

ROLE AND RESPONSIBILITIES OF LONG-TERM CARE OMBUDSMEN REGARDING SYSTEMS ADVOCACY

State Long-Term Care Ombudsmen

“In addition to working on individual cases and complaints, ombudsmen must address and attempt to rectify the broader or underlying causes of problems for residents of LTC facilities. When working on the systems level, ombudsmen advocate for policy change by evaluating laws and regulations, providing education to the public and facility staff, disseminating program data, and promoting the development of citizen organizations and resident and family councils.”¹

OVERVIEW

The Older Americans Act (OAA) outlines the responsibilities of the State and their Long-Term Care Ombudsman Programs (LTCOPs), clearly stating that the primary role of Long-Term Care Ombudsmen is to serve as resident advocates. Ombudsmen are charged with serving as the resident advocate in response to individual complaints as well as advocating for the concerns of residents and need for change on a systems level. This quick reference guide will briefly define systems advocacy, review the federal mandate and support for systems advocacy work by Ombudsmen, define several systems advocacy strategies, share examples of Ombudsmen involved in systems advocacy and provide resources for additional information.

KEY POINTS

What is Systems Advocacy?

“Advocacy” means “the act of pleading for, supporting or recommending” and “system” is a broad term that means, “a combination of things or parts forming a complex or unitary whole” or “a coordinated body of methods or a scheme or plan of procedure.”² Therefore, “systems advocacy” means to recommend changes to a system (e.g. a long-term care facility, a government agency, an organization, a corporation, policies, regulations and law) to benefit long-term care residents. Effective and credible systems advocacy should generally be supported by data and complaint trends, but can also be in response to policy, regulatory and legislative proposals that could negatively impact residents.

Older Americans Act Provisions

Systems advocacy is a core responsibility of the Office of the State Long-Term Care Ombudsman (OSLTCO) as the Older Americans Act requires States to establish and operate its OSLTCO to:

- Represent the interests of residents before governmental agencies and 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, that pertain to the health, safety, welfare, and rights of the residents, with respect to long-term care facilities and services in the state;
- Facilitate public comment on laws, regulations, policies, and actions related to residents of long-term care facilities and the ombudsman program;

¹ Institute of Medicine. *Real People Real Problems: An Evaluation of the Long-Term Care Ombudsman Programs of the Older Americans Act*. 1995. p.72.

² Dictionary.com. 2013. Dictionary.com LLC (IAC Corporation). March 6, 2013.

- Recommend any changes in laws, regulations, policies, and actions that will further promote the interests, well-being and rights of residents.

Additionally, the OAA states that the State agency must require the OSLTCO to:

- Provide such information as the OSLTCO determines to be necessary to public and private agencies, legislators, and other persons, regarding: (1) the problems and concerns of individuals residing in long-term care facilities; (2) and recommendations related to these problems and concerns.

Designated Local Ombudsmen Entities and Representatives are likewise to:

- Represent the interests of residents before government agencies and seek administrative, legal, and other remedies to protect the health, safety, welfare, and rights of the residents;
- Review, and if necessary, comment on any existing and proposed laws, regulations, and other government policies and actions, that pertain to the rights and well-being of residents;
- Facilitate the ability of the public to comment on the laws, regulations, policies, and actions;
- Support the development of resident and family councils; and
- Carry out other activities that the [State] Ombudsman determines to be appropriate.

(Older Americans Act of 1965, Sec. 712(a)(3), 712(a)(5)(B), 712(h)(3), 42 U.S.C. §3058g)³

In 1987, amendments to the Older Americans Act provided additional protection of OSLTCO responsibilities by requiring each state to:⁴

- Protect from liability ombudsmen who properly carry out the functions of the Office; and
- Make unlawful the willful interference with representatives of the OSLTCO in the performance of their official duties.
- Prohibit retaliation against an LTCO, resident or other individual for assisting representatives of the program in the performance of their duties

In order for the OSLTCO to fulfill the program's core responsibility of systems advocacy, the State must ensure that the OSLTCO has full authority granted by the OAA, such as:

- Access to long-term care facilities and residents;
- Access to decision-makers within state agencies;
- Adequate legal counsel;
- Authority to make recommendations to legislators without interference;
- Freedom to discuss non-confidential information with the media.⁵
- Access to the administrative records, policies, and documents, to which the resident have, or the general public has access, of long-term care facilities; and
- Access to and, on request, copies of all licensing and certification records maintained by the State with respect to long-term care facilities.⁶

Administration on Aging Statements Regarding the LTCOP and Systems Advocacy

In addition to the program requirements regarding systems advocacy outlined in the Older Americans Act, the Administration on Aging has responded to questions regarding the OSLTCO's systems advocacy responsibilities. Three examples are below.

³ Systems Advocacy: Issue Brief Prepared for the Long-Term Care Ombudsman Guidance Strategy Session. December 8, 2011

⁴ Special Committee on Aging. United States Senate. Older Americans Act of 1987: A Summary of Provisions. Public Law 100-175. An Information Paper. December 1987. p. 14

⁵ National Association of State Long-Term Care Ombudsman Programs. *White Paper: Systems Advocacy and The Long-Term Care Ombudsman Program*. March 2007.

⁶ Older Americans Act of 1965. Sec. 712(b)(1)

- “The State [Unit on Aging] must affirmatively require the LTCOP to carry out issue advocacy and logically may not simultaneously erect barriers to the advocacy.”⁷
- “The State agency does not have the right to approve the communications that the Ombudsman’s Office chooses to make to policy makers, including a State legislature. However, the OAA does not prohibit [the Agency] from adopting a policy requiring proposed testimony from being shared in advance or circulated for comments or in-put, provided that in the end the ombudsman retains the absolute right to decide what finally should be presented by that Office.”⁸
- “...Information dissemination is often one of the most effective ways for the LTCO to conduct issue advocacy on behalf of residents and their interests as well as to provide valuable information to the public...Effectively conducting information dissemination depends upon the program’s ability to freely respond to media inquiries, issue press releases and hold press conferences.”⁹

HOW CAN OMBUDSMEN GET INVOLVED IN SYSTEMS ADVOCACY?

The OAA requirements regarding systems advocacy apply to the Long-Term Care Ombudsman Program and the program’s representatives, meaning State *and* Local Ombudsmen are expected to engage in systems advocacy. The role of the State LTCO in regards to systems advocacy varies from the role of Local LTCO (e.g. the SLTCO may create a statewide systems advocacy plan and typically represents the Office of the SLTCOP in testifying before the legislature). As the “head” of the OSLTCO, the State Ombudsman has a responsibility to set the tone and messaging as it relates to systemic advocacy in order to maintain program consistency and coordination in advocacy work for all Ombudsman Program representatives. Although the roles and approach of State and Local Ombudsmen in systems advocacy differ, the requirement to voice resident concerns at a systems level is the same whether in individual facilities, a corporation, locally or statewide.

Legislative advocacy is an excellent example of systems advocacy, but it is not the only strategy as there are a variety of ways for State and Local Long-Term Care Ombudsmen to voice resident concerns and address issues that impact residents at the systems level. The four strategies listed below and the examples are not comprehensive, rather they are a sampling of Ombudsman systems advocacy work.

SYSTEMS ADVOCACY STRATEGIES

PROCEDURAL ADVOCACY

When the LTCOP strengthens its policies, procedures and program tools related to systems advocacy, provides information and training regarding the LTCOP role in systems advocacy or when the program pursues meaningful, regular communication and coordination with other entities related to systemic issues in long-term care, the LTCOP is engaging in procedural systems advocacy.

Example of Procedural Advocacy

The Texas SLTCO provided training to the 28 Area Agency on Aging (AAA) Directors regarding the LTCOP provisions of the Older Americans Act (OAA) in order to clarify the role and responsibilities of the OSLTCO, especially in regards systems advocacy.

⁷ Administration on Aging. *Review of the State of Florida Long-Term Care Ombudsman Program*. September 1, 2011. p. 14.

⁸ Administration on Aging Region V Memorandum to Iowa State Agency, April 26, 2010.

⁹ AoA. *Review of the Florida LTCOP*. op.cit, p. 19.

COALITION BUILDING/DEVELOPMENT OF PARTNERSHIPS

Another effective way to engage in systems advocacy and expand the reach of the LTCOP is to develop partnerships or build or join a coalition with other entities that share an interest in improving long-term care. Working with other entities, such as Citizen's Advocacy Groups (CAGs), Culture Change Coalitions, resident or family councils or serving on advisory committees or task forces ensures that the resident or consumer of long-term care services is represented.

Example of Coalition Building/Development of Partnerships

The Maine LTCOP co-chairs the Maine Partnership to Improve Dementia Care with the state's LANE (Local Area Network of Excellence). They have established a large, statewide coalition to work on this effort that includes representatives of the long-term care provider industry, the state survey agency, the culture change coalition, medical directors, the QIO (Quality Improvement Organization) and more. To share and promote best practices in dementia care the coalition has provided a webinar for the state's nursing homes and a statewide conference for the nursing facilities, which included presentations from national dementia care experts.

ISSUE ADVOCACY

Issue advocacy occurs when a LTCOP analyzes their complaint and activity data to identify trends and develop a systems advocacy approach in response to the identified issues or a timely "hot topic" issue outside of LTCOP complaint data. State Ombudsmen may choose an issue for statewide systems advocacy after analyzing statewide program data and/or Local Ombudsmen may determine their own local systems advocacy agenda based on their local data. There may be different local issues and concerns across the state. State and Local Ombudsmen share information a variety of ways including: utilizing the internet, press releases, letters to the editor, community education sessions, discussions with Resident and Family Councils and creating and distributing fact sheets.

Example of Issue Advocacy

The Connecticut LTCOP is the sponsor and partner of the Statewide Coalition of Presidents of Resident Councils and the VOICES Forum. The annual VOICES Forum provides Presidents of Resident Councils from across the state with an opportunity to share their experiences and issues in their homes. Due to a resident question during the 2005 VOICES Forum, the Connecticut LTCOP created a statewide work group and commissioned the University of Connecticut Health Center to study the fear of retaliation in nursing homes. The study found that "retaliation and the fear of retaliation is a reality in any supportive housing situation [and] retaliation can be either egregious or subtle; many forms of retaliation may not even be recognized by residents or staff." In response to these findings, the LTCOP developed the Voices Speak Out Against Retaliation training video and training guide to share the reality of residents' fear of retaliation and how staff, family members, ombudsmen and other residents could help reduce and overcome that fear.¹⁰

LEGISLATIVE ADVOCACY

The OAA requires the LTCOP and program representatives to participate in legislative advocacy. Legislative advocacy occurs when the LTCOP and program representatives analyze, comment on and monitor the development and implementation of federal, state, and local laws, regulations, and policies related to long-term care; facilitate public comment on laws, regulations, policies, and actions related to residents of long-term care facilities and recommend changes in laws, regulations, policies, and actions in order to further promote the interests, well-being and rights of residents. State and Local LTCOP engage in legislative advocacy in a variety of ways including, but not limited to: sharing information about pending legislation or regulations that impact residents; encouraging consumer participation in the legislation or rule-making process; providing testimony on behalf of residents before the legislature; meeting with individual legislators; submitting comments; participating in the drafting of local, state and federal laws and regulations; communicating with local, state and federal representatives; determining legislative activities and agenda for the LTCOP.

¹⁰ CT.gov. 2012. State of Connecticut. <http://www.ct.gov/ltcop/cwp/view.asp?Q=473774&A=3821>. June 21, 2012.

Example of Legislative Advocacy

The Washington SLTCO worked closely with other advocates to secure passage of HB 1494. This law provides consumer protections by establishing minimum requirements for elder placement referral agencies regarding fees and refunds, documentation, disclosure statements and intake forms. It became law in January 2012. Achieving successful passage required meeting with individual legislators to explain the need for the bill (both in their office and in the hallways), working with the OLTCO legal counsel on drafting amendments, numerous meetings with stakeholders to negotiate provisions of the bill, providing testimony, raising public awareness through various media activities including e-mailing legislative alerts, and contacting local newspapers to follow the story and include articles and favorable opinion-editorials. Local ombudsmen assisted by forwarding e-mail alerts and, at request of the SLTCO, identified volunteers who had positive relationships with their local legislators, allowing for the SLTCO to request their assistance as appropriate. The SLTCO developed a feedback grid to track each legislator’s support, concern or opposition to the bill and was used by those seeking its passage to tailor the legislative strategy.

LONG-TERM CARE OMBUDSMAN PROGRAM CONSIDERATIONS WHEN DEVELOPING A SYSTEMS ADVOCACY AGENDA

There are some fundamental questions Ombudsmen should consider prior to engaging in systems advocacy. For the purpose of this paper, the questions below are not a comprehensive list; rather they are a sampling of questions to be used when developing a systems advocacy agenda or plan. Ombudsmen often need to respond to time-sensitive issues; therefore, not all systems advocacy work will be part of a predetermined systems advocacy agenda or plan. However, the questions below will help all Ombudsmen assess their program and lay the foundation for effective systems advocacy. For Ombudsmen seeking a more in-depth discussion and considerations regarding systems advocacy, please review the materials listed in the “Resources” section.

BASIC QUESTIONS TO CONSIDER WHEN ENGAGING IN SYSTEMS ADVOCACY ¹¹	
PREPARATION	<p>Plan Development</p> <ul style="list-style-type: none">• In addition to federal law, does the LTCOP, state level and local level, have a clear <i>state mandate</i> to pursue systems changes on behalf of residents?• What changes, if any, in the program will need to occur (e.g. reallocation of time, delegation of tasks within the office)?• What are the priorities of the OSLTCO and in what areas do you need to respond to as part of your systems advocacy agenda (e.g. do you have clear legislative or regulatory priorities)?• Are you including local LTCOPs in this effort? How will you share your plan and systems advocacy activities?• What external influences are impacting your systems advocacy agenda (e.g. media attention, budget cuts, changing landscape of LTC)?• Do you and your program representatives understand all of the processes and procedures relevant to the issue your program plans to address using systems advocacy (e.g. legislative process, regulatory process)?• Are there critical deadlines to take into considerations (e.g. legislative session cut-off dates, regulatory rule making dates, media deadlines)?• Do you know experts who can assist you and your program (e.g. legal counsel to help interpret laws and regulations, someone with policy expertise, someone to help you learn the legislative process)?

¹¹ The National Long-Term Care Ombudsman Resource Center. *Ombudsman Best Practices: Using Systems Advocacy to Improve Life for Residents*. June 2002.

PREPARATION (continued)	<p>Data/Problem Identification</p> <ul style="list-style-type: none"> • Is this issue significant to residents and supported by LTCOP data and information? • Do you have clear examples of the impact on residents and stories to share? • What goals do you want to accomplish and how will “success” be measured? • How does local program data compare to statewide data? Are there significant variations across regions?
	<p>Potential collaboration and coordination</p> <ul style="list-style-type: none"> • What have others already done pertinent to this issue? • Are there other agencies and/or organizations with which your program should work? • What needs to be considered prior to and while working with other agencies or organizations (e.g. advocacy goals/objectives, perceived or actual conflict of interest)?
	<p>Scope</p> <ul style="list-style-type: none"> • How widespread does the strategy need to be implemented? • Is the strategy to change facility practices and policies? Regulations? Legislation? For example: <ul style="list-style-type: none"> ○ Can the issue be resolved by changing procedures within one corporation/chain of facilities? ○ Does it require work at the state level to change state laws or regulations (e.g. improving abuse and neglect laws)? ○ Can it only be resolved by changing procedures within a federal region (e.g. CMS guidance,) or on a national basis? ○ Will you seek assistance from all local LTCOPs or will you target specific regions? ○ If the strategy goes beyond your state and is a federal or federal regional issue have you identified other partners?
	<p>Risks and Rewards</p> <ul style="list-style-type: none"> • What are the potential ramifications of your advocacy strategies (e.g. positive, negative, possible unintended consequences)?
RESOURCES	<p>What program resources will be devoted to systems advocacy?</p> <ul style="list-style-type: none"> • Do you have internal program resources that could be utilized (e.g. staff or volunteers with skills or expertise related to the issue)? • Will your program need support from external sources? If so, is there a potential for perceived or actual conflict of interest or other concerns when enlisting such support (e.g. university research, experts)?¹² • Will there be any expenses to your program for this advocacy (e.g. administrative costs, creating and printing educational materials, travel)?
	<p>How will this advocacy impact your program?</p> <ul style="list-style-type: none"> • Is this a long term or short term commitment? • Is this on-going? Or cyclical? For example, a rule making process has an end point; legislative sessions have a start and end date, but they happen routinely and advocacy with the legislature occurs in the interim and sometimes over more than one legislative session. • Has the statewide LTCOP discussed how to focus on systems change and continue to respond to the concerns of individual residents? • Does the impact on residents justify the amount of resources required to pursue this issue?
PROGRAM MANAGEMENT	<p>Roles, Responsibility and Training</p> <ul style="list-style-type: none"> • Is the SLTCO providing leadership and support for local ombudsmen in understanding and making an impact on the pertinent process, system or issue? • Who will be involved and what are their roles (e.g. Local LTCO staff and/or volunteer LTCO)? • Is additional training necessary for the individuals involved?

¹² Office of the Ombudsperson. Province of British Columbia. Planning Checklist.

ADDRESSING POTENTIAL BARRIERS	<p>Host Agency Support</p> <ul style="list-style-type: none"> • Is the LTCOP located in an agency or organization that supports the program’s requirement to act on behalf of residents even if the result is a public stance that differs from that of the placement organization or agency? <ul style="list-style-type: none"> ○ If so, does the LTCOP receive support if its advocacy actions are questioned by an umbrella agency or by the agency responsible for contracting for the statewide program? ○ If not, are you advocating within your host agency regarding the OAA systems advocacy responsibilities? Is this done in advance of a need to engage in systems advocacy? • Is this type of support available at the local level?
	<p>Communication</p> <ul style="list-style-type: none"> • Are individuals in the chain-of-command over the LTCOP: <ul style="list-style-type: none"> ○ Informed of the program’s statutory responsibility in the OAA to pursue a variety of remedies on behalf of residents? ○ Informed of the system advocacy agenda and actions taken? • Do you and your program representatives have experience communicating with outside entities (such as the legislature or the media)? If not, prior to communicating with an outside entity seek training, advice and/or examples from people with experience working with that entity. • In addition to the submission of required LTCO reports, do you plan on sharing the outcome of your systems advocacy action? If so, how? • Is there any opposition to your systems advocacy agenda? If so, do you have responses to their concerns?

SHARE YOUR EXPERIENCE

We invite and encourage you to share your policies, practices, training and activities regarding systems advocacy by sending an email to ombudcenter@theconsumervoice.org.

RESOURCES

Long-Term Care Ombudsman Program Strategy Session: Final Report. Issue Brief- Systems Advocacy (Appendix D4). December 8, 2011. <http://www.ltombudsman.org/sites/default/files/norc/ltcop-strategy-session.pdf>

Ombudsman Best Practices: Using Systems Advocacy to Improve Life for Residents. Sara S. Hunt. National Long-Term Care Ombudsman Resource Center. June 2002. <http://www.ltombudsman.org/sites/default/files/norc/systems-advocacy-paper.pdf>

Real People Real Problems: An Evaluation of the Long-Term Care Ombudsman Programs of the Older Americans Act. Institute of Medicine. 1995. http://www.nap.edu/catalog.php?record_id=9059

Systems Advocacy and the Local Long-Term Care Ombudsman Program. Brooke Hollister. 2008. <http://www.ltombudsman.org/sites/default/files/library/documents/Systems-Advocacy-and-LTCOP-Hollister.pdf>

Systems Advocacy and the Long-Term Care Ombudsman Program. National Association of State Long-Term Care Ombudsman Programs. March 2007. <http://www.nasop.org/papers/45.pdf>

The Long-Term Care Ombudsman Program: Rethinking and Retooling for the Future. NASOP Retreat Proceedings and Recommendations. Appendix IV: Independence and LTCOP's Ability to Fully Represent Residents. National Association of State Long-Term Care Ombudsman Programs. April 2003. <http://www.nasop.org/papers/Bader.pdf>

The Long-Term Care Ombudsman Program: Rethinking and Retooling for the Future. NASOP Retreat Proceedings and Recommendations. Appendix V: Systems Advocacy in the Long-Term Care Ombudsman Program. National Association of State Long-Term Care Ombudsman Programs. April 2003. <http://www.nasop.org/papers/Bader.pdf>

**Additional systems advocacy resources available on the NORC website: http://www.ltombudsman.org/ombudsman-support/systemic-advocacy#Ombudsman_Program_Examples*

The National Long-Term Care Ombudsman Resource Center (NORC) is a program of the National Consumer Voice for Quality Long-Term Care (the "Consumer Voice"), funded by a grant from the Administration on Aging (AoA), Administration for Community Living (ACL), U.S. Department of Health and Human Services (HHS). Grantees undertaking projects under government sponsorship are encouraged to express freely their findings and conclusions. Points of view or opinions do not, therefore, necessarily represent official Administration on Aging policy.