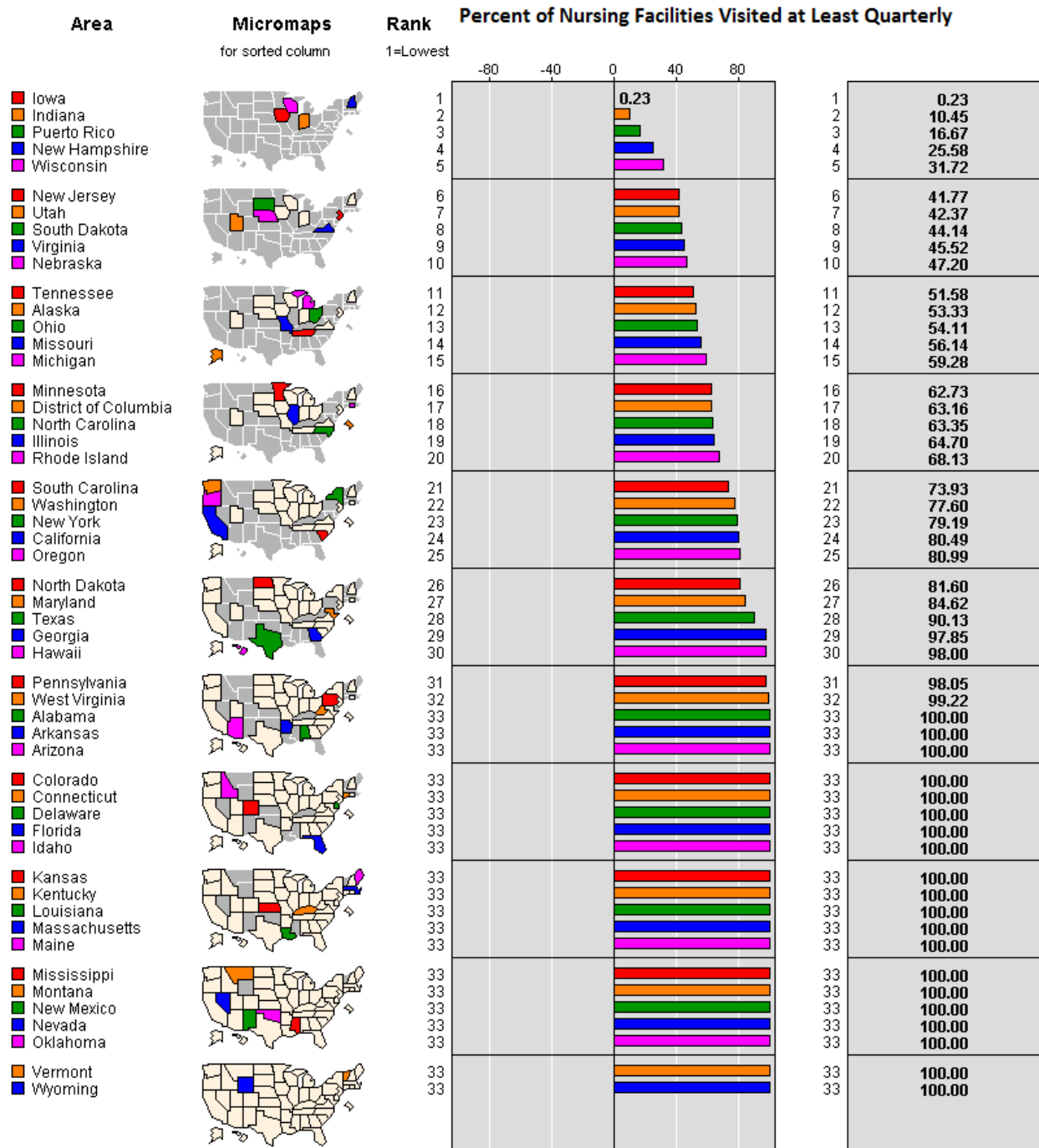
Data Elements	Existing Data				New Data						
	Program Records	NORS	MDS	CASPER	In-person Interview	Telephone Interview	Survey	Focus Group	Media Tracking	Policy Analysis	Cohort Study
Extent of involvement in LTCO-led systems advocacy								X		x	
<b>Outcomes Core</b>											
<i>State, Local and Volunteer Ombudsmen</i>											
Perceived effectiveness in systems advocacy overall						x	x			x	
Program/policy/practice changes toward person-centered or individualized care						x	x		x	x	
Additional funds for LTC or LTCO as result of systems advocacy						x	x		x	x	
Specific advocacy issues placed on policy agenda at state, regional, local level						x	x		x	x	
Policies/regulations/program changes including enforcement adopted or blocked						x	x		x	x	
<i>LTCOP complainants</i>											
Demographic and health information											x
Demographic information on ombudsman											x
Volunteer or paid status of ombudsman											x
Manner of accessing ombudsman											x
Ease of contacting ombudsman											x
Type of complaint		x									x
Complexity of complaint											x
Time to initiate processing of complaint		x									x
Resolution time		x									x
Result of complaint investigation		x									x
Consumer satisfaction with resolution		x									x
Substantiated referrals											x
Willingness to use LTCOP services again											x
Willingness to recommend services											x
Availability of other options to pursue complaint											x

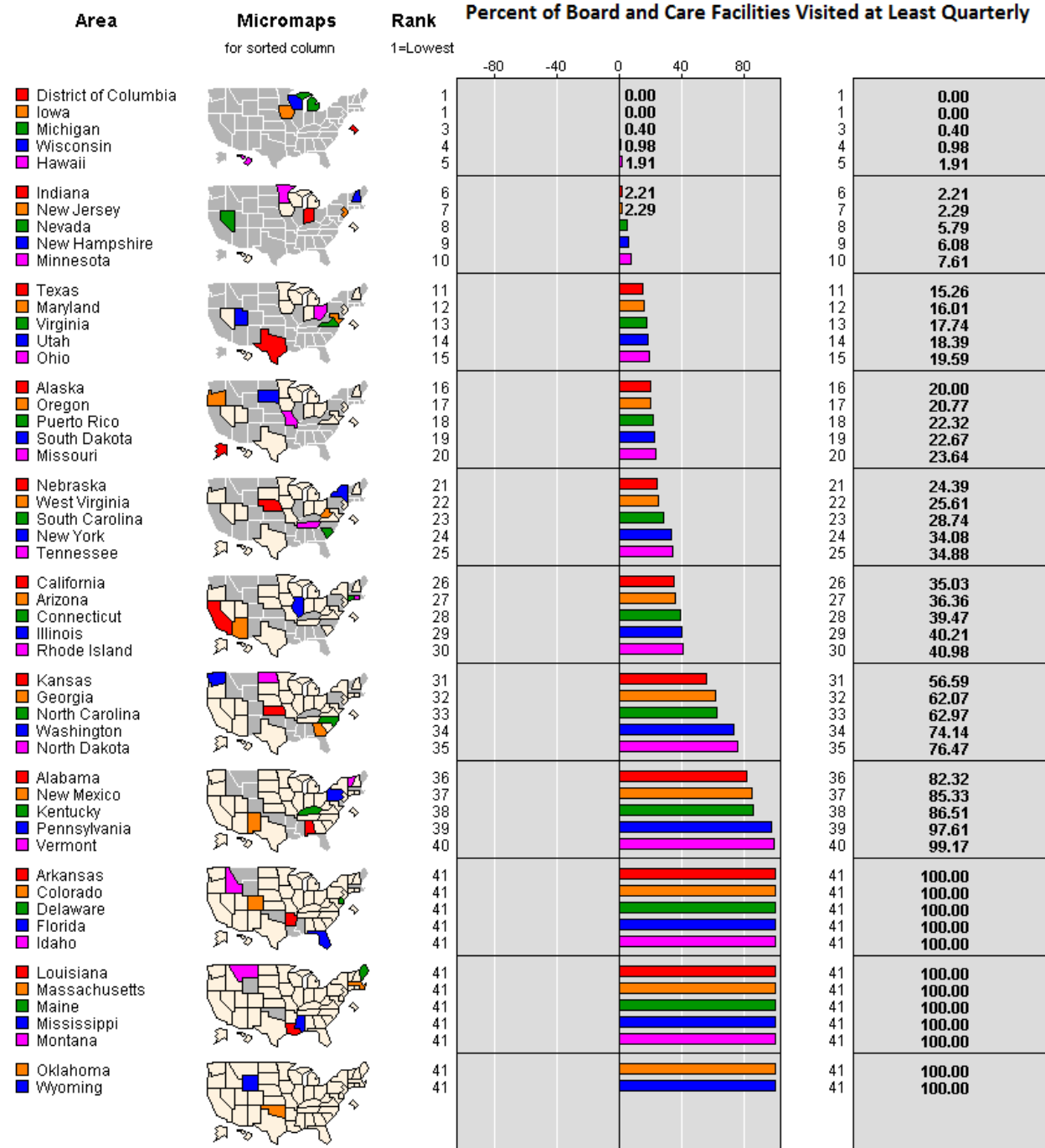
Data Elements	Existing Data				New Data						
	Program Records	NORS	MDS	CASPER	In-person Interview	Telephone Interview	Survey	Focus Group	Media Tracking	Policy Analysis	Cohort Study
Perception of effectiveness of ombudsman											X
Type of facility											X
Size of facility											X
Facility ID code											X
<i>LTSS consumers</i>											
LTSS consumers awareness of resident rights, LTCOP and LTSS							X	X			
Accessibility of services							X	X			
Availability of services							X	X			
Council participation							X	X			
Unmet need							X	X			
Perception of role of ombudsmen							X	X			
Perception of role of volunteers							X	X			
Prevention of problems								X			
<i>Facility administrators and staff</i>											
Provider knowledge of resident rights, LTCOP and LTSS							X				
Willingness to contact LTCOP							X				
Perception of effectiveness							X				
Referral of program to residents and their families							X				
Recognition of LTCOP's value							X				
Change in practices							X				
Change in policies							X				
<i>Stakeholders</i>											
Knowledge of resident rights, LTCOP and LTSS							X				
Inter-organizational relationships							X				
Coalitions							X				

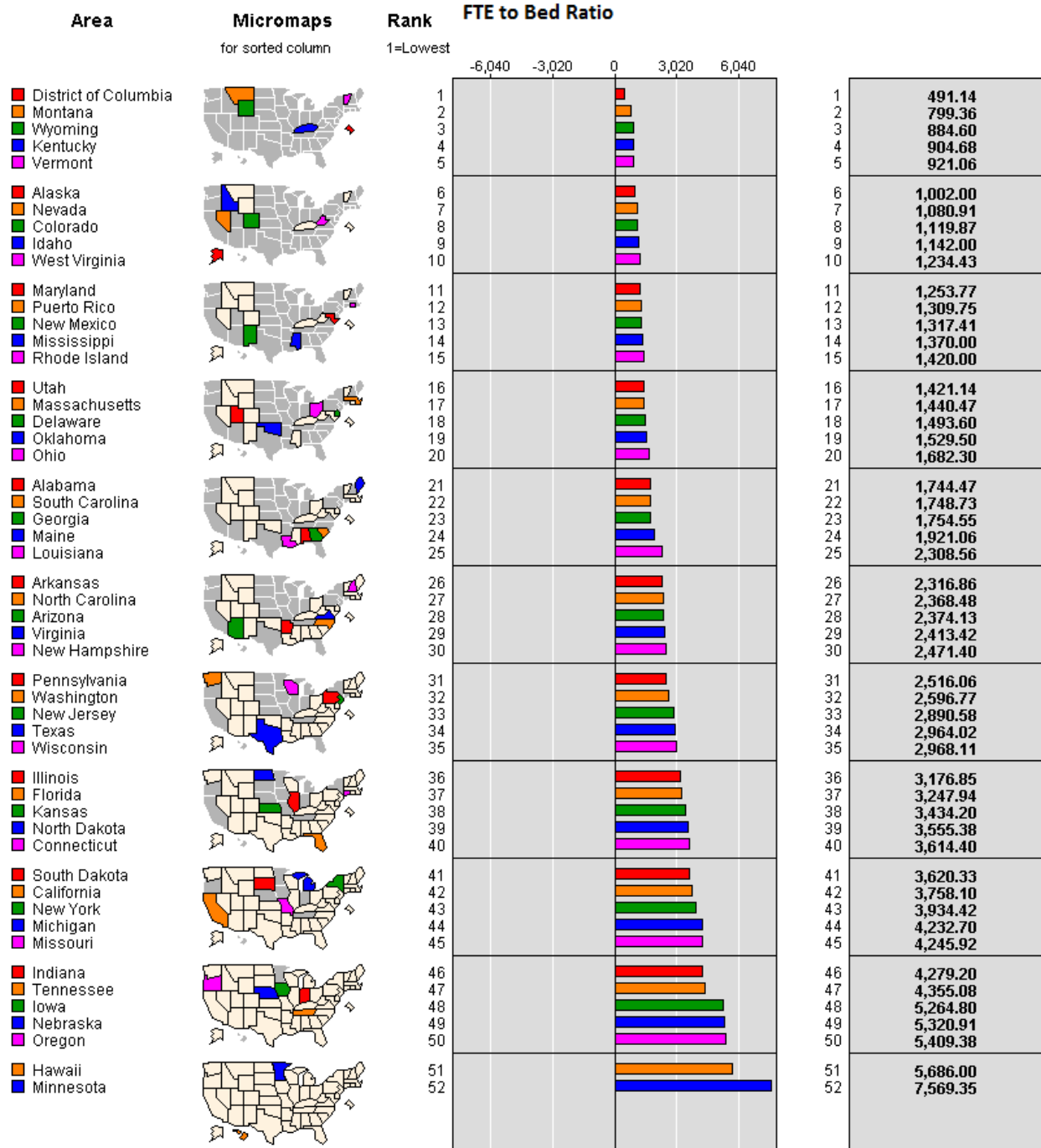
Data Elements	Existing Data				New Data						
	Program Records	NORS	MDS	CASPER	In-person Interview	Telephone Interview	Survey	Focus Group	Media Tracking	Policy Analysis	Cohort Study
Participation in surveys							x				
Strength of supporting agency/stakeholder							x				
Perception of ombudsman leadership							x				
<i>Resident &amp; Family Council Members, LTC consumers &amp; caregivers</i>											
Perceived effectiveness of LTCO	x							X		x	
Program/policy/practice changes toward person-centered or individualized care									x	x	
Additional funds for LTC or LTCO as result of systems advocacy									x	x	
Specific advocacy issues placed on policy agenda at state, regional, local level									x	x	
Policies/regulations/program changes including enforcement adopted or blocked									x	x	
<b>Process and Outcomes Modular Topics</b>											
State mandates: home care responsibility	x						x				
State mandates: mandated reporter, investigation of abuse, neglect, exploitation	x										
Significant time devotion to systems advocacy work	x	x					x				
Rebalancing & transition to least restrictive settings: nursing home closures, Money Follows the Person demonstrations, involuntary discharges	x		x				x				
Natural disasters	x						x				
Consumer financial protection	x						x				
Efforts at culture change	x						x				
Absence of volunteers	x						x				
Senior Medicare Patrol (SMP) collaboration	x						x				
Behavioral/mental health: dementia among LTCO clients, safety threat to LTCO clients by other residents	x						x				

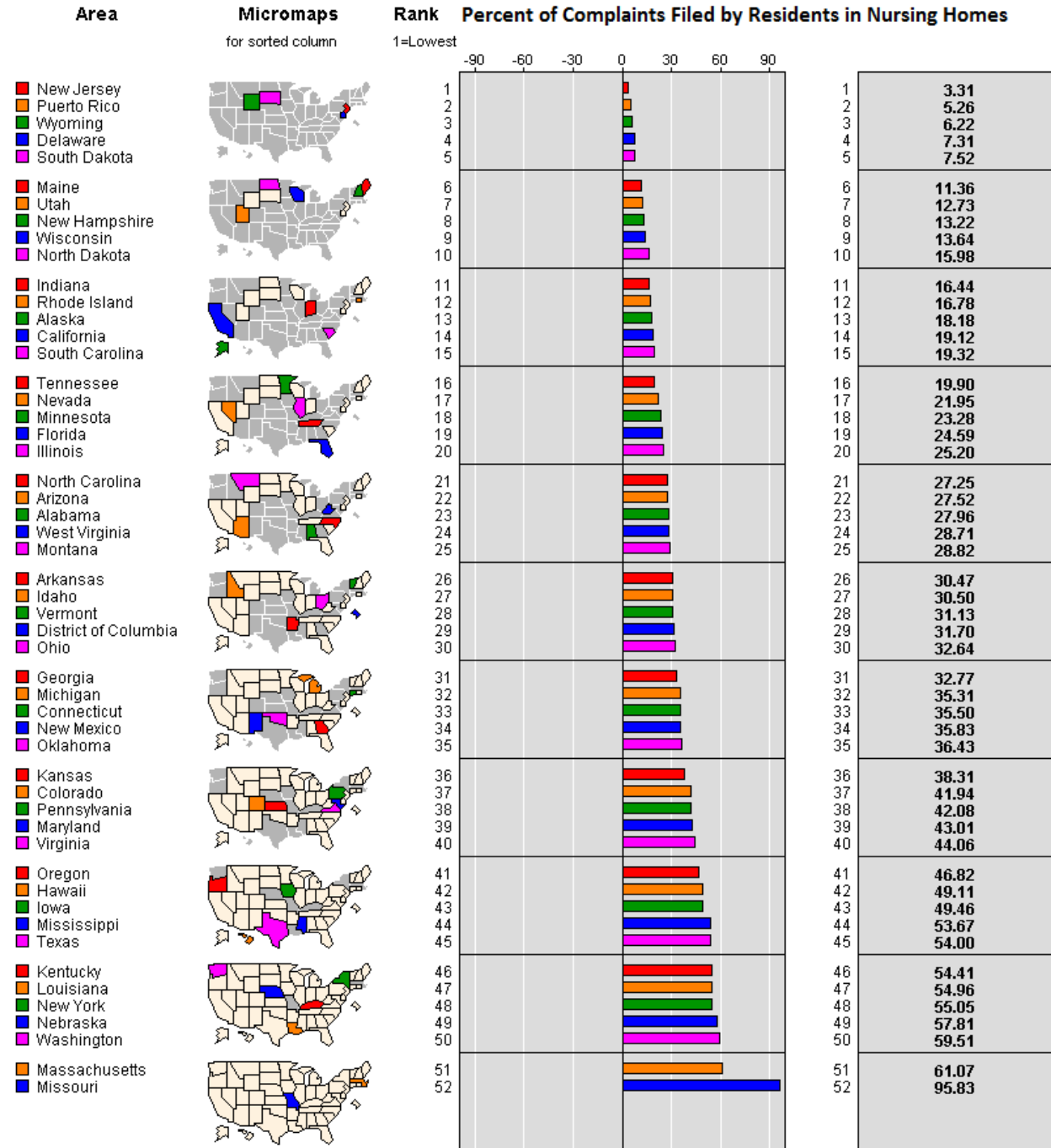


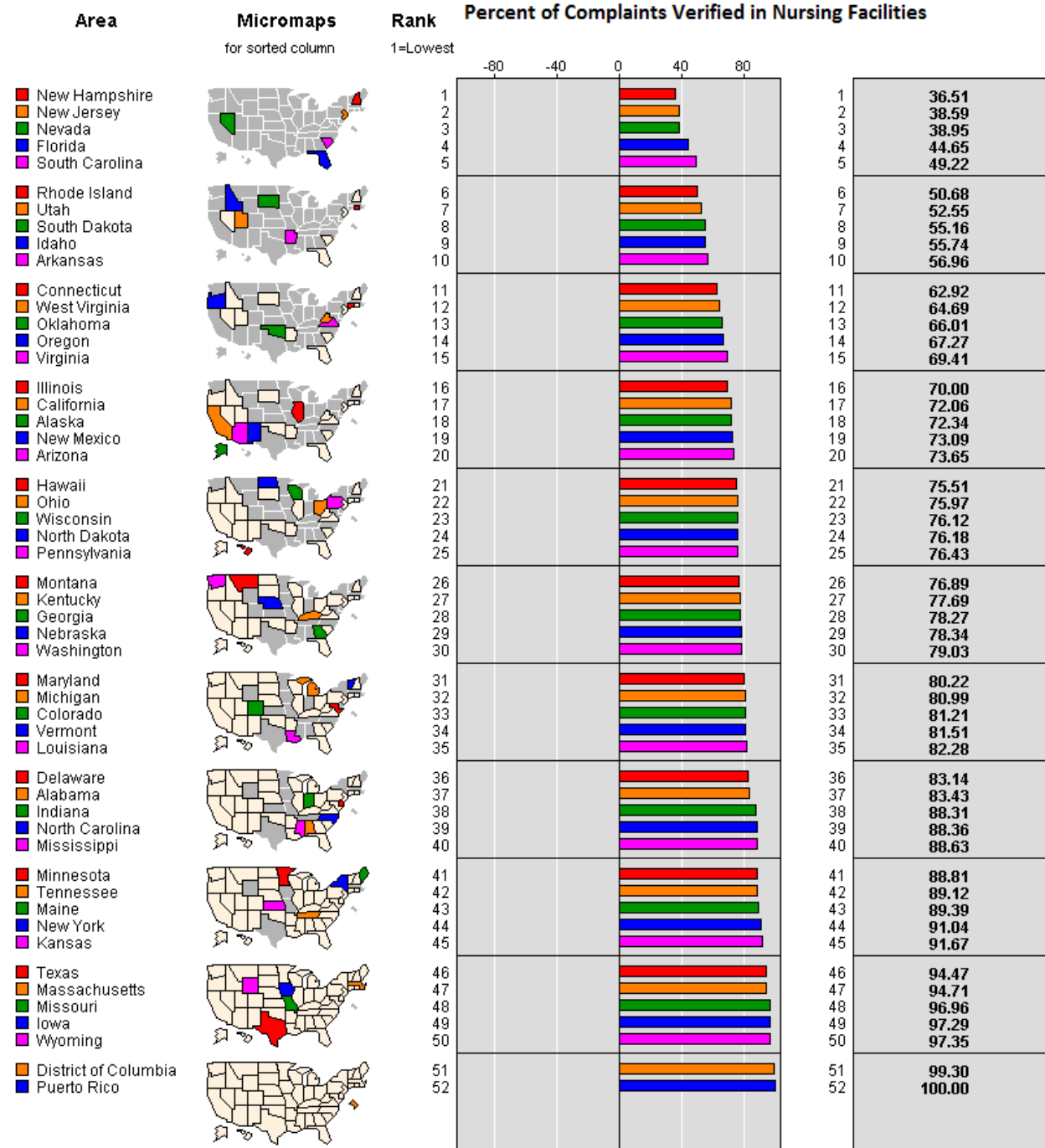
## Appendix G: Micromaps

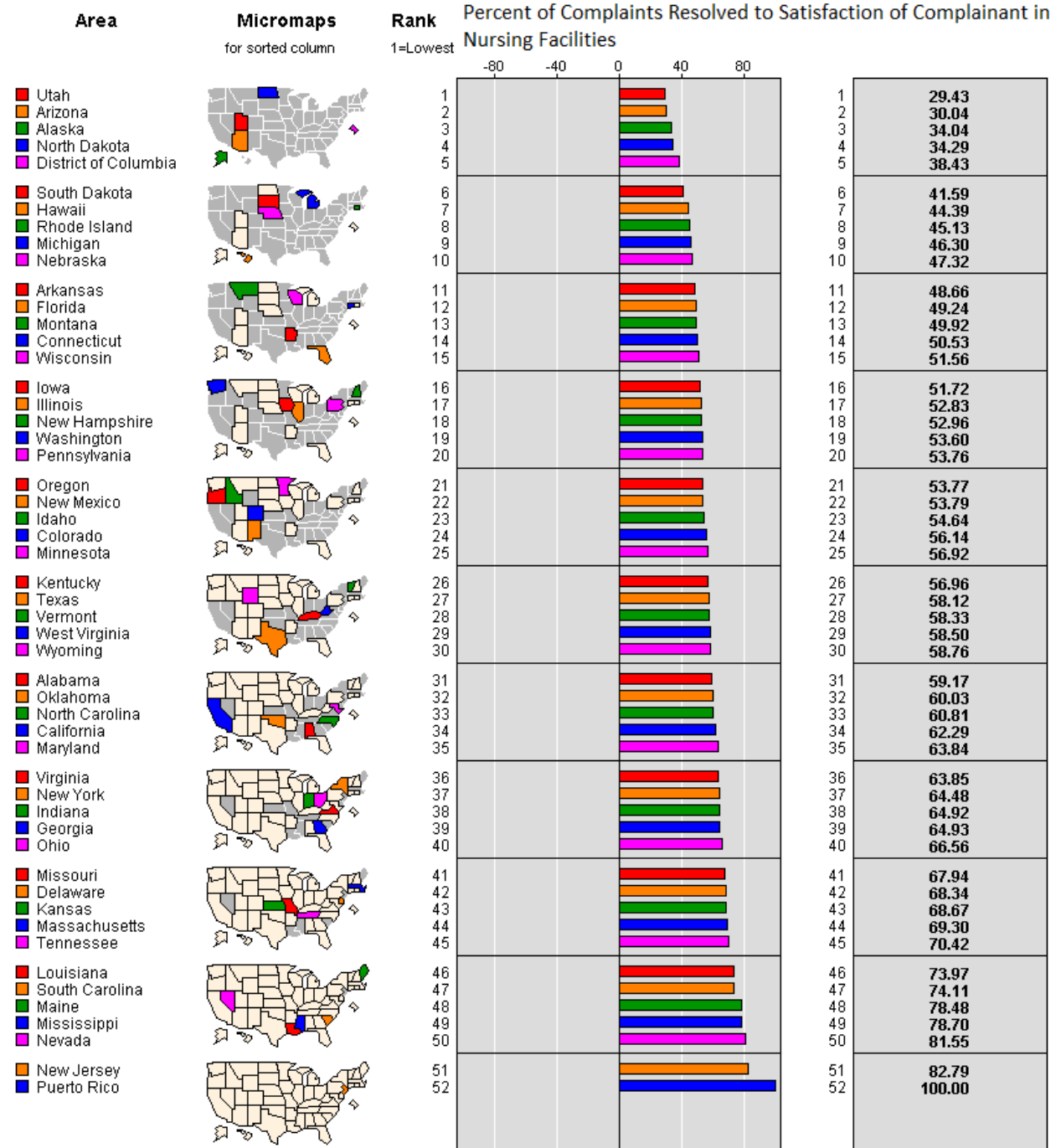


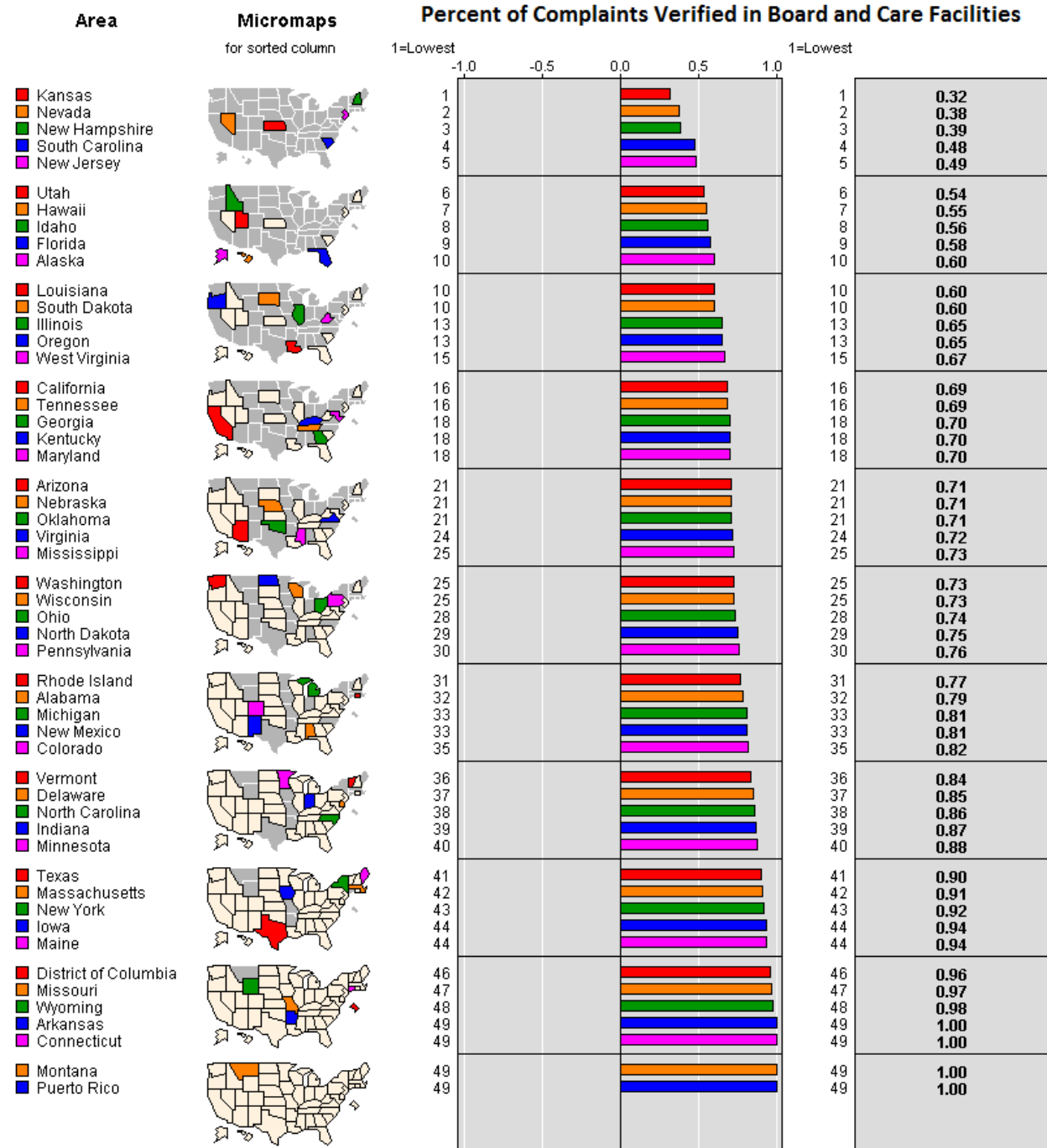


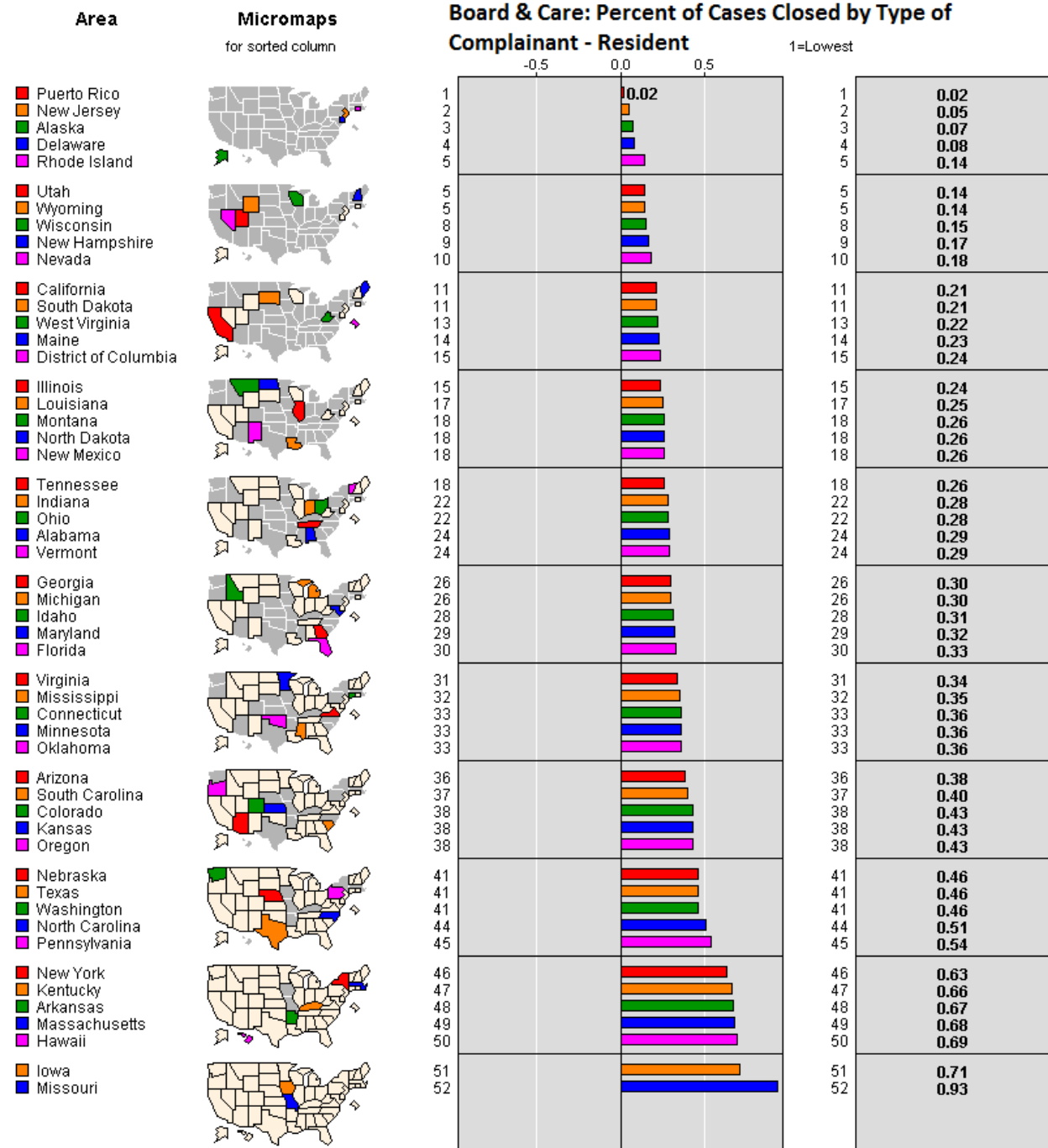




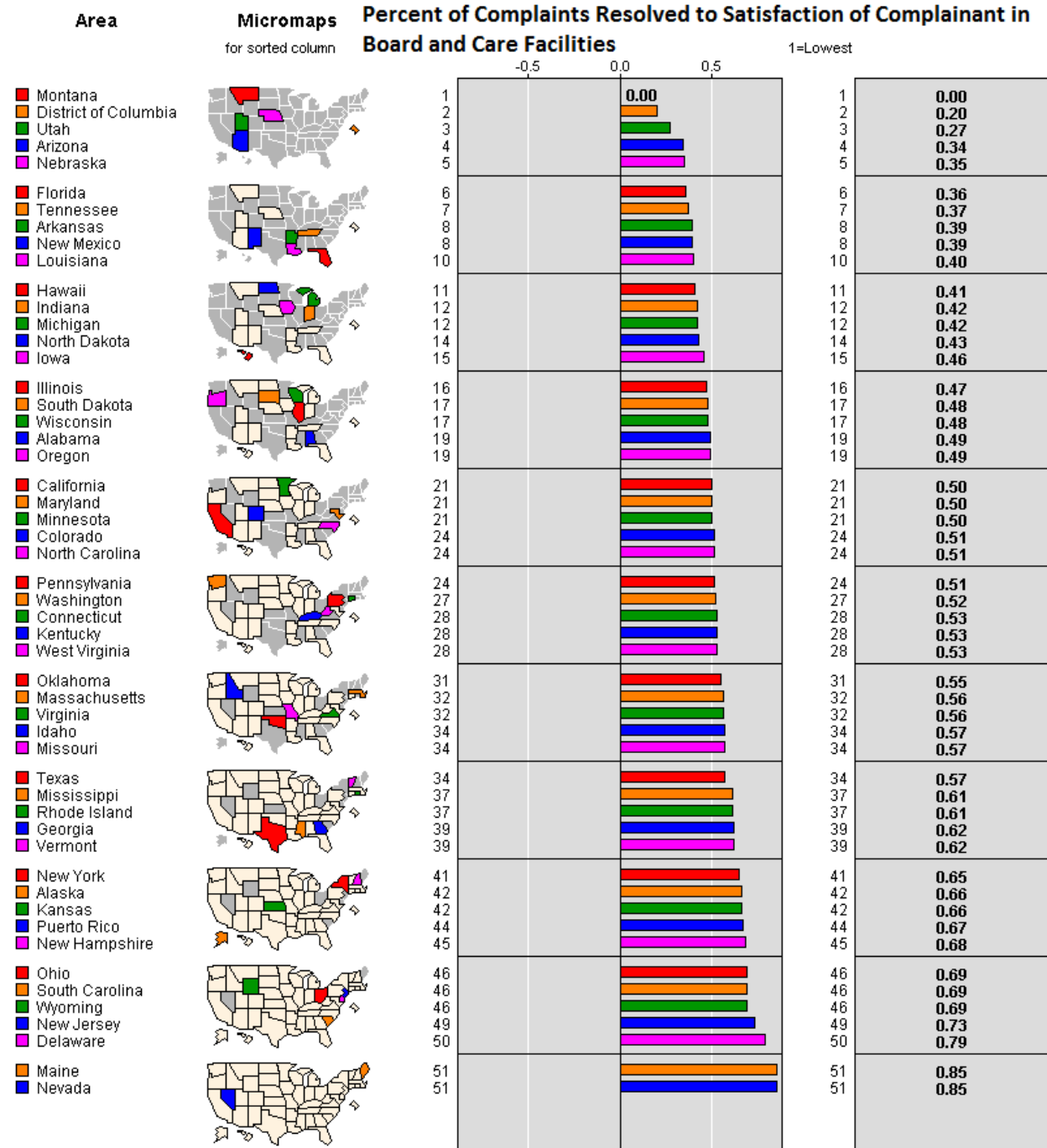


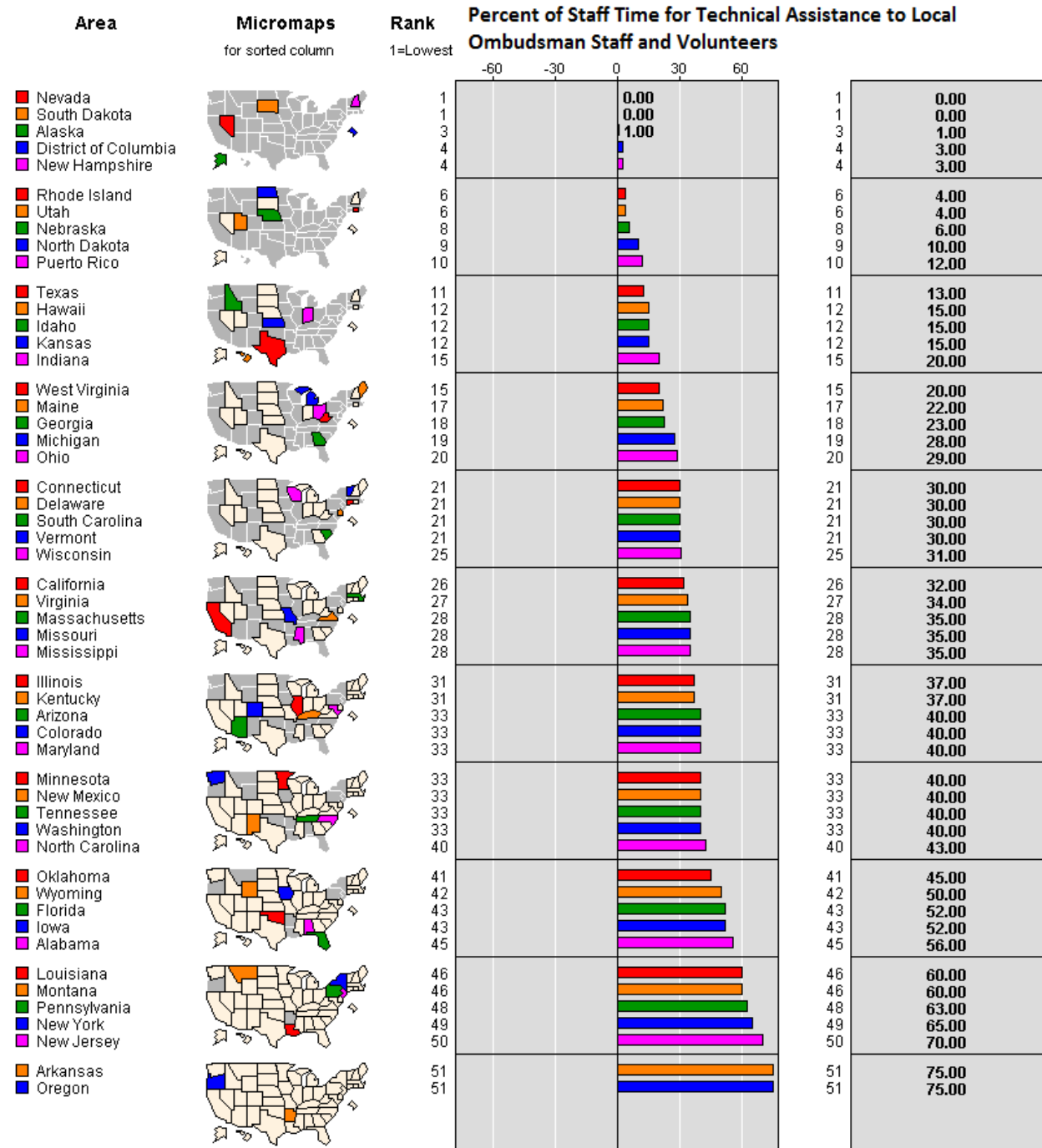


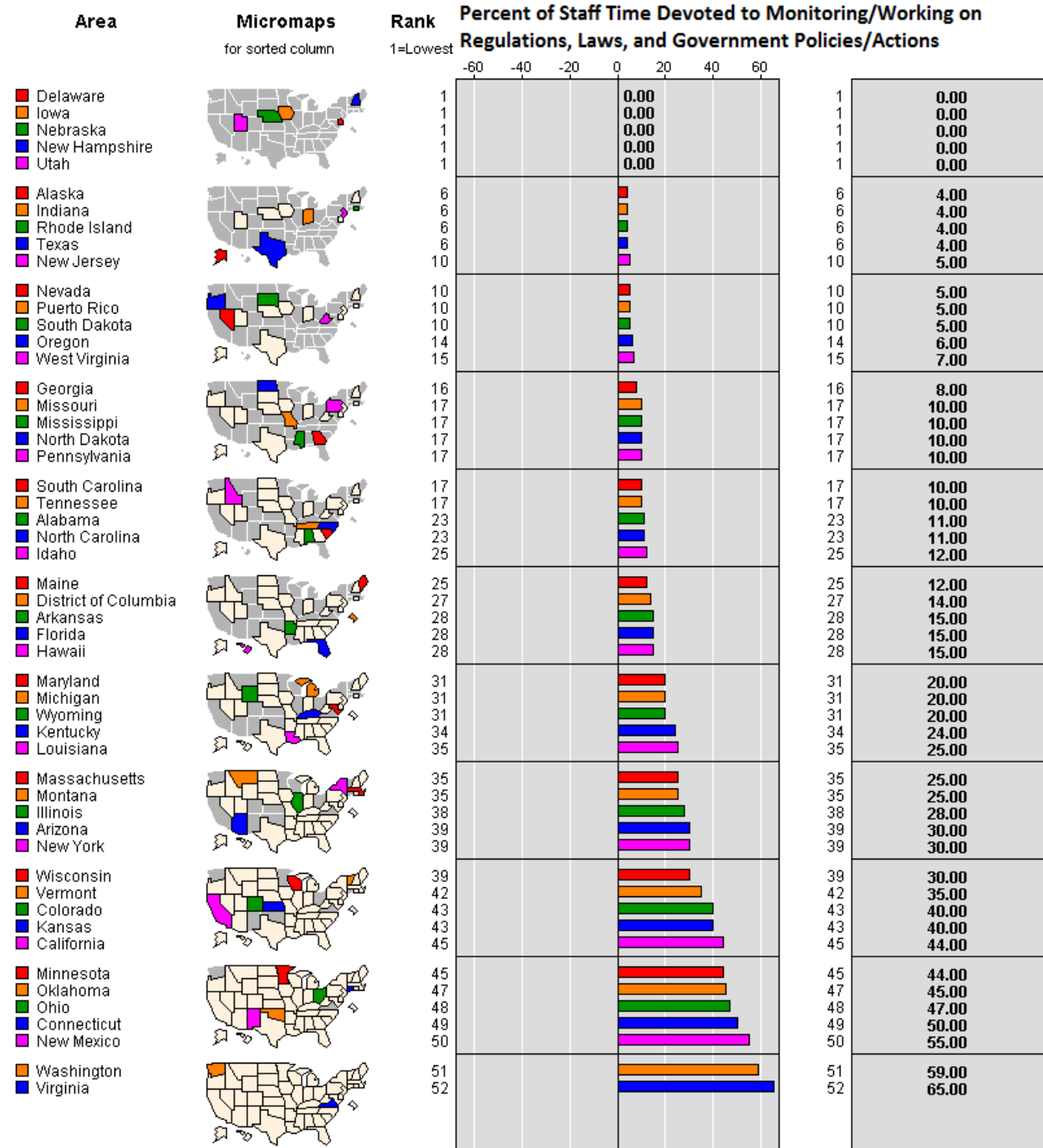




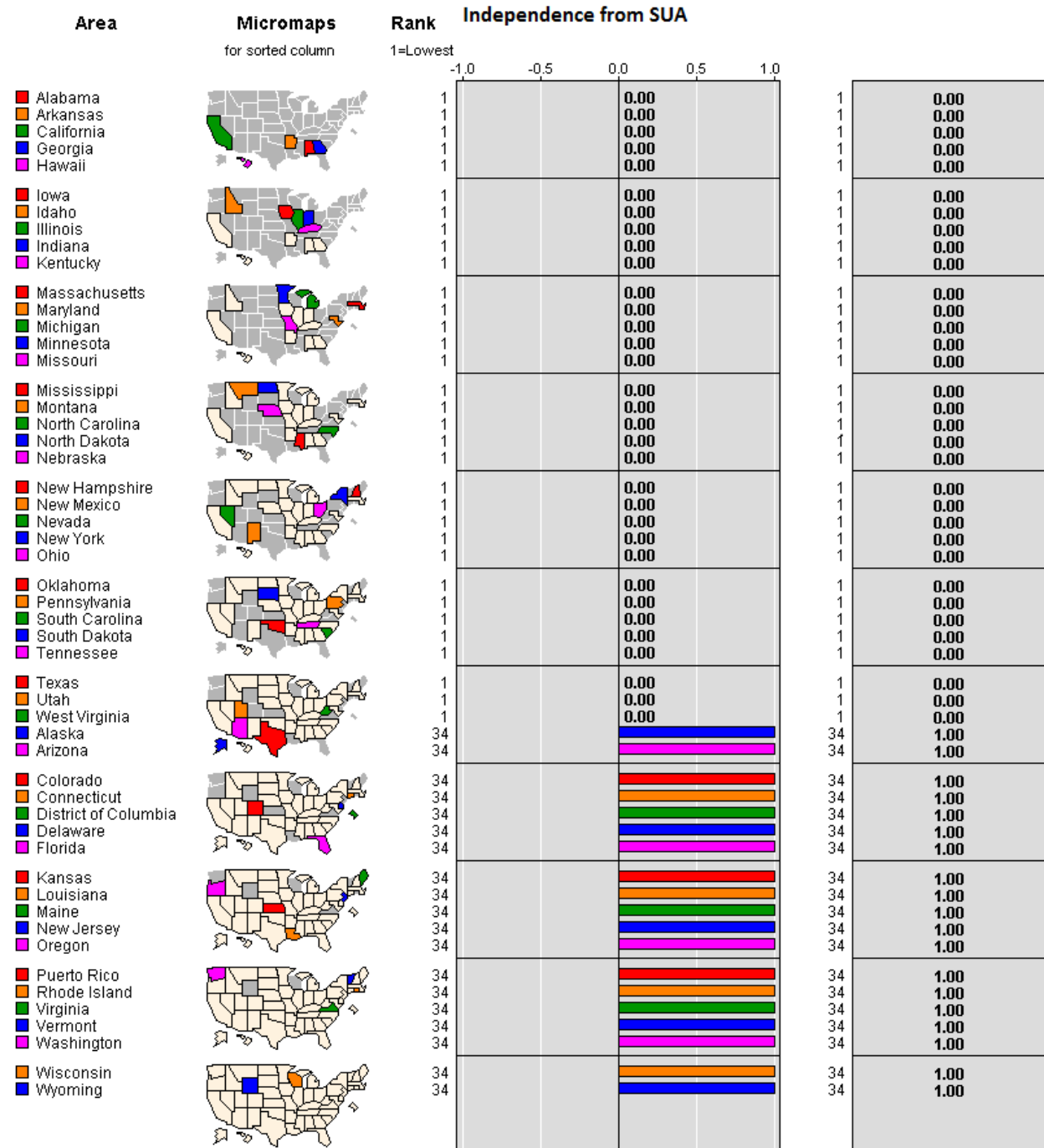








Information on “Independence from SUA” was drawn from the “Ombudsman Quick Tip Sheet” prepared by Carol Scott and passed out at the 2012 NASOP meeting.



## Appendix H: Annotated Bibliography on Data Collection Tools & Data Sources

### Aging Integrated Database (AGID)

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The Administration on Aging (AoA) maintains the Aging Integrated Database (AGID), an on-line query system based on AoA-related data files and surveys, including State Program Reports (SPR) 2005-2010, National Ombudsman Reporting System (NORS) 2000-2010, Title VI Services by Tribal Organization 2002-2010, National Survey of OAA Participants 2003-2011, and National Survey of Area Agencies on Aging (AAAs) 2005/2006. To aid the interpretation of Older Americans Act (OAA) program information, Census data on the 60 and older population are also available through AGID. These include the American Community Survey (ACS) Demographic Data 2004-2010, Population Estimates Data (2000-2011), and Census 2010.

There are four options to access the data, depending on the particular level of focus and data aggregation, from single data elements with Data-at-a-Glance to more expansive views of the data through State Profiles, Custom Tables, and Data Files – the last of which offers full database access to facilitate more detailed analyses. For example, estimates can be quickly tabulated and supplemented by maps and charts through Data-at-a-Glance while Custom Tables allows users to generate detailed, multi-year tables and output the results in print or spreadsheet form.

Data provided by AGID may be useful for understanding state-by-state variation as well as the context within which the LTCOP operates, particularly with respect to population and client characteristics (demographic and disability data), types and levels of services, expenditures of funds, and SUA and AAA administration, including staffing levels and responsibilities. The web address for AGID is [www.agidnet.org](http://www.agidnet.org).

### Customer Satisfaction Surveys

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LTCOP customer satisfaction surveys are administered in several states throughout the country and may serve as useful guides for developing measures for consumer-related outcomes. One such example is the LTCOP Customer Satisfaction Survey administered by the Program Integrity Section of the Georgia Division of Aging Services. For this survey, representatives call or visit residents who have consented to be interviewed and ask them a series of questions about their encounter with the LTCOP and their perception of the assistance provided. The table below identifies several questions in the Customer

Satisfaction Survey that relate to consumer-level outcomes of interest in the proposed LTCOP evaluation design.

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Georgia Office of the State Long-Term Care Ombudsman Consumer Satisfaction Survey

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Outcome	Survey Question
Consumer satisfaction with LTCOP	<ul style="list-style-type: none"> <li>• How satisfied were you with the length of time the process took to finish working on your concerns?</li> <li>• How well did the LTCOP involve you in the plan to work on your concerns?</li> <li>• In general, how satisfied were you with the individual ombudsman who assisted you with this particular case?</li> <li>• How helpful was the LTCOP to you?</li> <li>• Would you use the services of the LTCOP again if the need arises or recommend this program to a friend?</li> <li>• Was there anything else the LTCOP could have done to assist you with the problem you reported?</li> <li>• How could we make the LTCOP service better?</li> </ul>
Awareness of LTCOP	<ul style="list-style-type: none"> <li>• Was there an LTCOP poster displayed in a visible and prominent location?</li> </ul>
Consumer access to services	<ul style="list-style-type: none"> <li>• How did you hear about the LTCOP?</li> <li>• Did you initiate contact with the LTCOP?                             <ul style="list-style-type: none"> <li>- If, yes, what method was used?</li> <li>- If yes, how easy was it to contact the LTCOP?</li> <li>- If yes, how soon did the LTCOP respond to your contact?</li> </ul> </li> </ul>

Source: Georgia Department of Human Services, SFY 2012 Long-Term Care Ombudsman Customer Satisfaction Survey for SFY2011 Services.

While survey questions on consumer perception of LTCOP services will likely differ in other states, these existing customer satisfaction surveys are useful for informing new data collection efforts. Questions can be developed and standardized across states for consistency and comparison purposes and programs’ experience with various methods for survey administration to residents or family members can also be taken into account. Copies of customer satisfaction surveys are available through states as well as the National Ombudsman Resource Center (see entry below).

### Long-Term Services and Supports (LTSS) Scorecard<sup>38</sup>

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AARP, The Commonwealth Fund, and the SCAN Foundation have developed measures to assess state long-term services and supports (LTSS) system performance by compiling data from a variety of sources, including the Centers for Medicare and Medicaid Services (CMS), the U.S. Census Bureau, and AARP. The Scorecard provides data on all states for 25 indicators grouped along four dimensions: (1) affordability and access; (2) choice of setting and provider; (3) quality of life and quality of care; and (4)

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<sup>38</sup> Reinhard SC, Kassner E, Houser A, & Mollica R. September 2011. Raising Expectations: A State Scorecard on Long-Term Services and Supports for Older Adults, People with Physical Disabilities, and Family Caregivers. AARP, The Commonwealth Fund, and the SCAN Foundation.

support for family caregivers. The Scorecard ranks states from highest to lowest performance on each of these indicators. Of these indicators, the dimension on quality of life and quality of care may be particularly relevant for the purposes of the LTCOP evaluation. The table below lists each of the dimensions and their associated indicators.

Dimension and Indicator	Year
<b>Affordability and Access</b>	
Median annual nursing home private pay cost as a percentage of median household income age 65+	2010
Median annual home care private pay cost as a percentage of median household income age 65+	2010
Private long-term care insurance policies in effect per 1,000 population age 40+	2009
Percent of adults age 21+ with ADL disability at or below 250% of poverty receiving Medicaid or other government assistance health insurance	2008-09
Medicaid LTSS participant years per 100 adults age 21+ with ADL disability in nursing homes or at/below 250% poverty in the community	2007
ADRC/Single Entry Point functionality (composite indicator, scale 0–12)	2010
<b>Choice of Setting and Provider</b>	
Percent of Medicaid and state-funded LTSS spending going to HCBS for older people and adults with physical disabilities	2009
Percent of new Medicaid LTSS users first receiving services in the community	2007
Number of people consumer-directing services per 1,000 adults age 18+ with disabilities	2010
Tools and programs to facilitate consumer choice (composite indicator, scale 0–4)	2010
Home health and personal care aides per 1,000 population age 65+	2009
Assisted living and residential care units per 1,000 population age 65+	2010
Percent of nursing home residents with low care needs	2007
<b>Quality of Life and Quality of Care</b>	
Percent of adults age 18+ with disabilities in the community usually or always getting needed support	2009
Percent of adults age 18+ with disabilities in the community satisfied or very satisfied with life	2009
Rate of employment for adults with ADL disability ages 18–64 relative to rate of employment for adults without ADL disability ages 18–64	2008-09
Percent of high-risk nursing home residents with pressure sores	2008
Percent of long-stay nursing home residents who were physically restrained	2008
Nursing home staffing turnover: ratio of employee terminations to the average number of active employees	2008
Percent of long-stay nursing home residents with a hospital admission	2008
Percent of home health episodes of care in which interventions to prevent pressure sores were included in the plan of care for at-risk patients	2010
Percent of home health patients with a hospital admission	2008
<b>Support for Family Caregivers</b>	
Percent of caregivers usually or always getting needed support	2009
Legal and system supports for caregivers (composite indicator, scale 0–12)	2008-10
Number of health maintenance tasks able to be delegated to LTSS workers (out of 16 tasks)	2011

For the LTCOP evaluation, the Scorecard data identifies the highest need areas in each state. Low scores on certain indicators may represent areas that pose particular challenges to LTCOPs in those states and

may help account for factors affecting LTCOP performance. Because the data on these measures come from several different data collection efforts, moreover, an exploration of these sources may lead to other potentially useful information on LTSS in each state.

### Minimum Data Set (MDS)

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The Minimum Data Set (MDS) is a standardized, primary screening and clinical assessment of health status of all residents in Medicare or Medicaid certified nursing homes, regardless of the individual resident's source of payment. MDS is part of the Resident Assessment Instrument (RAI), a federally mandated process designed to comprehensively assess each resident's functional capacity and to guide care planning in nursing homes. MDS 3.0 includes residents in the assessment process and contains measures for the following domains: physical, clinical, psychological, psycho-social functioning, and life care wishes. As a condition of participation in the Medicare and Medicaid programs, long-term care facilities are required to complete and electronically transmit MDS information to a designated state agency. This information is subsequently captured into the national MDS database which is maintained by CMS.

Information on resident characteristics is important for the LTCOP evaluation, but given that CASPER/QIES also contains this information (in addition to facility characteristics), we focus our attention on CASPER/QIES as a potential data source in this review.

### National Ombudsman Resource Center (NORC)

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The National Long-Term Care Ombudsman Resource Center (NORC) provides support, technical assistance, and training to state and local programs. NORC is a rich source of material on the LTCOP's history, operations, program and volunteer management, best practices, accomplishments, advocacy efforts, training materials, customer satisfaction surveys, summaries of annual meetings, and general resources for ombudsmen. The range of information NORC provides on ombudsman activities is extensive and particularly helpful for the process evaluation of the LTCOP. The web address for NORC is [www.ltcombudsman.org](http://www.ltcombudsman.org). For relevant information not found on the website, Lori Smetanka, Director, and Sara Hunt, Consultant, are the key contacts.

### National Ombudsman Reporting System (NORS)

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The National Ombudsman Reporting System (NORS) is the administrative reporting system for the LTCOP. Collected since 1996, NORS provides national and state-specific summaries of programmatic efforts, including facility visits, complaint investigations, consultations, staffing, resident and family



councils, community outreach and education, and systems advocacy, among others. States report aggregated data annually to the AoA, which is then summarized into NORS. The reporting contains information on not only nursing homes but any type of unregulated and regulated long-term care setting, including nursing facilities, board and care, assisted living, residential care and other settings. Data from NORS 2000-2010 may be accessed through AGID (discussed above). Each state is also asked to submit a narrative section which describes systems advocacy work during the reporting period and identifies priorities in long-term care issues and barriers and efforts to address their resolution. These qualitative data are not included in NORS but can be accessed through the Ombudsman Program Specialist, Louise Ryan, at the AoA.

### **Nursing Home Enforcement Data – Certification and Survey Provider Enhanced Reporting system and the Quality Improvement Evaluation System (CASPER/QIES)**

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Formerly the Online Survey Certification and Reporting (OSCAR) file, the Certification and Survey Provider Enhanced Reporting (CASPER) system and the Quality Improvement Evaluation System (QIES) replaced the CMS's OSCAR administrative database in July 2012. Maintained by CMS in cooperation with state survey agencies, CASPER/QIES includes detailed information on all institutional health care providers certified to provide services under either Medicare and/or Medicaid and represents the most comprehensive source of information on facilities, patient characteristics and regulatory compliance of nursing homes.

CASPER/QIES is potentially of great value for the LTCOP evaluation because the nursing home data it contains can provide contextual information on the facilities and their residents. The data, however, are limited to residential settings that participate in the Medicare and Medicaid programs; CASPER/QIES does not have data on assisted living facilities or other types of long-term care facilities not certified by Medicare or Medicaid. States may collect data on the facilities they regulate, but the form and quality of these data vary by state. Among the evaluation activities that NORC is proposing, these data may be used as part of the analysis of NORS, state certifications and CASPER/QIES data on nursing home complaints comparing LTCOP and non-LTCOP users as well as the ecological study on systems advocacy. However, it should be noted that some data cleaning of duplicate reporting is required, because the same cases may be reported to both the LTCOP and to state surveyors.

**Data details.** CASPER contains data that facilities submit by completing two forms, Form CMS-671 and Form CMS-672. Form 671 contains information about the facility such as ownership and staffing. Form 672 contains information on the residents in the facility, such as mobility and mental status. CASPER

also contains data on deficiencies identified at these facilities during the standard survey. This data can be linked to the complaint survey database with the facility identifier.

**Obtaining the data.** While CASPER/QIES data can be obtained directly from CMS, any new data collected overwrites the previous data. Because Form 671 data on facility characteristics overwrites the previous year's data, CMS would only have one year of data available, while the Form 672 data on resident characteristics overwrites the fourth oldest record. Cowles Research Group (CRG), an independent research company specializing in customizing information extracted from government health databases, archives CASPER/QIES data in order to make historical data available. To purchase the four most recent years of data for the whole country, the cost would be approximately \$2,200.<sup>39</sup> The complaint survey database costs \$750 if purchased with the CASPER/QIES data. The lag time for obtaining state-specific data varies and may be as little as a month. To obtain data on all states, the lag time is 9 months (which allows for some late data submitters). CRG receives monthly CASPER reports and archives and cleans the data and formats it according to the specifications of the software being used for the analysis.<sup>40</sup>

The following is the main contact information for CRG:

Mick Cowles  
Cowles Research Group  
[www.LongTermCareInfo.com](http://www.LongTermCareInfo.com)  
(202) 903-2403 voice  
(509) 984-2403 fax

## Nursing Home Inspect

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Developed by investigative journalism newsroom ProPublica, Nursing Home Inspect is a consumer-targeted, online tool that allows users to search government nursing home inspection reports and deficiencies. The Nursing Home Inspect database uses data from surveyor reports published on CMS's Nursing Home Compare website and currently covers over 118,000 deficiencies at 14,565 homes (there are over 15,000 nursing homes in the U.S. and ProPublica will add new inspection reports in the future as CMS releases them). Unlike the CMS site, however, Nursing Home Inspect enables users to search by keyword, city, and facility name and sort results by state or severity level. In addition, searches can be performed across all reports simultaneously.

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<sup>39</sup> The Troyer and Sause (2011) study upon which this evaluation activity is based, compared complaint handling over a four year period by two different agencies – the LTCOP and the North Carolina Division of Health Service Regulation (the state certification agency), drawing on complaint data from NORS and state certifications and facility measures from (then) OSCAR.

<sup>40</sup> This source of this information is Cowles Research Group (<http://www.longtermcareinfo.com/index.html>) and will be confirmed with CMS. At present, however, there is no information about how to access this data through CMS' website.

The ProPublica project relies on narrative reports of surveyors' most recent periodic review (known as standard surveys) where nursing home conditions and deficiencies are described as well as complaint investigations from the past 12 months. The majority of deficiencies in Nursing Home Inspect are from the beginning of 2011 and beyond, while approximately 2,700 are from 2009 and 2010. These narrative data are not available through CRG (see above) although CASPER/QIES data do include the specific deficiency (tag number) cited and its scope and severity level.

It should be cautioned that Nursing Home Inspect results are a snapshot and not necessarily comprehensive of nursing homes nationwide. Any new deficiencies identified by CMS during follow-up visits after a standard survey is completed are not currently included in the narratives that are posted online. Additionally, inspection reports focus only on a facility's problems, and do not highlight the improvements that nursing homes have made.

The web address for Nursing Home Inspect is [projects.propublica.org/nursing-homes](https://projects.propublica.org/nursing-homes).

## Program Records

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State program records are an essential source of data for understanding the structure and operations of the LTCOP. Of particular interest for the LTCOP evaluation is the availability of information in the following areas: characteristics of paid and volunteer staff (including demographics, skills, qualifications, and tenure), training and management of staff, cost data, funding sources, and organizational placement at the state and local levels. In addition, information regarding specific data systems is critical for understanding the availability and accessibility of data. For example, states using OmbudsManager may be in a position to provide detailed information on programmatic activities (e.g., response and resolution times for various types of complaint investigations, service delivery broken out by paid and volunteer ombudsman) than those without a similar system. Given the diversity in data collection systems and access to budgets across programs, however, the ability of state programs to provide certain data (program activities, costs, staffing, surveys, etc.) should be confirmed by direct conversation with individual ombudsmen.

## Appendix I: Data Collection Tools & Sources Chart

Outcome	Data collection target	Qualitative, numeric, or categorical?	Data element to measure outcome	Existing data source?	New data collection method?
<b>Consumer-level Outcomes</b>					
Awareness of resident rights, LTCOP, & LTCOP advocacy	Resident/family	Qualitative; categorical	Questions related to awareness (e.g., Do you know what services the LTCOP provides?; Are you aware of your rights as a resident? Can you summarize residents' rights?)		Surveys, focus groups
Consumer access to services (complaint handling, consultations, etc.)	Resident/family	Qualitative; categorical	Questions related to perception of ease and manner of accessing ombudsmen, timeliness of response; Questions about the posting of information about residents rights and/or poster about the LTCOP; Has anyone discussed your rights with you or do you know where to find that information?		Surveys, focus groups, cohort study
	Ombudsmen	Numeric	Frequency of facility visit	NORS	
Complaint resolution rate/proportion	Ombudsmen (collecting data on complaint)	Numeric; qualitative; categorical	Rate calculation includes cases opened, cases resolved, time to resolve, complexity of case; Do you believe the ombudsman resolved your complaints to the best of his/her ability? Did the ombudsman do everything he/she could to resolve your complaints?		Cohort study
		Numeric	Complaints resolved to the satisfaction of resident or complainant; complaints verified	NORS	
		Numeric	Complaints substantiated	CASPER/QIES	
Support for development and maintenance of resident/family councils	Resident/family	Qualitative; numeric	Questions about whether LTCOP provides adequate technical assistance and promotes participation in councils as well as alternative forms of resident councils (fireside chats, etc.)		Surveys, focus groups

Outcome	Data collection target	Qualitative, numeric, or categorical?	Data element to measure outcome	Existing data source?	New data collection method?
Consumer satisfaction with LTCOP	Resident/family	Qualitative; categorical	Questions about satisfaction with consumer problem solving, consultations, and education services, participant satisfaction with staff ability to listen, to understand and to address issues apart from the outcome itself	Customer Satisfaction Surveys	Surveys, focus groups
	Ombudsmen (collecting data on behalf of complainant)	Numeric	Complaints resolved to the satisfaction of resident or complainant	NORS	Cohort study
Efficiency of services	Ombudsmen (collecting data on complaint)	Numeric	Response time to complaints; resolution time of complaints	NORS	Cohort study
	Ombudsmen	Numeric	Cost per service; questions about medical services utilization that resulted from abuse or other complaints; cost-benefit ratios	Program cost data	
Consumer confidence raising issues	Resident/family	Qualitative; categorical	Questions about consumer confidence in raising issues to LTCOP		Surveys, focus groups
Prevention of problems	Resident/family	Qualitative; categorical	Questions about the extent to which consumers feel the presence of the ombudsman program keeps residents safe and protects their rights		Surveys, focus groups
	Former residents of nursing homes				Focus groups
<b>Facility Level Outcomes</b>					
Provider knowledge of consumer rights, LTCOP	Facility	Qualitative; categorical	Questions about ability to summarize residents' rights, understanding of the LTCOP's role, types of services it provides, identification of their ombudsmen, and residents' ability to reach the LTCO		Surveys
Prevention of problems	Ombudsmen	Numeric	Reduction in repeat complaints; reduction in the number of facilities that have multiple complaints in the same complaint category	NORS, CASPER/QIES	
	Facility	Qualitative	Question about awareness of and prevention of problems due to LTCO intervention; Questions about the inclusion of any education/training provided to facility staff by the LTCOP where there have been repeat complaints and/or facility staff request for training in areas of complaints; Questions about the ability of the LTCOP to keep problems from escalating into a bigger issue		Surveys

Outcome	Data collection target	Qualitative, numeric, or categorical?	Data element to measure outcome	Existing data source?	New data collection method?
Perception of ombudsmen professionalism and helpfulness to residents and facility	Facility	Qualitative	Questions include: Does the ombudsman conduct him/herself in a professional manner?; Has the LTCOP been helpful to residents in your facility?; To your facility?; Does the ombudsman consistently conduct himself/herself in a manner that represents the interests of the residents even when that may be in conflict with the facility viewpoint?		Surveys
Consistency and efficiency of LTCOP services	Facility	Qualitative	Questions include (and identifying whether the ombudsman assigned is a volunteer or a paid staff person): Has your facility had more than one ombudsman assigned during the past year?; If so, were there any differences between the effectiveness of these ombudsmen?		Surveys
	Ombudsmen	Numeric	Turnover rates among state ombudsmen	Program data	
Ombudsmen provision of information and resources to support person-centered care provided by staff	Facility	Qualitative	Questions about providing information on "person-centered care" to facilities or the effect of the ombudsmen on person-centered care		Surveys
Management and allocation of LTCOP resources	Facility	Qualitative	Questions include: Does the ombudsman assigned to your facility seem to be adequately trained and supervised?; Does the ombudsman visit the facility often enough to be familiar with residents?; Does the ombudsman come to facilities prepared?		Surveys
Coalition/stakeholder engagement	Facility	Qualitative; categorical	Questions include: If residents of your facility have problems that require help from organizations outside the facility, is the ombudsman able to effectively identify and engage those organizations?; Does the ombudsman encourage the facility to identify and engage outside resources?; Does the LTCO encourage facility participation in initiatives, such as Advancing Excellence, Culture Change Coalitions, or other nursing home or board and care initiatives?		Surveys

Outcome	Data collection target	Qualitative, numeric, or categorical?	Data element to measure outcome	Existing data source?	New data collection method?
<b>Local/State/Program-level Outcomes</b>					
Stakeholder knowledge of consumer rights, LTCOP and understanding of program among advocates, partner agencies, legislators and policy makers	Advocates, partner agencies, legislators, policy makers	Qualitative; categorical	Questions include: Do legislators and policymakers consult with the LTCOP as they draft legislation/policy affecting residents or adult care facilities?; Is the ombudsman program effective in addressing residents' rights, care and protection?; What might make it more effective?		Surveys, interviews
LTCOP staff competencies	Ombudsmen	Qualitative; categorical	Questions related to staff's perception of their knowledge, understanding of their role, desire for additional training, value of existing training, receipt of adequate training and supervision, and whether certain job responsibilities are difficult to meet on a routine basis		Surveys, interviews
Stakeholder collaboration	Partner agencies; advocates; legislators, policy makers	Qualitative; categorical	How does the LTCOP collaborate with critical partners?	State Plans	Surveys, interviews
	Ombudsmen	Qualitative	What workgroups, task forces, agencies, and/or organizations do you participate with in your advocacy efforts?; What policy, legislative, or administrative advocacy has the LTCOP participated in? What were the outcomes of that work? How did the LTCOP contribute to those positive outcomes or prevent policies that would have been problematic for residents?		Surveys, interviews

Outcome	Data collection target	Qualitative, numeric, or categorical?	Data element to measure outcome	Existing data source?	New data collection method?
Management and allocation of LTCOP resources	Ombudsmen	Qualitative	Questions related to budgeting challenges and staffing issues (e.g., approach to volunteer outreach and adequate staff training and supervision)		Surveys, interviews
		Numeric	Average program cost per staff ombudsman; average cost per certified ombudsman (staff or volunteer); average number of complaints/consultations per staff ombudsman; average number of complaints/consultations per certified ombudsman; average number of resolved complaints per staff ombudsman; average number of resolved complaints per certified ombudsman; program budgets relative to number of facilities/agencies (e.g., home health) under LTCOP purview; time spent per facility, per resident, dividing up FTEs by residents and facilities. In looking at dollars, questions about the full dimension of the program including systemic advocacy, training, home care complaints, etc.	Program cost data	Cohort study
<b>Federal-Level Outcomes</b>					
Federal stakeholder knowledge of consumer rights, LTCOP, among advocates, partner agencies, legislators, and policy makers	Federal legislators; national stakeholder organizations	Qualitative; categorical			Interviews
LTCOP staff competencies	ACL	All			Interviews
ACL monitoring and feedback to State program	ACL	Qualitative; numeric			Interviews
	State ombudsmen	Qualitative; numeric	Do you receive feedback in response to data that are submitted?		Interviews
Level of other Federal funds	ACL	Numeric	Percentage of program funding from sources other than the ACL	Program revenue data	
Federal stakeholder coordination/collaboration	Federal legislators; national stakeholder organizations	Qualitative; categorical			Interviews
	ACL	Qualitative; categorical			Interviews
Management and allocation of LTCOP resources	ACL	Numeric		Program cost data	