Chapter 1

Equipping California Long-Term Care Ombudsman Representatives for Effective Advocacy: A Basic Curriculum

HISTORY AND ROLE OF THE LONG-TERM CARE OMBUDSMAN PROGRAM

Curriculum Resource Material for
Local Long-Term Care Ombudsman Programs

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I. INTRODUCTION

This chapter discusses the history, development, and unique aspects of the national Long-Term Care Ombudsman Program (LTCOP) and the California program. The program's rich history has guided its implementation on the national level and within each state. To fully understand the program and to be effective as a long-term care ombudsman representative (LTCO), knowledge of the program's history, legal basis, and development is essential. Topics covered in the sub-sections of this chapter are: how the LTCOP began, the LTCOP under the Older Americans Act (OAA), unique aspects of the LTCOP, the California LTCOP, accountability, LTCOP associations, the National Long-Term Care Ombudsman Resource Center, why LTCO staff and volunteers stay with the program, and a summary of the program's role and continuing challenges.

Long-Term Care Ombudsmen[1]

Briefly defined, a LTCO is an advocate for residents[2] of nursing homes and residential care facilities for the elderly. Ombudsman representatives are trained to resolve problems. They provide information about how to select a facility and what to do to get quality care. They also represent the perspective of residents in monitoring laws, regulations, and policies.

Extent of the Long-Term Care Ombudsman Program

Federal law requires each state to have an Office of the State LTCO headed by a State Long-Term Care Ombudsman (SLTCO). In many states, residents are served by a combination of paid staff and of volunteer ombudsman representatives. There were more than 1,270 paid program staff, 9,180 certified volunteers, and 4,630 other ombudsman volunteers in 2005.[3]

Ombudsman Activities	**Nationwide Data 2005**
☞ Provide information to individuals	342,207 contacts
☞ Investigate complaints	306,867 by 187,603 individual complainants
☞ Work with resident councils	25,260 events
☞ Conduct training for:	# of sessions
☞ Ombudsman staff and volunteers	11,903
☞ Facility staff	9,083
☞ The local community	13,126

[1] Some sections of this chapter refer to long-term care ombudsmen in reference to the language in the federal law and as used by the National Long-Term Care Ombudsman Resource Center. In California, long-term care ombudsmen are called long-term care ombudsman representatives.
[2] Although *resident* is used throughout this document, LTCO also work with the families of residents as well as with families and individuals who are seeking information about long-term care facilities.
[3] National Ombudsman Reporting System Data, Fiscal Year 2005, Administration on Aging.

II. HOW THE LONG-TERM CARE OMBUDSMAN PROGRAM BEGAN[4]

Precipitating Events

The advent of Medicare and Medicaid in 1965 laid the groundwork for the nursing home "industry" as we know it today. These programs brought about tremendous growth in the number of nursing homes in the United States. Before that, there was no public money to provide an incentive for private owners to build facilities.

In the late 1960s and early 1970s, many publications were written about abuse, neglect and substandard conditions in nursing homes. Several congressional committees convened to hear testimonies, compile data and propose reforms for the nursing home industry.

One notable report, *Old Age:* *The Last Segregation,* issued by consumer advocate Ralph Nader in 1970 was a catalyst for public action.[5] Gerontologist Robert Butler illustrates this neglect with the following two items:

- Hearings before the United States Senate on February 26, 1970 brought out the fact that the carpeting in a Marietta, Ohio, nursing home spread the flames in a January fire that resulted in the deaths of 32 of 46 patients from asphyxiation from the acrid smoke. Other stories of poor care resulting in the death of residents continue to make headlines.
- Twenty-five residents in a Baltimore nursing home died in a salmonella food poisoning epidemic in August 1970, after delays in seeking medical help. After 12 residents died, the Washington Post stated, "...in a telephone interview, Gould [the owner] complained about the focus of the news media on the 12 deaths over the weekend, saying is it really that big?"[6]

Ample publicity attesting to poor care and personal profit for owners created a climate in which more specific federal regulations for standards of care were enacted in the early 1970s.

[4] Unless otherwise indicated this section is adapted from the Arkansas LTCOP Annual Report, 1996-1997, prepared by Raymon Harvey, State LTCO; the Georgia LTCO Training Manual, Chapter A.I. History of the LTCOP, developed by Leigh Ann Clark, 1998, and the Virginia LTCO Training Curriculum.

[5] Statement by Elma Holder, Founder, National Citizens' Coalition for Nursing Home Reform, in a presentation, "Tapping and Nurturing Grassroots Support," for State Long-Term Care Ombudsman Representatives, Rhode Island, April 2000.

[6] Butler, R.N. *Why Survive? Being Old in America.* NY: Harper & Row, 1975.

Presidential Directive Includes Ombudsman

President Nixon formulated an eight-point nursing home program, announced in 1971. The eight points were:

1. Training of 2,000 state nursing-home inspectors;
2. Complete (100 percent) federal support of state inspections under Medicaid;
3. Consolidation of enforcement activities;
4. Strengthening of federal enforcement of standards;
5. Short-term training for 41,000 professional and paraprofessional nursing home personnel;
6. Assistance for state investigative "Ombudsman" units;
7. Comprehensive review of long-term care; and
8. Crackdown on substandard nursing homes: cut-off of federal funds to them.

As a result of a 1971 directive by President Nixon, the Department of Health, Education and Welfare (HEW, now the Department of Health and Human Services) established a new office, the Office of Nursing Home Affairs (ONHA, without current equivalent) to oversee all HEW programs relating to nursing homes. ONHA was to be responsible for coordinating efforts by different agencies in the department to upgrade standards nationwide for the benefit of nursing home residents. Establishment of ONHA and the appointment of Mrs. Marie Callender as its head presumably meant that for the first time a single official was responsible for pulling together different HEW nursing home efforts into a single coordinated program. Two hundred twenty-seven new personnel were added to federal enforcement.

The idea for the ombudsman program was developed by Dr. Arthur S. Flemming, Counselor on Aging to President Nixon. He envisioned the program as an *advocacy* program for residents and personally wrote the first guidelines for it.[7] In summary, the rapid growth of nursing homes and a concern for the quality of care and quality of life experienced by the residents of these facilities were in part responsible for the creation of the LTCOPs that exist today.

[7] Holder, op.cit.

The Genesis of the Long-Term Care Ombudsman

The Long-Term Care Ombudsman Program was initiated to improve the quality of care in America's nursing homes and to respond to complaints submitted to the White House and to HEW about abuse and neglect of nursing home residents. President Nixon directed HEW "to assist the States in establishing investigative units which would respond in a responsible and constructive way to complaints made by or on behalf of individual nursing home patients."

An interdepartmental task force was formed under the direction of the Health Services and Mental Health Administration to develop models for investigative/ombudsman units. In the Supplemental Appropriations Act of December 1971, Congress made funds available for the establishment of nursing home ombudsman demonstration projects. On June 30, 1972, five contracts were awarded. Four were with state governments to establish a state level office linked to a local unit: Idaho, Pennsylvania, South Carolina, and Wisconsin. A fifth contract was awarded to the National Council of Senior Citizens to test the effectiveness of an independent nursing home ombudsman project operating outside government jurisdiction and to assess the feasibility of linking of a national voluntary organization to state and local units. The National Council selected Michigan's Citizens for Better Care, a citizen advocacy group, as the site of their demonstration. Additional projects were started in Massachusetts and Oregon in July of 1973, increasing the total number to seven projects.

In 1973 the Health Services and Mental Health Administration was reorganized, and the Nursing Home Ombudsman Program was transferred to the Administration on Aging (AoA). Assignment of the program to AoA was consonant with the Commissioner on Aging's responsibility for serving as an advocate for older persons.

In May of 1975, Commissioner on Aging Arthur S. Flemming invited all State Agencies on Aging to submit proposals for grants *to enable the State Agencies to develop the capabilities of the Area Agencies on Aging to promote, coordinate, monitor and assess nursing home ombudsman activities within their service areas* (AoA-PI-75-30). The primary goal of the program was to inaugurate, in as many areas as possible, community action programs dedicated to identifying and dealing with the complaints of older persons, or their relatives, regarding the operation of nursing homes.

One year grants ranging from $18,000 in most states to $57,900 in the state with the largest elderly population (New York) were made to the State Agencies on Aging which submitted proposals designed to meet this goal. All states except Nebraska and Oklahoma received grants the first year and hired a Nursing Home Ombudsman Developmental Specialist, who frequently worked out of the State Office on Aging.

Formative Intent and Structure

In a technical assistance memorandum dated January 13, 1976, the Administration on Aging recommended approaches to State and Area Agencies on how to develop the State and sub-state programs. This memorandum stated, "The success of this effort in the first year will be judged solely on the basis of the number of community action programs [community-based ombudsman programs] that are launched and the effectiveness of these programs in receiving complaints and then resolving them in an effective and constructive manner." (AoA-TAM-76-24.)

> *"Our nation has been conducting investigations, passing new laws and issuing new regulations relative to nursing homes at a rapid rate during the past few years. All of this activity will be of little avail unless our communities are organized in such a manner that new laws and new regulations are utilized to deal with the individual complaints of older persons who are living in nursing homes. The individual in the nursing home is powerless. If the laws and regulations are not being applied to her or to him, they might just as well not have been passed or issued."*
>
> Commissioner Flemming (AoA-TAM- 76-24.)

From 1975 through 1978 the LTCOP was a departure from the demonstration program in two particularly significant ways.

1. Where the demonstration program focused on complaint resolution from one to three central points in a state, the 1975-78 program stressed development of local/area programs throughout the state.

2. Where the director of the demonstration project had been called an ombudsman and had worked directly on complaints, the individuals hired under the 1975-78 grants were designated "ombudsman developmental specialists," and were charged by AoA with developing sub-state programs, rather than working directly on complaints.

In addition, the early nationwide program stressed reliance on volunteer, rather than paid, ombudsman representatives.

AoA believed that locally-based complaint resolution and resident advocacy programs would provide the most effective services.

These changes in approach were made because the Administration on Aging believed that locally-based complaint resolution and resident advocacy programs would provide the most effective services to those who needed them. The demonstrations had indicated that a small staff operating an ombudsman program out of one central location in a state would have great difficulty in responding to the volume and variety of needs of individuals throughout the state. Given the limited funding available, the

"developmental" approach was seen as the only means by which the goal of statewide ombudsman coverage could be attained. This approach was to have a significant impact on the direction of the program after passage of the ombudsman legislative mandate in 1978.

During this same time period, 1975 – 1978, there was simultaneous development in the citizen advocacy network. The National Citizens' Coalition for Nursing Home Reform[8] (NCCNHR) was established in 1975 as an outgrowth of Elma Holder's work with Ralph Nader and with the National Gray Panthers.

In 1977 AoA funded the National Paralegal Institute to provide the first training program for state ombudsmen, who were called "ombudsman developmental specialists." This training was developed and conducted by Elma Holder, employed by the National Paralegal Institute, with assistance and guidance from the NCCNHR Board comprised of citizen advocacy organizations. Thus, the growth and development of national networks of citizen advocates and of LTCO were simultaneous, spurred on by conditions in nursing homes.[9]

III. THE LTCOP UNDER THE OLDER AMERICANS ACT[10]

Salient Provisions and Expanding Responsibilities

The 1978 Amendments to the Older Americans Act (OAA) elevated the Nursing Home Ombudsman Program to a statutory level. The statute and subsequent amendments *required* all state agencies on aging to establish an ombudsman program that would carry out the following activities:

- Investigate and resolve long-term care facility residents' complaints;
- Promote the development of citizens' organizations and train volunteers;
- Identify significant problems by establishing a statewide reporting system for complaints, and work to resolve these problems by bringing them to the attention of appropriate public agencies;
- Monitor the development and implementation of federal, state, and local long-term care laws and policies;
- Gain access to long-term care facilities and to residents' records; and
- Protect the confidentiality of residents' records, complainants' identities, and ombudsman files.

These statutory provisions set the framework for development of state programs that encompassed both the sub-state (regional) program focus of the early nationwide program and the complaint investigation focus of the demonstration projects. Thus, states were able to build on their early ombudsman initiatives as they began implementing the legislative requirements. Many states developed

[8] In 2007, the National Citizens' Coalition for Nursing Home Reform changed its name to, NCCNHR: The National Consumer Voice for Quality Long-Term Care.
[9] *The Long-Term Care Ombudsman Program, 1972-2003, Program Milestones*. AoA, included in the Appendix and Holder, E. op.cit.
[10] Adapted from the Arkansas LTCOP Annual Report, op.cit.

and worked for enactment of state ombudsman legislation. Such legislation was necessary to comply with some specific requirements in the Act such as providing for access to facilities and to residents' records and providing for appropriate sanctions for interference, retaliation, and reprisals associated with LTCO services.

The 1981 reauthorization of the OAA resulted in a further expansion of ombudsman duties. In addition to nursing homes, board and care homes, known in California as Residential Care Facilities for the Elderly (RCFE), were included in the ombudsman responsibilities. The name was changed from Nursing Home Ombudsman to Long-Term Care Ombudsman (LTCO) to reflect this change. Other duties remained substantially the same.

The 1987 Amendments to the OAA made substantive changes related to the Long-Term Care Ombudsman Program resulting in a significant improvement in the program's ability to advocate on behalf of residents of LTC facilities. The changes required states to provide for:

- Ombudsman access to residents and residents' records;
- Ombudsman immunity to for the good faith performance of their duties; and
- Prohibition of willful interference with the official duties of an ombudsman and/or retaliation against an ombudsman, resident, or other individual for assisting the ombudsman program in the performance of their duties.

Subsequent amendments to the OAA have added specificity to the responsibilities of the LTCOP. A timeline depicting milestones in the growth and development of the LTCOP is in the Appendix. It provides a summary of the narrative in Sections II and III of this chapter.

Summary of Responsibilities, Structure, and Approach

The preceding bulleted list shows the steadily expanding responsibilities of the LTCOP. It also shows the addition of specific provisions that direct the way the program is structured and approaches its work. Each ombudsman should study the text of the OAA for a complete understanding of this program that is uniquely positioned to resolve resident complaints and to represent resident interests.
Another way of viewing the federal scope of the LTCOP is to think of it in terms of program responsibilities, program structure, and approach to ombudsman work as conceptualized in the following lists.

Responsibilities

Prevention

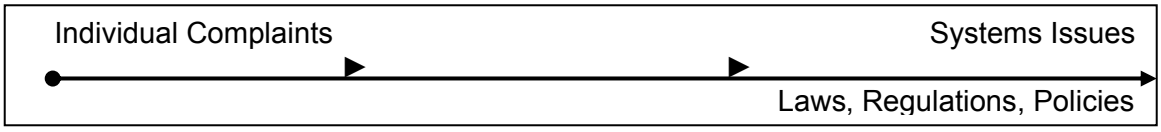
- Provide information to residents
- Promote the development of citizen organizations to participate in the LTCOP
- Provide technical support for the development of resident and family councils

- Recommend changes in laws, regulations, and policies pertinent to the health, safety, welfare, and rights of residents

Intervention

- Provide residents with regular and timely access to LTCOP services
- Assist residents in asserting their rights and expressing their grievance on issues pertaining to their health, safety, welfare and rights within the long-term care facility
- Identify, investigate, and resolve complaints made by, or on behalf of, residents
- Seek administrative, legal, and other remedies to protect the health, safety, welfare and rights of residents
- Analyze, comment on, and monitor the development and implementation of federal, state, and local laws, regulations, and other governmental policies and actions, on behalf of residents
- Facilitate public comment on laws, regulations, policies, and actions pertinent to residents
- Prepare an annual report describing the problems of residents and containing recommendations for improving their quality of care and quality of life. This report is submitted to the Assistant Secretary of AoA, the Governor, State Legislators, and others. It is also to be made available to the public.

The OAA connects the individual advocacy services ombudsman representatives provide with the program's responsibility to publicly represent the needs of residents and work to effect change in laws, regulations, and policies. In essence, the individual complaint cases provide the basis for changing systems. The federal mandate that the LTCOP has in the OAA is broad.[11]



In the words of some local LTCO,

> "We work individually, in groups and systemically to promote and protect the rights of residents before, during and after their placement in a long term care facility. The ombudsman advocacy is like making a snow cone on an iceberg with an ice pick. One chip at a time."
>
> Debi Lee, Cindy Kincaid, Linda Miller, Local Long-Term Care Ombudsman Program, North Carolina

[11] For information refer to *Ombudsman Best Practices: Using Systems Advocacy to Improve Life for Residents*. Hunt, S. National LTCO Resource Center. June 2002, PO 752. www.ltcombudsman.org.

In addition to the LTCOP's responsibilities for advocating on behalf of residents, the OAA also prescribes *how* the program is to be structured and is to approach its work in specific areas. These requirements allow for some flexibility among states but there is a *bottom line* in key provisions. This *bottom line* forms a foundation of consistency for the nationwide program.

Structure of the LTCOP

- The Office of the SLTCO is headed by a full-time SLTCO.
- The SLTCO may designate local entities [programs] *and* individuals to carry out the delegated responsibilities of the OAA.
- Procedures for ombudsman access to facilities and residents must be established.
- Uniform program data must be maintained and submitted to AoA. An annual report must be submitted as specified.

Approach to Work

The OAA contains:

- guidance for access to resident records
- provisions regarding confidentiality of information identifying a resident
- prohibitions against individuals serving as representatives of the LTCOP until they have been trained and certified by the SLTCO
- requirements that the disclosure of LTCOP files and records is subject to approval by the SLTCO and certain types of disclosure are prohibited
- requirements for states to establish prohibitions and sanctions for willful interference with ombudsman duties
- prohibitions for conflicts of interest for the Office of the SLTCO, entities, and individuals participating in the LTCOP

Structure of the Current LTCOP

Today, the LTCOP operates in all 50 states, the District of Columbia, Puerto Rico, and Guam. No single model can accurately describe these multifaceted programs. Variation in organizational placement, program operation, funding, and utilization of human resources has given rise to distinct approaches to implementing the program.

One illustration of this variability is an analysis of the organizational placement of LTCOPs.[12] As shown in Chart 1, states have chosen a variety of organizations to be the "home" of the SLTCOP.[13] Changes in the placement of the SLTCOP typically occur as states face governmental reorganization or review ways to improve the program's ability to fulfill its responsibilities. Similarly, as illustrated

[12] The data is based on information from the Center for Wellness and Community-Based Services, Office of Consumer Choice and Protection, Administration on Aging, 2006.

[13] Federal funding for the LTCOP goes to each state agency (state unit on aging) which may directly operate the LTCOP or may contract with another agency or organization to operate the program.

in Chart 2, there are variations among states regarding the placement and structure of local LTCOPs.

Chart 1
State LTCOP Placement 2006

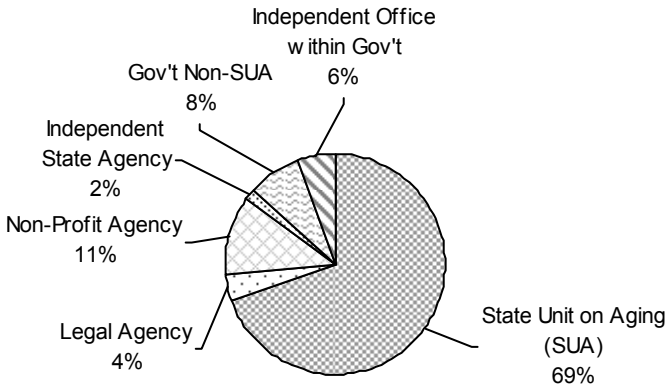
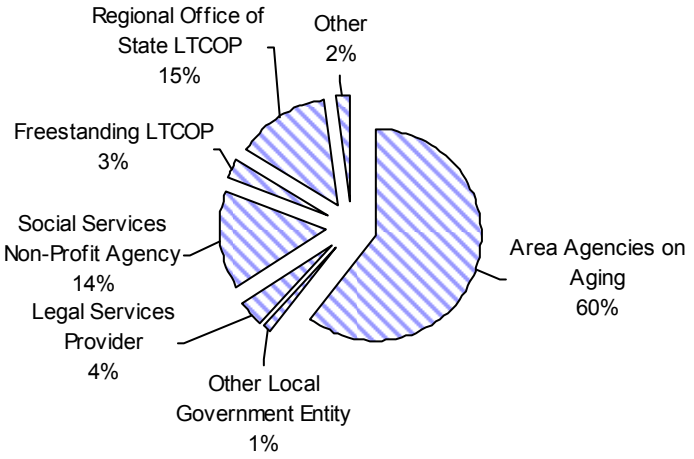


Chart 2
Local LTCOP Placement 2005



Another important variation among programs is their use of volunteers as local ombudsman representatives. The history of the LTCOP clearly cites the importance of volunteers in shaping this program. In order to make ombudsman services more accessible to residents, over three-fourths of the states use volunteers as LTCO in addition to paid ombudsman staff. The functions of

volunteers with the program differ among states according to state laws and policies. Despite variations in the role of volunteers (e.g., abuse investigations, witnessing Advance Health Care Directives), they, too, serve residents through the delegated functions of the SLTCO and as part of the statewide LTCOP.[14]

Even with these differences, many commonalities do exist among these various approaches. The strongest connection among programs is the common responsibilities delineated in the federal law and discussed in this sub-section on the OAA. Additional information regarding commonalities among all LTCOPs, regardless of placement, is discussed in Section V, "Unique Aspects of the LTCOP."

Before focusing on the unique aspects of the program, take a moment to learn about the history and development of the LTCOP in California as summarized in the following section.

[14] For more information on volunteer LTCO refer to, *Volunteers In Long-Term Care Ombudsman Programs: Training, Certification, and Insurance Coverage*. MacInnes, G. & Hedt, A., National Long-Term Care Ombudsman Resource Center. Dec. 1999. www.ltcombudsman.org

IV. THE CALIFORNIA LONG-TERM CARE OMBUDSMAN PROGRAM

History

In accordance with federal legislation, the California Long-Term Care Ombudsman Program (LTCOP) began in 1975 in the California Department of Aging (CDA). It was not until 1979 that the first significant legislation for the LTCOP was passed in California. AB 1433 (Welfare and Institutions Code beginning with Section 9700), gave statutory authority to the State Ombudsman to designate local LTCO and guarantee their right of access to residents of nursing homes and RCFEs. This legislation greatly strengthened the California LTCOP.

In January 1983, AB 2997 was passed, expanding the scope and authority of the Office of the State Long-Term Care Ombudsman (OSLTCO) and the local programs. In brief, the bill provided that:

- The Office may solicit and receive non-governmental funds provided they do not jeopardize the independence of the Program.
- Representatives of the Office shall not be held liable for LTCO activities when such activity is based on good faith performance of their official duties.
- All other State advocacy programs shall cooperate with the Office, where appropriate.
- The State Ombudsman shall approve and designate sub-state (local) programs.
- There shall be a close working relationship between the Office and the California Department of Aging Legal Services Office.
- The Program shall ensure that every long-term care facility shall post in a conspicuous location, a notice (poster) giving information and a telephone number for the nearest designated local LTCO.
- The State Ombudsman shall certify individuals to act as ombudsman representatives of the program, each receiving a minimum of 36 hours of initial training plus a minimum of 10 hours of internship supervised by an experienced certified Ombudsman and 12 hours of re-certification training per year thereafter.

In 1996 the Older Californians Act was amended. Division 8.5 was added to the Welfare and Institutions Code. The Older Californians Act unifies state law with the federal Older Americans Act.

In 1999, two bills affected the ombudsman program. AB 868 established new educational and professional requirements for the State Long-Term Care Ombudsman. AB 1731 required four ombudsman posters in specific locations in skilled nursing facilities. In 2006, SB 1759 required all Ombudsman representatives to pass a criminal background clearance.

Office of the State Long-Term Care Ombudsman (OSLTCO)

The California OSLTCO is located in Sacramento at the California Department of Aging. The ombudsman program is under the direction of a governor-appointed State Long-Term Care Ombudsman. The manager of the ombudsman program is responsible for coordinating the activities of the state staff. The state staff includes five analysts, one management services technician, and two support staff. Some of the duties of the State office include:

- Designating and directing the 35 local LTC Ombudsman Programs
- Certifying and de-certifying of ombudsman representatives
- Visiting and monitoring local ombudsman programs
- Developing policies, procedures and guidelines for the program
- Providing technical assistance and support to local programs
- Analyzing legislation in regards to long-term care facilities, elder abuse and ombudsman issues
- Operating the statewide CRISISline
- Developing the core curriculum used to train Ombudsman representatives
- Sponsoring training of ombudsman coordinators at least twice a year
- Maintaining the National Ombudsman Reporting System
- Producing an annual report for the program.

State staff meets regularly with agencies that either regulate or affect long-term care facilities. Examples include:

- Department of Public Health, Licensing and Certification Division
- Department of Social Services, Community Care Licensing Division
- Department of Justice, Bureau of Medi-Cal Fraud and Elder Abuse.

Each local ombudsman program is assigned an analyst in the State office to work with the program coordinator and staff, offering technical assistance and policy direction and problem resolution. When the problem cannot be solved at the local level, and upon request of the local program, State office staff may intervene with necessary licensing agencies to press for solutions in serious and complex cases.

Local Long-Term Care Ombudsman Programs

California has thirty-five local LTC Ombudsman Programs that operate in assigned geographic areas, usually in one or more counties. LTC Ombudsman services are contracted through the local Area Agency on Aging (AAA). Local LTCO programs operate with volunteer and paid Ombudsman representatives. Each LTCOP has, at a minimum, a paid LTCO Coordinator.

As of July 2007, the local LTCOPs are located in the following types of organizations:

- 10 programs are a direct service of the AAA, most of those are part of a county structure,
- 25 programs are subcontracted from the AAA to another organization, most of which are located in a multi-purpose umbrella agency that provides other services.

Single purpose agencies must have a Board of Directors which has oversight for the governance of the agency. LTCOPs housed in umbrella agencies or within the county structure are required to have an Advisory Council which provides support and advice to the coordinator and staff about specific problems relating to the program and the services it provides. Local advisory councils and Boards of Directors provide important input from the community on issues relating to the management and/or services the program offers. They may often be involved in recruiting and recognizing volunteers, fundraising and other areas of importance to the program. They also may act as spokespersons for the program to help inform the community about the problems of residents in long-term care facilities.

Long-Term Care Ombudsman Program Responsibilities

- Receive and investigate complaints on behalf of residents including allegations of abuse and neglect about residents in nursing homes and residential care facilities for the elderly.
- Visit facilities regularly to discover and resolve problems.
- Witness Advance Health Care Directives and Property Transfers for residents in skilled nursing facilities.
- Work with the licensing agencies responsible for long-term facilities to solve problems.
- Provide information and consultations to families and facility staff.
- Provide information and consultations to facility staff
- Provide education to community groups.
- Offer in-service training to facility staff.
- Work with resident and family councils.

LTC Ombudsman Representative

The heart of the LTCOP is the visible volunteer representative working out in the community. To become a certified LTC Ombudsman requires:

- Successful completion of 36-hour classroom training program, plus a minimum of 10 hours of field internship supervised by an experienced certified Ombudsman. Some local programs have more stringent training requirements.
- Pass a California Department of Justice and Federal Bureau of Investigation criminal background clearance.
- To maintain certification, annually complete 12 hours of continuing education provided by the local program.
- Compliance with State and local program protocols.

Snapshot of the California LTCOP

Ombudsman Personnel	**California Data July 2007**
LTCO volunteers	998
LTCO paid staff (state and local)	192

Ombudsman Activities	**California Data 2005-2006**
☞ Information and consultation to individuals	35,416
☞ Information and consultation to LTC facility staff	7,219
☞ Complaints investigated	46,121 from 34,908 individual complaina
☞ Work with resident councils	3,601 meetings
☞ Work with family councils	429 meetings
☞ Training conducted for:	# of sessions
☞ Ombudsman Representatives	369
☞ Facility staff	410
☞ The local community	1,576

V. UNIQUE ASPECTS OF THE LTCOP[15]

An understanding of the history and statutory development of the Ombudsman Program provides the basis for examining the aspects of the program that set it apart from other programs and roles in the long-term care system. This sub-section explores a number of these unique characteristics. Because these frequently are sources of misunderstanding and tension when long-term care ombudsman representatives interact with others, it is imperative to have a clear understanding of the LTCO role based on the OAA. Explaining and clarifying LTCO responsibilities to others is a continual process.

LTCO as Resident Advocate

Since its inception, the LTCOP has been distinct from the classic model of the ombudsman.[16] The traditional purpose of the ombudsman was to be an impartial mediator who receives complaints, determines the pertinent facts, and seeks resolution. That role continues and is adhered to in many settings, both public and private. Traditional ombudsman representatives see themselves primarily as neutral parties, making sure that the system works as it was designed to work. As ombudsman positions have proliferated, variations on the original ombudsman model have emerged. The American Bar Association's Standards for the Establishment and Operation of Ombuds Office recognizes three types of ombudsman: classical, organizational, and advocate.[17]

The LTCO takes the resident's perspective in trying to resolve a problem.

The LTCO is an *advocate ombudsman.* The LTCO is *impartial* in investigation, determining the facts pertinent to a case. The ombudsman representative must gather sufficient information to gain an accurate understanding of the problem in order to develop a resolution plan. Then the LTCO becomes an *advocate*, seeking a resolution the resident wants. In many cases, the institutional long-term care system is not working as it was designed to work, not meeting the needs that it is intended to meet and requires reform. The LTCO represents residents and resident concerns by seeking resolution for both individual issues and systemic issues.

The LTCO's first role is to help residents help themselves. Whenever possible, a LTCO assists the resident in developing specific strategies to address problems. These strategies may include educating and negotiating with the facility staff,

[15] Much of the content in Sub-Sections V and VI is adapted from "The LTCOP Unique Characteristics," Hunt, S., National LTCO Resource Center, NCCNHR, Washington, DC, October 2002.

[16] *Ombudsman* is a Swedish term. In 1809 the office of *riksdagens justitieombudsman* was created to act as an agent of justice, that is, to see after the interests of justice in affairs between the government and its citizens. Excerpted from *The American Heritage® Dictionary of the English Language, Third Edition* © 1996 by Houghton Mifflin Company.

[17] Recommendations, Standards, and Report approved by the American Bar Association's House of Delegates at its 2001 Annual Meeting. http://www.abanet.org/adminlaw/ombuds.

working with a resident council, getting a group of residents with similar concerns together to work on a problem, or filing a complaint on behalf of the resident.

> "As an Ombudsman I receive great personal satisfaction when the resident feels they received fair treatment, and their voice was heard regarding the problem they asked us to assist them with."
>
> Carol Kriemelmeyer, Regional Long-Term Care Ombudsman, Wisconsin

> "Each time I visit the nursing home and have a resident tell me that she or he wants a sandwich, and if I can persuade the staff to get it for her or him my mission is accomplished. In the ten years of my ombudsman work, it is helping one resident at a time that has made it all worthwhile."
>
> Leslie Roberts, Local Long-Term Care Ombudsman Volunteer, Maryland

> "Information is power and the knowledge we have can be a powerful tool for residents. Ombudsmen develop expertise and special understanding of the long-term care environment. Residents need us to supply them that empowering information. I stay [with the LTCOP] because I am needed."
>
> Ruth Morgan, District Long-Term Care Ombudsman, Kentucky

There may be times when a resident wants the ombudsman to speak on his or her behalf or needs the support of the ombudsman in pursuing resolution. This usually occurs when resources within the facility or community are unknown, when family or legal problems arise, or when there is fear of causing tension in resident-staff relationships. There are also cases where an ombudsman may represent a resident who is unable to communicate his/her wishes and has no one else to uphold his or her rights.

> "I have chosen the Ombudsman Program to do my volunteer work because this program deals with the nursing home residents which are very vulnerable and need us to advocate for them since so many are unable to do so for themselves, either because of their medical condition, do not have relatives to do so for them, or because they are afraid of reprisal. We see that their resident rights are protected against any violation.
>
> Many of these residents have contributed to the community and the economy in the past, and now are entitled to receive the help we can provide. I feel very fortunate that I am able to fulfill my needs of helping others, and at the same time give back to the community."
>
> Hilda Woel, Local Long-Term Care Ombudsman Volunteer, Maryland

"The rewards of being an ombudsman are when a resident calls your name and just wants to visit; a staff person introduces you to a family member who is having problems with the facility and the family AND staff want you help to help them; and the family sends a note after a resident you visited has died to thank you for caring."

Richard Krajeck, Local Long-Term Care Ombudsman Volunteer, Maryland

Ethical Issues

With the advocacy privilege and responsibility of representing residents comes another major responsibility. That is to exemplify ethical behavior and decision-making. By its very nature, LTCO work is filled with ambiguity regarding how to proceed. Furthermore, actions taken by an individual LTCO can have a long-term impact on the credibility of the statewide LTCOP. Ombudsman representatives need to be able to work in situations where there might not be clearly "right" or "wrong" actions. Working through "gray" issues is typical for an ombudsman representative. A key challenge is remaining sensitive to such issues by identifying the ethical dimensions of a situation and working through them with some thoughtfulness. Ombudsman representative should always consult with their Program Coordinator before taking action in these types of situations. The National Association of State Long-Term Care Ombudsman Programs (NASOP) has developed and adopted a Code of Ethics for Ombudsmen which is in the Appendix of this chapter. This Code is an excellent tool that ombudsman representatives can use to help guide and direct their work in these complex situations. A few examples of such situations follow.

- Several younger residents in a facility engage in activities that intimidate the older residents. The younger residents say they are exercising their choices and preferences. The older residents ask the LTCO to represent them in making the younger residents change their behavior. Who does the LTCO represent?
- A small residential care facility for the elderly provides individualized care and the residents like living there. On a routine visit, the LTCO spots some major safety violations. The home operator does not have the funds to fix all of these. Does the LTCO report the safety issues to the regulatory agency, risking displacing all of the residents if the action results in closing the facility? If the LTCO does not report and residents die in a fire, how does that reflect on the LTCOP?
- A resident with dementia has no one to represent her. Some of her behaviors and statements lead the LTCO to conclude that the resident needs some changes in her plan of care. What is the role of the LTCO? What authority, if any, does the LTCO have in seeking changes for the resident? What if there are negative ramifications to the resident based on the ombudsman's actions? Under what circumstances might the ombudsman represent this resident?

- A facility calls the LTCO asking what to do with a resident who is facing an involuntary transfer and discharge notice. Knowing that this facility is lacking in good care practices, does the LTCO tell the facility what to do? If so, will the facility later say it has taken those actions and issue a discharge notice because the situation has not improved? Will the LTCO be able to assist this resident who will want to fight the discharge? Will other residents trust the LTCO because the facility has made it known that it followed the LTCO's instructions?
- The LTCO is asked to serve on an ethics committee in a facility. Is this a way to bring a resident perspective into the deliberations? Will this be a conflict of interest for the LTCO who must be viewed and trusted as not being too close to the facility and its policy development? What happens if a resident needs the LTCO to represent her and the issue comes before the ethics committee?
- The LTCO is clearly instructed to publicly support a policy change that will be detrimental to residents. Although the LTCO has voiced concerns about the policy within the agency, the message is that the LTCO is expected to follow agency policies regarding supporting agency policies. What does the LTCO do? What is the potential impact on the LTCOP or on residents?

Unique Elements of the LTCOP

While many types of ombudsman programs wrestle with ethical issues, confidentiality issues and other issues similar to those of the LTCOP, this program has a few unique elements.

- Jurisdiction: The jurisdiction of the LTCOP is the *interest* of the resident.
- Resolution Standard: At the end of the investigation and resolution process, the key question for a LTCO is, *has this complaint/issue been resolved to the satisfaction of the resident?*
- Works on Issues Apart from Specific Complaint: The LTCOP has a mandate to advocate on behalf of the needs of a resident, or residents, separate from individual complaints. Therefore, the LTCOP is to be involved in broader long-term care issues. The LTCOP is expected to be involved in public policy work affecting residents in general.
- Promotes Development of Groups: The LTCOP promotes the development of citizen organizations to participate in the program and provides technical support for the development of resident and family councils to protect the well-being and rights of residents.

Distinctions within the Aging Network

Within the network of services provided under the Older Americans Act (OAA), the LTCOP has some mandates that are not typical of other programs. Much of the structure of the program and operational guidelines are specified in the federal law. These federal provisions also mean that the LTCOP does not easily fit within a typical bureaucratic agency or structure.[18] As a result of these mandated distinctions, LTCO sometimes have policies and procedures different from other programs in areas such as opening mail, handling files, sharing case information.

Some of the key areas of distinctions for the LTCOP are listed below and briefly discussed. The LTCOP is:

1. Established as a separate program with an Office of the SLTCO, headed by a State Long-Term Care Ombudsman (SLTCO), responsible for the statewide program,

2. Able to pursue administrative, legal, and other appropriate remedies on behalf of residents

3. Subject to specific conflict of interest provisions,

4. Responsible for upholding strict confidentiality provisions,

5. Protected from willful interference, and

6. Has legal counsel available that is free of conflict of interest.

1. The LTCOP is established as a separate program with an Office of the SLTCO, headed by a State Long-Term Care Ombudsman (SLTCO), responsible for the statewide program.

The SLTCO may delegate some responsibilities of the Office to other individuals only after assuring that these individuals are free of conflict of interest, have the necessary training, and meet any other qualifications established by the Office. Likewise, the SLTCO may choose to designate local entities (programs) to carry out the activities of the program. Designation is contingent upon compliance with conflict of interest provisions and other criteria.

2. The LTCOP is able to pursue administrative, legal, and other appropriate remedies on behalf of *residents*.

The ombudsman role establishes a different loyalty requirement than is traditional in the workplace. The OAA clearly directs the LTCOP to represent *residents*. Other programs serve individuals. While some represent an individual's needs

[18] "Conflict of Interest," Chapter 7. *Real People, Real Problems: An Evaluation of the Long-Term Care Ombudsman Programs of the Older Americans Act*. Institute of Medicine. 1995.

such as protective services or legal services, the LTCOP has the additional responsibility of engaging in more broad based actions on behalf of residents.

A local LTCO, by delegated authority, can also represent resident interests. These activities range from engaging in administrative remedies such as representing and/or assisting a resident with an administrative hearing to legal actions, such as initiating a lawsuit or seeking injunctive relief for residents. Fulfilling the representative aspects of the LTCO role may be different from the policies of the agency where the LTCOP is located.

The OAA provisions clearly require LTCO to advocate in relation to the development and implementation of laws, regulations, and administrative action that affect residents. As an employee, the LTCO has a "function," an assigned role within the agency in which he or she is employed, which requires a loyalty not to the agency, but to those residents potentially adversely affected by the actions of the agency or government. By law, the LTCO is a surrogate voice for residents of long-term care facilities. The LTCO fulfills his or her loyalty to the employing entity by serving as an agent of residents.[19] Thus, the LTCO must view his or her *primary* role as one of being the resident's voice within a system, *instead of* viewing the primary role as being an employee within a larger agency.

The LTCO's loyalty is to residents.

> "It is our [LTCO] job to name problems so that people with the power to do something about them will be aware the problems exist. It is our job to generate the will to resolve these problems by bringing a human face to those who make the decisions."
>
> Barbara Frank, Connecticut State Long-Term Care Ombudsman, Testimony before the Connecticut Select Committee on Aging. February 20, 1997

3. <u>The LTCOP is subject to specific conflict of interest provisions</u>.

The organizational placement of the LTCOP, both state and local, *and* the individuals working with the program must comply with conflict of interest provisions. This includes individuals who make decisions about the selection of ombudsman representatives and other program entities. These requirements underscore the importance of maximizing the ability of the LTCO to adequately and freely represent residents on all levels — individual to system. In a specific facility, an ombudsman can resolve an individual's problem or achieve a change in the facility's practice affecting many residents. There are also times when an ombudsman needs to speak honestly and publicly about conditions experienced by residents and about the impact of actions, policies, and laws, on residents.

[19] Excerpted and adapted from "Ethical Dilemmas as a State Long-Term Care Ombudsman," unpublished and submitted to the Kennedy School of Government, by Frank, B. May, 1998.

4. The LTCOP is responsible for upholding strict confidentiality provisions.[20]

Although confidentiality is important in the human services field, the LTCOP has specific and strict confidentiality provisions stipulated in the OAA. The LTCOP is not allowed to share identifying information with other state agencies, providers, or anyone else about residents or complainants without the resident's or complainant's consent. Ombudsman representatives find themselves explaining this provision to others who expect the LTCO to share information about a case.

5. The LTCOP is protected from willful interference while fulfilling the duties of the program.

States are directed to create provisions for sanctions for willful interference with the work of the ombudsman and also for retaliation or reprisals against anyone who files a complaint with or cooperates with the ombudsman representative. The LTCO is to pursue complaint resolution and other program functions without intentional obstructions. Sanctions also protect individuals who work with an ombudsman either as a complainant or as a source of information. Individuals are to be free to use or to assist with LTCOP services.

6. The LTCOP has legal counsel that is available and is free of conflict of interest.

The State is required to ensure that the LTCOP has adequate legal counsel for advice, consultation, and assistance to the local Ombudsman Programs and their ombudsman representatives. The stipulation that legal counsel for the program be free of conflict of interest frequently creates another aberration from standard practice in the agency/organizational "host" of the program.

The LTCOP
- *Serves residents*
- *Asks others to do their job for residents;*
- *Gives a public voice to resident concerns.*

To summarize, the LTCOP is unique because it delivers services to individual residents, it calls upon others to fulfill their responsibilities to residents, *and* it is a public voice advocating for improvements needed by residents. Most other OAA programs deliver services. They may also work for legislative and regulatory changes on behalf of their clients. It is rare that other programs have the complete range of responsibilities — individual to system changes on behalf of residents — that the LTCOP does.

Distinctions in Definitions

There are a number of words in the OAA describing the LTCOP's responsibilities that other programs also use to discuss their responsibilities. When these words are used in the LTCOP they have different connotations than they do when used by most other programs. Just as the term *ombudsman* has been adapted in the

[20] For more information on confidentiality, refer to *Ombudsman Best Practices: Confidentiality*. Grant, R. National Long-Term Care Ombudsman Resource Center. December 2000. www.ltcombudsman.org.

OAA to include a resident advocate function, these other words have some distinct meanings based on the OAA.

These distinctions shape a LTCO's role and contribute to its uniqueness. The preceding section, "Distinctions within the Aging Network," discussed some of these words in explaining the requirements for the operation of the LTCOP. This section on definitions is intended to help LTCO identify when a term used by the program might have a different meaning to someone else. If this occurs, LTCO find themselves explaining what the term means within the LTCOP. A few primary examples follow.

Investigation

Investigation is listed as a LTCOP function in the provisions of the OAA. Many other agencies also conduct investigations and employ investigators. Everyone agrees that the purpose of an investigation is to determine facts. Although many agencies use the term *investigate* to describe what they do, the LTCOP typically uses this term with a different connotation than do others. There are two primary distinctions.

- Purpose of the Investigation

LTCO investigate to resolve problems.

The purpose of an ombudsman investigation is to determine whether the complaint is valid and to gather the information necessary *to resolve* it. A key aspect of a LTCO investigation is to determine what the real issue is. In seeking information about the presenting issue, an ombudsman representative might discover that a different issue must be addressed in order to resolve the complaint. An example is a complaint stating that there are not enough activities. The problem might be: a lack of activities, the time the activities are scheduled, a lack of information and assistance for the resident who wants to participate, or a lack of activities individualized for the resident. During the investigation, the ombudsman discovers which of the possible problems is the one that must be resolved—the real issue.

In contrast to the primary outcome sought by the LTCOP, the primary purpose of other agencies is determining whether enforcement action is needed. These other agencies gather facts to determine whether there has been a violation of a law, standards, or regulations. The outcome of the investigation leads to a decision regarding any official action that needs to be taken.

- Standards of Evidence

  The LTCO gathers enough evidence to understand what the real issue/problem is in order to resolve it as the resident desires. Reflecting their federal mandate, ombudsman representatives work *on behalf of residents*. Thus, the LTCO advocates on behalf of the resident even without a direct violation of a standard or regulation.

  "I listen to them [residents]. Too often their concerns are not taken seriously or misunderstood because no one really listens. Often, once the facility staff hears the resident's real concern and understands the real issue they can find a way to accommodate the resident."
  Ruth Morgan, District Long-Term Care Ombudsman, Kentucky

  Other agencies, such as Licensing and Certification, Community Care Licensing, the Bureau of Medi-Cal Fraud and Elder Abuse, police departments, or county prosecutors, use different and possibly, higher evidentiary standards. Unlike other agencies which conduct investigations, LTCO are not bound by legal standards of evidence. Laws and regulations are the beginning point for LTCO, not a limiting or end point.

Confidentiality

The OAA stipulates strict parameters for protecting the confidentiality of the *identity* of residents and complainants. There are also very specific provisions for the release of LTCOP information. Virtually all human services agencies have confidentiality provisions. The LTCOP's distinction is the narrow limits the OAA puts on sharing of resident specific information even with other agencies or departments.

Several states, including California, have adult abuse and neglect laws that list LTCO as mandated reporters. Such laws conflict with the federal OAA confidentiality provisions. Ombudsman representatives must always obtain consent from the resident, their legal representative, or the complainant, before referring a report of abuse or neglect. California state law includes LTCO as mandated reporters of abuse and neglect of elders and dependent adults residing in long-term care facilities; however, California law prohibits an ombudsman or the ombudsman program from disclosing the identity of the resident or complainant without the consent of the resident or complainant. This prohibition extends to disclosure of any information that might identify the resident or complainant. Section 15640 (d) of the California Welfare and Institutions Code states:

A long-term care ombudsman coordinator may report the instance of abuse to the county adult protective services agency or to the local law enforcement agency for assistance in the investigation of the abuse *if the victim gives his or her consent.* A long-term care ombudsman program and the Licensing and Certification

Division of the State Department of Health Services shall immediately report by telephone and in writing within two working days to the bureau any instance of neglect occurring in a health care facility, that has seriously harmed any patient or reasonably appears to present a serious threat to the health or physical well-being of a patient in that facility. If a victim or potential victim of the neglect withholds consent to being identified in that report, the report shall contain circumstantial information about the neglect *but shall not identify that victim or potential victim* and the bureau and the reporting agency shall maintain the confidentiality of the report until the report becomes a matter of public record.

A letter to the Center for Social Gerontology clarified the intent of the LTCOP confidentiality provisions. Two of the authors of the OAA provisions made the following statement.

> Senator Glenn, Congressman Bonker:
>
> "Section 307(a) (12) (1) of the OAA clearly prohibits an ombudsman from disclosing the identities of nursing home residents and complainants. It would also violate the spirit of the law to provide other information that would serve to help identify a resident or complainant without officially naming them. The federal law, therefore, takes precedence over a state law that is in conflict with it.
>
> Moreover, beyond the particular identities of individuals, Section 307(a) (12) (E) limits disclosure of information in the ombudsman program files. It gives to the ombudsman the sole discretion over whether to reveal any information in program files; thus state law cannot force disclosure of such information. The law does not, however, preclude ombudsmen from encouraging residents or complainants who allege abuse, or are the subject of an abuse allegation, to consent to disclosure of their identities."[21]

An example of information that might identify a resident is reporting the abuse of a middle-aged woman with multiple sclerosis whose family feeds her dinner, when no one else in the facility has these characteristics and the resident refuses to be identified. Adhering to these confidentiality provisions sometimes can be challenging. However, the credibility of the LTCOP relies on residents and families trusting the LTCO to keep their information confidential unless they give permission. The LTCOP does have confidentiality provisions that are more stringent than those of many other programs.

Conflict of Interest

Many agencies, particularly governmental agencies, have conflict of interest provisions. Some also have ethical guidelines that extend to post-employment services for a period of time. In its early days, the conflict of interest provisions of

[21] "Best Practice NOTES." The Center for Social Gerontology, Inc. 2307 Shelby Ave., Ann Arbor, MI 48103 (734) 665-1126. tcsg@tcsg.org. Vol. 2, No. 4. Nov. 1988.

the LTCOP were typically defined as having a financial or spousal conflict of interest. These concepts are commonly accepted among other programs and agencies. With the growth in long-term care services and the maturing of the LTCOP, *conflict of interest* has encompassed some additional dimensions.
The Institute of Medicine's study of the program devoted Chapter 4 to this topic.[22] It identifies three dimensions of conflict of interest: loyalty, commitment, and control.

- *Loyalty*: These involve issues of judgment and objectivity. These are the typical situations almost everyone understands—financial and employment considerations. An ombudsman's ability to be fair and a resident advocate might be questioned if the ombudsman also is a consultant to a facility, a board member of a facility or management company, or works as a case manager with responsibility for assisting individuals with moving into long-term care facilities. Loyalty might also be an issue if the individual is an ombudsman in a facility which was the ombudsman's previous employer.
- *Commitment*: These are issues of time and attention. Which goals are being addressed? Who establishes the goals and work priorities of the "full-time" State Ombudsman? If a local ombudsman is part time, where is their greater commitment in terms of time and loyalty?
  The LTCO, whether state or local, is required to be a voice for residents. This mandate takes precedence over being a voice for the positions of the employer. Ombudsman representatives fulfill their role to be loyal to carrying the *resident's* message; their loyalty to their employer may be questioned. Thus, the commitment called for in the LTCOP is not the typical view of commitment expected by most employers.
- *Control:* These are issues of independence. Do other interests, priorities, or obligations of the agency that houses the ombudsman materially interfere with the LTCOP's advocacy on behalf of residents? Do administrative or political forces materially interfere with the professional judgment of the ombudsman? Is the ombudsman able to act responsibly without fear of retaliation by superiors?

The credibility of the LTCOP rests upon fulfilling its primary responsibility—acting on behalf of residents. If the program acts without being grounded in what residents want, its credibility and effectiveness will be lost.

[22] Institute of Medicine. op. cit.

Additional Roles for California LTCO Representatives

In addition to the LTCO approach to empowerment, advocacy, investigation, confidentiality, and conflict of interest, the California Legislature has given the LTCOP additional roles that go beyond the federal law. A brief description of these roles follows.

The Witnessing of Advance Health Care Directives and Property Transfers

California law requires that any Advance Health Care Directive (AHCD) executed by a resident of a skilled nursing facility must be witnessed by an ombudsman and a second witness. This is done to ensure that the resident is not coerced into signing this document against his or her will and to assure that the resident understands the meaning of an AHCD (California Probate Code Section 4675).

All property transfers between residents of long-term health care facilities and staff with a fair market value over $100 must also be witnessed by an ombudsman. (California Health & Safety Code Section 1289)

Mandated Reporter and Responding to Reports of Abuse

California law identifies the LTCO as a mandated reporter of suspected abuse of elders and dependent adults residing in a long-term care facility (California Welfare & Institutions Code 15630).

Additional responsibilities for responding to allegations of abuse are specified in California law (California Welfare & Institutions Code 15650(a), California Health & Safety Code, Section 1502). The role of the LTCO volunteer may not include this responsibility in your particular local program; your program coordinator will provide more information and direction regarding your role.

More information about elder abuse and the role of the LTCO is in Chapter 8, *Responding to Elder and Dependent Adult Abuse in Long-Term Care Facilities*.

VI. ACCOUNTABILITY

Over the years the LTCOP has been scrutinized and has received increasing attention and recognition for its work on behalf of residents. Many of the evaluations of the program have been prompted by LTCO themselves. Ombudsman representatives expect to be held accountable and are continually seeking to determine if their advocacy makes a difference for residents. They want to be effective.

In *Long-Term Care Ombudsman Program Core Principles: Independence in Representing Residents*[23] accountability is discussed as follows.

> "The State Long-Term Care Ombudsman and the LTCOP they lead and manage are accountable to two primary groups: residents and citizens. The OAA is clear that the LTCOP's advocacy is to be on behalf of residents and determined by representing their interests. The LTCOP must account for its actions in an annual report required by the Administration on Aging and in other reports required by the State and/or other funding sources. Ombudsmen are responsible for the good faith performance of their duties as specified in the OAA and in state enabling legislation."

Through the years, there have been several studies of the LTCOP designed to determine if the program is fulfilling its OAA responsibilities. Four of these are listed below. The first three sources are widely used as referent points for discussion of program effectiveness. The fourth is expected to provide guidance for further development and assessment within each state as well as on the national level. All of these reports have stated that the LTCOP provides a needed service not duplicated by other services or programs.

- As previously mentioned the Institute of Medicine (IOM) thoroughly examined the LTCOP in 1995 and issued a number of recommendations. Following that report, many states reviewed the structure and placement of the LTCOP. Several states made changes in placement and/or in policies and procedures based on those recommendations.
- Some of the issues raised in the IOM study were examined in 2000 in a nationwide study of State LTCOPs, "State Long Term Care Ombudsman Programs: Factors Associated with Perceived Effectiveness." Three broad dimensions identified in the IOM study as key elements of effectiveness were reaffirmed: resources, organizational autonomy, and LTCOP relationships with others.[24]

[23] A position paper adopted by the National Association of State Long-Term Care Ombudsman Programs in March, 1998.

[24] "State Long Term Care Ombudsman Programs: Factors Associated with Perceived Effectiveness." Estes, C.L., Zulman, D., Goldberg, S.D., Ogawa, D.D. *The Gerontologist*. 44, 104 -115, 2004. Also available on http://ltcombudsman.org/ombpublic/49_346_965.CFM#orc_ref. It is under Library, Basics, IOM, Study of State LTCOP.

- Other studies have been conducted by the Office of Inspector General.[25] The LTCOP in individual states has been assessed by various entities such as legislative auditors, independent contractors, and the U. S. General Accounting Office.
- The National Association of State Long Term Care Ombudsman Programs (NASOP) commissioned six papers on aspects of the LTCOP and convened a group of sixty-five participants to examine the past, present and future of the LTCOP. The report of this meeting contains recommendations for NASOP regarding ways to strengthen the program.[26]

[25] *Successful Ombudsman Programs.* Department of Health and Human Services. Office of Inspector General. June 1991. OEI-02-90-02120. *Long Term Care Ombudsman Program: Overall Capacity*. Department of Health and Human Services. Office of Inspector General. March 1999. OEI-O2-98-00351.
[26] *The Long-Term Care Ombudsman Program: Rethinking and Retooling for the Future*. A Report from the National Association of State Long Term Care Ombudsman Programs retreat, January 31 – February 2, 2002.

VII. LONG-TERM CARE OMBUDSMAN ASSOCIATIONS

There are two national membership associations for LTCO. Several states, including California, also have statewide associations of local LTCOPs.

- The National Association of State Long-Term Care Ombudsman Programs (NASOP) was organized in 1985 and is a not-for-profit association. Its members are SLTCO. Its mission statement says, "NASOP is dedicated to improving the quality of life and quality of care of long-term care consumers through strong, effective state ombudsman programs."
- The National Association of Local Long-Term Care Ombudsman (NALLTCO) adopted by-laws in 1996 following many years of informal meetings. Its membership consists of local LTCO, both paid and volunteer. Its purpose is:

  > "to organize and provide a common voice for local long-term care ombudsman for the advancement of their mutual objective of providing for their professional development, insuring the integrity of local programs and their ability to effectively advocate for long-term care residents; the exchange and sharing of information, opportunities and resources available through the Administration on Aging as well as other organizations; the mutual sharing of information, ideas and experiences among local ombudsman's staff; and providing information to policy makers on legislation and regulations impacting local ombudsman program and long-term care residents."

- The California Long-Term Care Ombudsman Association (CLTCOA) was incorporated in 1980 as a membership association of the Ombudsman Coordinators of local programs. Initially, CLTCOA worked with the some of the first State LTCO to help develop the statewide program. From the beginning CLTCOA was, and continues to be, a vehicle to advocate legislatively and systemically on behalf of long-term care residents and the LTCOP. The Association enables local LTCOPs to maintain an independent voice at legislative hearings, and in other venues where regulation-packages require comment and correction. CLTCOA provides support to local LTCOPs and contributes to the overall operation of the statewide LTCOP.

VIII. NATIONAL LONG-TERM CARE OMBUDSMAN RESOURCE CENTER

The National Long-Term Care Ombudsman Resource Center (NORC) provides support, technical assistance and training to the 53 State Long-Term Care Ombudsman Programs and their statewide networks of almost 600 regional (local) programs. The Center's objectives are to enhance the skills, knowledge and management capacity of the State programs to enable them to handle residents' complaints and represent resident interests (individual and systemic advocacy). Funded by the AoA, the Center is operated by NCCNHR: The National Consumer Voice for Quality Long-Term Care, in cooperation with the National Association of State Units on Aging (NASUA). Many of the resources developed by the Center and by LTCOPs are available via the Internet at www.ltcombudsman.org

IX. WHY OMBUDSMAN STAY WITH THE PROGRAM

In spite of the broad scope of ombudsman responsibilities and the continual struggle for adequate resources, many LTCO remain committed to serving residents. They stay on the job in the face of on-going challenges and few monetary rewards. Some LTCO shared their reasons for sticking with the program. Additional quotes are in *Celebrate 30 Years of the Long-Term Care Ombudsman Program* on www.ltcombudsman.org

> "I had spent several years working with and for nursing homes. Over time I became demoralized by my inability to make the lasting systemic changes I thought were necessary for even just adequate resident care. I felt I couldn't stay in the field if there was virtually no hope of making things better. It wasn't until I worked with the Ombudsman Program and NCCNHR that I felt hope return - there IS a place where I can contribute to making care not only adequate but exemplary; and there are actually people who feel the same way."
>
> Mary Edwards, Local Long-Term Care Ombudsman, Maryland

> "I have discovered to really help people and teach self advocacy, you have to be able to do for yourself what you ask others to do for themselves. The ombudsman program works on problems that are very similar but very different when looking at it from an individual's perspective. There are times you may have to support individual decisions when you don't necessarily agree with them. The greatest experiences I have had working as an ombudsman are listening to people and treating them as a valued human being; working with citizens to become volunteer ombudsman; and facilitating staff, residents, and families to communicate with each other.

I have stayed in this position for many years because of the following: the clients telling staff if your program had not been there this problem would not have been resolved; the problem still exists but I feel much better because you have taken the time to listen to what I have to say and you don't think I am crazy; and the families voiced how much more empowered they feel since they have an organized council and administration is providing them with more information and listening and taking more action with their concerns."

Vivian Omagbemi, Local Long-Term Care Ombudsman, Maryland

"I have stayed in the LTCO job for 20 years because of the satisfaction of helping someone who is generally powerless to prevail against the 'system'; the joy of meeting and coming to know very interesting people; the challenge of working out complex problems and then building a repertoire of solutions to use again and again. There is a deep satisfaction in becoming 'expert' in an area where so much help is needed. Folks really don't know where to turn and there is so much personal satisfaction in being able to help in a very concrete, useful manner."

Kathy Gannoe, District Long-Term Care Ombudsman, Kentucky

X. SUMMARY

The Long-Term Care Ombudsman Program is indeed unique in its purpose and scope. Ombudsman programs are designed and directed by law to provide an ideal program of advocacy services for residents. They are also obligated by law to support volunteer services and citizen action. There are high expectations from citizens and others for the LTCOP to fulfill the *public trust* of its mandated responsibilities.

The strength of each program, or its ability to achieve full implementation of the federal law and state law, depends on several realities and the resulting challenges.

- The amount of continuing philosophical, motivational and financial support the program receives from federal/state government, especially the state unit on aging and from the public.
- The leadership skills of the SLTCOP and the local LTCOP such as: communication, networking, negotiating, and management.
- Personal characteristics of the LTCO including: accessibility, adaptability, compatibility, tolerance, humility, civility, patience, and courage.
- The liberty and the skills of the SLTCO and local LTCO, paid and volunteer, to advocate openly and firmly:

- To help resolve problems so that residents' needs are met,
- To help ensure that necessary changes are made in facility care delivery, *and*
- To provide information to providers, agencies, legislators, and the public, about serious flaws in the nursing home system and to help correct them.[27]

Whenever the LTCOP deviates from its unique characteristics and becomes more like other programs or services, it risks losing its purpose. It risks becoming a duplicative service. The LTCOP must continually strive to clarify its unique role in the aging network in order to carry out its mandate under the Older Americans Act to be a resident advocate.

[27] Holder, op.cit.

APPENDIX

The Long-Term Care Ombudsman Program 1972-2005

Program Milestones

1972 In implementing President Nixon's 1971 Eight Point Initiative to improve nursing home care, the Health Services and Mental Health Administration funded nursing home ombudsman demonstration projects in Idaho, Pennsylvania, South Carolina, Wisconsin and Michigan (through the National Council of Senior Citizens) to respond in a responsible and constructive way to complaints made by or on behalf of individual nursing home patients.

1973 Additional demonstration projects were started in Massachusetts and Oregon. The Ombudsman Program was transferred to the Administration on Aging (AoA).

1975 Amendments to the Older Americans Act authorized funding for state ombudsman programs.

Following an assessment of the findings and accomplishments of the seven demonstration projects, Commissioner on Aging Dr. Arthur S. Flemming invited all State Agencies on Aging to submit proposals to enable the State Agencies to develop the capabilities of the Area Agencies on Aging to promote, coordinate, monitor and assess nursing home ombudsman activities within their service areas. All states except Nebraska and Oklahoma applied for and received one-year grants ranging from $18,000 for most states to $57,900 for New York, which was then the state with the largest elderly population. Total funding was about one million dollars.

1976 Dr. Flemming issued the first Ombudsman Program guidance, which said the program would be judged in the first year solely on the basis of the number of community-based ombudsman programs launched and the effectiveness of these programs in receiving and resolving complaints.

The early nationwide program stressed reliance on volunteer, rather than paid ombudsman staff.

1977 The Administration on Aging funded the National Paralegal Institute to provide the first training program for state ombudsmen, who were called "ombudsman developmental specialists".

1978 In June AoA Commissioner Robert Benedict announced an Advocacy Assistance grant program which provided additional assistance for the state Ombudsman and Legal Services programs. The focus was on both individual advocacy and systems advocacy. Grants ranged from $50,000 for most states to $135,390 for California, which by then had the largest elderly population. To support the state and area agencies in carrying out their advocacy functions AoA awarded contracts in 1979 and 1980 for five Bi-Regional Advocacy Assistance Resource Centers.

The 1978 Amendments to the Older Americans Act, passed in October, required every state to have an Ombudsman Program and specifically defined ombudsman functions and responsibilities.

1979 AoA awarded a grant to the newly formed National Citizens Coalition for Nursing Home Reform to promote citizen involvement to improve the quality of life for nursing home residents and strengthen linkages with the ombudsman network, including providing training and technical assistance.

1981 Older Americans Act Amendments expanded Ombudsman Program coverage to include board and care homes. The name was changed from Nursing Home Ombudsman to Long-Term Care Ombudsman to reflect this change. Other duties remained substantially the same.

AoA issued a program instruction (AoA-PI-81-8) which provided substantial guidance and direction to the states in the implementation of the ombudsman provisions in the Act.

1983-84 AoA issued a series of twenty-two papers, which constituted chapters of an Ombudsman Technical Assistance Manual.

1984 Older Americans Act Amendments made no major changes in the Ombudsman provisions.

The number of local programs and complaints and the amount of program funding and increased substantially; and the number of state and local paid staff and volunteers increased 50% over 1982 levels.

1987 Older Americans Act Amendments made substantive changes in the Ombudsman Program, including requiring states to provide for ombudsman access to residents and residents' records; immunity to ombudsman for the good faith performance of their duties and

prohibitions against willful interference with the official duties of an ombudsman and/or retaliation against an ombudsman, resident or other individual for assisting representatives of the program in the performance of their duties.

1988 AoA funded the National Association of State Units on Aging (NASUA) to operate the National Center for State Long-Term Care Ombudsman Resources, in conjunction with the National Citizens' Coalition for Nursing Home Reform.

1992 Older Americans Act Amendments strengthened the Ombudsman Program and transferred it to a new title in the Act, Title VII Vulnerable Elder Rights Protection Activities, which also included Programs for Prevention of Elder Abuse, Neglect and Exploitation, the State Elder Rights and Legal Assistance Development Program and an Outreach, Counseling and Assistance Program.

1993 The National Citizens' Coalition for Nursing Home Reform received an AoA grant to operate the National Long-Term Care Ombudsman Resource Center, in conjunction with the National Association of State Units on Aging.

1994 AoA Regional Offices conducted on-site assessments of the State Ombudsman Programs, issuing their reports in January 1995.

AoA held four training conferences around the country and issued several program instructions and proposed regulations on the new Title VII. AoA also held a major symposium on "Coordination Between Long-Term Care Ombudsman and Adult Protective Services Programs and Related Issues".

1995 AoA implemented the National Ombudsman Reporting System (NORS), which provided substantial state and national data on ombudsman cases, complaints and program activities, beginning in 1996.

AoA convened a task force to discuss and develop ways to document the impact of the Ombudsman Program and issued a report on the meeting entitled "An Approach to Measuring the Outcomes of the Long-Term Care Ombudsman Program".

Ombudsman Programs in California, Florida, Illinois, New York and Texas participated in Operation Restore Trust, a U.S. Department of Health and Human Services pilot Medicare and Medicaid anti-fraud and abuse effort, which returned $23 to the Medicare Trust Fund for every $1 spent; the program was expanded to all states in 1997 and re-named the Senior Medicare Patrol.

2000 Older Americans Act Amendments retained and updated ombudsman provisions in Titles II, III and VII.

2005 Over 1,200 paid long-term care ombudsman and 9,000 volunteers provide services to the 2.8 million residents in over 62,000 facilities. In nursing facilities 34% of complaints handled involve resident care, 28% are related to residents' rights. In board and care facilities, almost 34% of complaints handled involve residents' rights, 22% are related to resident care.

CODE OF ETHICS FOR LONG TERM CARE OMBUDSMEN

The National Association of State Long Term Care Ombudsman Programs

1. The ombudsman provides services with respect for human dignity and the individuality of the client[28], unrestricted by considerations of age, social or economic status, personal characteristics, or lifestyle choices.

2. The ombudsman respects and promotes the client's right to self-determination.

3. The ombudsman makes every reasonable effort to ascertain and act in accordance with the client's wishes.

4. The ombudsman acts to protect vulnerable individuals from abuse and neglect.

5. The ombudsman safeguards the client's right to privacy by protecting confidential information.

6. The ombudsman remains knowledgeable in areas relevant to the long term care system, especially regulatory and legislative information, and long term care service options.

7. The ombudsman acts in accordance with the standards and practices of the Long Term Care Ombudsman Program, and with respect for the policies of the sponsoring organization.

8. The ombudsman will provide professional advocacy services unrestricted by his/her personal belief or opinion.

9. The ombudsman participates in efforts to promote a quality, long term care system.

10. The ombudsman participates in efforts to maintain and promote the integrity of the Long Term Care Ombudsman Program.

11. The ombudsman supports a strict conflict of interest standard that prohibits any financial interest in the delivery or provision of nursing home, board, and care services, or other long term care services that are within their scope of involvement.

12. The ombudsman shall conduct himself/herself in a manner that will strengthen the statewide and national ombudsman network.

[28] In the Code of Ethics, *client* refers to the range of consumers served by LTCO such as residents, their family members, and individuals who are seeking information about long-term care facilities.