

*Equipping State Long-Term Care Ombudsmen for Their Leadership
Role: A Self-Study Guide*

HISTORY AND ROLE OF THE LONG-TERM CARE OMBUDSMAN PROGRAM

**Ombudsman Desk Reference Section for
State Long-Term Care Ombudsmen**

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I. INTRODUCTION

This section of the *Ombudsman Desk Reference* discusses the history, development, and unique aspects of the Long-Term Care Ombudsman Program (LTCOP). 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 (LTCO), a knowledge of the program's history, legal basis, and development is essential.

This section provides information for ombudsmen to use in training staff and volunteers. Sub-sections might be useful in educating others about the purpose and scope of the program. Topics covered in the sub-sections are:

- how the LTCOP began, the LTCOP under the Older Americans Act (OAA),
- unique aspects of the LTCOP,
- accountability,
- LTCOP associations,
- the National Long-Term Care Ombudsman Resource Center,
- why ombudsmen stay with the program, and
- a summary of the program's role and continuing challenges.

Long-Term Care Ombudsman Defined

Briefly defined, a LTCO is an advocate for residents¹ of nursing homes, board and care homes, and assisted living facilities. Ombudsmen provide information about how to select a facility and what to do to get quality care. They are trained to resolve problems. They also represent the perspective of residents in monitoring laws, regulations, and policies.

Extent of the Long-Term Care Ombudsman Program

A State Long-Term Care Ombudsman (SLTCO) heads each state program. In many states, residents are served by a combination of paid staff and of volunteer ombudsmen. There were more than 1,000 paid program staff, more than 8,700 certified volunteers, and more than 2,600 other ombudsman volunteers in 2002.²

Ombudsman Activities

- Provide information to individuals
- Investigate complaints
- Work with resident councils
- Work with family councils
- Conduct training for:
 - Ombudsmen
 - Facility staff
 - The local community

Nationwide Data 2002

282,964 contacts
261,257 by 158,413 individual complainants
15,692 events
5,509 events
of sessions
9,585
7,622
10,109

II. HOW THE LONG-TERM CARE OMBUDSMAN PROGRAM BEGAN³

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 1960’s and early 1970’s, 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.⁴ 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?”⁵

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 1970’s.

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 Health, Education and Welfare Department (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.⁶ 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.

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 the Department of 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.”

1960's-70's	Nursing Home Abuse Scandals
1971	Presidential Directive
1972-73	NH Demo Projects
1973	NH Omb Program moved to AoA
1975	Grants to 48 States for NH Omb Program
1978	OAA requires NH Omb Program
1981	Renamed Long-Term Care Omb Program

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.

Funding levels for the project were:

Idaho	\$161,067 for 3 years
Massachusetts	92,564 for 2 years
Oregon	60,000 for 2 years
Pennsylvania	270,000 for 3 years
South Carolina	191,250 for 3 years
Wisconsin	457,722 for 3 years
NCSC/Michigan	498,091 for 3 years
TOTAL FUNDING:	\$1,730,694 over the 3-year period

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). This transfer to AoA was consonant with the Commissioner on Aging's responsibility for serving as an advocate for older persons.

An impressive record of complaint resolution was submitted by the demonstration projects in quarterly reports and program assessments provided at the end of the demonstration period. Other prominent program accomplishments included the identification of problems related to long-term care and bringing them to the attention of the public, agencies, and providers; a variety of changes in nursing home policies, regulations, and legislation designed to benefit residents; the interjection of the needs and perspectives of residents into the deliberations of policy makers; and the design, organization and implementation of training programs and informational forums for the public and for staff of nursing homes. Details of these accomplishments can be found in an assessment of the ombudsman demonstration projects available from AoA.

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)

The LTCOP for State

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

1. Where the demonstration program had 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 directors of the demonstration projects had been called ombudsmen 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, ombudsmen.

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.

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

During this same time period, 1975 – 1978, there was simultaneous development in the citizen advocacy network. The National Citizens’ Coalition for Nursing Home Reform (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.⁷

The LTCOP and Advocacy Assistance

In June of 1978, AoA Commissioner Robert Benedict announced that he was combining the ombudsman and legal services efforts into a common framework “in order to maximize their interrelationship, improve coordination, and more effectively deal with the concerns of institutionalized and non-institutionalized vulnerable elderly.” (AoA-PI-78-12). To support this effort, AoA made available to State Agencies on Aging model projects grants ranging from \$50,000 for most States to \$135,390 for California, the state with the largest number of older persons.

In addition to providing continuing support for the states’ ombudsman and legal services development activities, the advocacy assistance grants were intended to assure more legal back-up for the ombudsman program. Another objective was to deal with the problems of the institutionalized

elderly in general and to encourage the increased use of advocacy by non-lawyers to serve the elderly. The focus was on both advocacy for individual older persons (personal advocacy) and advocacy that affects large numbers of older persons (issues advocacy).

To support the state and area agencies, as well as other community agencies and organizations in carrying out their advocacy functions, AoA awarded contracts in 1979 and 1980 for five Bi-Regional Advocacy Assistance Resource and Support Centers and a national center. Under these awards, the contractors provided training for state and local advocacy programs and technical assistance in the design and implementation of statewide ombudsman programs.

Also in 1979, AoA awarded a grant to NCCNHR to promote and organize citizen involvement to improve the quality of life for nursing home residents. One of the objectives of the grant was to strengthen and maintain NCCNHR's linkages with the ombudsman network. In its activities to meet this objective, NCCNHR provided considerable information and technical assistance to those involved in the Ombudsman Program as well as training for local ombudsmen.⁸

The AoA's pairing of the LTCOP and legal services demonstrated a clear intent for the LTCOP to be an advocacy service. It also underscored the importance of knowledgeable legal support for the program and of training for state and local program personnel. Advocacy, legal support, and training have continued to be essential elements of the LTCOP surviving the original "Advocacy Assistance" framework.

III. THE LTCOP UNDER THE OLDER AMERICANS ACT⁸

Salient Provisions and Expanding Responsibilities

The 1978 Amendments to the Older Americans Act (OAA) elevated the Nursing Home Ombudsman Program to a statutory level. Under the OAA, federal funding goes to each state agency on aging (state unit on aging) which is given the option to directly operate the program or to contract with another agency or organization to operate the program. The statute *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 and worked for enactment of state ombudsman legislation. Such legislation is 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 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;
- Immunity to ombudsmen 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.

In 1992 the Amendments to the OAA strengthened and clarified the LTCOP and the role of the State LTCO (SLTCO). Some of the changes these amendments made were the:

- Creation of an Office of the State Long-Term Care Ombudsman;

- Clarification of the responsibility of the SLTCO in designating entities and individuals to participate in the LTCOP;
- Prohibition of individuals from serving as LTCO until being trained and being approved by the SLTCO;
- Clarification of conflict of interest;
- Requirement for AoA to establish an Office of Long-Term Care Ombudsman Programs headed by an Associate Commissioner for Ombudsman Programs who would establish model standards for ombudsman training; and
- Requirement for the Commissioner of AoA to issue and periodically update regulations for the LTCOP.

Additional refinements were enacted by the 2000 Amendments to the OAA. The changes included:

- Further clarification of financial conflict of interest;
- Coordination of the LTCOP with law enforcement and the courts;
- Clarification that LTCOPs may solicit voluntary contributions and retain these to expand services; and
- Prohibited cost sharing for LTCOP services.

A timeline depicting milestones in the growth and development of the LTCOP is in the Appendix. It provides a quick summary of the narrative in Sections II and III of this paper.

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. All ombudsmen 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

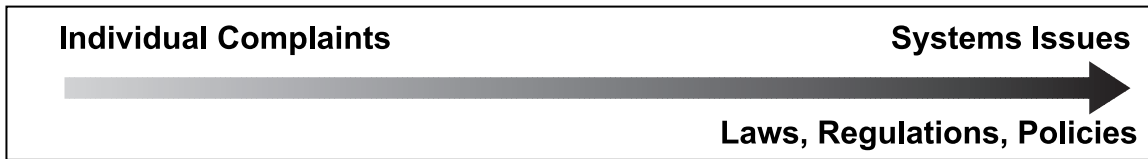
Intervention

- Provide residents with regular and timely access to LTCOP services

The LTCOP for State

- 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 ombudsmen 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 is broad.⁹



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 approved 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.
- Prohibitions and sanctions for willful interference with ombudsman duties are required to be established by the state.
- Conflicts of interest for the Office of the SLTCO, entities, and individuals participating in the LTCOP are prohibited.

Status of the Current LTCOP

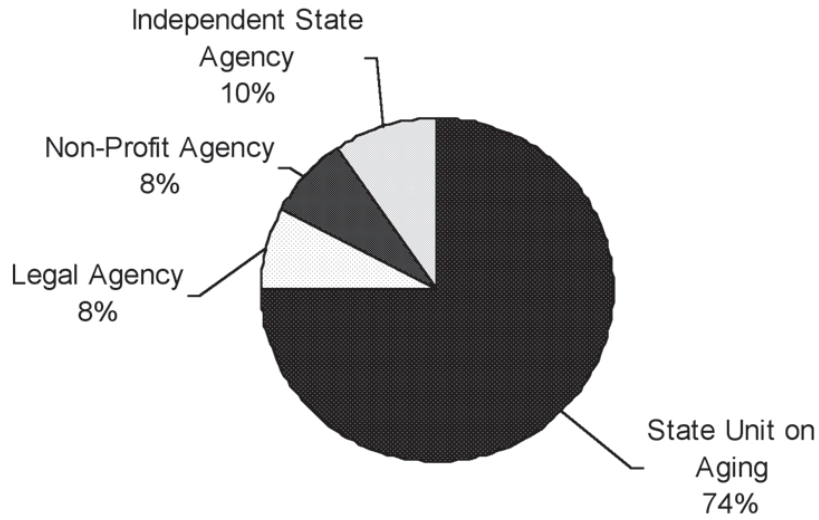
Today, the LTCOP operates in all 50 states, the District of Columbia, Puerto Rico, and Guam. No single model can accurately describe these multifaceted programs. Variability in organizational placement, program operation, funding, and utilization of human resources has given rise to distinct approaches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

One illustration of this variability is an analysis of the organizational placement of LTCOPs.¹⁰ As shown in Chart 1 on the following page, states have chosen a variety of organizations to be the “home” of the SLTCOP.¹¹ 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 in Chart 2, there are variations among states regarding the placement and structure of local LTCOPs.

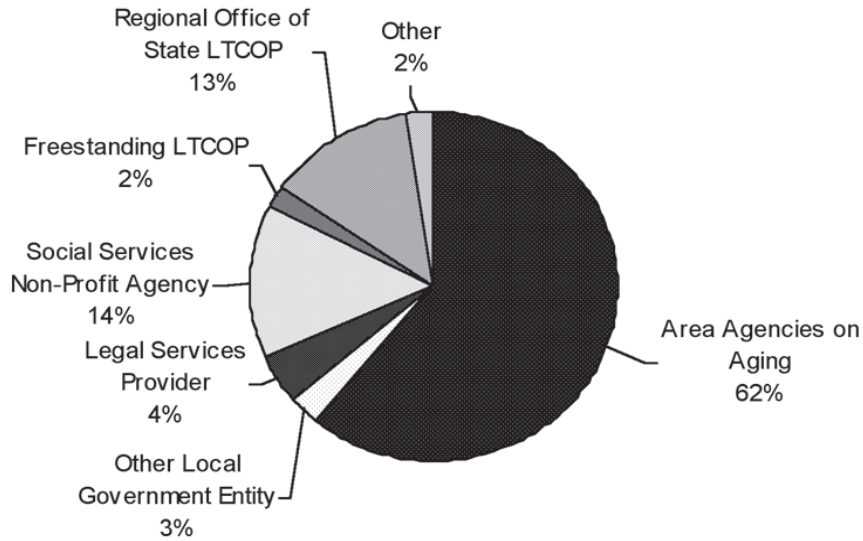
Another important variation among programs is their use of volunteers as local ombudsmen. The history of the LTCOP clearly cites the importance of volunteers in shaping this program. In order to make ombudsman services more accessible to residents, over three-fourths of the states use volunteers as LTCO in addition to paid staff ombudsmen. The functions of volunteers with the program differ among states according to state laws and policies. Despite variations in the role of volunteers, they, too, serve residents through the delegated functions of the SLTCO and as part of the statewide LTCOP.¹²

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 IV, “Unique Aspects of the LTCOP.”

State LTCOP Placement 2002



Local LTCOP Placement 2002



IV. UNIQUE ASPECTS OF THE LTCOP¹³

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 from other employee 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 ombudsmen 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.¹⁴ 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 ombudsmen primarily see themselves 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 ombudsmen: classical, organizational, and advocate.¹⁵

Long-Term Care Ombudsmen take 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. Ombudsmen 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. Long-Term Care Ombudsmen represent residents and resident concerns by seeking resolution for both individual issues and systemic issues.

The ombudsman'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 persuading or negotiating with the facility staff, 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.

“Having people recognize that they have life-skills in solving problems, and then helping them apply those skills in the “brave new world” of a nursing home...both empowers the consumer and provides a sweet reward to the ombudsman who facilitates that process.”

Esther Houser, Oklahoma State Long-Term Care Ombudsman

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 home 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.

“Ombudsman advocacy gives me the opportunity to side with our everyday heroes—our parents, teachers, veterans, farmers, laborers, health practitioners, and spiritual leaders. These folks are now also survivors of chronic illness or catastrophic health events who occasionally need a little help to maintain their dignity and autonomy. I am so proud to work with a team of staff and volunteers who recognize these heroes and have the courage to challenge providers to do the right thing; to treat people fairly with dignity and respect for their quality of life while providing quality health care.”

Sharon Zoesch, Minnesota State Long-Term Care Ombudsman

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. Ombudsmen work in situations where there might not be clearly “right” or “wrong” actions. Working through “gray” issues is typical for ombudsmen. A key challenge is remaining sensitive to such issues by identifying the ethical dimensions of a situation and working through them with some thoughtfulness. 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 personal care home 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?

There are several resources to guide LTCO in working through ethical issues. Some of these were developed following training sessions where ombudsmen grappled with an issue and received guidance from professionals in the field. Others are based on research and filtered through dialogue with LTCO and field testing training on the topic. These resources are listed in the Resource Guide section of this Ombudsman Desk Reference.

Many state LTCOPs have incorporated program guidance on addressing ethical issues into their training and into their program policies and procedures as well as their resource manuals. Some of these are available on the Ombudsman Resource Center web site, www.ltcombudsman.org. A code of ethics for LTCO was developed and adopted by the National Association of State Long-Term Care Ombudsman Programs. It is in the Appendix to this document.

Unique Elements of the LTCOP¹⁶

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 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. Implementing these mandates may result in other aging programs feeling they must compete with the LTCOP for certain perceived “privileges.” Sometimes misunderstanding of motives and of what ombudsmen are seeking results in tension and conflict. These federal provisions also mean that the LTCOP does not easily fit within a typical bureaucratic agency or structure.¹⁷ As a result of these mandated distinctions ombudsmen might hear comments such as, “Why do you always want special privileges? What makes you different? Why do you need an office with a door when everyone else has a cubicle? The LTCOP isn’t a team player. The LTCOP always wants to be an exception.”

Some of the key areas of distinctions that might prompt such comments are listed below and briefly discussed. The LTCOP is:

1. Established as a separate program with the 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 the 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.

While many agencies house more than one program, the type of specific decision-making responsibilities stipulated for the SLTCO are not the norm for agencies with a hierarchical management structure. The delegation and designation authority of the SLTCO is at odds with the process many agencies follow for approving contracts as well as other administrative functions. When the SLTCO seeks to fulfill the OAA responsibilities, the ombudsman may be perceived as usurping authority or as challenging accepted, formally approved procedures.

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

Local ombudsmen, 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 ombudsman role may be different from the policies of the agency where the LTCOP is located

The Institute of Medicine's study of the LTCOP has the following comment about the program's mandate to speak out about government laws, regulations, policies and actions when justified by the circumstances.

“Taking such steps, however, is antithetical to the hierarchical rules of government. It is not surprising therefore, that conflicts occur. The imposition of a state's routine chain-of-command rules on the ombudsman can significantly constrain his or her independence, although no person in such situations may intentionally act to interfere with the work of the ombudsman.”¹⁸

**The LTCO's
loyalty is to
residents.**

The OAA provisions clearly require ombudsmen 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 government system, 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 ombudsman is a surrogate voice for residents of long-term care facilities. The ombudsman fulfills his or her loyalty to the employing entity by serving as an agent of residents.¹⁸ Thus, the SLTCO 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 a program administrator within a larger agency.

“Few other jobs so empower and compel a person to identify and speak the truth in all circumstances, even when doing so may draw criticism, anger, or even punishment. The opportunity to speak up for someone who cannot do so for herself, to advocate for individuals or groups of people who otherwise might have no voice, no ‘seat at the table,’ keeps every day fresh and gives every meeting the potential to be important.”

Esther Houser, Oklahoma State Long-Term Care Ombudsman

“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. The LTCOP is subject to specific conflict of interest provisions.

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 ombudsmen and program entities. These requirements underscore the importance of maximizing the ability of the ombudsman 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 ombudsmen need to speak honestly and publicly about conditions experienced by residents and about the impact of actions, policies, and laws, on residents.

4. The LTCOP is responsible for upholding strict confidentiality provisions.¹⁹

Although confidentiality is important in the human services field, the LTCOP has specific and strict confidentiality provisions stipulated in the Older Americans Act. The LTCOP is not allowed to share identifying information with other state or provider agencies about residents or complainants without the resident’s consent. This provision can become a source of misunderstanding with other agencies or even other programs co-located with the ombudsman program.

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. 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 program and representation of ombudsmen. 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 individuals;**
- **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 *and* 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 OAA to include a resident advocate function, these other words have some distinct meanings based on the OAA. These distinctions can lead to misunderstanding. Ombudsmen may find themselves in a disagreement with someone from another program or agency because each person is attaching a different meaning to the same word. 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

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 an ombudsman investigation is to determine what is the real issue. In seeking information about the presenting issue, an ombudsman 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.

LTCO investigate to resolve problems

In contrast to the primary outcome sought by ombudsmen, 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

There are three legal standards of evidence used by the courts: preponderance of the evidence, clear and convincing, and beyond a reasonable doubt. Agencies with investigatory responsibility must meet specific evidentiary standards to prove intent or harm before they can act. State survey agencies must meet only the preponderance of evidence standard. Other agencies, such as the Medicaid Fraud and Abuse Control Unit, 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.

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, ombudsmen work *on behalf of residents*. Thus, the LTCO advocates on behalf of the resident even without a direct violation of a standard or regulation.

Other agencies may discount the quality or thoroughness of the LTCOP investigation because it does not follow their agency's protocols. The root of this perception is a lack of understanding of the *purpose* of the ombudsman's investigation.

Confidentiality

The OAA stipulates strict parameters for protecting the confidentiality of the *identity* of complainants. There are also very specific provisions for the release of LTCOP information. Virtually all human services agencies have confidentiality provisions. Typically there is some mutual sharing of client information among programs or agencies serving the same population, particularly among programs within the same agency. 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 have adult abuse and neglect laws that list LTCO as mandated reporters. Such laws conflict with the federal OAA confidentiality provisions. In a letter to the Center for Social Gerontology clarifying 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.”²⁰

Adhering to these confidentiality provisions can be misconstrued. Some may think the LTCOP believes it has some kind of moral superiority to other programs because others in the agency cannot access the ombudsman files. Others may feel that the program is trying to circumvent supervision by not opening its files to administrative supervisors. Hard feelings can result if others

think the program is unfairly withholding information. In reality, 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 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. These additional dimensions are the source of misunderstanding and tension between the LTCOP and other programs or agencies.

The Institute of Medicine's study of the program devoted Chapter 4 to this topic.²¹ 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 local ombudsmen are part time, where is their greater commitment in terms of time and loyalty? This issue is very evident in states where the local ombudsmen are employed by another agency without direct participation from the SLTCO. The commitment of the local ombudsmen to their direct employer may be greater than their commitment to fulfilling the responsibilities of the LTCOP and working with the SLTCO.

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. As ombudsmen 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?

Credibility rests on acting on behalf of residents.

Because conflict of interest provisions are commonplace, when the LTCOP calls for a more strict view of what constitutes such conflicts, the program is viewed as wanting to be free from accountability. Just the opposite is true. 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.

V. 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. Ombudsmen 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*²² accountability is discussed as follows.

“State Long-Term Care Ombudsmen 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.” p. 1

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 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 Institute of Medicine’s (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.²³
- Other studies have been conducted by the Office of Inspector General.²⁴ 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.²⁵

VI. LONG-TERM CARE OMBUDSMAN PROGRAM ASSOCIATIONS

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

- The National Association of State Long-Term Care Ombudsman Programs 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 Ombudsmen (NALLTCO) adopted By-Laws in 1996 following many years of informal meetings. Its membership consists of local LTCO. Its purpose is:

“to organize and provide a common voice for local long-term care ombudsmen 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 ombudsmen’s staff; and providing information to policy makers on legislation and regulations impacting local ombudsman program and long- term care residents.”

VII. NATIONAL LONG-TERM CARE OMBUDSMAN RESOURCE CENTER

The National Long-Term Care Ombudsman Resource Center 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 the National Citizens' Coalition for Nursing Home Reform (NCCNHR), 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.

Center Activities

All tasks undertaken by the Center are designed and developed with input from state and local long-term care ombudsmen, the National Association of State Long-Term Care Ombudsmen, the National Association of Local Long-Term Care Ombudsmen and other relevant organizations to ensure that the needs of ombudsman programs across the country are being addressed. These tasks are developed with the understanding that in supporting the long-term care ombudsmen, the Center is ultimately contributing to the improvement of the quality of life and care of frail, vulnerable residents in long-term care facilities. The Center engages in the following activities and services:

- Provides consultation and information and referral for ombudsmen and for the residents, families and others who use ombudsman services;
- Provides training opportunities and training resources for state and local programs;
- Promotes public awareness of the role of ombudsmen in long term care;
- Works to improve ombudsmen effectiveness in meeting the needs of residents, including those served by managed care organizations and those in alternative settings, such as Medicaid waiver programs;
- Identifies research needs and promotes research on issues which affect the ombudsman programs or their constituents;
- Supports the ombudsman volunteer component through work with the American Association of Retired Persons (AARP) and other national or state-wide efforts to recruit volunteers for the program;
- Works cooperatively with all organizations and agencies which have as their mission the protection of the frail elderly who reside in long-term care settings; and
- Promotes understanding and cooperation between ombudsman programs and citizen advocacy groups.

During recent years, the National Long-Term Care Ombudsman Resource Center has been increasingly responsive to the ever more sophisticated needs of long-term care ombudsmen. Each week, Center staff respond to an average of thirty requests for technical assistance from state and regional (local) ombudsman programs and/or consumers needing referral to a long-term care ombudsman program. Center staff provide information and guidance on a variety of issues, some of which are quite complex, related to resident quality of care and life, state and federal law and regulations on enforcement and long-term care financing, nursing home closure, and ombudsman programmatic concerns.

The LTCOP for State

The Center also coordinates training opportunities for the ombudsman network. A training conference for state ombudsmen is held each spring. Special orientation sessions for new state ombudsmen are conducted semi-annually, in conjunction with the spring conference and with the NCCNHR Annual Meeting. Center staff develop sessions on a wide variety of topics ombudsmen have identified as being important to their work for the NCCNHR meeting.

VIII. WHY OMBUDSMEN 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.

“In the past 27 years I have served the public in various capacities...None of these positions has been more satisfying and rewarding than serving the frail and elderly residents of our long-term care facilities. This is truly a labor of love for me and I know that I speak for all of the volunteers and program staff when I say that our reward comes from knowing that these individuals are better off because of the work we do.”

John Sammons, Kentucky State Long-Term Care Ombudsman

“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 ombudsmen; 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 feel so lucky to have had a position [for 21 years] where I could act on my values. Lucky, so lucky to be able to work out solutions for individuals and at the same time work with the finest colleagues to change systems.”

Virginia Fraser, Former Colorado State Long-Term Care Ombudsman

IX. 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 and their representatives. 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 office 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.²⁶

The uniqueness of the LTCOP is also the source of inherent misunderstanding and tension as the program carries out its mandates. 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.

APPENDIX

The Long-Term Care Ombudsman Program – 1972-2003

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, former Commissioner on Aging Arthur S. Flemming invited all State Agencies on Aging to submit proposals for “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 services 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. In explaining this goal, he stated,
- 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. (AoA TAM 76-24)*
- The early nationwide program stressed reliance on volunteer, rather than paid, ombudsmen.
- 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 ombudsmen 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 Long-Term Care 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.

2003 Over 1,000 paid long-term care ombudsmen and 8,400 volunteers provide services to the 2.8 million residents in over 63,000 facilities. 32% of complaints handled involve resident rights; 30% are related to resident care; and 21% are about quality of life.

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 client², 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.

² In the Code of Ethics, *client* refers to the range of consumers served by LTCO such as residents, their families members, and individuals who are seeking information about long-term care facilities.

References

1. 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.
2. National Ombudsman Reporting System Data, Fiscal Year 2002, Administration on Aging.
3. 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.
4. 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 Ombudsmen, Rhode Island, April 2000.
5. Butler, R.N. *Why Survive? Being Old in America*. NY: Harper & Row, 1975.
6. Holder, op.cit.
7. *The Long-Term Care Ombudsman Program, 1972-2003, Program Milestones*. AoA, included in the Appendix and Holder, E. op.cit.
8. *The Long-Term Care Ombudsman Program: Development from 1975-1980*, A report by the Long-Term Care Ombudsman Staff, Office of Program Development, Administration on Aging, Washington, D.C. January, 1981.
9. Adapted from the Arkansas LTCOP Annual Report, op.cit.
10. For information regarding the LTCOP's role in addressing systems issues, refer to *Ombudsman Best Practices: Using Systems Advocacy to Improve Life for Residents*. Hunt, S. National Long-Term Care Ombudsman Resource Center. June 2002, PO 752. www.ltombudsman.org.
11. The data is based on Fiscal Year 2002 National Ombudsman Reporting Systems data submitted to the Administration on Aging.
12. 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.
13. 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.ltombudsman.org
14. Much of the content in Sub-Sections IV and V is adapted from "The LTCOP Unique Characteristics," Hunt, S. National LTCO Resource Center, NCCNHR, Washington, DC. October 2002.
15. *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.
16. 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>.
17. Based on a conversation with Becky Kurtz, Georgia State LTCO, and NASOP representative to the ABA Ombudsman Standards Committee, October 2002.
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.
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.
20. For more information on confidentiality, refer to *Ombudsman Best Practices: Confidentiality*. Grant, R. National Long-Term Care Ombudsman Resource Center. December 2000. www.ltombudsman.org.
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.
22. Institute of Medicine. op. cit.
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://ltombudsman.org/ombpublic/49346965.CFM#orc> ref. It is under Library, Basics, IOM, Study of State LTCOP.
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-02-98-00351.
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. published in 2003.
27. Holder, op.cit.