



The National **Long-Term Care**  
**Ombudsman** Resource Center

# SYSTEMS ADVOCACY

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*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

# Basic Questions to Consider When Engaging in Systems Advocacy

## Preparation

- (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)?
- (Local) What direction and guidance have you received from the State LTCO?

## Resources

- (State) Do you have internal program resources that could be utilized (e.g., staff or volunteers with skills or expertise related to the issue)?
- (Local) Does the impact on residents justify the amount of resources required to pursue this issue?

## Program Management

- (State) Is the SLTCO providing leadership and support for program representatives in understanding and making an impact on the pertinent process, system or issue?
- (Local) Is additional training necessary for the individuals involved?

## Addressing Potential Barriers

- (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?
- (Local) How will you share your plan and systems advocacy activities with your State Ombudsman?

# 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.

# 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.”



# 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?

## Benefits

- Expand reach of the program
- More engaged, empowered volunteers
- Utilizing individual volunteer skills
- Reallocation of tasks
- Better volunteer retention

## Risks

- More opportunities for error
- “Rogue” volunteer
- New volunteer responsibilities may cause strain between staff and volunteers
- Lack of resources for adequate oversight and training

# 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

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MELANIE MCNEIL, GEORGIA SLTCO

# Presentation Overview

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## Systems Advocacy

- State Level
- Local Level

# State Level

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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

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## 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

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## 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

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## 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

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## Regulation work groups

- Develop new sanctions for PCHs

- Develop Assisted Living Rules

- Develop Proxy Caregiver Rules

# State to Local Systems Advocacy

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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

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Presented by:

Elaine Wilson

Local Ombudsman Representative

SOWEGA Council on Aging

# Local Level Systems Advocacy

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One example:

Unlicensed Board and Care Homes

(in Georgia described as Personal Care Homes)

# Unlicensed Personal Care Homes in Georgia

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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

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Residents with mental illness

Elderly and physically disabled residents

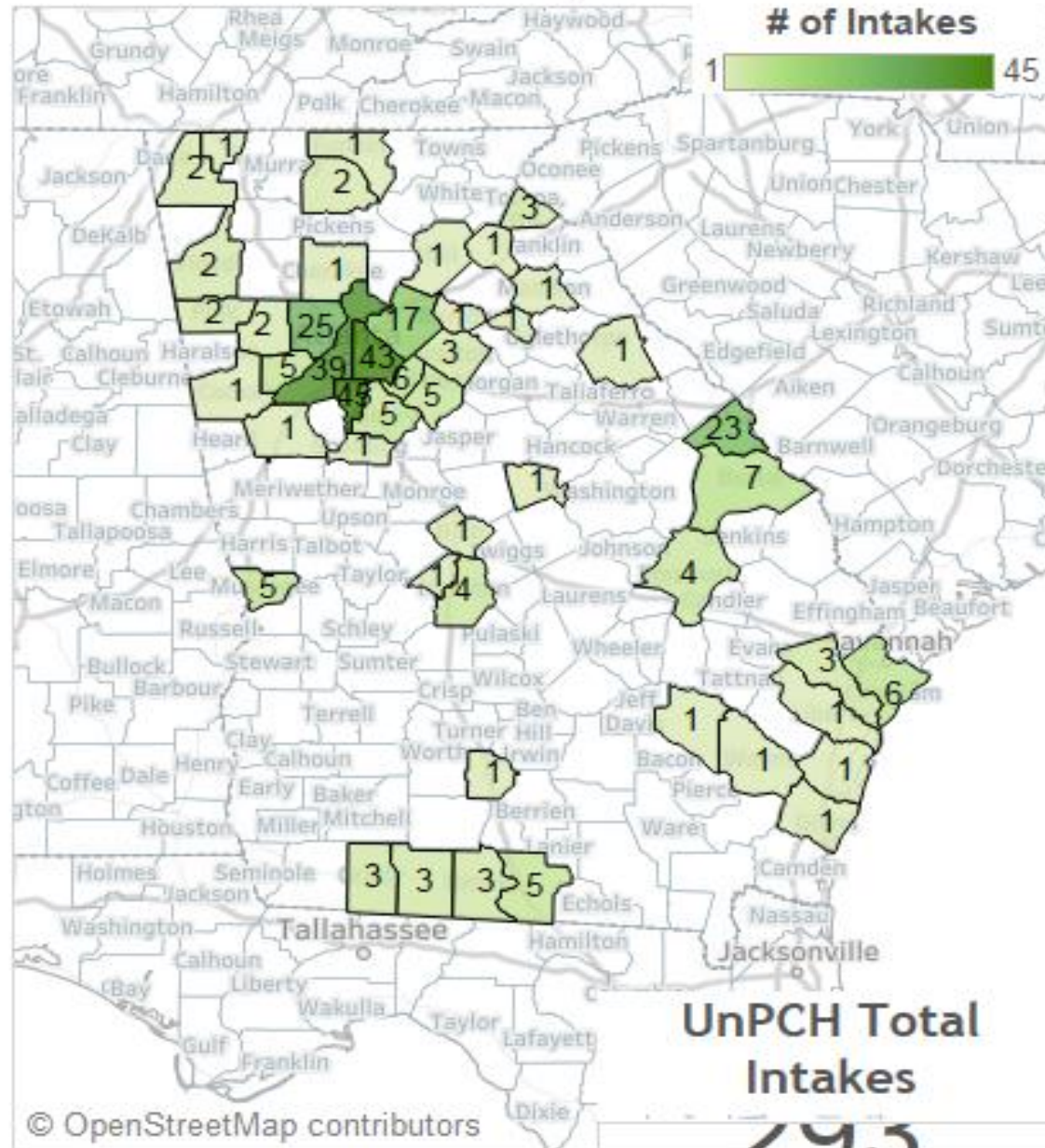
Homeless and person who may have substance use disorders

Individuals who were formerly incarcerated

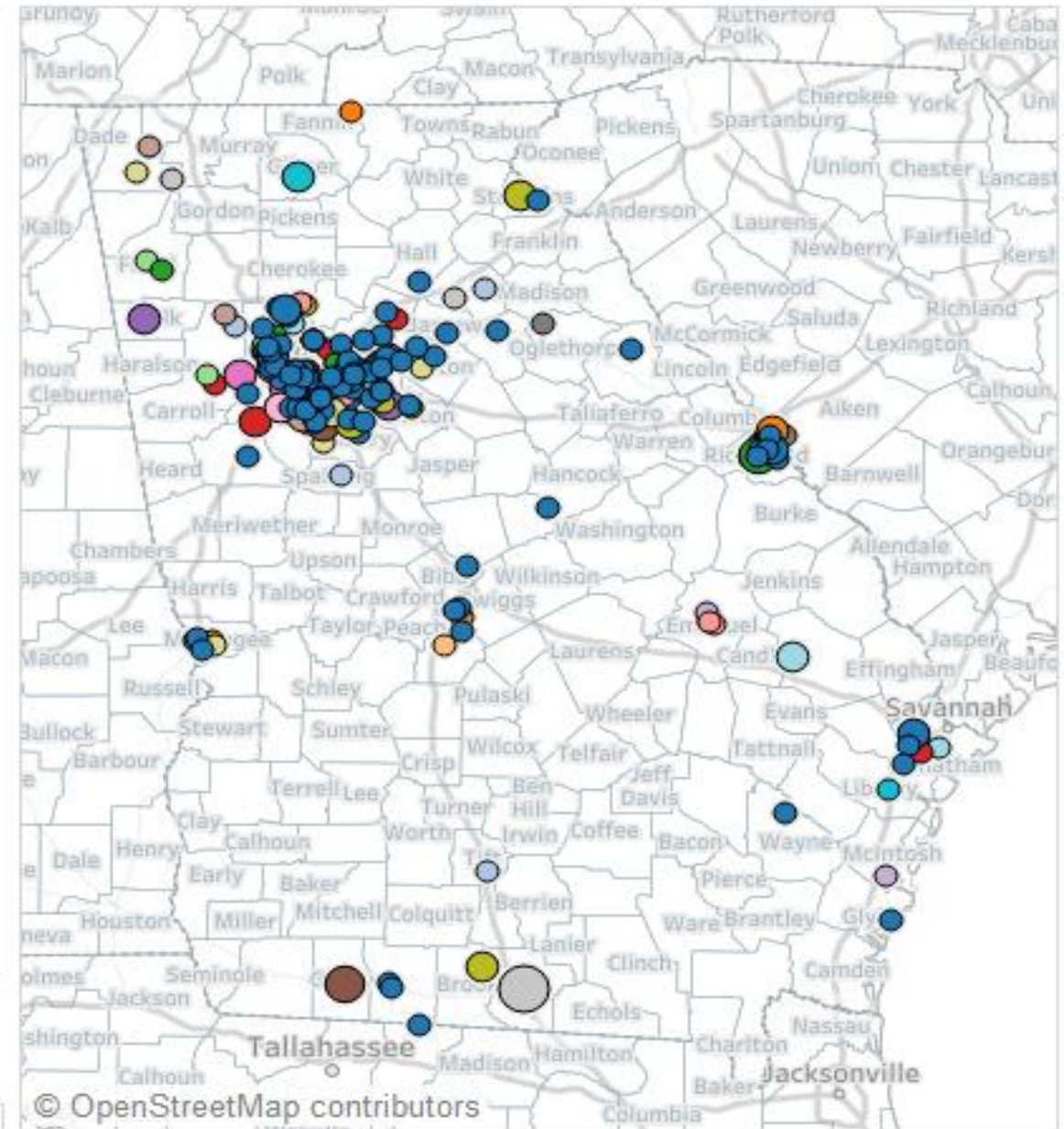
Neglect, unmet health needs, unsafe and unsanitary conditions, abuse, financial exploitation, false imprisonment, and moving residents to different care homes across communities and states to evade detection.

# Substantiated Unlicensed Personal Care Homes in Georgia 2013 – 2016

## UnPCH County Selection



## UnPCH Locations



# Interagency and Multidisciplinary Teams

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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

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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

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Following are pictures of conditions

Residents were rescued

LE was involved because of neighbor complaints

















































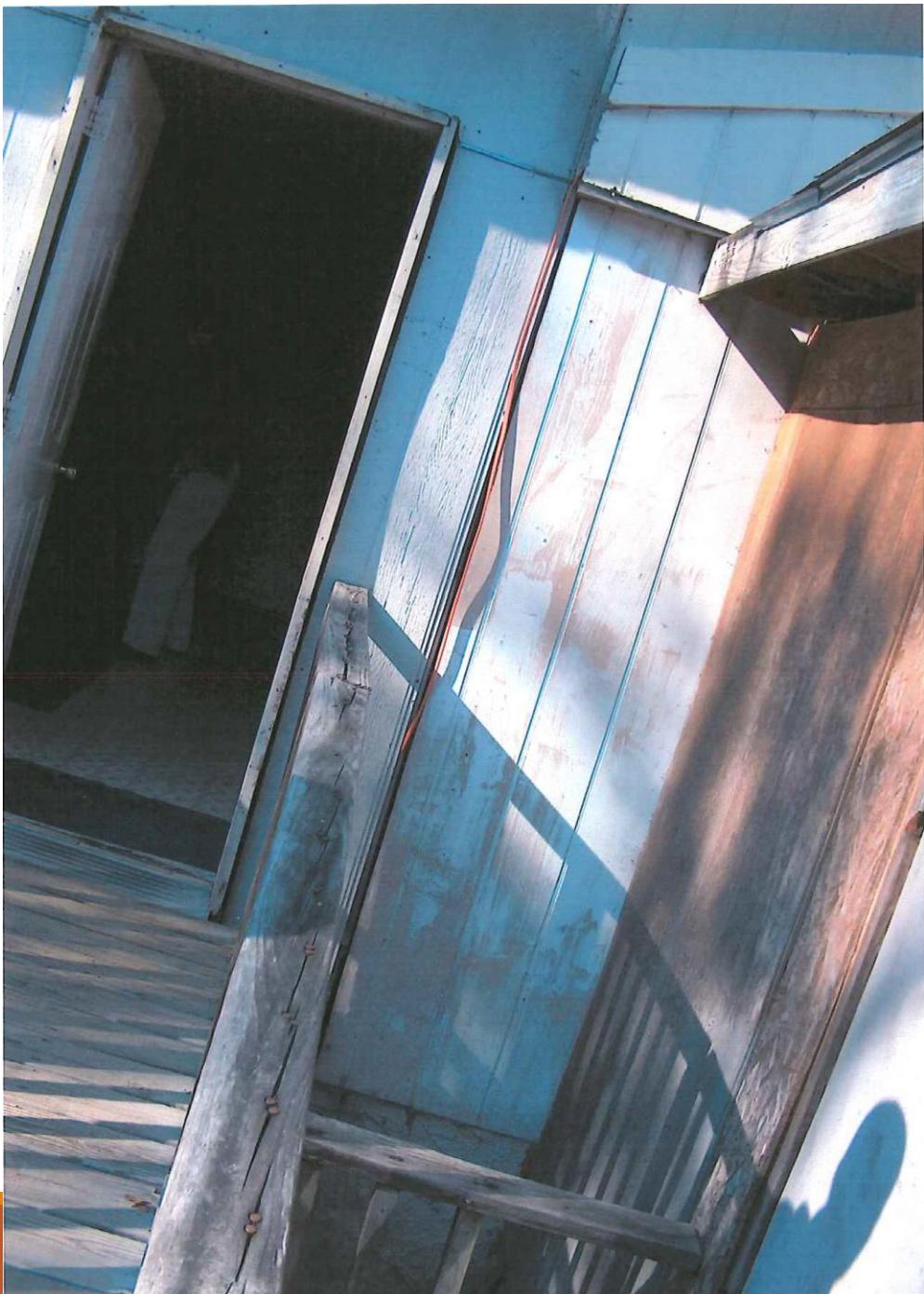






















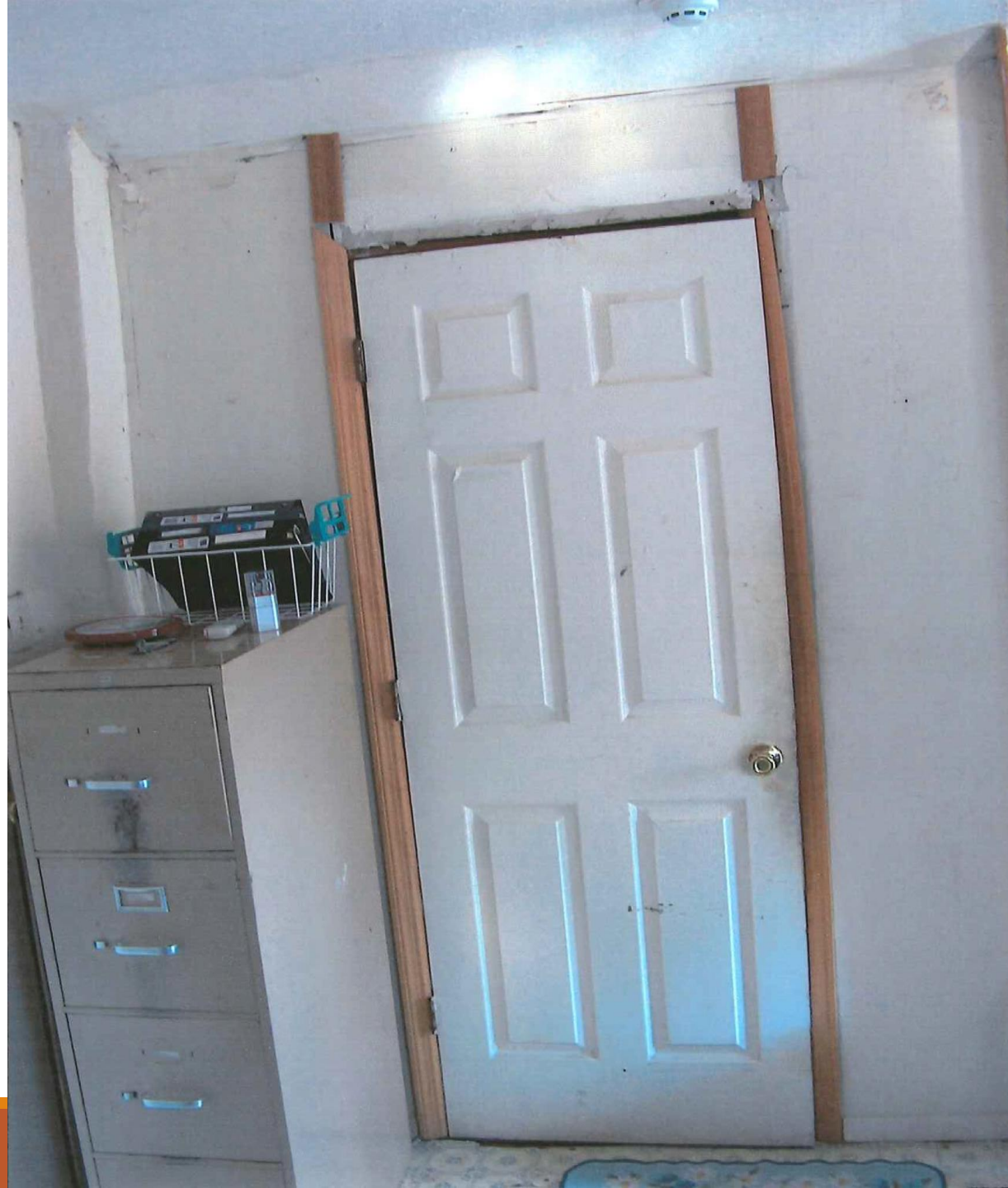




















# Questions?

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# RESOURCES

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# Key Resources

- **NORC LTCOP Reference Guide: Role and Responsibilities of Ombudsman Programs Regarding Systems Advocacy**
  - State Ombudsmen <http://ltcombudsman.org/uploads/files/support/sltco-systems-advocacy-ref-guide-final.pdf>
  - Local Ombudsman Program Representatives  
<http://ltcombudsman.org/uploads/files/support/lltco-systems-advocacy-ref-guide-final.pdf>
- **NORC Curriculum: LTCOP History and Role PPT and module**  
[http://ltcombudsman.org/omb\\_support/training/norc-curriculum](http://ltcombudsman.org/omb_support/training/norc-curriculum)

NORC Conference  
Calls/Webinars

NORC Notes

National Ombudsman  
Reporting System -  
(NORS)

Program Management

Program Promotion

**Systems Advocacy**

► Communication

► Legislative Advocacy

► Ombudsman Program  
Examples of Systems  
Advocacy

Technical Assistance FAQs

Training

Volunteer Management



Locate an  
Ombudsman

## 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](#)

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### 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](http://ltcombudsman.org/omb_support/advocacy)

# NORC Notes — March 2018

Archived issues available here:

[http://ltcombudsman.org/omb\\_support/norc-notes](http://ltcombudsman.org/omb_support/norc-notes)



## NORC Notes

*A monthly reminder of available resources and tips for using them.*

March 1, 2018

### The Long-Term Care Ombudsman Program and Systems 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;

# NORC Website

[www.ltcombudsman.org](http://www.ltcombudsman.org)

[National Consumer Voice](#) [State Ombudsman Login](#) [f](#) [t](#) [Shop Our Store](#)

[Home](#) [News](#) [About ▾](#) [New ombudsman?](#) [Library ▾](#) [Events ▾](#) [Support ▾](#) [Issues](#)

 **The National Long-Term Care Ombudsman Resource Center**

Specialized Information for:  
[Nursing Homes](#) [Assisted Living/Board & Care](#) [Home and Community Based Services](#)

## Be Prepared: Emergency Preparedness Resources

In light of recent natural disasters across the country, review important emergency preparedness resources.

[Learn more](#)



 [Locate an Ombudsman program, volunteer opportunities, and help near you](#) [Visit our map](#)

## News and Press

- **Texas State Ombudsman, Patty Ducayet, Quoted in NY Times Article about Nursing Home Discharges**

## Resource Center Updates

- **Updated Reference Guide on Responding to Allegations of Abuse**

Posted: March 5th, 2018

**The National Long-Term Care  
Ombudsman Resource Center**

Specialized Information for:

[Nursing Homes](#)[Assisted Living/Board & Care](#)[Home and Community Based Services](#)

### Locate an Ombudsman

Locate an  
Ombudsman, Citizen  
Advocacy Group and  
other resources near  
you



### Are You A New Ombudsman?

Access resources to  
get you started!

## Learn About the Issues

Search issues alphabetically by topic:

**A B C D E F G H I L M N O Q R S T V Y**

### ► 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, over-sedation, confusion and falls.

### ► Bankruptcy Law and the LTCOP

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?**

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# 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](mailto: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

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

[www.ltcombudsman.org](http://www.ltcombudsman.org)

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The National LTC Ombudsman Resource Center



@LTCombudcenter

*This project was supported, in part, by grant number 90OMRC0001-01-00, from the U.S. Administration for Community Living, Department of Health and Human Services, Washington, D.C. 20201. 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 for Community Living policy.*