SYSTEMS ADVOCACY

It’s More Than Legislative Work

March 7, 2018
What is Systems Advocacy?

• **Advocacy**: the act of pleading for, supporting or recommending

• **System**: combination of things or parts forming a complex or unitary whole or a coordinated body of methods or a scheme or plan of procedure

• **Systems Advocacy**: recommend changes to a system to benefit long-term care residents
  • For example: a long-term care facility, a government agency, an organization, a corporation, policies, regulations and law

Polling Question #1

• Are you currently involved in a systems advocacy project?
  State Ombudsman: Yes
  State Ombudsman: No
  LTCOP Representative: Yes
  LTCOP Representative: No
# Systems Advocacy (SA) Strategies

## Coalition Building/Partnerships

- Expand the reach of the LTCOP by developing partnerships, building or joining a coalition with other entities that share an interest in improving long-term care.

## Issue Advocacy

- Develop a systems advocacy approach in response to the issues identified after data analysis or a timely “hot topic” issue outside of LTCO complaint data.

## Legislative Advocacy

- Required to participate in legislative advocacy.

- Analyze, comment on and monitor the development and implementation of federal, state, and local laws, regulations, and policies related to long-term care.
<table>
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<tr>
<th>Basic Questions to Consider When Engaging in Systems Advocacy</th>
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<tr>
<td><strong>Preparation</strong></td>
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<tr>
<td>• (State) 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)?</td>
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<td>• (Local) What direction and guidance have you received from the State LTCO?</td>
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<td><strong>Resources</strong></td>
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<td>• (State) Do you have internal program resources that could be utilized (e.g., staff or volunteers with skills or expertise related to the issue)?</td>
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<td>• (Local) Does the impact on residents justify the amount of resources required to pursue this issue?</td>
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<td><strong>Program Management</strong></td>
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<td>• (State) Is the SLTCO providing leadership and support for program representatives in understanding and making an impact on the pertinent process, system or issue?</td>
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<td>• (Local) Is additional training necessary for the individuals involved?</td>
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<td><strong>Addressing Potential Barriers</strong></td>
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<td>• (State) Are individuals in the chain-of-command over the LTCOP: Informed of the program’s statutory responsibility in the OAA and Rule to pursue a variety of remedies on behalf of residents?</td>
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<td>• (Local) How will you share your plan and systems advocacy activities with your State Ombudsman?</td>
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Older Americans Act (OAA)

• **Requirements**
  - Represent interests of residents before government agencies
  - Seek administrative, legal, or other remedies
  - Analyze, comment on, and recommend changes in laws and regulations pertaining to the health, safety, welfare, and rights of residents as the Office of the SLTCO deems appropriate
  - Facilitate public comment on laws, regulations, policies, and actions

• **Application**
  - Requirements regarding systems advocacy apply to the LTCOP and program representatives, meaning State and Local LTCO
  - As the “head” of the OSLTCO, the SLTCO sets the tone and messaging regarding systems advocacy and may:
    - Create a statewide systems advocacy plan
    - Represent the OSLTCOP in testifying before the legislature
1324.11 Establishment of the Office of the State Long-Term Care Ombudsman

• 1324.11(e) (5) Systems Advocacy Key Points
  • Policies and procedures must assure that the Office is required (and has sufficient authority) to carry out its statutory responsibilities, as the Office determines is appropriate, and regardless of State lobbying laws.

  • AoA response to a comment acknowledges that systems advocacy has been a challenge in some states, especially when the Ombudsman is a state employee.

  • Clarifies that consultation with the SUA is encouraged--but cannot be used to control positions or communications of the Office.

*content adapted from State Long-Term Care Ombudsman Programs: Final Rule (2015) Overview presentation by Becky Kurtz
1324.13 Functions and Responsibilities of the State Long-Term Care Ombudsman

- Reiterates functions from OAA, including systems advocacy, and provides further clarification that:
  - Ombudsman fulfillment of systems advocacy function of OAA does not violate federal lobbying restrictions and positions of the Office do not necessarily represent those of the State agency or other agency where the Office is housed.
  - Ombudsman is responsible for providing leadership for “statewide systems advocacy efforts of the Office.”

*content adapted from State Long-Term Care Ombudsman Programs: Final Rule (2015) Overview presentation by Becky Kurtz*
Role of SLTCO in Systems Advocacy

- **Develop a plan/agenda**
  - Listen to staff and volunteer LTCO experiences to identify issues
  - Analyze data for trends (not just complaint information)
  - Involve LTCOP representatives in systems advocacy

- **Leadership**
  - Develop a systems advocacy agenda/plan
  - “Model” systems advocacy (e.g., provide testimony)

- **Support**
  - Include information regarding the role of LTCO in systems advocacy in initial certification training
  - Provide training to LTCOP representatives regarding issues and systems advocacy
  - Provide support and assistance to address barriers
Role of Representatives of the Office Regarding Systems Advocacy

• **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)
Polling Question #2

- Are volunteers included in your systems advocacy project?
  - Yes
  - No
  - We're not doing any systems work at this time.
## Why involve volunteers in systems advocacy?

<table>
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<th>Benefits</th>
<th>Risks</th>
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<td>Expand reach of the program</td>
<td>More opportunities for error</td>
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<td>More engaged, empowered volunteers</td>
<td>“Rogue” volunteer</td>
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<tr>
<td>Utilizing individual volunteer skills</td>
<td>New volunteer responsibilities may cause strain between staff and volunteers</td>
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<tr>
<td>Reallocation of tasks</td>
<td>Lack of resources for adequate oversight and training</td>
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<td>Better volunteer retention</td>
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</table>
Opportunities for Volunteer Engagement

• Issue Advocacy
  • Coordinated education and outreach (e.g., letters to the editor, presentations, training, informational materials)
  • Quarterly “hot topics” or “areas of focus” (e.g., statewide, regional, specific to facility type, issue-based, linked to continuing education)

• Coalition Building/Partnerships
  • Join local/state CC coalition or elder abuse taskforce and report back to staff

• Legislative Advocacy
  • Research
  • Draft form letters and resources
  • Testimony
  • Collect stories from consumers, share information with consumers
Quick Tips!

• Make it easy for others to get involved

• Create a sense of purpose

• Define clear and specific goals

• Prioritize goals
  • If possible, start with the goal with the greatest potential for success

Georgia

- The Governor and law makers received more than 1,100 signed letters and petitions from Nursing Home residents, urging an appropriation to fully fund a $20 increase in the Personal Needs Allowance (currently just $50.00 a month).

*Picture above: PNA letters and petitions signed by residents from Vol. 8, Issue 62 of the GA LTCOP e-newsletter*
State Level Systems
Advocacy

PRESENTED BY

MELANIE MCNEIL, GEORGIA SLTCO
Presentation Overview

Systems Advocacy

- State Level
- Local Level
State Level

Governor’s Older Adult Cabinet
Governor’s appointee to Commission on Family Violence
(squeaky wheel for aging)
US Attorney Elder Abuse Working Group
Patient Care Ombudsman
State Level

Provider Level

Nursing Home Association

◦ Virtual Dementia Tour CMP grant – interviews with residents
◦ Music and Memory Advisory Committee
◦ Training at NH statewide conferences – best practices in T/D and working with LTCO
State Level

General Assembly

◦ Collaborate with other advocacy groups – state and local advocates raise issues – PCH regulation problems
◦ Assist residents to advocate for an increase in the PNA
  More than 1,100 signatures on letters and petitions
  Testimony at budget hearings
State Level

Executive Agencies

Monthly meeting with State Unit on Aging, Licensure and Certification, Law Enforcement, Behavioral Health and Developmental Disabilities agency re: Board and Care Home resident relocations
State Level

Regulation work groups

Develop new sanctions for PCHs
Develop Assisted Living Rules
Develop Proxy Caregiver Rules
State to Local Systems Advocacy

Technical assistance to Local Ombudsman Reps regarding local issues

Example:
SNF on busy road; didn’t want residents crossing
Local Ombudsman Reps and residents could advocate with County Commission for traffic regulation device
Local Level Systems Advocacy

Presented by:
Elaine Wilson
Local Ombudsman Representative
SOWEGA Council on Aging
Local Level Systems Advocacy

One example:

Unlicensed Board and Care Homes
(in Georgia described as Personal Care Homes)
Unlicensed Personal Care Homes in Georgia

Usually found in residential and rural areas
Private homes which have been found to have 3-50+ residents
Not regulated, no oversight or inspections
Provide PCH services without a license to provide the service
No staffing requirements: education and criminal background
Owners may not be present at location
Transient – when they become “visible” to authorities, they move to undisclosed locations
Populations Served and Conditions in Unlicensed Care Homes

Residents with mental illness
Elderly and physically disabled residents
Homeless and person who may have substance use disorders
Individuals who were formerly incarcerated

Neglect, unmet health needs, unsafe and unsanitary conditions, abuse, financial exploitation, false imprisonment, and moving residents to different care homes across communities and states to evade detection.
Substantiated Unlicensed Personal Care Homes in Georgia 2013 – 2016
Interagency and Multidisciplinary Teams

Georgia Bureau of Investigation
Law enforcement
District Attorney Office
Office of the Attorney General
Office of the Inspector General (OIG)
Representatives from Mental Health and Developmental Disabilities
Department of Community Health – Healthcare Facility Regulation
Adult Protective Service
Local Long-Term Care Ombudsman Program
Case Study: Thomasville

Unlicensed home Resident:
- Age: 18 to 100+
- Held against their will
- Charged SSI Limit up to $3,000/Month
- Required to sign over SSA / EBT
- Resident’s often locked inside their bedrooms or inside the house with locks on the outside doors
Case study: Thomasville

Following are pictures of conditions
Residents were rescued
LE was involved because of neighbor complaints
Questions?
RESOURCES
Key Resources

• NORC LTCOP Reference Guide: Role and Responsibilities of Ombudsman Programs Regarding Systems Advocacy

• NORC Curriculum: LTCOP History and Role PPT and module
  http://ltcombudsman.org/omb_support/training/norc-curriculum
Systems Advocacy

The ombudsman program promotes systems change to address the quality of life for residents of long-term care facilities. The resource documents contained here are organized by topic.

- Communication
- Legislative Advocacy
- Ombudsman Program Examples of Systems Advocacy

General Systems Advocacy Resources

UPDATED: Role and Responsibilities of Long-Term Care Ombudsmen Regarding Systems Advocacy (February 2018)

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. 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.

- Role and Responsibilities of Long-Term Care Ombudsmen Regarding Systems Advocacy – State Ombudsmen
- Role and Responsibilities of Long-Term Care Ombudsmen Regarding Systems Advocacy – Local Ombudsman Program Representatives

http://ltcombudsman.org/omb_support/advocacy
What is Systems Advocacy

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.

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 to the system that promote the interests, well-being and rights of residents.

The Ombudsman and program 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;
Learn About the Issues

Search issues alphabetically by topic:

A B C D E F G H I J K L M N O P Q R S T U V W X Y Z

- Abuse, Neglect, and Exploitation in Long-Term Care Facilities
  Sadly, older persons are not always treated with respect nor do they always get the care they need.

- Advance Care Planning and End of Life Care
  Find resources and information related to advance care planning and end of life care.

- Antipsychotic Drugs
  Ending overmedication of nursing home residents and halting the misuse of antipsychotic drugs as chemical restraints is critical. Antipsychotic drugs, when prescribed for elderly persons with dementia, can have serious medical complications, including death, loss of independence, overt sedation, confusion and falls.

- Bankruptcy Law and the ITCOP
  The Bankruptcy Abuse Prevention and Consumer Protection Act of 2005 allows the appointment of a “Patient Care Ombudsman,” which may be the State Ombudsman.
QUESTIONS?
Website and Resources

• Please share your success stories, challenges, state and local newsletters, materials, and resources

• Looking for something? We can help! Contact us at: ombudcenter@theconsumervoice.org
Never doubt that a small group of thoughtful concerned citizens can change the world...

Indeed it is the only thing that ever has.

Margaret Mead
The National Long-Term Care Ombudsman Resource Center (NORC)

www.ltcombudsman.org

Connect with us:

The National LTC Ombudsman Resource Center

@LTCombudcenter

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