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Long Term Care Ombudsman Program (LTCOP) in United States:

Time to Establish the Program in Israel

By Eilon Caspi PhD

Photo credit: Ofir Ben Natan, ESHEL

The meaning of the word Ombudsman:

"A Swedish word meaning agent, representative, or someone who speaks on behalf of another."

The Long Term Care Ombudsman Program is administered by the Administration on Aging, within the Administration of Community Living (ACL) of the U.S. Department of Health and Human Services (DHHS): https://tinyurl.com/7xahtzhz

"*The local long-term care ombudsman is just a priceless resource*."

– Sam Brooks, Director of Public Policy,
The National Consumer Voice for Quality Long Term Care, Washington, D.C.,
October 26, 2022

"*The effectiveness of the LTC Ombudsman Program is integral to the quality of care and quality of life of residents in LTC facilities*."

– Brooke A. Hollister & Carroll L. Estes (2012)

"I am not on anybody's side but on the resident's side"

– LTC Ombudswomen

LONG-TERM CARE OMBUDSMAN PROGRAM

FACT SHEET

What You Must Know

https://tinyurl.com/4mezbmdp

Frequently Asked Questions

about the LTC Ombudsman Program

https://tinyurl.com/mwxs694e

To learn more about the Long Term Care Ombudsman Program, watch **a series of videos** on the webpage of the National Long-Term Care Ombudsman Resource Center:

https://ltcombudsman.org/omb_support/promo/videos

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Acknowledgments

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Acronyms

ACL. Administration for Community Living

CMS. Centers for Medicaid and Medicare Services. The federal agency responsible for setting federal nursing home standards and for regulatory oversight. CMS contracts with state survey agencies to carry out the federal guidelines for surveys, complaint investigations, and enforcement compliance.

LTC. Long Term Care

LTCOP. Long Term Care Ombudsman Program

SLTCO. State Long Term Care Ombudsman

OAA. Older Americans Act

NORS. National Ombudsman Reporting System

GAO. Government Accountability Office

History

The idea for the Long Term Care Ombudsman Program (LTCOP) was developed by Dr. Arthur Flemming, Commissioner on Aging to President Nixon. He envisioned the program as an advocacy program for residents.

The Older Americans Act (OAA). The OAA of 1965 created a National Aging Network comprised of federal, state, and local supports and services for individuals ages 60 and older. In addition to providing comprehensive services for older adults, the OAA established the LTCOP. OAA Title VII, Chapter 2, Sections 711/712 pertains to the LTCOP.

Table 1

Year	Milestones
1972	In response to poor quality of care in nursing homes, the LTCOP began as a demonstration project. An independent, person-centered consumer protection service aiming to provide a voice for residents.
1978	The Older Americans Act (OAA) established the Ombudsman program nationwide.
1981	OAA expanded the program's scope to board and care homes and adult care facilities.
2006	OAA amendments expanded the definition of board and care to include assisted living residences.

Source: NORC at the University of Chicago (September 30, 2019). Final report: Process evaluation of the Long-Term Care Ombudsman Program (LTCOP). https://tinyurl.com/3kvzc5ar

The LTCOP Final Rule

The Administration for Community Living (ACL) published the LTCOP Rule (45 CFR Part 1324) in February 2015 and effective on July 1, 2016. The LTCOP Rule guides states in their operation of the LTCOP and clarifies program responsibilities and requirements of the OAA.

The LTCOP Rule includes but is not limited to:

- Responsibilities of key figures in the system, including the Ombudsman and representatives of the Office
- Responsibilities of the entities in which LTCOPs are housed
- Criteria for establishing consistent, person-centered approaches to resolving
- complaints on behalf of residents
- The appropriate role of LTCOPs in resolving abuse complaints
- Conflicts of interest

To access The Final Rule: https://ltcombudsman.org/library/fed_laws/ltcop-final-rule

Funding Sources

LTCOP's primary federal funding source is through the OAA (Title III and VII). Through grants to states and territories, the LTCOP operates in 50 states, as well as the District of Columbia, Puerto Rico, and Guam.

That said, the State LTCOP can apply to other funding sources. Specifically, "some programs apply for and receive additional funding through federal grants, private foundations, and state government" (Hollister & Estes, 2012).

OAA requirements of the LTCOP

1. Identify, investigate, and resolve complaints made by or on behalf of residents.

2. Provide information to residents about their rights and long-term care (LTC) services and supports.

3. Ensure that residents have regular and timely access to ombudsman services.

4. Represent residents' interests before governmental agencies and seek administrative, legal, and other remedies to protect residents.

5. Analyze, comment on, and recommend changes in laws and regulations re the health, safety, welfare, and rights of residents.

Scope of Service

In 2017, the LTCOP advocated on behalf of over 3 million residents in 16,376 nursing homes and 58,031 board and care homes (including assisted living and similar residential settings).

During that year, the program received 201,460 complaints and Ombudsmen staff resolved or partially resolved 73.5% of claims at a satisfactory level.

In both settings, Ombudsmen were most effective in resolving complaints related to residents' Autonomy, choice, preference, exercise of rights, and privacy.

Program Structure – Centralized versus Decentralized

In 21 states, the LTCOP is operating under a centralized model while in 32 states it is decentralized. In the centralized structure, all program staff are employees of the agency housing the Office of the State Long Term Care Ombudsman (SLTCO). Centralized programs do not have local entities. However, some centralized programs have offices located outside the State Office that facilitate statewide access to the program. By contrast, in the decentralized structure, the Office of the SLTCO is housed in a state agency or contracted agency, but local Ombudsman staff are employed by another contracted entity designated by the State Ombudsman as a local Ombudsman entity.

Paid Staff and Certified Volunteer Staff

The State Ombudsman is responsible for statewide program administration and oversight of designated representatives of the office, including paid staff and volunteers. In FY 2017, 1,319 full-time equivalent staff (FTEs) and 6,625 volunteer Ombudsmen supported the program.

That is, 20% FTE Staff vs. 80% Certified Volunteers.

That being said, "The use of volunteers and beliefs about their roles within the LTCOP vary widely in practice (Nelson et al. 2004; Netting & Hinds, 1989, as cited in Hollister & Estes, 2012).

Training Requirements

Certification training is required as part of the process to become a representative of the Office of the SLTCO. A representative of the Office of the SLTCO (representative) is an individual (employee or volunteer) designated by the State Long-Term Care Ombudsman (Ombudsman) to fulfill the duties as defined in federal law and regulations.

Each state is required to provide a minimum of 36 hours of initial certification training that includes:

- Up to 7 hours of independent study
- At least 10 hours in the field
- 16-20 hours of classroom training

Once designated, at least 18 hours of in-service training is required annually.

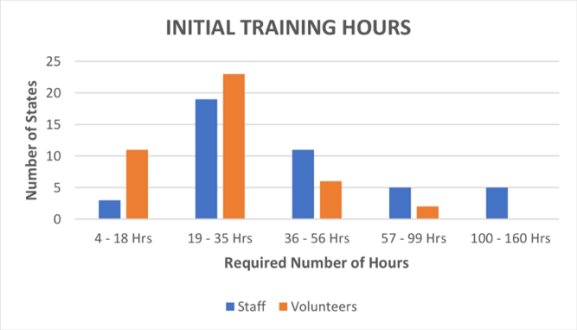
The training standards apply to all representatives of the Office, paid or volunteer. The Final LTCOP Rule clarifies that a "representative of the Office" means volunteer or employees, as long as they completed the training and were designated as a representative by the State Ombudsman. Specifically, "*Representatives of the Office of the State LTC Ombudsman,* as used in sections 711 and 712 of the Act, means the employees or volunteers designated by the Ombudsman to fulfill the duties set forth in § 1324.19(a), whether personnel supervision is provided by the Ombudsman or his or her designees or by an agency hosting a local Ombudsman entity designated by the Ombudsman pursuant to section 712(a)(5) of the Act."

Amity Overall-Laib (personal email communication, November 7, 2022) explains, "To perform duties, have access to residents and resident information, investigate complaints, etc., individuals must be trained and designated as representatives of the Office. Since there is no distinction in the Older Americans Act or LTCOP Final Rule between staff or volunteer representatives, minimum standards needed to strike a balance between being comprehensive enough for basic, initial certification training and achievable by both volunteers and staff."

Overall-Laib adds, "The federal training requirements are only minimum requirements, and many states have higher standards for staff than volunteers. The Administration for Community Living (2019) stated in the minimum training standards that more hours are encourage for paid representatives."

As can be seen in the bar chart (Diagram 1), several states required initial training hours in levels higher than the minimum 36 hours of initial certification training for paid staff compared to volunteers (National Consumer Voice for Quality Long-Term Care, 2017).

Diagram 1



Note: Data in bar chart are based on information collected from State Ombudsmen in 2016

To view the 10 Modules of Initial Certification Training Curriculum for LTCOP, see: https://tinyurl.com/46jmnznv

The LTCOP is a Distinct Entity

Under the OAA, the LTCOP "has some mandates that set it apart from other services." Specifically, the program's services are "not duplicated by any other federal agency." By Congressional intent, "the administration and functions of the State LTCOP are distinct" (National LTC Ombudsman Resource Center, 2019). Based on this literature review and interviews held for this report, the unique roles and authorities of the LTCOP are summarized in Table 2.

Table 2

What is Within and Outside the LTC Ombudsman Program Role and Authority?
The Long Term Care Ombudsman Program (LTCOP) is **part of** the **elder rights system.**
It is ***not* a regulator**.
It is **a resident advocate**.* It follows the resident's direction to the fullest extent possible (even if that is not what others think is in the resident's best interest). It does *not* determine what is best for residents, not does it make decisions for them.
Independent voice for residents. It represents the views, interests, and wishes of the resident. Its opinion is independent of other agencies. The Ombudsman doesn't necessarily represent the interests of the state, nor should its independence be threatened by any other agency. To protect its independence, it should *not* be appointed "to serve at the pleasure of the Governor." If the LTCOP is placed in a government agency, the placement must not create a conflict of interest.
Empowerment. Its primary role is to empower residents to exercise their right to **self-determination by educating them about their rights and options**, discussing all possible outcomes, and encouraging them to do something about their concerns, needs, or wishes.
It can assist in starting and supporting a Family Council and Resident Council and assure that that it is operated in ways that preserve, protect, and enhance residents' rights.
Care Plan Meetings. At a resident's request, the Ombudsman can attend these meetings to ensure that the resident's voice is heard and her/his needs and rights are realized.
Privacy and Access. The Ombudsman is **exempt from Federal privacy rule** under HIPAA. **It has** regular, timely, and unimpeded **access to residents and their records** (access to records is allowed only after resident's / legally authorized representative's permission). Since the LTC Ombudsman Program is **a "health oversight agency,"**

nursing homes and other "covered entities" may, in response to appropriate ombudsman inquiries, share other information without fear of violating the Privacy Rule."
Identify, investigate, and resolve complaints** made by or on behalf of residents; that is, complaints related to "action, inaction or decisions that may adversely affect the health, safety, welfare, or rights of the residents" (individual complaints, multiple residents, and care home-wide). The Ombudsman **does investigate allegations of abuse, neglect, and financial exploitation but it does so as directed by the resident's goals** for complaint resolution. **The unique goals of the Ombudsman's investigations are**: 1. to resolve complaints to resident's satisfaction; 2. Help ensure that the health, welfare, and rights of the resident are protected. Its goal is ***not* to substantiate** whether abuse or other allegation occurred. The Ombudsman **doesn't investigate whether any law or regulation has been violated** for purposes of civil or criminal enforcement action. The Ombudsman seeks resolution "on behalf of a resident regardless of whether violation of any law or regulation is at issue."
Handling situations where a family complains but resident is not concerned and does not want to pursue it. If the resident who is cognitively capable of making and expressing his or her choice is not concerned about the issue brought up by his family member, the Ombudsman follows the resident's direction. Even in situations where the family member has a Power of Attorney (PoA), the family still has a duty to honor the wishes and rights of the resident. The resident may still have capacity to make decisions about her life and care. Furthermore, even a PoA may have limitations with regards to their relevance to the family concerns (i.e., health care concerns vs. financial concerns vs. quality of life issues).
The LTCOP **does *not* conduct licensing and regulatory inspections or investigations**.
It does not perform Adult Protective Services investigations.
The Ombudsman **can review state investigation reports** to assure accuracy. If flaws are found, such as missing information or unwarranted conclusions, or new evidence is discovered, the ombudsman office requests a supplementary investigation.
Ombudsmen are ***not* mandatory reporters***** of abuse, neglect, and financial exploitation (per requirements in the Older American Act and the Final Rule override state laws).
Confidentiality. The Ombudsman is required to keep all identifying information about a resident and a complainant private, within the program. **Resident-identifying information cannot be shared with anyone without the permission** of the resident, the resident's representative, the State Ombudsman, or by court order. The representative needs permission from the resident to discuss the resident's concerns with anyone, including facility staff and family. An **exception** may include a situation where the Ombudsman **personally** witnesses abuse, neglect or exploitation of a resident who is unable to provide informed consent and doesn't have a legally authorized representative. In these cases, the Ombudsman or representative "shall refer the matter and disclose the identifying information of the resident to the facility and/or appropriate agency for substantiation of abuse and may refer the matter to other appropriate agencies."
General complaint. When the Ombudsman finds out that other residents have similar concerns as a resident, the Ombudsman can pursue it as a general complaint.
It cannot act without the resident's consent. The resident – *not* the Ombudsman program – has the authority to make the decision about when and where the resident's information can be disclosed. That said, the Ombudsman has a duty to refer the complaint to authorities (state survey agency or law enforcement) when requested by the resident and with informed consent from her or him.
Assist and support residents during state inspections and complaint investigations such as by assisting the resident in voicing and realizing their goals and rights.
Represent residents' interests before government agencies and **seek** administrative, legal, and other **remedies** to protect residents.
Systems advocacy. The Ombudsman is required to provide systems advocacy on behalf of residents such as making recommendations for changes to a system (e.g., LTC home, government agency, an organization, policies, regulations, and law) to benefit residents.
The Ombudsman provides technical assistance to administrators and staff training (such as about residents' rights, care practices, and how to deal with a resident and/or family perceived by staff as "difficult").
The Ombudsman has a right and **freedom to speak with the media**.
It does *not* provide direct care to residents.

Notes

* What is an advocate? “It basically means that you stand besides someone, you listen to their concerns, and you try to resolve that.”

** Definition of complaint: “An expression of dissatisfaction or concern brought to, or initiated by, the Ombudsman program which requires Ombudsman program investigation and resolution on behalf of one or more residents of a LTC facility.”

***Reporting without resident permission discredits the integrity of the program and harms the representative-resident relationship. Residents have to feel safe talking with an ombudsmen, that nothing will be shared without their permission, even descriptions of events or care that would be considered as abuse, neglect or exploitation. This is a critical issue.

“But we already have a social worker”

Many social workers are skilled and successful advocates for residents’ rights and care. However, they often operate “between a rock and a hard place” when they walk a fine line between protecting residents’ rights and ensuring that their care needs are met on one hand and accommodating administrator’s pressures to meet the nursing home’s needs on the other. In addition, social workers are employed by the nursing home while the Ombudsmen are not (this may have implications for social workers’ ability to operate in a truly independent way). Furthermore, while most are, not all social workers are professional and skilled.

Moreover, federal regulations require U.S. nursing homes with 120 or more beds to hire a qualified social worker on a full-time basis, but this “qualified social worker” needs not have a social work degree. Specifically, the “qualified social worker” is defined as an individual with a minimum of a B.S.W. or a bachelor’s degree in human service field including, but not limited to, sociology, gerontology, special education, rehabilitation counseling, or psychology and who has one year of supervised social work experience in a health care setting working directly with individuals. Because this requirement applies only to nursing homes with 120 or more beds, approximately two-thirds of nursing homes do not have to employ a social services staff member (National Academies of Sciences, Engineering, and Medicine, 2022).

Complaint Handling

Complaint handling is “central to not only the Ombudsman function, but in large part the foundation upon which all other Older Americans Act mandated activities rest” (Nguyen et al. 2019). A complaint is defined as “an expression of dissatisfaction or concern brought to, or initiated by, the Ombudsman program which requires Ombudsman program investigation and resolution on behalf of one or more residents of a long-term care facility.”

The Ombudsman program investigates and resolves complaints that “relate to action, inaction or decisions that may adversely affect the health, safety, welfare, or rights of the residents” and that includes complaints about abuse, neglect, and exploitation” (National Consumer Voice for Quality Long Term Care).

The Final Rules states, "While the complaint resolution function of the Ombudsman program requires "investigation," an Ombudsman investigation is not for the same purpose as an investigation by protective services, licensing and regulatory agencies, law enforcement or other entities. When an Ombudsman program receives any complaint (including, but not limited to, an abuse-related complaint), the goal is to resolve the complaint to the resident's satisfaction, rather than to substantiate whether the abuse or other allegation occurred. The Ombudsman program does not have a duty to collect sufficient evidence to meet the higher legal standard of proof that protective services, licensing or regulatory agencies, or law enforcement may need to meet their respective purposes. The Ombudsman program investigates solely for the purpose of gathering necessary information to resolve the complaint to the resident's satisfaction, not to determine whether any law or regulation has been violated for purposes of a potential civil or criminal enforcement action."

Examples of complaints received by Ombudsman program:

- "I've been waiting for someone to answer my call light for the last hour."
- "No one knocks before they enter my bedroom. They don't understand this is my home too."
- Resident doesn't like showering at 6am and wants help getting a later shower time.
- Staff are not properly administering resident's medication; need help investigating the situation.
- "I found my dad with bed sores the last two times I visited."
- "I just got a discharge notice but don't know how to appeal it."

It is important to note that the LTCOP may investigate and resolve individual resident complaints, complaints potentially affecting multiple residents, or care home-wide complaints.

Types of Complaints

Table 3 describes the general types of complaints received and resolved by the LTCOP.

Table 3 - Complaint Codes and Definitions

Complaint Code	
A	Abuse, Gross Neglect, Exploitation
B	Access to Information
C	Admission, Transfer, Discharge, Eviction
D	Autonomy, Choice, Rights
E	Financial, Property
F	Care
G	Activities, Community Integration, and Social Services
H	Dietary
I	Environment
J	Facility Policies, Procedures, and Practices (including staffing, etc.)
K	Complaints About an Outside Agency (non-facility) such as Regulatory Agency
L	System: Others (non-facility) such as resident representative or family conflict. Also includes Services from outside provider.

Source: (National Ombudsman Reporting System; NORS): https://tinyurl.com/mrxr5f72

Sources of Complaints

Table 4 provides a breakdown of the different sources of 128,091 cases closed by the LTCOP in Fiscal Year 2017.

Table 4 – Source of Complaints / Type of Complainants

Exhibit 3: Type of Complainant and Number and Percentage of Cases Closed (FFY 2017)

Type of Complainant	Number of Cases Closed	Percent of Cases Closed
Resident	51,350	40%
Relative/Friend	23,409	18%
Non-Relative, guardian, legal representative	1,294	1%
Ombudsman, volunteer Ombudsman	13,332	11%
Facility administration, staff	24,008	19%
Other medical - physician/staff	3,539	3%
Other agency representative	5,808	4%
Unknown/Anonymous	3,337	3%
Other	2,014	2%

Source: Nguyen et al. (2019). Protecting rights and preventing abuse: handling resident complaints in long-term care facilities. Research Brief. NORC at the University of Chicago. https://tinyurl.com/mr333zcz

Complaint Investigation Process

Once a complaint investigation is initiated, Ombudsmen generally undertake the following steps (Nguyen et al. 2019):

(1) Gather information relevant to the complaint (through interviews, observations, and/or review of documents such as resident medical records, regulations, facility policies, etc.)

(2) Assess the validity of the complaint (determining whether the circumstances described in the complaint are accurate).

(3) Seek resolution of the complaint through identified strategies and alternative solutions. Over the course of the investigation, Ombudsmen will identify and speak with relevant participants and agencies related to the case, such as facility staff, legal assistance, family members, and representatives of Adult Protective Service, law enforcement, or the state's survey and certification agency. Given the number of individuals that are potentially involved in a case, obtaining cooperation among various parties and skillfully navigating sometimes sensitive relationships is an important part of Ombudsmen's work.

For a comprehensive guide to Ombudsmen Complaint Investigation process, see:

Module 7: LTC Ombudsman Program Complaint Processing: Intake and Investigation (Trainee Manual): https://ltcombudsman.org/uploads/files/support/module-7-trainee-manual.pdf

Module 8: LTC Ombudsman Program Complaint Processing: Analysis, Planning, Implementation, and Resolution (Trainee Manual): uploads/files/support/module-8-trainee-manual.pdf

Videos Illustrating Ways the LTCOP Handles Residents' Concerns / Complaints

1. How the Ombudsmen handles a resident's concern re ban on visits from friends after 8pm:

Long Term Care Ombudsman Casework: Brian Brashear (13 minutes): https://tinyurl.com/5h6pyhup

2. How the Ombudsmen handle a resident's concern re 6am showers:

Long Term Care Ombudsman Casework: Anne Walker (22 minutes): https://tinyurl.com/yh68e8s4

Ombudsman Role with Families

According to Robyn Grant and Amity Overall-Laib, "The role of the ombudsman when working with family members will vary depending on the resident's capacity and the situation. Ombudsmen may serve as mediators, negotiators, educators, brokers, or consultants. When working with families, sometimes the most important role of the ombudsman is to provide them with support and information. Family members need someone outside of the LTC facility who understands the regulations and knows about good care practices and how facilities operate. They need someone who can tell them that their concerns are valid and they are on the right track, or if not – to guide them. For families with a loved one in a LTC facility, sometimes just knowing that they are not alone and that another person understands the difficulties they are facing can make all the difference."

For additional resources on this issue, see:

Working with Families: Tips for Effective Communication and Strategies for Challenging Situations: https://ltcombudsman.org/uploads/files/support/fm-paper.pdf

Webinar (audio recording): https://ltcombudsman.org/uploads/files/support/family-recording.mp3

Empowerment

The primary role of the LTC Ombudsman program is empowerment. Specifically, "As resident advocates, it is a core program responsibility to empower residents and encourage others to realize the extent of the resident's decision-making abilities" (National LTC Ombudsman Resource Center, 2022).

The LTCOP empowers residents by:

- Educating residents on their rights
- Educating residents on their options
- Discussing all possible outcomes
- Encouraging residents to do something about their concerns, needs, or wishes

In this context and with the intent of resident-directed advocacy, it is important to recognize that "Often, residents feel more comfortable discussing concerns with the LTCOP than they do complaining to facility staff, medical providers, or even their own family members."

It is as important to recognize that "This may lead to the misperception that the program is creating problems when, in fact, the problems were there all along" (LTC Ombudsman: Roles, Responsibilities, and Authorities, 2022).

Residents' Best Interest versus Interest/Wishes

Best interest is subjective and based on individual thoughts, experiences, morals, values, etc. It is a personal determination about what is beneficial for someone else. The LTCOP does not determine what is best for residents, nor does it make decisions for residents. Rather the program supports and advocates on behalf of the resident's wishes. This approach may conflict with the perspective of LTC facility staff, medical professionals, family members, and others as they might feel that resident-directed advocacy is not in the best interest of the resident on specific issues.

In general, the Ombudsman does not focus on the "best interest" of the resident.

The following are examples of professions that work in the best interest of the resident: Nurses, social workers, doctors. They are taught to work in the "best interest" of the resident. At issue is the fact that thinking about the "best interest" of another can have a judgmental component.

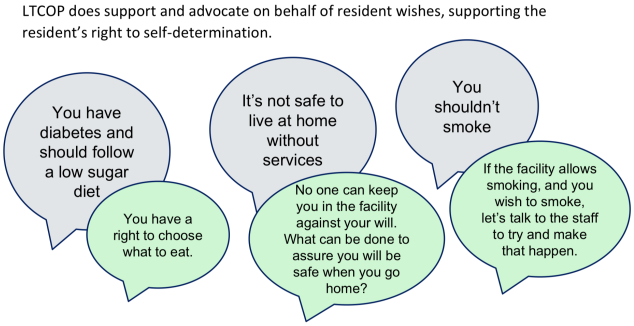
Things someone who looks through best interest lens would say:

"You need to…." / "It's too risky" / "You should…" / "Oh, you don't want to do that."

As stated by a resident: "Who can tell me what is in *my* best interest?"

Diagram 2 illustrates the difference between "best interest" (in grey) and residents' wishes and right for self-determination (in green).

Diagram 2



Source: Carol Scott, Ombudsman Specialist, NORC, January 26, 2022

Note: The resident with diabetes wants to eat what she wants and she understands the consequences of doing so.

It is important to recognize this issue because, as Mark Miller explains, "The resident's interest is not necessarily what the facility or family want." He gives the example of a resident's right to refuse medications. The family may complain but the resident is not concerned about it. As Miller points out, "As long as the resident has capacity, we'll follow their direction."

Resident-Directed Advocacy

The foundation of all Ombudsman program advocacy is to follow the direction of the resident to the fullest extent possible. In general, Ombudsman cannot act without the resident's consent.

The LTCOP has a responsibility to:

- Determine the resident's perception of the problem.
- Explain potential solutions and outcomes.
- Work with the resident to determine steps towards the resident's goals.

Informed Consent

According to The National Long-Term Care Ombudsman Resource Center (2022), Informed consent is defined as, "The permission from a resident or a resident representative after a full explanation has been given of the facts, options, and possible outcomes of such options in the manner and language in which the resident or resident representative understands."

Knowing the resident and their ability to make decisions "is important because the Ombudsman program seeks direction from the resident when resolving a complaint."

Capacity is the ability to make and communicate an informed choice. There is no simple test for capacity. Often, understanding the person's personal values, preferences, or goals can assist in understanding their capacity to make decisions.

Capacity is issue-specific, a spectrum, and transient. The first question is: "capacity to decide what?" Different types of decisions require varying levels of memory and distinct cognitive skills. The memory needed depends on how relevant past information is to the choice at hand. For example, very little memory is needed to decide what to wear or eat today. Different decisions require different cognitive skills, such as calculation, comparison, or organizing data.

Capacity is a spectrum. The ability to understand and make choices is not an on-off function. Capacity varies in subtle degrees, from no or very low levels of understanding, to the ability to understand and make decisions on very sophisticated and complex issues. Capacity is affected by health, pain, medication, illness, or injury. Capacity can be developed by learning and experience, and it can decrease with illness or injury. As these factors change, capacity can increase, decease, and return.

Confidentiality

Federal and state laws mandate that the LTCOP keep all identifying information about a resident and a complainant private, within the program.

There are strict federal requirements regarding disclosure of LTCOP information (e.g., resident and complainant identity, observations, complaint, and case documentation).

Resident-identifying information cannot be shared with anyone without the permission of the resident, the resident's representative, the State Ombudsman, or by court order.

Disclosure of Resident's Information. The Final Rule of the LTCOP states, "Congress provided the resident – and not the Ombudsman program – with the authority to make the decision about when and where the resident's information can be disclosed." This is important for several reasons. To give one example, "Residents may be concerned about retaliation or have other reasons why they do not want the Ombudsman to share their information." That said, the final rule clarifies that "the Ombudsman program has a duty to make such a referral when requested by the resident."

Mandatory Reporting

Question: Is the Ombudsman program required to report allegations of abuse?

Answer: According to The National Consumer Voice for Quality Long Term Care, "There are strict federal requirements regarding disclosure of Ombudsman program information. Resident-identifying information cannot be disclosed without resident consent, the consent of the resident representative, or a court order. Therefore, these disclosure requirements prohibit Ombudsman programs from being mandatory reporters of suspected abuse."

Question: *When an Ombudsman or representative of the Office holds a professional license which compels reporting of certain information (e.g., mandatory abuse reporting), how should the Ombudsman program handle the conflicting mandates regarding disclosure of resident-identifying information*?

Answer: The OAA and implementing regulations include strict disclosure provisions. The regulations specifically prohibit the Ombudsman or representatives of the Office from reporting suspected abuse, neglect or exploitation of a resident without informed consent, *notwithstanding State laws to the contrary.* 45 CFR 1324.19(b)(3)(iii). The Preamble to the Final Rule addresses the Congressional intent "for the Ombudsman program to be a safe place for the concerns of residents to be brought, knowing that their information will not be disclosed without their consent …" 80 Fed. Reg. 7732.

In addition, the OAA provides that the Ombudsman must consider individual conflicts of interest that may impact the effectiveness of the office. 45 CFR 1324.21. If a professional licensing organization has mandatory reporting requirements that do not comport with the disclosure provisions under the OAA, this may create a conflict of interest.

The Administration for Community Living (ACL) understands that State agencies and Ombudsmen are working to implement the LTC Ombudsman program in accordance with the Act and the Rule and to address any potential conflicts of interest. ACL encourages State agencies and Ombudsmen who identify licensing organization requirements that are in conflict to determine whether the professional licensing entity is able to provide a waiver or other type of remedy.

If individual concerns remain after such State agency or Ombudsman implementation activities, ACL encourages individuals who hold professional licenses and also serve as Ombudsmen or representatives of the Office to notify their respective licensing organization of this requirement in order to determine whether the professional licensing entity is able to provide a waiver or other type of remedy in order to avoid these conflicts.

Question: *What About Mandated Reporters such as Licensed Professionals Serving as Ombudsmen?*

Answer provided by The National LTC Ombudsman Resource Center (2018):

"Most states have mandatory reporting laws that require certain individuals (e.g. facility staff, social workers) to report suspected elder abuse. However, "state law may not require reporting of suspected abuse, neglect or exploitation by the LTC Ombudsman Program where such reporting violates the Federal requirement that an Ombudsman is prohibited from the disclosure of the identity of a complainant or resident without appropriate consent pursuant to Section 712(d) of the OAA."

Question: *Why Aren't Ombudsmen Mandated Reporters?*

Answer: Ombudsmen and representatives are required to act on behalf of a resident per the resident's wishes and direction. Reporting without resident permission discredits the integrity of the program and harms the representative-resident relationship.

Explanation. "Congress provided the resident – and not the Ombudsman program – with the authority to make the decision about when and where the resident's information can be disclosed." – Final Rules LTCOP

"Residents may be concerned about retaliation or have other reasons why they do not want the Ombudsman to share their information." The final rule clarifies that the Ombudsman program has "a duty to make such a referral when requested by the resident."

The Final Rules LTCOP state: "The Ombudsman program may inform complainants who report suspected abuse that they may (and, under some circumstances, must) report the complaint information to protective services, the licensing and regulatory agency and/or law enforcement. The Ombudsman program may advise the resident of the appropriate role and limitations of the Ombudsman program, assist the resident in understanding his or her options, and encourage the resident to report—and/or consent to the Ombudsman program referral—to protective services, the licensing and regulatory agency and/or law enforcement. However, the Ombudsman program is designed to represent the interest of the resident (and not necessarily the interest of the State) in order to support the resident to make informed decisions about the disclosure of his or her own information."

While we have provided, in § 1324.19(b) of the final rule, limited exceptions for reporting resident-identifying information where residents are unable to communicate informed consent, we do not believe that the Act provides us with the authority to promulgate a rule that would permit reporting of a resident's identifying information when the resident (or resident representative) who is able to communicate informed consent has not done so. Nor would we support a rule that would permit such reporting, as a matter of policy.

Mark Miller, president, National Association of State Ombudsman Program, explains (personal communication, October 17, 2022):

"The issue of mandatory reporting comes up frequently. The federal law and regulations are very specific that ombudsmen are not mandated reporters. And of course, federal statute overrides any state laws. I agree that this is critical, because confidentiality is the cornerstone of the program. Residents have to feel safe talking with an ombudsmen, that nothing will be shared without their permission, even descriptions of events or care that would be considered as abuse, neglect or exploitation. This is a bit foreign to many folks, including concerned families. It could be considered similar to attorney-client privilege. Since this is such a critical issue, I would advise Israel to adopt a similar rule."

He added, "There are a number of reasons for this, however, in practice this issue does not arise that often unless it involves a family member financially exploiting a resident. Often the resident does not want to get the family member (e.g., adult son or daughter) in trouble. These types of issues can often be complicated."

Exception

The Final Rules LTCOP state: "The Act is silent on how to best handle situations when the Ombudsman personally witnesses an incident of abuse, neglect, or exploitation and the resident is unable to communicate informed consent and has no resident representative available to do so.

In these cases, the Ombudsman or representative shall refer the matter and disclose the identifying information of the resident to the facility and/or appropriate agency for substantiation of abuse and may refer the matter to other appropriate agencies."

"When a report has been made to the Ombudsman program or when a representative of the Office discovers information through review of resident records, someone else is necessarily aware of the circumstances and can (and in many instances is mandated to) report this information to the agency which is responsible for substantiating abuse."

Education and Outreach

To build capacity for both the individual and systems advocacy, the program also carries out education and outreach activities:

- Providing education and consultation to staff of LTC homes, residents, families, the local community, and collaborating with other agencies.
- Supporting Family and Resident Councils.
- Developing citizen organizations.
- Empowering residents, families, and caregivers to be effective advocates.

Individual versus Systems Advocacy

The Ombudsman program is unique in that it is required to provide individual and systems advocacy on behalf of LTC residents. Individual advocacy occurs when the representative takes direction from a resident and works to resolve their concern or concerns.

Systems advocacy occurs when the LTCOP recommends changes to and improvements in local, state, or federal system (LTC home, government agency, an organization, polices, regulations, and law) to benefit LTC residents. These activities are not limited to legislative advocacy, but include coalition-building, speaking to the media, and other strategies.

Positive Effects of the LTCOP

A research study by Berish et al. (2019) aimed to determine if deficiency outcomes vary with the presence of ombudsman during state survey inspections. The dataset consisted of 95,237 surveys from 14,996 unique nursing homes during the 2009 to 2015 period.

Types of deficiencies (F-Tags) examined included: 1. All deficiencies 2. Quality of care 3. Quality of life 4. Administration. "Administration" F-Tags included F-Tags such as: "In compliance with all applicable federal, state, and local laws;" "Must not use nurse aide for >4 months unless competent and has completed nurse aide training;" "Nurse aide registry verification, retraining;" "Proficiency of nurse aides;" "In-service training of nurse aides;" "Laboratory services;" "Documentation that is in accordance with professional standards or quality;" "Must

not release information that is resident identifiable;" "Detailed plans to mee potential emergencies and disasters; and "Train all employees in emergency procedures."

The presence of an ombudsman during state survey inspections varied across states (range 0.8% – 82%) with an average of 29.9%.

Ombudsmen presence was found to be "associated with more deficiencies and higher deficiency scores."

Moreover, the presence of an ombudsman had "larger effects on deficiencies related to quality of life and administration, two areas of care about which ombudsmen would potentially have accumulated important information in the course of conducting their duties."

The results showed that ombudsman had "a higher probability of being present at surveys of nursing homes with persistently poorer quality, though there is still a wide variation within states and across the nation in whether ombudsmen are present at surveys."

The ombudsman presence seems to "lead to additional deficiencies and higher deficiency scores, even after accounting for the fact that ombudsmen are more likely to be present at nursing homes with persistently lower quality." The researchers concluded that "this suggests that ombudsmen may serve to bring issues to the attention of the surveyors that they might otherwise have missed."

Similarly, the LTCOP's presence during complaint investigations conducted by the state survey agency could also be helpful. Specifically, the National LTC Ombudsman Resource Center (2018) states, "If a resident says s/he was abused and wants to file a complaint with the agency that serves as the state's "official finder of fact," such as the state licensing and certification agency, the LTCOP representative should support the resident during the agency's investigation to "assist the resident in voicing and realizing his or her goals."

Nelson et al. (1995) explain, "When the survey team enters the facility, the Ombudsman office is contacted and takes responsibility for notifying the volunteer of the survey team's presence. Once notified, ombudsmen are expected to share their informed concerns with the surveyors and to take part in the exit interview." In addition, "Volunteer ombudsmen typically report serious concerns to paid Ombudsman supervisors, who may contact the licensing agency and ultimately influence the inspection process."

Additionally, the ombudsman representative "could support the resident by following up with the resident and making sure she is aware pf available support services (e.g., facility social worker, victims' services, and counseling). Whether or not a resident chooses to pursue a complaint regarding abuse, a representative should support the resident as much as the resident wants them to be involved" (National LTC Ombudsman Resource Center, 2018).

A study by Nelson et al. (1995) found that regulatory agency activity was "significantly greater in nursing homes with ombudsmen than in nursing homes without ombudsmen." Specifically, the presence of ombudsmen was related to increased abuse reporting and abuse complaint substantiations, more survey deficiencies, and higher sanction activity." The researchers stated, "While this study does not prove causality, it provides strong evidence that ombudsmen do make a difference."

An early study by Litwin & Monk (1987) examined a sample of LTC homes that utilized ombudsman services in comparison to LTC homes not in receipt of such services.

Independent assessment measures were derived from State Department of Health ratings and complaint statistics for LTC homes. Findings revealed that ombudsman-served LTC homes were not appreciably different from those not served by ombudsmen. LTC homes served by ombudsmen, however, received a relatively higher amount of complaints than did the LTC home group not served by ombudsmen, particularly in areas not covered by statutory abuse reporting requirements. The findings suggested that nursing home ombudsmen "call attention to aspects of quality care not currently assured by other protective mechanisms."

Lack of Comparative Studies on LTCOPs Effectiveness But National Standards Exists

It is not currently possible to compare the effectiveness of different LTCOPs across the U.S. (Mark Miller, personal communication, October 14, 2022). To address this gap in knowledge, the National Academies of Sciences, Engineering, and Medicine (2022) recently called for data collection and research on the "effectiveness of long-term care ombudsman programs."

That said, national standards for Local LTCOPs have been identified over two decades ago in The Huber Badrak Borders Scales (Huber et al. 2001). These standards, which could be used to strengthen existing LTCOPs as well as to guide the development of new LTCOPs, include:

- Structure of Ombudsman Programs (e.g. autonomy; fit to host agency)
- Qualifications of Ombudsmen (e.g. skills)
- Legal Authority of Ombudsman (e.g. facility & records access; conflict of interest)
- Financial Resources (e.g. staff funds)
- Management Information Systems (e.g. use of data)
- Legal Resources (e.g. legal council)
- Human Resources (e.g. staff-bed ratio; staff training; staff turnover)
- Individual Resident Advocacy Services (e.g. visibility; advocacy services & training)
- Systemic Advocacy Work (e.g. system advocacy)
- Educational Services (e.g. materials and presentations)

For detail about each of the 10 standards, see Table 5:

Table 5 – The Structure of the Huber Badrak Borders Scales

1. Structure of Local Ombudsman Progams (mean of four 1–10 subscales)
   - 1.1 Working relationship
   - 1.2 Fit of host agency
   - 1.3 Autonomy
   - 1.4 Resources
2. Qualifications of Local Ombudsmen (mean of eight 1–10 subscales)
   - 2.1 Skills
   - 2.2 Advocacy
   - 2.3 Long-term care ties
   - 2.4 Regulatory ties
   - 2.5 Regulatory functions
   - 2.6 Adult protective services/Guardianship
   - 2.7 Training
   - 2.8 Performance
3. Legal Authority of Local Ombudsman (mean of four 1–10 subscales)
   - 3.1 Facility access
   - 3.2 Liability
   - 3.3 Conflicts of interest
   - 3.4 Access to records
4. Local Financial Resources (mean of five 1–10 subscales)
   - 4.1 Administrative fees
   - 4.2 Staff funds
   - 4.3 Audits
   - 4.4 Maintenance of effort
   - 4.5 Funds
5. Local Management Information Systems Resources (mean of five 1–10 subscales)
   - 5.1 Management information systems
   - 5.2 Use of data
   - 5.3 Shared information
   - 5.4 Scope of data use
   - 5.5 Regulatory links
6. Local Legal Resources (mean of four 1–10 subscales)
   - 6.1 Legal counsel
   - 6.2 Legal expertise
   - 6.3 Legal autonomy
   - 6.4 Legal expenses
7. Local Human Resources (mean of five 1–10 subscales)
   - 7.1 Roles
   - 7.2 Staff:Bed ratio
   - 7.3 Staff size
   - 7.4 Staff training
   - 7.5 Staff turnover
8. Individual Resident Advocacy Services (mean of three 1–10 subscales)
   - 8.1 Visibility
   - 8.2 Individual resident advocacy services
   - 8.3 Advocacy service training
9. Systemic Advocacy Work (mean of three 1–10 subscales)
   - 9.1 System advocacy
   - 9.2 Diverse issues
   - 9.3 Systems network
10. Educational Services (mean of two 1–10 subscales)
    - 10.1 Educational materials
    - 10.2 Educational presentations

[a]Adapted from Harris-Wehling, Feasley, & Estes (1995).

Underreporting by U.S. Nursing Homes

Multiple reports over the years have shown that nursing homes' underreporting of care-related problems and mistreatment is substantial. The U.S. Office of Inspector General (OIG) found that nursing homes reported only 16% of incidents where residents were hospitalized for "potential abuse and neglect" (OIG, 2019). In addition, a study by Sanghavi et al. (2019) found that from 2011 to 2015, nursing homes didn't tell Medicare about 40% of residents who were hospitalized after serious falls."

Table 6 describes factors that often serve as barriers for nursing homes' reporting of one of the most common forms of elder mistreatment in LTC homes: Neglect of Healthcare.

Table 6

Barriers for Reporting of Neglect in Nursing Homes
Lack of awareness of the problem
Lack of protocols for detection / Poor recognition
Lack of knowledge of reporting processes
Concern it'll reflect negatively on job performance
Concern about disciplinary action
Concern about regulatory issues (e.g., citations)
Adverse publicity
Fear of lawsuits
Residents' memory loss
Resident and family fear of retaliation

Source: Friedman et al. (2017)

Annual Survey Inspections Miss Quality of Care Violations

Although the standard survey approach can be helpful in identifying care-related problems and improving nursing home quality of care and safety, the process consists of limitations.

According to Liu et al. (2021), "On-site standard surveys, taking place approximately annually, may not reflect nursing home care practices throughout the year but rather during a narrow time period prior to the survey."

For example, the U.S. Government Accountability Office (GAO, 2008) reported that federal comparative surveys found that in all but five states, the number of state surveys missing deficiencies at the lowest level of noncompliance was greater than 40%. The GAO stated, "Undetected care problems at this level are a concern because they could become more serious if nursing homes are not required to take corrective action." The most frequently missed type of deficiency was "poor quality of care such as ensuring proper nutrition and hydration and preventing pressure sores."

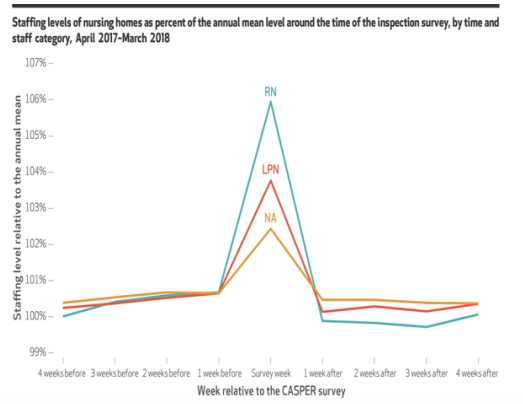
The Problem of Understatement

A GAO (2009) study identified weaknesses in the survey methodology and guidance to surveyors in identifying deficiencies. These weaknesses contribute to failures to cite serious deficiencies or citing them at seriousness levels lower than warranted—a problem known as understatement.

The Problem of "Staff Up" Around the Inspection Date

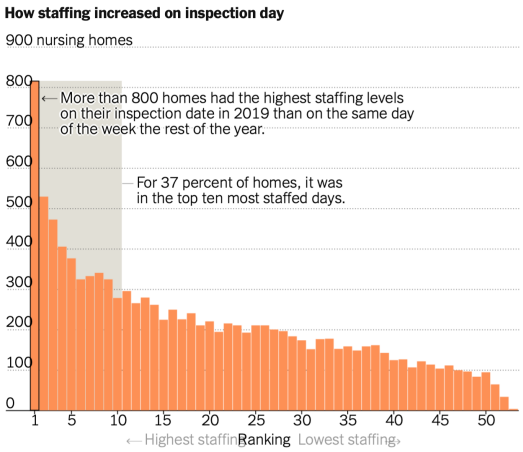
Many nursing homes increase their nursing staffing levels around the time of the annual inspection. The line graph in Diagram 3 and the bar chart in Diagram 4 illustrate this issue.

Diagram 3



Source: Geng et al. (2019)

Diagram 4



Source: NY Times (March 13, 2021): https://tinyurl.com/28af2avn

Inaccurate "Unsubstantiated" Determinations

In some cases, allegations of neglect may be inadequately determined by state survey agencies as unsubstantiated. For example, 77-year-old James Parker was beaten severely by his roommate in a nursing home in Minnesota. He sustained brain injuries requiring emergency surgery. The Minnesota Department of Health (MDH) investigated and determined: "Based on a preponderance of evidence, the allegation of neglect is not substantiated. Two residents had been roommates for over one month with no history of altercations... Staff could not have anticipated the unexpected and sudden altercation."

But, reportedly, there were warning signs prior to the attack. James reported: "I told them that if I have to spend one more night with this man, then I would kill myself. They still ignored me." His daughter reported that she begged the administration for a different roommate**.** After her father's injury, she said: "How many times we were supposed to warn them?"

She sued the nursing home for neglect and won. Given the roles of the LTCOP, one can see how it might have listened to the concerns of the resident and his daughter and with the resident's permission, advocated early for a bedroom change and other protections, which could have helped prevent the brain injury. That is, someone knowledgeable about residents' rights who is skilled in working with the resident and his family on an advocacy plan for a timely change.

Mistreatment Not Investigated by State Survey Agency

Information about significant number of mistreatment incidents is not being reported to and investigated by the state survey agency. The following case of neglect illustrates this problem.

A 90-year-old woman with Alzheimer's disease was living in a dementia care home operated within an assisted living residence in Minnesota. One evening, while in her bed, she called for staff help 99 times over a period of 39 minutes. No one came to assist her. She then fell of the bed. While on the floor, she called and cried out for help for an additional 143 times. At some point, she said: "Please help me Lord." In total, she called for staff help 242 times over a period of one hour and 38 minutes. Staff were not aware that all this has been taking place.

The woman's daughter saw her mother on the floor on a remote hidden camera from her home. She alerted the staff who only then came to assist her off the floor. Her daughter said, "Something is fundamentally wrong with a system that allows an elderly woman, anyone elderly, to be disregarded." Beyond lack of adequate supervision, part of the problem was that the bed alarm was malfunctioning on an ongoing basis (bed alarms are used to notify staff when a resident at risk of falls is leaving her or his bed). Despite multiple family requests to fix it, the bed alarm was not working.

Early involvement of an Ombudsman could have assisted the family in advocating for repair of the bed alarm and enabling the staff to assist the older woman in a timely manner.

Addressing Problems When They Are Still Small

As noted earlier, Ombudsmen assist residents by resolving complaints about their care and help ensure that their rights are protected. Through visits, Ombudsmen help address residents' concerns before they rise to the level of complaints requiring intervention by preventing actions or inactions that unfavorably impact residents' care, rights, and quality of life.

This key issue of the identification of care-related problems and mistreatment before it causes harm to residents has been repeatedly recognized over the years. Arcus 1993 (as cited in Nelson et al. 1995) stated, "Ombudsmen settle small problems before they become large ones." Nelson et al. (1995) stated, "One effect of ombudsman involvement is that troubles and concerns are brought to light that might otherwise go unnoticed…" In accordance, the Final Rules LTCOP state, "One of the hallmarks of the Ombudsman program is its ability to resolve potentially dangerous problems before they escalate."

This principle is also consistent with CMS guidance to state surveyors in the context of state complaint investigations with regards to complaint procedures. As described in the CMS State Operations Manual (July 19, 2019): "One of the primary objectives of the federal complaint process is prevention. It highlights the importance of identification and correction of less serious complaints "to prevent the escalation of these problems into more serious situations that would threaten the health, safety, and welfare of the individuals receiving the service."

For example, in 2017, the MDH reported, "Thousands of complaints are not investigated so maltreatment continues, and less severe issues may escalate to more serious harm." Examples of care-related problems and mistreatment left not investigated by the state survey agency (MDH) included falls, resident-to-resident altercations, unexplained injuries, unexplained fractures, medication mismanagement, abuse by staff (such as emotional abuse), and drug theft.

The MDH stated, "If less serious issues like these were addressed early on, individuals might not be seriously harmed in subsequent incidents."

The MDH provided the following example: A resident at a nursing home had numerous falls which did not result in any serious injury. An investigation was not conducted by the state survey agency. The resident continued to fall. Eventually one of the subsequent falls led to a serious injury and death.

This issue highlights the role LTCOPs can play in early identification, advocacy, and prevention of harm to residents.

Fear of Retaliation

A Connecticut Statewide Workgroup (Robison et al. 2007) convened by the State LTCOP to address the issue of Fear of Retaliation. Residents were asked the following survey question:

Do you worry about retaliation if your were to report a complaint or concern?

Findings. 23% of nursing home residents, 13% of assisted living residents, and 19% of residents of residential care homes reported that they are afraid of staff retaliation. The survey demonstrated that residents' fear of retaliation in LTC homes is fairly common.

Examples of things residents have said about their fear of staff retaliation:

Deliberating whether to report a complaint to a state surveyor, one resident told a state surveyor: "I am really afraid of her. She intimidates. Are you sure nothing will happen to me?"

Another resident said: "They know how to get even so I try to keep my mouth shut."

Yet another resident said: "Oh yeah, always. That's why nobody makes the complaint. The administrator scares everyone and he's very belittling and yells at people."

In a recent case, a resident with quadriplegia (a condition where all 4 limbs experience paralysis) in an assisted living residence in Minnesota became upset about staff handling of mechanical lift for transfer. The resident said that he's going to report it to management. A staff member overheard it and responded by physically threatening, harassing, and humiliating the physically disabled resident. Other staff members witnessed it. The Minnesota Department of Health investigated the allegation and concluded on September 20, 2021 that "emotional abuse" was substantiated.

According to the National LTC Ombudsman Resource Center (2018), "Fear of retaliation is one of the most common reasons residents do not want to pursue a complaint and disclose their identity. Since residents live in a facility and rely on staff for their basic needs, their fear of retaliation cannot be overemphasized. It is critical that LTCOP representatives understand how fear of retaliation influences a resident's or another complainant's choices regarding complaint reporting and resolution."

Protections from Retaliation. Ombudsmen work to address potential or actual retaliation against residents. Specifically, under the general category of Complaint Code D: Autonomy, Choice, Rights, the LTCOP has a unique Complaint Code (D06), which is defined as "Acts of retaliation / revenge by facility staff in response to complaint to the facility, Ombudsman program, or state survey agency." Examples and reporting tips under this code include "Use for threat of discharge, lack of care, requests ignored, call lights unanswered, rough handling, monitoring resident's phone, mail or visits without resident permission."

Right to Complain

The LTCOP works to ensure that residents' right to complain about the care they receive. Towards this end, the Ombudsmen uses complaint code D05, which is defined as "Facility staff ignores or trivializes a resident complaint or there is no facility grievance process thereby limiting the resident's ability to resolve a problem directly with the administration." Examples and reporting tips under this code include "Use if the grievance procedure is not followed or made known to residents."

Right for Resident Council or Family Council

The LTCOP can help start and support Resident Councils and Family Council and assist in ensuring that they are operated as intended with primary focus on residents' and families' voice, rights, and care needs. The LTCOP uses a unique complaint code (D08) to ensure that this right is realized. It is defined as "Interference with or prevention of the formation of a resident or family council. Staff does not assist in the promotion of councils or exerts too much control; does not respond or follow-up on council requests and similar problems."

Lack of Consumer (Resident / Family) Satisfaction Surveys in CMS Care Compare Website

Nursing home satisfaction surveys are designed to provide information on the experiences of residents and their family members. Surveys may cover topics such as the environment of the nursing home, the care provided, the communication and respect provided to the resident by nursing home staff, and activities available for residents (GAO, 2016).

According to The National Academies of Sciences, Engineering, and Medicine (NASEM, 2022), "The Ombudsman can help fill current gap related to lack of consumer satisfaction surveys in U.S. nursing homes and CMS Care Compare website. That is, satisfaction surveys done by a qualified and independent organization; not the nursing home."

The committee concluded: "the lack of inclusion of measures of resident and family satisfaction and experience in Care Compare impedes the ability of individuals and their families to make fully informed choices about providers and facilities." It added, "Failure to capture the voices of residents and their families in quality measurement neglects this crucial aspect of quality."

GAO 2016 analysis showed that nursing homes with higher Overall quality ratings did not necessarily have higher resident satisfaction scores or fewer complaints. It concluded, "The rating systems is missing important information that could help consumers distinguish between high and low performing NHs." In accordance, a study by Williams et al. (2016) compared CMS Star-Rating System to nursing home satisfaction data in Ohio. It found high rate of inconsistency between overall rating and consumer satisfaction scores.

Brief Summary

Taken together, in the current LTC home environment, the implementation of the LTCOP duties (as required under the OAA and The Final Rule) is clearly essential. That is, the LTCOP is necessary to ensuring that each resident's federal right "to attain or maintain the highest practicable level of physical, mental, and psychosocial well-being" will be realized. As described in Table 7, the LTCOP with its unique roles, mandates, and contributions can help bridge critical gaps in care, oversight, and care providers' accountability.

Table 7

Unique Contributions of the LTCOP
Independent administration and function
More resident-directed boots on the ground
Heavy focus on resident's rights, preferences, and empowerment
Informing residents and families of their rights
Identifying care-related problems when they are still small
Notification of survey agency (with resident's / LAR permission)
Data collection to identify trends and inform prevention at multiple levels
Role in advocacy for change at systems level (legislation, etc.)
Provision of technical assistance to care homes as well as staff training
Educating other agencies
Working with media

Note: LAR stands for Legally Authorized Representative

According to the National LTC Ombudsman Resource Center (2019), "The Ombudsman has unique expertise and understanding of long-term care services and supports, offers an independent perspective, and has direct, open lines of communication with residents in long-term care facilities."

Through its role, the LTCOP fulfills its historic mission of increasing scrutiny and accountability" of LTC homes (Nelson et al. 1995). In so doing, since its inception, the LTCOP played a unique role in protecting and promoting LTC residents' health, safety, welfare, and rights.

Hollister & Estes (2012) argue that without LTCOP, "regulatory agencies will likely require to conduct more visits, legal service agencies will receive fewer referrals, law enforcement may not have the evidence they need, the LTC will have reduced sources of quality control, and state governments will have to find other efficient ways to meet the needs of residents and the public."

Key Factors Necessary for Success of the LTCOP

This review of the literature and interviews conducted for this report with Ombudsman officials identified key factors for necessary for the success of the LTCOP. These include:

- Adequate Funding
- Distinct mandate
- Centralized
- Independent / Autonomy
- Adequate Organizational Placement / No conflict of interests
- Head of Ombudsman program should not be Governor appointee
- Professional paid staff – the core (start the program only with them)
- Volunteers can be very helpful, but recruitment, management, and retainment (turnover) can be challenging
- Direct access to decision making (government, policy, systems, legislation)
- Freedom to speak with the press

Main Challenges of the LTCOP

The main challenges in successful operation of the LTCOP typically have to do with the program's resources (Administration for Community Living, 2020). Specifically, insufficient funding and difficulty recruiting and supporting volunteers (though some LTCOPs are considered better than others on this latter front). Specifically, the lack of financial and human resources prevent the program from achieving regular nursing home and board of care home visits and performing complaint investigations.

In 1995, the Institute of Medicine commissioned a report evaluating the LTCOP and its work in representing residents of LTC homes. It identified insufficient resources as a factor associated with the effectiveness of sate LTCOPs. Budget uncertainty is a major concern in many LTCOPs across the country for decades (Hollister & Estes, 2012).

A study by Estes et al. (2004) held telephone interviews with Ombudsmen in 50 state programs. The study found that factors limiting perceived effectiveness of State LTCOPs included insufficient funding and insufficient LTCOP autonomy caused by organizational placement. The findings showed positive associations between (a) program funding and paid and volunteer staff levels; (b) the ratio of LTC beds per ombudsman and % of nursing home visited by the ombudsman; (c) sufficient funding and perceived effectiveness of work with nursing homes.

Another challenge experienced by the LTCOP has to do with the fact that "Individuals receiving services and their families may not completely understand the role of the ombudsman" (National Ombudsman Reporting System). Some residents may not be aware that the LTCOP exists and/or how to access it (Wood and Stephens, 2003).

Finally, Mark Miller reports on the challenge of using volunteers in LTCOP. He states, “We have 3 or 4 times as many volunteers as paid staff nationally. This makes recruiting, training, and retention huge issues related to the success of any program.” He added, “Volunteers are a big wild card.”

HIPAA – Health Insurance Portability and Accountability Act of 1996 (HIPAA) Privacy Rule

Under HIPAA Privacy Rule, the LTCOP is a “health oversight agency” (Administration on Aging, 2003). Specifically, “State Ombudsman are exempt from Federal privacy rule under HIPAA.”

The OAA authorizes the Ombudsman and representatives of the Office regular, timely, private, and unimpeded access to residents and to their records.” Mark Miller states, “You train and certify a volunteer and they are the full representatives of the Ombudsman program. With the resident’s permission, we can access their records and share their identity. We have access to records at any time day and night.”

The direct access Ombudsmen have to residents is a critical asset to their ability to realize its duties under the Older Americans Act.

When thinking about Ombudsmen access to residents and their records, it is helpful to consider Miller’s observation, “It’s the other way around. It is the resident’s right to access me. Because the resident has a right to refuse it.”

Sara Hunt, consultant, National Ombudsman Resource Center explains, “The Privacy Rule does not preclude release of residents’ clinical records to the LTCOP, with or without authorization of resident or resident’s legal representative.” She adds, “Since the LTCOP is a Health Oversight Agency, nursing homes and other “covered entities” may, in response to appropriate ombudsman inquiries, share other information without fear of violating the Privacy Rule.”

To legally enable the LTCOP to fulfill its duties, there is a need to develop and pass a law in Israel, one that will grant LTCOP paid staff and certified volunteers direct access to the LTC building, residents, and their clinical records (the latter after resident / family / legally authorized representative’s permission).

The Need to Establish a Long Term Care Ombudsman Program in Israel

The majority of people living in U.S. nursing home are physically frail, have cognitive disability due to Alzheimer's disease or other forms of dementia, and many have serious complex health conditions. The majority are dependent on care staff assistance when it comes to meeting their personal care needs (activities of daily living such as walking, eating, bathing, using the toilet, incontinence care, transfers, and medication administration). Many residents require close staff supervision to ensure that their health, well-being, and safety are not compromised. In short, most people living in U.S. nursing homes are considered a vulnerable population.

A review of studies by Harrington et al. (2016) found that "half of U.S. nursing homes have low staffing and at least one quarter have dangerously low staffing." McConnell et al. (2010) adds, "the sheer size of the gap between what we have and what we need to ensure adequate nursing staffing in long-term care is staggering."

With the lack of adequate staff training in many U.S. nursing homes, the low and dangerously low nursing staffing levels (i.e., Certified Nursing Assistants, Licensed Practical Nurses, and Registered Nurses) often place residents at risk of harm.

Exacerbated by the gross asymmetry of power that exists between physically and cognitively disabled residents and staff/nursing homes, the role of the LTCOP can help balance this asymmetry of power as its core mission is to ensure that residents' rights and wishes are protected and respected.

In addition, a significant number of residents do not have family members or close friends. Others have family members that aren't involved in their daily care. Still others have family members that live far away and don't visit frequently. The question that needs to be asked is:

Who is going to be their voice?

While most direct care staff are dedicated and caring, all too often they are understaffed, overworked, underpaid, receive limited training, and lack adequate guidance and support from managers. While many direct care staff members do everything within their power to ensure adequate care for residents, many others are not in a strong position to advocate for residents' rights in general and certainly not as can be accomplished with the unique mandates, specialized knowledge and skill set of the LTCOP.

To the extent that the conditions in LTC homes in Israel resemble those in U.S. LTC homes, it is time to establish the LTCOP in Israel.

I recently asked the following question to leaders of the LTCOP in the United States:

What is your reaction when you hear that Israel doesn't have a LTC Ombudsman Program?

Mark Miller, President, National Association of State Long-Term Care Ombudsman (currently, head of D.C. Ombudsman; he started working as an Ombudsman in 1984):

"Bad. People need an independent, resident-focused advocate. Why? The state survey agency can't do that. The state's job is to ensure long-term care homes meet the minimal requirements for compliance with the regulations…and they come once a year." He added, "We focus on quality of life issues, not regulatory issues and we take direction from the resident. There is no one else that can do that except Ombudsman. Not to have an Ombudsman is a real disservice."

Mairead Painter, Connecticut State Long-Term Care Ombudswomen, said:

"It's heartbreaking."

In her recent testimony at the U.S. House Appropriations on Labor, Health and Human Services, Education, and Related Agencies, Painter asserted,

"Without our eyes and ears in these facilities, residents are at risk of abuse, neglect, and exploitation, and any number of rights violations."

When I asked professor Ariela Lowenstein whether she thinks there is a need for an LTCOP in Israel, she wrote (personal email communication, October 2022).

Professor Israel Doron wrote, "There is definitely a need to consider it."

In light of the above, I would like to ask: Do *you* have a voice?

People living in LTC homes have the same right to have their voice heard and respected.

The LTC Ombudsman Program can help realize this right and through it contribute to improving the quality of life, quality of care, and safety of residents.

How Can We Get There?

1. Raise awareness among key stakeholders to the need for a LTCOP in Israel.

2. Build a broad and strong coalition of key / interested stakeholders.

3.a Craft and pass a law and regulation mandating the LTCOP roles, authority, and responsibilities.

3.b Tie adequate annual funding required under the law.

4. Fund pilot demonstration projects first (to demonstrate need, contributions, and credibility).

5. Implement across Israel.

6. Evaluate effectiveness and improve over time.

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