

# **SUPPORTING WELL INFORMED CONSUMERS: THE ROLE OF THE LONG-TERM CARE OMBUDSMAN**

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## **ABOUT THE PAPER**

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## **SUPPORTING WELL INFORMED CONSUMERS: THE ROLE OF THE LONG-TERM CARE OMBUDSMAN<sup>1</sup>**

The Long-Term Care Ombudsman Program is distinguished by its mandate to represent long-term care residents. This is carried out in many ways including facility visits, resolving complaints on behalf of residents, consumer education, and expressing the needs of residents to others such as policy makers. Consequently, the Long-Term Care Ombudsman Program (LTCOP) has a wealth of knowledge about long-term care facilities.

Ombudsmen have been advising consumers about factors to consider when choosing a facility since the program began. Ombudsmen also use their knowledge and data in many ways to represent residents in effecting systemic changes. With the increasing amount of information available on the Internet and periodic media reports of poor care and mistreatment of long-term care residents, questions are raised about the type of information LTCOPs should share with the public.

This paper discusses the responsible sharing of LTCOP complaint data including current practices and parameters for extending these practices. The section topics are:

- **Background:** covers the federal requirements and national recommendations regarding the release of LTCOP data,
- **Multiple Uses for LTCOP Data:** lists some of the most typical ways LTCOPs are using their data and information,
- **Sharing LTCOP Complaint Data:** explains the range of program practices and considerations when sharing complaint data with consumers,
- **Essential Elements for Responsible Sharing:** discusses the prerequisites to enable more LTCOP data to be shared with consumers,
- **Summary:** comments on key points regarding the hallmarks of programs that are sharing the most specific data with consumers and the need for continued dialogue about responsible sharing of LTCOP data.

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<sup>1</sup> This information is based on a session with the same title at the Annual State Long-Term Care Ombudsman National Training Conference 2004, and conversations with Ombudsman Resource Center staff, Alice Hedt and Mark Miller; a review of LTCOP annual reports from several states; discussions among ombudsmen about the use of program information at annual meetings and conferences; and information submitted to the Center.

## BACKGROUND

The Older Americans Act<sup>2</sup> establishes parameters for the release of Long Term Care Ombudsman Program files and records. Identifying information can be released only with the consent of the resident or complainant, or the resident's legal representative, or in response to a court order. Other information is released at the discretion of the State Long Term Care Ombudsman. The program also is required to collect and analyze data and publish an annual report.

If a LTCOP is fulfilling its legal requirements what would the program be doing? What type of practices would that LTCOP have that could be identified? The Institute of Medicine asked these questions in its comprehensive study of the LTCOP. Its report, *Real People, Real Problems*,<sup>3</sup> contains a series of tables that describe exemplary practices, essential practices, and unacceptable practices for LTCOPs based on the Older Americans Act mandates. The tables' exemplary practices set a high benchmark for programs. These practices have become the goal for many LTCOPs nationwide, with significant progress being made in some states. Two of tables, excerpted below, address sharing and using LTCOP information with consumers and others.

### Exemplary Practices

### Essential Practices

#### Information Management, Table 5.5b

The Office shares information generated from its own resident advocacy services, without violating confidentiality, and shares public information about residents' concerns about health, safety, welfare, and rights with regulatory agencies, resident or family councils, citizen groups, other advocacy agencies, providers, and policymakers.

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#### Educational Services, Table 5.9

In conjunction with its systems agenda, the program (state and local) initiates and presents educational programs for residents, families, citizen organizations, facility staff, regulatory staff, policymakers, or the general public that answer their questions about health care in LTC facilities or the interests of residents.

Responding to requests, the program (state and local) presents educational programs for residents, families, citizen organizations, facility staff, regulatory staff, policymakers, or the general public that answer their questions about health care in LTC facilities or the interests of residents.

In 2002 the National Association of State Long-Term Care Ombudsman Programs (NASOP) convened a multidisciplinary group of individuals to review the LTCOP and make recommendations for future actions to strengthen the program. The results of this effort, *The Long-Term Care Ombudsman Program: Rethinking and Retooling for the Future: Proceedings and Recommendations*,<sup>4</sup> included the use of LTCOP data and information as one of six major areas of

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2 See the Appendix for the specific language from the Older Americans Act related to these provisions.

3 *Real People, Real Problems: An Evaluation of the Long-Term Care Ombudsman Programs of the Older Americans Act*. Institute of Medicine. 1995, <http://www.nap.edu/books/NI000028/html/>.

4 This report is available via the Internet, [http://longtermcare.state.wi.us/home/whitepaper03\\_FINAL.pdf](http://longtermcare.state.wi.us/home/whitepaper03_FINAL.pdf), or obtain a hard copy by phoning Becky Kurtz, NASOP President, (888)454-5826 (toll free).

examination. One of the recommendations from this topic is applicable to this paper.

#### LTCOP Data and Information

4.7) NASOP and the National Association of Local Long-Term Care Ombudsmen should develop policies for providing complaint, inquiry, and other information to consumers and providers. These policies must provide for privacy and confidentiality concerns consistent with federal laws.

The LTCOP takes its responsibility to serve residents seriously. The development of the National Ombudsman Reporting System (NORS) was a collaborative effort between NASOP and the Administration on Aging. Improving NORS and making data collection more consistent, within each state and across the country, has been an ongoing process. The exemplary practices from the Institute of Medicine report and the recommendation from the NASOP project are goals that keep the program moving forward to find better ways of sharing information with consumers.

## **MULTIPLE USES FOR LTCOP DATA**

Ombudsmen use their data for many purposes that range from internal applications, such as program management, to external purposes, such as advocacy on behalf of residents. A list of the primary uses of LTCOP information follows.

### **Internal Use**

One of the most common uses of LTCOP information is for internal quality assurance and program management. On both a statewide and a regional basis, LTCOP use their data to determine factors such as:

- the accessibility of ombudsman services to residents on a routine basis;
- resource allocation such as ombudsman staffing, finances, or prioritizing cases;
- the types of complaints received, the source of the complaints, and their disposition;
- similarities and differences in various regions of the state;
- changes in complaints within the state and within regions over time;
- similarities and differences between the state and other states or the national average using National Ombudsman Reporting System (NORS).

Programs also use their information to identify issues that need to be addressed. If an issue is prevalent throughout the state, a training program or additional resources might be developed to assist ombudsmen and consumers. Analyzing program information also leads to the identification of

trends or of changes within the state. This type of analysis leads to using LTCOP data in external ways.

## External Use

There are many ways LTCOP use their data for purposes other than internal program management and quality assurance. Several of these are briefly described.

- Facility Surveys: LTCOPs share information about a facility's complaint history with surveyors prior to a certification survey.
- Patterns: Patterns are identified such as facilities with chronic problems; an issue impacting residents throughout the state; an issue that reflects the policy of a corporation or a chain of facilities; the state's response to facilities with chronic problems; the types of problems that are cited as deficiencies on facility surveys. This analysis of patterns is used in various ways, a few examples follow.
  - Developing consumer information materials: Requests for information and assistance and complaint data are analyzed to determine the most frequently asked questions and complaints to develop fact sheets around those issues. The fact sheets are mailed to individuals contacting the program for assistance and are used in consumer information presentations.
  - Developing educational sessions for consumers and providers: The identified patterns are the focus of in-service training sessions or educational programs offered to facilities and to consumers.
  - Advocating for changes within a provider corporation: LTCOP data specific to facilities owned by one corporation has been shared with corporate management to focus on specific, persistent areas that need to be changed within the corporation as a whole. On a selected basis, ombudsmen at both regional and state levels use such data to support the need for change. Changes in the language in admission contracts and discharge notices, in menus, and in facility approaches to collecting payment owed to the facility, are examples of the results of such advocacy.
  - Advocating for changes in laws, regulations, provider payment, or enforcement: LTCOPs typically use their statewide data to identify changes that need to be made in laws or systems that impact residents. LTCOP data is often used to support increases in nursing home staffing ratios and wages for direct care staff, to seek residents' rights protections for assisted living residents, and to strengthen the survey and enforcement process.
- Assisting consumers in making choices about long-term care facilities: Many LTCOPs use their complaint information to advise consumers who request information about facilities. The way in which LTCOPs do this varies across the country. The lack of uniformity warrants a separate section in this paper.

## SHARING LTCOP COMPLAINT DATA

Ombudsman programs have a wealth of knowledge and complaint information about long-term care facilities. Typically LTCOs are the most frequent “outside” visitors with residents other than family and friends of residents. Because of their presence in facilities, ombudsmen have a firsthand knowledge of the impact of changes in owners, administration, and other staff. Ombudsmen use their knowledge to resolve complaints on behalf of residents as well as to carry out the range of activities listed in the preceding section of this paper.

Without question all LTCOPs want to help consumers make informed decisions about differences in facilities and care. The sharing of LTCOP complaint data with consumers is the subject of much discussion among state and local ombudsmen. There are differences of opinion regarding what can be shared and how it can be shared. Furthermore, LTCOPs sometimes are criticized by consumers for not sharing as much specific information as is expected. The lack of consensus on this topic among LTCOs led to a dialogue and consensus building session at the 2004 Annual Training Conference for State Long-Term Care Ombudsmen.<sup>5</sup> The information in this section and in the remainder of the paper is based on notes from that discussion.

### Role of the LTCO

Ombudsmen seek to educate consumers as well as to provide information. There are numerous sources of public information about facilities. Ombudsmen provide an important service by talking with consumers regarding needs, preferences, options, and explaining how to use the information that is available. All LTCOPs inform consumers about the federal survey information and quality measures and how to access and use this information. Having a personal contact with a consumer enables the ombudsman to share additional information that might be useful in a particular situation such as information on hydration or pressure sores.

Differences among LTCOPs exist regarding the sharing of LTCOP complaint data on specific facilities with consumers. Programs range from not sharing specific LTCOP complaint data on a facility to programs that share this information with some qualifiers. An overview of the range of LTCOP practices with a brief explanation follows. These delineations apply to statewide LTCOPs and local LTCOPs.

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<sup>5</sup> The conference, *The Gateway to Advocacy: Ensuring Quality and Consistency in Service*, was held in St. Louis, Missouri, coordinated by the National Long-Term Care Ombudsman Resource Center, supported by a grant from the Administration on Aging.

## Range of LTCOP Practice Regarding Sharing Facility Specific Complaints with Consumers

Sharing LTCOP Complaint Data by Facility Share this because	Sharing LTCOP Complaint Data by Facility Do <b>Not</b> share this because
<b>LTCOP Knowledge Helps Consumers</b>	
<p>LTCOP data can be helpful to consumers regarding types and patterns of issues and responsiveness of a facility. The ombudsman data usually is more current than the survey report and is an important indicator about a facility.</p>	<p>LTCOP data could be misleading. An absence of complaints could be due to residents who are reluctant to complain or who are unable to complain due to their physical and mental conditions, infrequent LTCO visits, or unresolved problems with reporting and collecting LTCOP data. Conversely, a lot of complaints might be due to a younger resident population or residents who are well informed and not hesitant to ask for ombudsman help.</p> <p>Background use: The data might be used by a LTCO when talking with a consumer to suggest more specific questions the consumer might ask and observations to make in a facility without saying that the suggestions are based on ombudsman data for that facility.</p>
<p>Sharing LTCOP data is being accountable to residents and consumers.</p>	<p>Sharing LTCOP could be irresponsible without an opportunity to provide a context, other resources, and help the consumer make an <i>informed</i> decision.</p> <p>LTCOP data is driven by residents' needs and issues. It is not designed to assess the quality of a facility except through inference. The LTCOP data has a different focus and process of being generated than data from a regulatory or credentialing organization. LTCOP data also is different from customer satisfaction data.</p>
<p>In some states, the LTCOP data is the only data available from an independent, reliable source regarding consumer complaints and conditions in certain types of facilities such as adult care homes or assisted living facilities.</p>	<p>If the LTCOP data is the sole public source of information on a facility, sharing this data by facility could lead to consumers and LTCO being pressured to present data that conforms to a particular reputation, either good or bad.</p>

<b>Sharing LTCOP Complaint Data by Facility</b>	<b>Sharing LTCOP Complaint Data by Facility</b>
<b>Share this because</b>	<b>Do <b>Not</b> share this because</b>
The State LTCOP has policies or some form of guidance that clearly state what is appropriate information to share and how to document this activity. Training and support on the policies is provided to all LTCO.	There are a few LTCOPs without written or statewide policies.

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### **Confidentiality**

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Do not report complaint data that could reveal a resident’s identity without consent.	Do not report complaint data that could reveal a resident’s identity without consent.
LTCO share facility specific information for a specified time increment. Some LTCOPs share the information on data compiled for one year. Data is not shared for a shorter time period. Other programs share complaint information for a three month period or whatever time period is pertinent to the request.	Facility specific complaint data is not shared due to confidentiality concerns. This is a major concern in states whose population is primarily rural and where there are few facilities. LTCO are concerned about the potential misuse of data and also about potential retaliation or intimidation for residents or staff who talk with ombudsmen.  There also are concerns that the LTCOP would be viewed as a punitive program and the program’s ability to resolve residents’ issues would become unnecessarily adversarial. Another concern is that facilities with few complaints would use the LTCOP data in promoting their facilities. Facilities with many complaints might be continually challenging the LTCOP on every complaint because the facility believes it has more at stake than when the data is not publicly shared by facility.
Legal liability is not an issue when LTCOP data is shared according to program policies and the sharing of information is clearly documented.	There are concerns about potential legal liability.
LTCOP complaint data by facility is not accessible via the Internet but is mailed upon request after a LTCO talks with a consumer.	Complaint data by facility is not shared. One exception is when this data is used for the LTCOP to comment on a certificate of need application or for some other type of systems advocacy issue that needs to be addressed on behalf of residents. LTCOPs sometimes use their
The Georgia LTCOP plans to post facility specific complaint data covering a twelve month period on its website when the logistics are	

<b>Sharing LTCOP Complaint Data by Facility</b>	<b>Sharing LTCOP Complaint Data by Facility</b>
<b>Share this because</b>	<b>Do <b>Not</b> share this because</b>
resolved.	data to advise consumers when a facility is being closed.
LTCOP complaint data is reported by category of complaint and verification and resolution information. Specific dates for complaints are not reported as an added confidentiality protection.	LTCOP data is publicly shared in aggregate as part of the annual report of the State LTCOP.

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### **LTCOP Presence**

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The LTCOP has consistent, regular visits to long-term care facilities throughout the state.	LTCO visits to long-term care facilities are not consistent and regular throughout the state. This could mean that facilities with more frequent LTCO visits have more complaints than the facilities that are not regularly visited. Therefore the LTCOP data might be connected to the frequency of LTCO visits, not necessarily to the quality of services and responsiveness to residents within facilities.
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### **Accuracy of LTCOP Data**

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The State LTCOP conducts ongoing training on using the LTCOP reporting system, focusing on consistency.	The State LTCOP conducts training on using the LTCOP reporting systems, focusing on consistency. More training needs to be conducted before there is a high level of confidence in the accuracy of the statewide data.
The State LTCOP has a reporting system that is reliable, provides reports on an as needed basis, is accessible to local LTCOPs, and is used by all local LTCOPs.	The State LTCOP needs a reliable software and/or hardware system for data reporting and management. This is needed at the state level as well as for every local LTCOP.
The State LTCOP examines the data to spot any problems and makes the regional and/or state data available to local programs. There are periodic in-depth reviews of case records.	There is no one at the State LTCOP level whose expertise and job function is devoted to data management for the LTCOP.

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While LTCO want to use their knowledge and information to benefit consumers, LTCO also want to be confident in the reliability of their data and ensure that it is properly interpreted. One of the most helpful educational services a LTCOP provides is talking with consumers on an individual basis regarding their needs, rights, options, resources, and how to use the resources such as facility survey reports. Before a LTCOP can share facility specific information with consumers, some factors need to be addressed.

## **ESSENTIAL ELEMENTS FOR RESPONSIBLE SHARING**

There are a number of issues without easy solutions that constrain the use of LTCOP information outside of the program. The State LTCO attending the 2004 Spring Training Conference identified the following elements as essential before a program could responsibly share data identified by facility. Other factors such as the potential for changing the role of the ombudsman when resolving complaints within a facility and protecting confidentiality in rural areas need further consideration.

### **Prerequisites**

- There is consistent ombudsman presence in facilities throughout a state.
- Reporting by all LTCO is accurate and consistent within a state.
- Hardware and software is used that enables the LTCOP data to be reported, analyzed and used by all LTCOPs within a state.
- Ongoing training for local LTCO on reporting occurs every year.
- The State LTCOP has someone whose ongoing focus is the LTCOP data, including quality assurance activities, identifying and addressing training needs, and providing technical assistance to local LTCOPs.
- LTCOP policies or guidance on the responsible sharing of facility information with consumers are in place and are consistently followed throughout the state. Training is provided on these as well as support from the SLTCOP when questions arise.
- Adequate legal counsel without conflict of interest is available for state and local LTCOP for consultation regarding policy development, procedures and to respond to relevant issues that might issues arise.
- Resources, fiscal and human, are essential to enable this use of LTCOP data. Programs might take incremental steps in the direction of sharing more information with consumers as resources are available.

## Characteristics

- LTCOP data that is shared needs to have characteristics that are consistent with the intent and purpose of the program and consistent with the Older Americans Act responsibilities.
  - The identity of complainants and residents is protected.
  - The type of data that is shared and the way in which it is shared is consistent with the resident directed, advocacy focus of the LTCOP. The data is not presented in a way that creates an impression of the LTCOP as a regulatory or monitoring program.
- The sharing of LTCOP data includes an explanation about the data and that the data does not measure quality.
- The way that the data is presented is designed to connect consumers with a LTCO.
- The availability and sharing of LTCOP data is part of a larger plan to educate and inform consumers. It is not a stand alone piece of information without context and purpose.
- There is a continual awareness that LTCOP complaint data is only one piece of information to use in making decisions about facilities. It is a tool but is not to be used in isolation.
- The reason LTCOP data is shared is to help consumers make decisions.

## SUMMARY

Since it was created, the LTCOP has periodically scrutinized the type of data it collects, the consistency of the data, and the program's responsibility to use that data to benefit residents and consumers beyond resolving individual complaints. Progress in all of these areas has been made, yet everyone agrees that more needs to be done. There is an acknowledgement among ombudsmen that programs need to find better ways to use their data to help consumers. The state LTCOPs that are on the leading edge of sharing facility specific data are programs with a solid infrastructure, regular LTCOP presence in facilities, clear policies and guidance, data management systems used by all LTCOPs, and multiple staff at the state LTCOP level. Many programs are making progress toward strengthening their infrastructure to equip them to better serve consumers. The essential elements listed in this paper are hallmarks for programs. The content and methods of sharing LTCOP data in ways that will be "exemplary practices" undoubtedly will be the source of ongoing dialogue among ombudsmen.

## **APPENDIX**

**Excerpts From  
State Long-Term Care Ombudsman Provisions  
In the Older Americans Act, as Amended in 2000**

**By Topic, With Policy Interpretations**



**U.S. Department of Health and Human Services  
Administration on Aging, Office of Elder Rights Protection**

**Note: All provisions which follow are in Sec. 712, unless otherwise indicated.**

## **Sec. 712. STATE LONG TERM-CARE OMBUDSMAN PROGRAM**

### **Functions—State Long-Term Care Ombudsman**

(a)(3) Functions.— The Ombudsman shall serve on a full-time basis, and shall, personally or through representatives of the Office--

(B) provide services to assist the residents in protecting the health, safety, welfare, and rights of the residents;

### **Confidentiality and Disclosure**

(a)(5)(D)(iii) Confidentiality and disclosure.--The State agency shall develop the policies and procedures in accordance with all provisions of this subtitle regarding confidentiality and conflict of interest.

(Skip to 712(d)(1) for disclosure.)

(d)(1) In general.--The State agency shall establish procedures for the disclosure by the Ombudsman or local Ombudsman entities of files maintained by the program, including records described in subsection (b)(1) or (c).

(2) Identity of complainant or resident.--The procedures described in paragraph (1) shall--

(A) provide that, subject to subparagraph (B), the files and records described in paragraph (1) may be disclosed only at the discretion of the Ombudsman (or the person designated by the Ombudsman to disclose the files and records); and

(B) prohibit the disclosure of the identity of any complainant or resident with respect to whom the Office maintains such files or records unless--

(i) the complainant or resident, or the legal representative of the complainant or resident, consents to the disclosure and the consent is given in writing;

(ii)(I) the complainant or resident gives consent orally; and

(II) the consent is documented contemporaneously in a writing made by a representative of the Office in accordance with such requirements as the State agency shall establish; or

(iii) the disclosure is required by court order.

## **Policy Interpretation on Mandatory State Abuse Reporting Laws and Ombudsman**

**Disclosure** – Representatives of the Ombudsman Program may not be required to disclose the identity of a complainant or resident except under conditions outlined in Section 712(d) of the Act. Federal law supersedes states law in instances where state law mandates that ombudsmen report all incidents of abuse. In such instances, ombudsmen must follow the disclosure procedure outlined in Section 712 (d).

## **Policy Interpretation on Freedom of Information Act Requests**

Ombudsman records are not subject to the federal Freedom of Information Act (FOIA), inasmuch as the FOIA applies only to federal agency records, and records maintained by a state ombudsman are not federal records. Regarding state FOIA statutes, which many legislatures have enacted for purposes of disclosure of state records, the requirements and exemptions are similar but not necessarily identical to those in the federal FOIA. If disclosure were requested pursuant to such a state statute, it is likely but not certain that there would be an exemption for records, such as ombudsman records, that are made confidential by statute. If there were no such exemption in the state FOIA statute and a conflict between the state statute and the OAA could not be avoided, then the federal position would be that the OAA prevails under the Supremacy Clause of the U.S. Constitution.

## **Statewide Uniform Reporting System and Reports**

(c) Reporting System.--The State agency shall establish a statewide uniform reporting system to--

(1) collect and analyze data relating to complaints and conditions in long-term care facilities and to residents for the purpose of identifying and resolving significant problems; and

(2) submit the data, on a regular basis, to--

(A) the agency of the State responsible for licensing or certifying long-term care facilities in the State;

(B) other State and Federal entities that the Ombudsman determines to be appropriate;

(C) the Commissioner; and

(D) the National Ombudsman Resource Center established in section 202(a)(21).

(h) Administration.--The State agency shall require the Office to--

(1) prepare an annual report--

(A) describing the activities carried out by the Office in the year for which the report is prepared;

(B) containing and analyzing the data collected under subsection (c);

(C) evaluating the problems experienced by, and the complaints made by or on behalf of, residents;

(D) containing recommendations for--

(i) improving quality of the care and life of the residents; and (ii) protecting the health, safety, welfare, and rights of the residents;

(E)(i) analyzing the success of the program including success in providing services to residents of board and care facilities and other similar adult care facilities; and

(ii) identifying barriers that prevent the optimal operation of the program; and

(F) providing policy, regulatory, and legislative recommendations to solve identified problems, to resolve the complaints, to improve the quality of care and life of residents, to protect the health, safety, welfare, and rights of residents, and to remove the barriers;

(3)(A) provide such information as the Office determines to be necessary to public and private agencies, legislators, and other persons, regarding--

(i) the problems and concerns of older individuals residing in long-term care facilities; and

(ii) recommendations related to the problems and concerns; and

(B) make available to the public, and submit to the Commissioner, the chief executive officer of the State, the State legislature, the State agency responsible for licensing or certifying long-term care facilities, and other appropriate governmental entities, each report prepared under paragraph (1);