

Role and Responsibilities of Ombudsman Programs 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) and State Long-Term Care Ombudsman Programs Rule outline the responsibilities of the State Ombudsman and their representatives, clearly stating that the primary role of the Long-Term Care Ombudsman Program is to serve as resident advocates.² Ombudsman programs 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 reference guide will briefly define systems advocacy, review the federal mandate and support for systems advocacy work by Ombudsman programs, 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.”³ 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;

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 Older Americans Act of 1965. Section 712 (a)(3)(A) <https://legcounsel.house.gov/Comps/Older%20Americans%20Act%20Of%201965.pdf>; State Long-Term Care Ombudsman Programs Final Rule <http://ltcombudsman.org/uploads/files/library/2015-01914.pdf>.

³ Dictionary.com. 2013. Dictionary.com LLC (IAC Corporation). March 6, 2013.

- Facilitate public comment on laws, regulations, policies, and actions related to residents of long-term care facilities and the ombudsman program;
- 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)⁴

In 1987, amendments to the Older Americans Act provided additional protection of OSLTCO responsibilities by requiring each state to:⁵

- 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

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.⁶
- Access to the administrative records, policies, and documents, to which the resident has, 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.⁷

⁴Systems Advocacy: Issue Brief Prepared for the Long-Term Care Ombudsman Guidance Strategy Session. December 8, 2011

⁵ 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

⁶ National Association of State Long-Term Care Ombudsman Programs. *White Paper: Systems Advocacy and The Long-Term Care Ombudsman Program*. March 2007.

⁷ Older Americans Act of 1965. Sec. 712(b)(1)

State Long-Term Care Ombudsman Programs, Final Rule⁸

The State Long-Term Care Ombudsman Programs Final Rule was published in February 2015 and went into effect July 2016. The Rule expands upon the intent of the Older Americans Act and gives more detail regarding the role and responsibilities of the LTCOP, including systems advocacy. In response to comments on the proposed Rule, ACL states, “the Act creates the Ombudsman program to resolve problems for residents of long-term care facilities on individual as well as systemic levels. Therefore, the ability to take positions and make recommendations that reflect the interests of residents is critical to the effectiveness of the Ombudsman program.”

§1324.11 (e)(5)

Systems advocacy. Policies and procedures related to systems advocacy must assure that the Office is required and has sufficient authority to carry out its responsibility to analyze, comment on, and monitor the development and implementation of Federal, State, and local laws, regulations, and other government policies and actions that pertain to long-term care facilities and services and to the health, safety, welfare, and rights of residents, and to recommend any changes in such laws, regulations, and policies as the Office determines to be appropriate.

- (i) Such procedures must exclude the Ombudsman and representatives of the Office from any State lobbying prohibitions to the extent that such requirements are inconsistent with section 712 of the Act.
- (ii) Nothing in this part shall prohibit the Ombudsman or the State agency or other agency in which the Office is organizationally located from establishing policies which promote consultation regarding the determinations of the Office related to recommended changes in laws, regulations, and policies. However, such a policy shall not require a right to review or pre-approve positions or communications of the Office.

§1324.13 Functions and responsibilities of the State Long-Term Care Ombudsman.

(a)(7)(iv) Provide leadership to statewide systems advocacy efforts of the Office on behalf of long-term care facility residents, including coordination of systems advocacy efforts carried out by representatives of the Office;

(a)(7)(vii) In carrying out systems advocacy efforts of the Office on behalf of long-term care facility residents and pursuant to the receipt of grant funds under the Act, the provision of information, recommendations of changes of laws to legislators, and recommendations of changes of regulations and policies to government agencies by the Ombudsman or representatives of the Office do not constitute lobbying activities as defined by 45 CFR part 93.

§1324.15 State agency responsibilities related to the Ombudsman program.

(j) Legal counsel.

- (1) The State agency shall ensure that:
 - (2) (i) Legal counsel for the Ombudsman program is adequate, available, has competencies relevant to the legal needs of the program and of residents, and is without conflict of interest (as defined by the State ethical standards governing the legal profession), in order to—
 - (A) Provide consultation and representation as needed in order for the Ombudsman program to protect the health, safety, welfare, and rights of residents; and
 - (B) Provide consultation and/or representation as needed to assist the Ombudsman and representatives of the Office in the performance of their official functions, responsibilities, and duties, including, but not limited to, complaint resolution and systems advocacy;

⁸ Published in the Federal Register, 02/11/2015, Vol. 80, No. 28. LTCOP Final Rule <https://www.federalregister.gov/documents/2015/02/11/2015-01914/state-long-term-care-ombudsman-programs>, correcting document with technical and typographical errors amended published in December 2016 <https://www.federalregister.gov/documents/2016/12/20/2016-30455/state-long-term-care-ombudsman-programs>

Administration on Aging (AoA)/Administration for Community Living (ACL) Statements Regarding the LTCOP and Systems Advocacy

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

- "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."⁹
- "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."¹⁰
- "...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."¹¹

HOW CAN OMBUDSMEN GET INVOLVED IN SYSTEMS ADVOCACY?

The OAA and Rule requirements regarding systems advocacy apply to the Long-Term Care Ombudsman Program and the program's representatives, meaning State Ombudsmen and local Ombudsman program representatives are expected to engage in systems advocacy. However, the role of State Ombudsmen regarding systems advocacy varies from the role of Ombudsman program representatives (e.g., the SLTCO creates 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 to maintain program consistency and coordination in advocacy work for all Ombudsman program representatives. Although the roles and approach of the Ombudsman and representatives 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 the Ombudsman and representatives to voice resident concerns and address issues that impact residents at the systems level. There are three strategies listed below. The examples are not comprehensive, rather they are a sampling of Ombudsman program systems advocacy work.

SYSTEMS ADVOCACY STRATEGIES

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.

⁹ Administration on Aging. *Review of the State of Florida Long-Term Care Ombudsman Program*. September 1, 2011. p. 14.

¹⁰ Administration on Aging Region V Memorandum to Iowa State Agency, April 26, 2010.

¹¹ AoA. *Review of the Florida LTCOP*. op.cit, p. 19.

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

When LTCOPs analyze their complaint and activity data to identify trends and develop a systems advocacy approach in response to identified issues or a timely "hot topic" issue outside of LTCO complaint data, the program is engaging in issue advocacy. State Ombudsmen may choose an issue for statewide systems advocacy after analyzing statewide program data and/or local Ombudsman program representatives may identify a local issue based on their local data and activities and coordinate with the State Ombudsman for systems advocacy locally to address the issue. There may be different local issues and concerns across the state. State Ombudsmen and program representatives share information in a variety of ways including: online and social media, 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.¹²

LEGISLATIVE ADVOCACY

The OAA and Rule requires the LTCOP to participate in legislative advocacy. Legislative advocacy includes analyzing, commenting on and monitoring the development and implementation of federal, state, and local laws, regulations, and policies related to long-term care; facilitating public comment on laws, regulations, policies, and actions related to residents of long-term care facilities and recommending changes in laws, regulations, policies, and actions to further promote the interests, well-being and rights of residents. The Ombudsman and representatives 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.

¹² 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, both in their office and in the hallways, to explain the need for the bill, working with the OSLTCO 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 Ombudsman representatives 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 the grid 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. The questions 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 on the last page.

BASIC QUESTIONS TO CONSIDER WHEN ENGAGING IN SYSTEMS ADVOCACY ¹³

PREPARATION	<p>Plan Development</p> <ul style="list-style-type: none"> • In addition to federal law and the Rule, does the LTCOP, state level and local level, have a clear state mandate 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 the processes and procedures relevant to the issue your program plans to address using systems advocacy (e.g., legislative process, regulatory process)?
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¹³ The National Long-Term Care Ombudsman Resource Center. *Ombudsman Best Practices: Using Systems Advocacy to Improve Life for Residents*. June 2002.

<p>PREPARATION (continued)</p>	<ul style="list-style-type: none"> • 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)?
	<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)?
<p>RESOURCES</p>	<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)? ¹⁴ • Will there be any expenses to your program for this advocacy (e.g., administrative costs, creating and printing educational materials, travel)?

<p>RESOURCES (continued)</p>	<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
<p>PROGRAM MANAGEMENT</p>	<p>Roles, Responsibility and Training</p> <ul style="list-style-type: none"> • Is the SLTCO providing leadership and support for program representatives 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?
<p>ADDRESSING POTENTIAL BARRIERS</p>	<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 and Rule 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 and Rule to pursue a variety of remedies on behalf of residents? • Informed of the system advocacy agenda and actions planned and 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?

¹⁴ Office of the Ombudsperson, Province of British Columbia. Planning Checklist.

RESOURCES

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

Older Americans Act. NORC Issue Page. <http://ltcombudsman.org/issues/older-americans-act>

Ombudsman Best Practices: Using Systems Advocacy to Improve Life for Residents. Sara S. Hunt. National Long-Term Care Ombudsman Resource Center. June 2002. <http://ltcombudsman.org/uploads/files/support/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

State Long-Term Care Ombudsman Programs, Final Rule. NORC Library. http://ltcombudsman.org/library/fed_laws/ltcop-final-rule

Systems Advocacy and the Local Long-Term Care Ombudsman Program. Brooke Hollister. 2008. <http://ltcombudsman.org/uploads/files/library/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.ltcombudsman.org/ombudsman-support/systemic-advocacy#Ombudsman_Program_Examples

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.

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